

Guidance on Commissioning Cancer Services

Improving Outcomes in

Head and Neck Cancers

The Manual

NICE Website Consultation version

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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 care¹, 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.

References

- 1 National Institute for Clinical Excellence. *Improving Supportive and Palliative Care for Adults with Cancer*. London: NICE, 2004.
- 2 Smith TL, Hillner BE, Bear HD. Taking action on the volume–quality relationship: How long can we hide our heads in the colostomy bag? *Journal of the National Cancer Institute*, Vol. 95, No. 10, May 21 2003.

Acknowledgements

These will follow in the final published document.

Key Recommendations

- Services for patients with head and neck cancers should be commissioned at the Cancer Network level. Over the next few years, assessment and treatment services will become increasingly concentrated in Cancer Centres serving populations of over a million patients.
- MDTs with a wide range of specialists will be central to the service, each managing at least 100 new cases of upper aerodigestive tract cancer per annum. They will be responsible for assessment, treatment planning and management of every patient. Specialised teams will deal with patients with thyroid cancer, and with those with rare or particularly challenging conditions such as salivary gland and skull base tumours.
- Arrangements for referral at each stage of the patient's cancer journey should be streamlined. Diagnostic clinics should be established for patients with neck lumps.
- A wide range of support services should be provided. Clinical nurse specialists, speech and language therapists, dietitians and restorative dentists play crucial roles but a variety of other therapists are also required, from the pre-treatment assessment period until rehabilitation is complete.
- Co-ordinated Local Support Teams should be established to provide long-term support and rehabilitation for patients in the community. These teams will work closely with every level of the service, from primary care teams to the specialist MDT.
- MDTs should take responsibility for ensuring that accurate and complete data on disease stage, management and outcomes are recorded. Information collection and audit are crucial to improving services and must be adequately supported.
- Research into the effectiveness of management – including assessment, treatment, delivery of services and rehabilitation – urgently requires development and expansion. Multi-centre clinical trials should be encouraged and supported.

1 **Background**

2

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

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

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

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

¹ Johnson NW, Warnakulasuriya KAAS. Epidemiology and aetiology of oral cancer in the United Kingdom.

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

34

35 **Table 1a. Registrations, incidence, and deaths, England ²**

36

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	<i>C00-06</i>	2329	5.9	3.7	<i>140-141, 143-145</i>	782	1.8	1.3
Salivary glands	<i>C07-8</i>	422	1.0	0.8	<i>142</i>	138	0.3	0.2
Pharynx (throat)	<i>C09-14</i>	1339	4.0	1.6	<i>146-149</i>	617	1.7	0.8
Nasal cavity, ear & sinuses	<i>C30-31</i>	352	0.8	0.6	<i>160</i>	110	0.3	0.2
Larynx (voice-box)	<i>C32</i>	1903	6.6	1.3	<i>161</i>	655	2.1	0.5
Thyroid	<i>C73</i>	1131	1.3	3.3	<i>193</i>	251	0.3	0.7

37

Comm Dental Health 1993. **10**, supplement 1: 13-29.

² Figures from the Office of National Statistics (ONS), Welsh Cancer Intelligence & Surveillance Unit

38 **Table 1b. Registrations, incidence, and deaths, Wales** ³

39

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

40

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

44 There are marked regional variations in the incidence of head and neck cancers, with rates
 45 ranging from roughly 8 per 100,000 in the Thames and Oxford regions to 13-15 per
 46 100,000 in Wales and in the North Western Region.⁵ Registration rates for two of the
 47 three most common forms of head and neck cancer - cancers of the mouth and pharynx -
 48 have risen by over 20% over the last three decades, particularly among people under the
 49 age of 65.⁶ This increase continued over the 1990s, but is counterbalanced somewhat by a
 50 recent decrease in incidence of cancer of the larynx (Figure 1).⁷

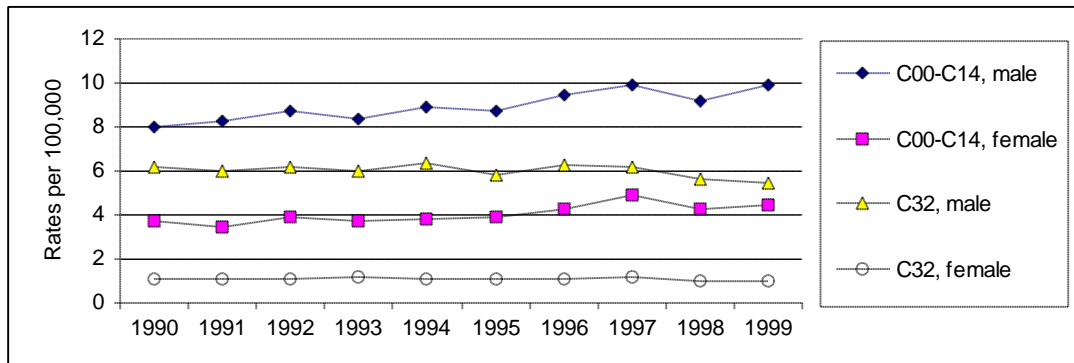
³ Figures from the Welsh Cancer Intelligence & Surveillance Unit, Office of National Statistics (ONS).

⁴ Available on the NICE website (www.nice.org.uk).

⁵ Consensus Group of Practising Clinicians. Practice care guidance for clinicians participating in the management of head and neck patients in the UK. *Eur J Surg Oncol*. 2001. **27**: supplement A.

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.

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



53

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

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

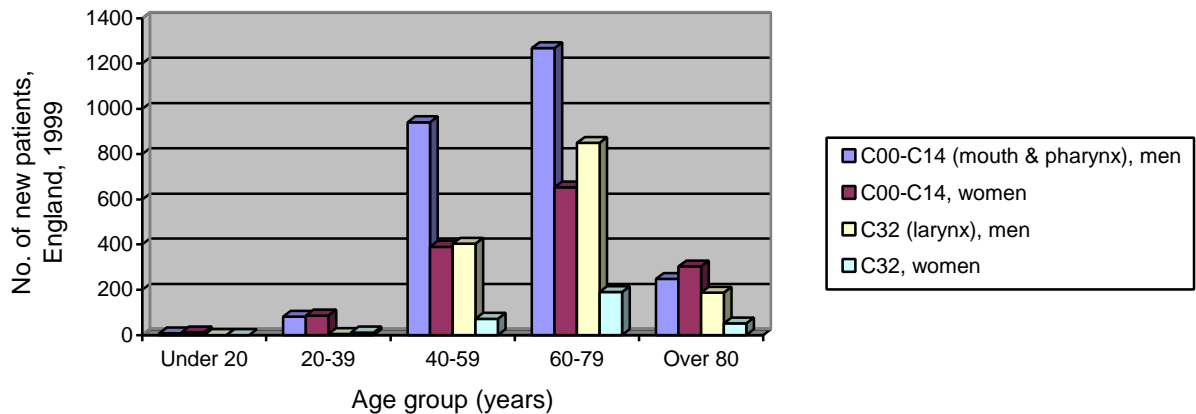
61

⁷ Quinn, 2001: *op.cit.*

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

⁹ Edwards DM, Jones J. Incidence of and survival from upper aerodigestive tract cancers in the UK; the influence of deprivation. *Eur J Cancer* 1999. **35**(6): 968-72.

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



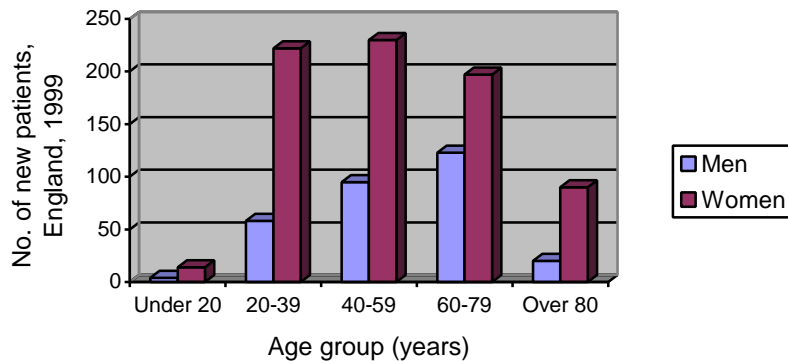
64
 65 Thyroid cancer incidence has an entirely different pattern. It is more common in women,
 66 among whom new cases peak between the ages of 30 and 54; the rate falls in middle age
 67 (from 4.4 to 2.9 per 100,000 among those aged 50-54 and 55-59, respectively), rising to a
 68 second peak in women over the age of 70 years. In men, the incidence is low, but reaches
 69 its maximum in later life.¹¹ Thyroid cancer is considerably more common among young
 70 women than other head and neck cancers.¹² The age distribution of new cases is shown in
 71 Figure 2b, below; note that because the numbers are much smaller than in Figure 2a
 72 (above), the scale of the value (X) axis is different; also note that the age-bands in this
 73 diagram are such that it does not show the dip in incidence among middle-aged women.

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

¹¹ Quinn, *op. cit.*, Appendix B4.

¹² Office of National Statistics, Cancer Registrations Series MB1, 2002.

74 **Figure 2b. Age distribution of patients with new diagnoses of thyroid cancer (C73).¹³**



75

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

77 **Survival rates**

78 Survival rates differ markedly according to the site and stage of the cancer. Data from the
 79 Eurocare 3 study shows that England and Wales are broadly similar to the European
 80 average.¹⁴ Table 2 shows figures for survival rates for the most common forms of UAT
 81 cancer (mouth, pharynx and larynx) and for thyroid cancers, in England, Wales and
 82 Europe as a whole.

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

¹³ 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).

¹⁴ Eurocare III, data not yet published.

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

94 **Table 2. Five-year age-standardised relative survival rates (with 95% confidence**
 95 **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)

96

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

104 There are similar problems with European outcomes data for thyroid cancer, although the
 105 numbers reported by some countries are probably sufficiently reliable to make
 106 comparisons between them. Five year relative survival rates in Norway, Finland and
 107 Sweden, which all have 100% coverage of cases in the Eurocare 3 database, are around
 108 85% - significantly better than in England, with 59% coverage and about 77% of patients
 109 surviving. For Europe as a whole, the five year survival rate is 80%.

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

118 **Table 3. Cancer stage and survival in the South and West of England, 1999-2000¹⁶**

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

119

120 A study of patients treated for cancers of the tongue or floor of the mouth in Scotland
 121 found that just over half of the patients had relatively small tumours (T₁ and T₂); these
 122 patients survived for about twice as long as those with large tumours (T₃ and T₄), after
 123 adjusting for other factors known to affect survival.¹⁷

¹⁵ South West Cancer Intelligence Service, *Second Head and Neck Audit Report*. SWCIS, 2001.

¹⁶ 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.

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

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

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

137 **Specific Cancers**

138 *Mouth, lip and oral cavity (oral cancer)*

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

415.

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

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

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

144 Roughly 90% of oral cancers are squamous cell carcinomas, arising from the lining of the
145 mouth, most often the tongue and the floor of the mouth. Approximately 10-30% of
146 patients with primary oral cancer develop second primary UAT tumours; these patients
147 also have higher rates of lung and bladder cancer than the general population.²²

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

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

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

161 *Cancer of the larynx*

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

²² Cancer Research Campaign. *Cancer Statistics: Oral – UK*. July 2000.

²³ Swerdlow AJ, Marmot MG *et al*. Cancer mortality in Indian and British ethnic immigrants from the Indian subcontinent to England and Wales. *Br J Cancer* 1995. **72**: 1312-19.

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

²⁵ Warnakulasuriya KA *et al*. An alarming lack of public awareness towards oral cancer. *Br Dent J* 1999. **187**(6): 319-22.

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

172 ***Cancer of the pharynx***

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

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

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

188 The geographical incidence of pharyngeal cancer (aside from nasopharynx) is similar to
 189 that of oral cancers. It is relatively low in England and Wales, but higher among those
 190 with a South Asian background; among immigrants from the Indian sub-continent, the risk

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

²⁷ Eurocare III, data not yet published.

191 of death from cancer of the pharynx is five times that of British natives.²⁸ Cancer of the
192 nasopharynx is particularly common among people of Southern Chinese origin.²⁹

193 *Thyroid cancer*

194 Thyroid cancer, although relatively rare, is most likely to develop in women of
195 reproductive age. It usually presents as a solitary nodule in a goitre (a swelling in the neck
196 due to enlargement of the thyroid gland); cancer is found in about 10% of such cases.

197 Other symptoms are rare, but include swollen glands in the neck (cervical
198 lymphadenopathy), hoarseness, difficulty in breathing or swallowing, and discomfort in
199 the neck.

200 The commonest type of thyroid cancer is described as “differentiated”; this accounts for
201 90% of cases. This is sub-divided into two forms: papillary and follicular
202 adenocarcinoma, which account for 80% and 10% of cases, respectively. Both develop in
203 cells that produce thyroid hormones, but papillary cancer tends to grow slowly and is not
204 regarded as being highly malignant. Differentiated thyroid cancers are usually treated
205 with surgery, which can be supplemented with radioiodine ablation. Survival rates are
206 excellent.

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

211 Finally, there are two rare types which occur in the elderly. About 1% of patients have
212 lymphoma of the thyroid, which presents as a rapidly expanding mass and is usually
213 diagnosed on the basis of the patient’s history, together with a tissue diagnosis. Many of
214 these patients can be cured. In contrast, the outlook is poor for the 3% of patients who

²⁸ Swerdlow AJ, Marmot MG *et al.* Cancer mortality in Indian and British ethnic immigrants from the Indian subcontinent to England and Wales. *Br J Cancer* 1995. **72**: 1312-19.

²⁹ 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.

215 have anaplastic thyroid cancer, which presents in a similar way and must be differentiated
216 from lymphoma with a biopsy.

217 ***Other cancers of the head and neck***

218 There are a wide range of other cancers of the head and neck which are not described
219 above. Taken together, these are responsible for 17% of cases of head and neck cancer.³⁰
220 All are relatively rare, the least rare being cancers of the salivary glands and cancers of the
221 nasal cavity, middle ear and accessory sinuses (Table 1). This diverse group also includes
222 cancers of the facial bones, peripheral nerves, connective and soft tissues, and various
223 glands.

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

227 **Risk Factors and prevention**

228 ***Cancers of the Upper Aerodigestive Tract (mouth, pharynx, and larynx)***

229 Most UAT cancers are triggered by alcohol and tobacco, which together probably account
230 for three-quarters of cases.³¹ Cigarette smoking is associated with increased risk of all of
231 the more common forms of UAT cancer; the risk among cigarette smokers may be ten or
232 more times that for non-smokers. Pipe or cigar smoking is associated with an even higher
233 excess risk of oral cancer.³² Chewing tobacco – with or without areca (betel) nut – is
234 strongly linked with oral and pharyngeal cancer, as well as to some extent with cancer of
235 the larynx and the thyroid.^{33,34}

³⁰ National Cancer Intelligence Centre, Office for National Statistics and Welsh Cancer Intelligence & Surveillance Unit

³¹ Blot WJ, McLaughlin JK, Winn DM. *et al.* Smoking and drinking in relation to oral and pharyngeal cancer. *Cancer Res* 1988. **48**:3282-87.

³² La Vecchia C, Tavani A, Franceschi S, Levi F, *et al.* Epidemiology and prevention of oral cancer. *Oral Oncology* 1997, **33**:302-312.

³³ Swerdlow AJ, Marmot MG *et al.* Cancer mortality in Indian and British ethnic immigrants from the

236 More intense use of tobacco increases risk, while ceasing to smoke for ten years or more
 237 reduces it to virtually equal to that among non-smokers. The heavier the smoking prior to
 238 diagnosis, the more likely people with cancer of the oral cavity, larynx or pharynx are to
 239 develop second primaries, i.e. tumours which did not develop from the first one. The same
 240 pattern is found among people who continue to smoke after diagnosis.³⁵

241 High alcohol consumption and smoking have synergistic or multiplicative effects on the
 242 risk of head and neck cancer. For heavy drinkers who are also heavy smokers, the risk of
 243 oral cancer is over 35 times that for those who neither smoke nor drink, and a similar
 244 pattern is found with cancer of the larynx.^{36, 37} Alcohol consumption is a particularly
 245 important risk factor for cancers of the mouth and pharynx, and to a lesser degree, for
 246 cancer of the larynx. Consuming 100g of alcohol or more per day (about twelve units –
 247 six pints of beer or twelve measures of wine or spirits) multiplies the risk of developing
 248 oral cancer at least six-fold, after adjustment for tobacco use; the more alcohol consumed,
 249 the greater the risk.³⁸

250 Diet also affects the risk of cancers of the oral cavity, pharynx and larynx; as with many
 251 other forms of cancer, frequent consumption of fruit and vegetables is associated with
 252 reduced risk. Poor diet is often associated with heavy smoking and alcohol use, and the
 253 malnutrition which can result exacerbates the risk of cancer. Eating Cantonese-style salted

Indian subcontinent to England and Wales. *Br J Cancer* 1995. **72**: 1312-19.

³⁴ Johnson NW & Warnakulasuriya KAAS. Epidemiology and aetiology of oral cancer in the United Kingdom. *Comm Dental Health* 1993. **10**, supplement 1: 13-29.

³⁵ 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.

³⁶ Blot WJ, McLaughlin JK, Winn DM. *et al.* Smoking and drinking in relation to oral and pharyngeal cancer. *Cancer Res* 1988. **48**:3282-87.

³⁷ Talamini R, Bosetti C, La Vecchia C, *et al.*: Combined effect of tobacco and alcohol on laryngeal cancer risk: a case-control study. *Cancer Causes Control* 2002, 13:957-964.

³⁸ 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.

254 fish increases risk – which may account for high levels of particular forms of head and
 255 neck cancer found among some Chinese ethnic groups.^{39,40}

256 Given the importance of tobacco, alcohol and diet as risk factors for many forms of head
 257 and neck cancer, it is clear that they are largely preventable. Smoking and alcohol
 258 cessation and reduction programmes are important. Effective interventions for reducing
 259 smoking are described in the guidance document on lung cancer in this series (*Improving*
 260 *Outcomes in Lung Cancer: The Manual*).⁴¹ A recent literature review found evidence that
 261 oral cavity cancer in young people (aged under 40) may not be associated with these
 262 traditional origins, and suggested that genetic disposition may play a role, but further
 263 research is needed.⁴²

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

³⁹ 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.

⁴⁰ 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.

⁴¹ Available on the Department of Health website (doh.gov.uk)

⁴² 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.

⁴³ Muscat J, Wynder E. Tobacco, alcohol, asbestos and occupational risk factors for laryngeal cancer. *Cancer*, 1992;69:2244-2251

⁴⁴ Merletti F, Boffetta P, Ferro G, Pisani P, et al. Occupation and cancer of the oral cavity or oropharynx in Turin, Italy. *Scand. J. Work Environ. Health*, 1991;17:248-254.

273 Infection by particular types of virus, notably human papillomavirus (HPV) – which is
 274 known to cause cervical cancer – is implicated in the development of some cancers of the
 275 oral cavity, pharynx and larynx.⁴⁵ The authors of an ongoing systematic review estimate
 276 that HPV could be involved in 30-40% of cases of oropharyngeal cancer in western
 277 countries.⁴⁶ Patients with cancer of the tonsil are particularly likely to show signs of
 278 previous HPV infection.⁴⁷ HPV positive tumours have a better prognosis than those
 279 associated with smoking and alcohol.

280 *Thyroid cancer*

281 A history of radiation exposure to the neck area is associated with increased risk of thyroid
 282 cancer, often after a delay of well over a decade; some cases can be traced to radiation
 283 treatment in childhood. Both deficiency and excess dietary iodine are associated with
 284 increased risk.⁴⁸ Other predisposing factors include prolonged stimulation with thyroid
 285 stimulating hormone (which can be due to chronic iodine deficiency), chronic lymphocytic
 286 thyroiditis (lymphoma), and genetic factors (linked with medullary thyroid cancer).
 287 Women are more than twice as likely as men to develop thyroid cancer.

288 **Diagnosis, treatment and rehabilitation**

289 *Identification of patients and diagnosis*

290 There is no national screening programme for any form of head and neck cancer and it is
 291 unlikely that such a programme will be established in the near future. Reasons for this
 292 include the following: First, although screening has been considered for oral cancer, this
 293 is relatively rare so the pick-up rate would be very low. Second, the natural history of
 294 these cancers is poorly understood. Finally - and crucially - there is no evidence to show

⁴⁵ Hobbs C, Birchall M. Human papillomavirus infection in the etiology of laryngeal carcinoma. *Current Opinion in Otolaryngology and Head and Neck Surgery*, 2004;12:88-92.

⁴⁶ Hobbs C, personal communication, 2004.

⁴⁷ Gillison BL, Koch WM, Capone RB, Spafford M, *et al.* Evidence for a causal association between human papillomavirus and a subset of head and neck cancers. *J Nat. Can. Inst.*,2000;92:709-718.

⁴⁸ 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.

295 that such screening would be beneficial for the population as a whole. More research is
296 needed, particularly on screening members of high risk groups and opportunistic
297 screening.

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

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

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

318 ***Primary treatment***

319 Most head and neck cancers are treated with surgery or radiotherapy or a combination of
320 both. Chemotherapy alone is rarely appropriate for these forms of cancer, but
321 chemotherapeutic agents are sometimes used to enhance the effects of radiotherapy; this is
322 known as chemo-radiation. Plastic or reconstructive surgery and specialised dentistry are

323 often needed. Patients need considerable help and support with nutrition and
324 communication, both during and after primary treatment.

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

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

335 ***Rehabilitation, support and palliative care***

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

348 The importance of psychosocial support is amplified by the nature of the patients who are
349 most likely to develop UAT cancer. A significant proportion are heavy users of tobacco
350 and alcohol, which can reflect pre-existing difficulties with social integration and means
351 that they are likely to need continuing help to achieve lasting abstinence. Depression is

352 relatively common in these patients. In addition, most are elderly and many have to cope
353 with socio-economic deprivation. These features act together to increase the need for
354 effective support in the community after definitive treatment. The primary care team
355 plays a crucial role in providing such support, but input from health care and other
356 professionals with specialised knowledge of the problems faced by these patients is also
357 required.

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

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

369 **Services for Patients with Head and Neck Cancer**

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

374 Some aspects of services for patients with head and neck cancer are less well developed
375 than for other cancers. For example, a recent national study found that slightly less than
376 half of hospitals/trusts had multidisciplinary teams (MDTs) for head and neck cancer,
377 compared to much higher proportions for more common types of cancer (over 80 per cent

378 in the case of breast cancer).⁴⁹ Some Trusts have multidisciplinary clinics, held jointly by
379 oncologists and surgeons, but few have formal head and neck MDTs which meet regularly
380 and fulfil the criteria for MDT working which are now well established for the
381 management of patients with breast cancer.

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

387 Many patients receive treatment at several hospitals, and this has been linked with poor
388 co-ordination of care at many stages of the patient's cancer journey.⁵⁰ A large number of
389 consultants are involved, most of whom do not specialise in head and neck cancer. A
390 major audit, carried out in 199/2000, revealed that the majority of patients in the South and
391 West were treated by consultants who carried out ten or fewer procedures for head and
392 neck cancer in a year.⁵¹ This must be a matter for concern because variety and complexity
393 of surgical interventions required by such patients means that specialised skill is essential
394 to achieve optimum results, both in terms of disease control and satisfactory cosmetic and
395 functional outcomes.

396 Thyroid cancer has traditionally been treated by general surgeons, although there have
397 been recent moves towards increased specialisation. Audit data from the Northern and
398 Yorkshire Cancer Registry area (1998-9) shows that over a third of patients were treated
399 by surgeons who dealt with two or fewer cases per year.⁵² A study from Birmingham
400 revealed that a substantial proportion of patients in that area did not receive adequate

⁴⁹ Commission for Health Improvement/Audit Commission. *NHS Cancer care in England and Wales*. London: Department of Health, 2001.

⁵⁰ Edwards, D. *Face to Face: Patient, family and professional perspectives of head and neck cancer care*. London: King's Fund, 1997.

⁵¹ South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001.

⁵² Northern and Yorkshire Cancer Registry and Information Service (NYCRIS): unpublished data, 2003.

401 treatment, but that this was less likely to occur when patients were managed by a
402 multidisciplinary team of specialists.⁵³

403 Two-fifths or less of hospitals/trusts had agreed guidelines for the treatment of head and
404 neck cancer in 2000. This was below the average for all cancers, although by no means
405 the worst. Perhaps more significantly, one third of hospitals/trusts surveyed had no
406 designated lead clinician for head and neck cancer and three quarters had no lead nurse.⁵⁴

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

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

⁵³ Kumar H, Daykin J, Holder R, Watkinson JC, Sheppard MC, Franklyn JA. An audit of management of differentiated thyroid cancer in specialist and non-specialist clinic settings. *Clinical Endocrinology* 2001,54:719-723.

⁵⁴ Commission for Health Improvement/Audit Commission. *NHS Cancer care in England and Wales*. London: Department of Health, 2001.

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

423 The British Association of Otorhinolaryngologists – Head and Neck Surgeons (BAOHNS)
424 set out standards for the treatment and care of patients with head and neck cancer in 1998.
425 These were updated in 2000 and substantially expanded in a new publication in 2003.⁵⁶
426 However, there is relatively little research into the effectiveness of treatment for head and
427 neck cancers, compared with breast or colorectal cancer.⁵⁷

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

439

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

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

⁵⁸ http://www.nhsia.nhs.uk/ncasp/pages/audit_topics/cancer.asp

1. Referral

A. Recommendations

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

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

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

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

- 29 • All clinicians working in the hospital – in particular, those who work in ENT and
 30 maxillofacial clinics – who are likely to discover new patients with head and neck
 31 cancers should be able to contact one of the designated clinicians without delay. Any
 32 patient with a suspicious lesion should be seen by a designated clinician.
- 33 • When biopsy of a suspicious lesion is appropriate, a designated clinician should
 34 arrange for this to be done promptly.
- 35 • Designated clinicians should refer patients who are strongly suspected to have cancer
 36 on to appropriate assessment clinics at Cancer Centres (see Topics 2 and 3).

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

42 **Urgent Referral**

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

48 ***Urgent Referral Guidelines (England)***

- 49 • Hoarseness persisting for more than six weeks.
- 50 • Ulceration of oral mucosa persisting for more than three weeks.
- 51 • Oral swellings persisting for more than three weeks.
- 52 • All red or red and white patches of the oral mucosa.

⁵⁹ Department of Health. *Referral Guidelines for Suspected Cancer*. Available on

- 53 • Dysphagia persisting for more than three weeks.
- 54 • Unilateral nasal obstruction, particularly when associated with purulent discharge.
- 55 • Unexplained tooth mobility not associated with periodontal disease.
- 56 • Unresolving neck masses for more than three weeks.
- 57 • Cranial neuropathies.
- 58 • Orbital masses.

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

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

67 ***Patients with neck lumps***

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

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

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

⁶⁰ National Institute for Clinical Excellence. *Improving outcomes in haematological cancers*. Available on the NICE website (www.nice.org.uk).

76 ***Thyroid cancer***

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

- 81 • Those with solitary thyroid nodules that are increasing in size;
- 82 • Patients with thyroid lumps, who have family histories of thyroid cancer or who have
 83 had neck irradiation;
- 84 • Thyroid lumps in patients over the age of 65;
- 85 • Patients with unexplained hoarseness or voice changes associated with a goitre;
- 86 • Cervical lymphadenopathy;
- 87 • Stridor (a harsh sound when the patient draws breath: this is a late presenting sign and
 88 patients should be seen immediately).

89 **Routine referrals**

90 ***UAT cancer***

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

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

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

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

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

115 ***Thyroid cancer***

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

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

124 **Prevention**

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

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

133

134 **B. Anticipated benefits**

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

139

140 **C. Evidence**

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

145 **Tumour stage, nodal status and survival**

146 A study of 206 patients with oral cancer from Scotland gives details of associations
 147 between tumour stage, lymph node involvement, treatment and survival.⁶² This study

⁶² Robertson AG, Robertson C, Soutar DS, Burns H, et al. Treatment of oral cancer: the need for defined

148 found that patients with relatively small, early tumours (T₁ and T₂), who account for about
 149 half the total group, survive for about twice as long as those with more extensive disease.
 150 Tumour in the lymph nodes is associated with poorer survival rates.

151 A study from Brazil investigated relationships between disease stage, treatment costs and
 152 hospital stay. This demonstrated a dramatic increase in hospital costs with more advanced
 153 disease. For example, duration of treatment (which is a major component of cost) for oral
 154 carcinomas ranged from a mean of 9 days for stage I disease (T₁, node negative) to 91
 155 days for stage III disease (T_{1/2}, node positive, or T₃). (B)

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

157 A brief, multi-component educational intervention designed to teach health care
 158 professionals about the oral sites at risk, etiological factors and early signs and symptoms
 159 of oral and pharyngeal cancers, as well as screening techniques, was assessed in a US
 160 study. The authors concluded that this type of intervention could increase some health
 161 care professionals' knowledge. However, knowledge levels among the dentists and nurses
 162 in the study did not change and no patient outcomes were measured. (B)

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

168 **Delays in access to diagnosis and treatment in the NHS**

169 The first source of delay in access to treatment is the delay between patients' awareness of
 170 symptoms of their cancer and visiting their GP, which is usually about two to three months
 171 but can be years.⁶³ There is no clear-cut relationship between delay in referral and
 172 survival, since patients with more acute symptoms are less likely to delay and are more

protocols and specialist centres. Variations in the treatment of oral cancer. *Clinical Oncology* 2001;13:409-415.

173 likely to be referred by their GPs within two weeks; consequently, those who are referred
174 quickly tend to have later stage disease and poorer survival rates.⁶⁴

175 Since 2001, the Department of Health has required that patients referred urgently for
176 possible cancer be seen by a specialist within two weeks. For England as a whole in the
177 last quarter of 2002, 99% of patients with potential head and neck cancer whose referral
178 was received within 24 hours, and 90.5% of those whose referral took longer, were seen
179 within this period.⁶⁵

180 The appointment with a specialist is only the first step in the assessment process and
181 waiting time figures do not indicate time to confirmed diagnosis or treatment, nor the time
182 that patients who are not referred under the two-week guidelines may wait. There are no
183 national data on these delays, but audit data for 1996-7 and 1999-2000 in the South and
184 West have been published (SWAHNI and SWAHNII).⁶⁶ These audits show that the
185 median time between GP referral to first outpatient visit was 14 days or less for patients
186 with oral and pharyngeal cancers, but patients with cancers of the larynx or salivary glands
187 waited a median of about 7 days longer. A further 18, 20 or 30 days, respectively, elapsed
188 before assessment at a joint clinic. The longest delays were between initial assessment
189 and treatment.

190 In 1997, the median waiting times for patients with oral cancer were 40 days between GP
191 referral and surgery, and 53 days to radiotherapy; very little of this time was taken in
192 testing procedures. SWAHNII shows that delays had grown about a week longer three
193 years later. The range of waiting times was large, with delays between first outpatient
194 appointment and assessment at a Joint Head and Neck Clinic ranging from less than a
195 week to more than 19 months (median 18 days).

⁶³ South West Cancer Intelligence Service, *Head and Neck Audit Report (SWAHNI)*, 1997.

⁶⁴ South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001.

⁶⁵ See www.doh.gov.uk/cancerwaits

⁶⁶ South West Cancer Intelligence Service, *Head and Neck Audit Report*, 1997, and *Second Head and Neck Audit Report*, 2001.

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

202 There are also no national data on the stage at which head and neck cancer is diagnosed,
203 but some information on the size and stage of tumours at this point is available. Figures
204 from the SWAHNII audit are given in Table 3, Background. Data collected by the Mersey
205 Region Maxillofacial Unit, based on nearly 700 patients with cancer of the oral cavity and
206 oropharynx, show that three-quarters of the cancers were classified as T2 (two to four
207 centimetres diameter, usually stage II-III) or more at the point of diagnosis. Over a quarter
208 were classified as T4 (stage IV, invading adjacent structures). A recent study, based on
209 smaller numbers, found that roughly one quarter of head and neck cancers fell into each
210 category T1-T4. There was no clear association between the nature of the symptoms and
211 the urgency with which they were viewed by patients.⁶⁷

212 **Specific referral routes**

213 *Persistent hoarseness*

214 xx Add evidence

215 *Neck lump clinics*

216 One report from an NHS hospital (published in 1998) describes a direct referral clinic for
217 patients with neck masses. It was staffed by a consultant otorhinolaryngologist and a
218 consultant radiologist, who carried out ultrasound assessment with fine needle aspiration
219 cytology (FNAC) when appropriate. Of the first 100 patients seen within the clinic's first
220 year of operation, 46 patients were referred with enlarged lymph nodes; 10 of these (22%)
221 had squamous cell carcinomas and 3 (7%) had lymphoma. 21 patients had thyroid

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

224 A second report, again from a clinic based in the otolaryngology department of a UK
225 teaching hospital, describes a one-stop clinic where staff were able to carry out FNAC.
226 During the first six months, the mean time from referral to clinic appointment was 17 days
227 and patients waited, on average, a total of 65 minutes (including time awaiting the initial
228 FNAC report) in the clinic. 54% of patients were discharged after a single visit; the
229 remainder were referred for surgery, radiological investigation, or further clinical review.
230 12% of patients presented with malignant disease affecting the lymph nodes or salivary
231 glands. The level of accuracy of FNAC in this clinic was 94%. (B)

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

- 233 1. Allocation of dedicated clinic time;
- 234 2. GPs should have access to fax number of the clinic;
- 235 3. A senior member of the surgical staff should assess each patient;
- 236 4. A cytopathologist should be based in the clinic to perform and interpret FNAC
237 specimens;
- 238 5. FNAC accuracy of cytopathologists should be known before clinic starts;
- 239 6. Continuing re-evaluation of the strategy.

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

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

247

248

249 **D. Measurement**

250 **Structure**

251 • Defined systems for routine and urgent referral as outlined, disseminated to all relevant
252 health professionals in the Network.

253 • Availability of head and neck lead clinicians and referral forms.

254 • Availability of neck lump clinics.

255 **Process**

256 • Evidence that patients are referred on to MDTs without delay.

257 • Audit of delay between initial referral by GP and confirmation of diagnosis.

258 **Outcome**

259 • Stage at diagnosis.

260

261 **E. Resource Implications**

262 [Note: The section on Resource Implications will be reviewed in the light of the “Analysis
263 of the Potential Economic Impact of the Guidance” – available in draft with the Research
264 Evidence. A summary is included as Appendix 1 in this draft of the Manual].

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 and commissioned at Network level. Each Network should review the range of professionals, services and specialist resources available and smaller Networks should consider co-operating with neighbouring Networks to develop joint services.

Management by 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. Some networks in sparsely populated areas may, however, elect to develop teams for smaller numbers. Where more than one Trust provides services in close geographical proximity (for example, where two Trusts operate in a single conurbation), Networks should consolidate services under a single MDT.⁶⁸

⁶⁸ BAHNO guidelines recommend that MDTs should deal with a minimum of 80 new cases per year. This is regarded as a conservative figure which might be appropriate for MDTs serving sparsely populated areas. (British Association of Head and Neck Oncologists, Practice care guidance for clinicians participating in the management of head and neck cancer patients in the UK. European Journal of Surgical Oncology, 2001, 27, Supplement A, pS4).

22 Networks should identify specific head and neck cancer MDTs which will provide
 23 treatment for patients with cancer in rare sites and patients whose cancers present
 24 especially challenging problems: in particular, salivary gland tumours and those that
 25 involve the base of the skull. These teams are likely to be located in large centres which
 26 have access to a wider range of resources.

27 ***Members of the Head and Neck Cancer core MDT***

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

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

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

- 48 • Surgeons. Each MDT should include three or more designated surgeons, who are
 49 likely to be ear, nose and throat (ENT), maxillofacial, or plastic surgeons. It is
 50 important that each MDT includes, or has access to, surgeons who are proficient in

51 reconstruction, including micro-vascular techniques. This document will refer to all
52 surgeons in the MDT as surgical specialists, whatever their individual background or
53 speciality. Each surgeon in the MDT should normally dedicate half of his or her time
54 to head and neck cancer.

55 • Clinical oncologists: each MDT should, if possible, include two clinical oncologists,
56 one of whom should always be present at meetings.

57 • Restorative dentist.

58 • Pathologists with expertise in both histopathology and cytopathology, who participate
59 in EQA schemes.

60 • Radiologist.

61 • Dedicated speech and language therapist.

62 • Clinical nurse specialists (CNSs).

63 • Senior nursing staff from the head and neck ward.

64 • Palliative care specialist (doctor or nurse), who should work with palliative care
65 services in the community.

66 • Dedicated dietitian.

67 • Team secretary who will provide clerical support for the MDT, recording all decisions
68 made by the team and communicating appropriate information promptly to all those
69 (such as GPs) who may require it.

70 • Data manager.

71 • MDT co-ordinator, who should take responsibility for organising MDT meetings (see
72 below). The co-ordinator may also take the role of team secretary and/or data
73 manager, but should not be a Clinical Nurse Specialist, since this would not be an
74 appropriate use of the CNS's skill or time.

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

78 ***Extended team members***

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

- 87 • Other specialist surgeons.
- 88 • Anaesthetist with a special interest in head and neck cancer.
- 89 • Gastroenterologists, radiologists and surgeons with expertise in gastrostomy creation,
90 feeding tube placement and support for patients who require tube feeding.
- 91 • Ophthalmologist.
- 92 • Pain management specialist.
- 93 • Nuclear medicine specialist.
- 94 • Maxillofacial/dental technician.
- 95 • Dental hygienist.
- 96 • Social worker.
- 97 • Benefits advisor.
- 98 • Liaison psychiatrist.

99 • Clinical psychologist.

100 • Counsellor.

101 • Physiotherapist.

102 ***Thyroid cancer MDTs***

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

- 106 1. Designated head and neck cancer teams, joined by experts in endocrinology for the
107 relevant part of the MDT meeting; or
- 108 2. Specialised endocrine oncology teams.

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

113 ***Members of the thyroid cancer MDT***

114 • Endocrinologist.

115 • Surgeon who specialises in thyroid/endocrine oncology.

116 • Oncologist.

117 • Radiologist

118 • Nuclear medicine specialist.

119 • Specialist pathologists (both histopathology and cytopathology).

120 • Clinical Nurse Specialist (who may be a head and neck cancer CNS).

121 • Secretarial and support staff, as above.

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

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

128 **Responsibilities of MDTs**

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

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

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

150 MDT and the MDT considers this to be appropriate. Such treatment should be consistent
151 with the treatment plan developed by the MDT.

152 *The Clinical Nurse Specialist (CNS)*

153 A named head and neck cancer clinical nurse specialist (CNS) should be available to
154 support every patient, throughout the course of the disease. The CNS should be informed
155 about each new patient when a definitive diagnosis is made, although she (or he⁶⁹) may
156 delegate provision of support at the time the patient is given the diagnosis to another
157 named nurse. Patients and carers should be given contact details for their CNS or named
158 nurse, so that they can get in touch if they have questions about their condition, or if they
159 need help to cope with their disease or its consequences.

160 The CNS requires highly developed communication and psychosocial skills, so that she
161 can recognise patients' non-clinical needs as well as problems directly associated with
162 their cancer or treatment. She should be closely involved in helping patients and their
163 families to understand the nature and potential impacts of the interventions that may be
164 required, and provide expert help when required with managing the practical, social and
165 psychological consequences of treatment. This type of help is essential during the post-
166 operative period and may be necessary for a considerable time after discharge from
167 hospital (see Topic 7, After-care, rehabilitation and follow-up).

168 The CNS should see and assess each patient before decisions about management are made
169 by the MDT.

170 The CNS should take a leading role in providing care for patients, working in a flexible
171 way with other professionals across institutional boundaries and in the community. The
172 provision of education and support for other members of the nursing team is an important
173 facet of this role. The CNS should be available to help and advise nurses working in ENT,
174 head and neck and maxillofacial departments and primary health care teams, and to
175 facilitate the development of the skills required to care for patients whose needs may be
176 unique to head and neck cancer. Other professionals should be able to consult the CNS for

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

177 expert advice on issues such as managing patients with tracheostomies, gastrostomies,
178 prostheses, or difficult wounds.

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

186 *The Speech and Language Therapist (SLT)*

187 Speech and language therapists, like Clinical Nurse Specialists, have wide-ranging roles in
188 supporting patients with head and neck cancer. Their expertise is essential for helping
189 patients whose cancer or treatment causes problems with communication or swallowing,
190 but they also provide psychosocial support and should contribute to MDT discussions on
191 treatment planning. They should share responsibility with other MDT members for
192 assessment of communication and swallowing before treatment, discussing the potential
193 impact of proposed treatments on the patient, and helping patients who have problems
194 with eating, drinking or communication during and after treatment. A dedicated SLT
195 should be available to work with such patients for substantial periods of time. (See Topic
196 6, After-care and rehabilitation.)

197 *Dietitian*

198 Dedicated dietitians should be available for all patients who may require their help, and
199 should work co-operatively with the SLT and CNS. The dietitian should be involved in
200 pre-treatment assessment, taking action to correct patients' pre-existing nutritional
201 deficiencies before treatment begins. The dietitian can play an important role throughout
202 the patient's cancer journey, providing nutritional support, and advice on tube feeding and
203 on coping with the after-effects of treatment.

204 ***Dental services***

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

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

213 ***Nuclear medicine specialist***

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

216 ***Psychological services***

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

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

227 **How the teams function**

228 Each MDT should have an administrative head (the Lead Clinician) who should work
229 closely with the co-ordinator, but a democratic ethos should be encouraged during

230 meetings. It is important that all clinical members of the MDT should play active parts in
231 discussing treatment plans, since each can offer a distinctive and valuable perspective; the
232 participation of clinical nurse specialists, speech and language therapists, dietitians, and
233 other allied health professionals should be regarded as essential to the function of the
234 team. MDTs should consider taking training in effective team-work.

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

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

244 **Organisation of MDT meetings**

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

- 249 • Every patient with a new diagnosis of cancer in any head and neck site with which
250 the MDT deals. The MDT co-ordinator should work with pathologists and
251 radiologists to ensure that all such cases are identified.
- 252 • All patients who have undergone initial surgery. Detailed review of pathology after
253 surgery is important to inform decisions about further treatment and has prognostic
254 value.
- 255 • All patients with newly identified recurrent or metastatic disease.

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

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

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

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

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

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

281 **Achieving consistency within networks**

282 Network-wide guidelines should be agreed, with joint protocols for clinical management,
283 referral and audit. Information about each patient should be recorded in the database
284 produced by BAHNO, as part of the ongoing nationwide audit known as DAHNO (see
285 Background, page 33). There should also be network-wide audit, not only of clinical
286 issues and outcomes, but also of patients' and carers' experience of the service.
287 Information derived from audit should be used to identify and reduce variations within
288 networks.

289

290 **B. Anticipated benefits**

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

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

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

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

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

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

330 At present, the service for patients with thyroid cancer is particularly fragmented. Many
331 are managed by general surgeons who do not have a special interest in thyroid cancer;
332 even in “specialist centres”, some patients do not receive adequate treatment. This may
333 explain why long-term survival rates are poorer in England than in Scandinavia (see
334 Background). Consolidation of services in the hands of experts will increase the
335 probability that every patient receives appropriate treatment.

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

339

340 **C. Evidence**

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

345 **The situation in the NHS**

346 *UAT cancers*

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

354 Professionals spoke of the value of teamwork. All participated in joint clinics, although
 355 the composition of these varied. Surgeons and oncologists reported that planning
 356 treatment in joint clinics with colleagues from different disciplines kept them up to date,
 357 made sure that they considered all options for treatment, and provided them with support
 358 and a chance to discuss their difficult cases. The concept of the team spoken about by the
 359 professionals in the study had moved away from separate cure and care teams, to one team
 360 which included all professionals, the patient and the family. The role of the surgeon
 361 within the team had also changed. “It used to be thought that the Captain (surgeon) knows

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

362 it all and can fly the whole plane and all its contents and crew out of danger. And they
 363 have very sensibly abandoned that idea years ago and it's a team that flies the aircraft,
 364 taking due recognition of everybody's contribution... We are not there to cut out a tumour
 365 we are there to provide a route of survival for a person."⁷¹

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

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

376 In the South and West Region, it was decided that 95% of all new head and neck cancer
 377 patients should be seen in a combined clinic prior to treatment. In 1997, no trust achieved
 378 this level; indeed, in 16 of the 22 trusts, fewer than 60% of patients were seen in a
 379 multidisciplinary clinic before treatment began. However, in each of the four trusts which
 380 treated the largest numbers of patients (50-65 per trust), about two thirds of patients did
 381 receive multidisciplinary assessment. Overall, 46% of patients were seen in combined
 382 clinics.⁷⁴ The SWAHNII audit revealed that this situation had changed substantially by
 383 1999/2000, when 74% of patients were seen in combined head and neck clinics.⁷⁵

⁷¹ *Ibid*, p19.

⁷² 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

⁷³ Commission for Health Improvement/Audit Commission. *NHS Cancer Care in England and Wales*. London: CHI/AC. 2001.

⁷⁴ 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.

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

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

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

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

403 Only 40 per cent of trusts/hospitals had a specialist nurse (CNS) for head and neck cancer
404 in 2000/2001.⁷⁶

405 ***Thyroid cancer***

406 In the Northern and Yorkshire Cancer Registry (NYCRIS) area in 1998-9, patients with
407 thyroid cancer were most likely to be treated by general surgeons working outside MDTs.
408 59% of patients were treated by surgeons who dealt with fewer than ten cases in the two-
409 year period studied (i.e. an average of five or fewer cases per year); and in over a third of

⁷⁶ Commission for Health Improvement/Audit Commission. *NHS Cancer Care in England and Wales*.

410 cases, treatment was given by surgeons whose case-load averaged two or fewer per year.
411 Audit based on questionnaires, with a response rate of 60%, revealed that half of the
412 consultants who performed surgery for thyroid cancer worked in MDTs; of those who did
413 not, 62% met regularly with oncologists and 81% discussed the diagnosis with a
414 pathologist or imaging specialist. Only 56% of MDTs which managed thyroid cancer
415 patients discussed every case. 44% of these MDTs also dealt with other endocrine
416 cancers, 22% were head and neck cancer teams, whilst 31% did not specify any other
417 cancers in their remit.⁷⁷

418 **Research evidence on patient volumes, specialisation and MDT management**

419 A study of outcomes in 206 patients with oral cancer in the west of Scotland found that
420 those treated by a specialist team (n=124) were less likely to have recurrent disease and
421 survived for significantly longer than patients managed in less specialised units (82
422 patients treated in 13 units by 24 surgeons). The hazard ratio for recurrence, calculated by
423 a multivariate analysis that included disease stage, sex, age and deprivation, in patients
424 treated in smaller units was 1.43 (95% CI 1.02 to 2.02); for death, it was 1.48 (95% CI
425 1.06 to 2.06). This difference disappeared when treatment strategy was accounted for,
426 which suggests that concentration of services in one hospital has allowed the MDT to
427 develop considerable experience in delivering individually-designed treatments. These
428 treatment strategies seem to be more effective than those designed by clinicians who see
429 fewer patients.(B)

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

London: CHI/AC. 2001.

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

435 A study of treatment for thyroid cancer from England found significant differences
436 between the adequacy of management by a multidisciplinary team of specialists and that
437 provided by other clinicians. The former group was much less likely to carry out
438 inadequate surgery, more likely to give radioiodine treatment when indicated, and more
439 likely both to monitor thyroglobulin⁷⁸ and deal appropriately with high thyroglobulin
440 levels. (B) All these have previously been shown to be independent predictors of long-
441 term survival.⁷⁹

442 A report from the US suggests that surgeons who carry out thyroidectomy (for benign or
443 malignant disease) relatively frequently achieve lower complication rates than those who
444 do so rarely. Among patients treated by surgeons who carried out the fewest
445 thyroidectomies (two or fewer per year), the complication rate was 16%, compared with
446 4% among those whose surgeons carried out 20 or more such procedures per year. The
447 authors conclude that individual surgeon experience is significantly associated with
448 complication rates and length of stay in hospital. (B)

449 A study from the West Midlands Cancer Registry of treatment received by patients with
450 parotid cancer between 1977 and 1986 found that management varied with surgical
451 specialty. 62% of 196 patients were treated by general surgeons, 14% by ENT surgeons
452 and 8% by plastic or dental surgeons. ENT surgeons were significantly more likely to
453 remove the parotid gland than others, whilst patients treated by general surgeons were
454 more likely to receive radiotherapy. (B)

455

456 **D. Measurement**

457 **Structure**

⁷⁸ High serum thyroglobulin levels can indicate residual or recurrent thyroid cancer.

⁷⁹ 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.

- 458 • Evidence that each Network has an appropriate range of MDTs, constituted as
459 recommended.
- 460 • Availability of sufficient numbers of Clinical Nurse Specialists, specialist dietitians and
461 speech and language therapists (SLTs) to handle the wide-ranging roles described in
462 this Manual.
- 463 • Access to specialist training in the needs of patients with head and neck cancer for
464 general dietitians, nurses who may wish to become head and neck cancer CNSs, and
465 less specialised SLTs.

466 **Process**

- 467 • Evidence that every patient is discussed by a suitable MDT at the first opportunity after
468 initial diagnosis and assessment, and when recurrent disease is identified.
- 469 • Evidence that each MDT works with written protocols for disease management.
- 470 • Evidence that every patient is interviewed by a CNS and given her contact telephone
471 number.
- 472 • Evidence of participation by individual specialists in MDT meetings.

473 **Outcome**

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

475

476 **E. Resource Implications**

477 Many more dedicated staff (both medical and non-medical) are required to create head and
478 neck cancer MDTs; resources will be needed for specialist training and employment.

479 [Note: The section on Resource Implications will be reviewed in the light of the “Analysis
480 of the Potential Economic Impact of the Guidance” – available in draft with the Research
481 Evidence. A summary is included as Appendix 1 in this draft of the Manual].

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. The desired model of diagnostic services is described below, and commissioners should work towards this. However, it is recognised that it will take some time before adequate numbers of appropriately trained staff are available to implement these recommendations fully. Interim arrangements should, as far as possible, be consistent with this model.

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

Initial investigations and diagnosis

At each local hospital which offers a diagnostic service for head and neck cancers, patients with symptoms that could be due to cancer should be seen by designated clinicians (See Topic 1) 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.

27 *Cancers of the upper aerodigestive tract*

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

34 An initial biopsy may be taken by the lead clinician at the DGH, but where there is little
35 doubt about the diagnosis, onward referral should not await pathology results. Clinicians
36 who have a particular interest in head and neck cancer may, if they wish, join the MDT for
37 meetings at which patients they referred are discussed.

38 Patients with neck lumps which persist for more than three weeks despite treatment, or
39 suspected salivary gland tumours should be referred to specialist lump clinics for
40 investigation. These lump clinics should be broadly similar to one-stop breast diagnosis
41 clinics, but organised collaboratively by haematology, ENT, and services for head and
42 neck cancer.

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

50 Any patient with an isolated neck lump should first be examined by flexible endoscopy.
51 There should be an experienced on-site cytologist who can provide FNAC in the clinic to
52 determine the nature of the lump; however, this may take some time to achieve and
53 interim arrangements may be necessary. Ultrasound guidance is a useful adjunct to either
54 FNAC or needle core biopsy and its use is expected to increase. No patient should

55 undergo surgical excision or biopsy of an enlarged lymph node without preliminary
56 discussion with a haematologist or oncologist.

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

59 ***Thyroid cancer***

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

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

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

74 **Informing patients**

75 Patients should be encouraged to bring a carer or relative to the appointment at which they
76 are to be told that they have cancer.

77 The diagnosis and its implications should be discussed with the patient by a senior
78 member of a Head and Neck Cancer MDT, in a quiet, private room with no distractions.
79 Each patient should be supported both during and after this consultation by a suitably
80 trained nurse. The Clinical Nurse Specialist (CNS) should be informed about each new
81 patient when a definitive diagnosis is made and may provide direct emotional support at

82 this time; alternatively, she (or he⁸⁰) may delegate provision of such support to another
83 named nurse. This nurse should give a contact telephone number to the patient and remain
84 available to answer questions and provide advice, information and support for both
85 patients and carers.

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

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

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

⁸⁰ 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.

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

- 109 • Any pre-treatment interventions that may be required;
- 110 • The likely nature, timing and duration of the forms of treatment that are likely to be
111 recommended (as far as this can be judged);
- 112 • A realistic assessment of anticipated outcome: in particular, the probability that initial
113 treatment will eradicate the tumour or that more than one form of treatment may be
114 required;
- 115 • Short- and long-term adverse effects of different types of intervention;
- 116 • Support services;
- 117 • Rehabilitation;
- 118 • Other treatment-related issues which may be relevant to the patient and his or her
119 particular form of cancer;
- 120 • Members of the MDT responsible for the patient;
- 121 • The hospital(s) where interventions are to be provided. This should include
122 information about car parking, access, visiting arrangements and other practical details
123 relevant to patients and carers.

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

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

133

134 **B. Anticipated benefits**

135 The benefits of giving patients adequate information, breaking bad news sensitively, and
 136 providing support at the crucial time of diagnosis, are well documented. These issues are
 137 discussed both in previous documents in this series and in the supportive and palliative
 138 care guidance.

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

141

142 **C. Evidence**

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

147 **Diagnostic value of FNAC and core biopsy in thyroid cancer**

148 In an Italian study, both FNAC and core biopsy were performed on 136 patients diagnosed
 149 with thyroid nodules by ultrasound scanning. Tissue samples were examined by
 150 experienced pathologists. The results suggest that both methods may permit accurate
 151 diagnosis, but whilst FNAC produced sufficient material in all cases, core biopsy did not.
 152 However, this study had serious methodological flaws. (B)

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

155 **Effectiveness of written information for patients with head and neck cancers**

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

159 A Canadian study assessed the effects of educational pamphlets for patients explaining
160 risks associated with surgery to remove the thyroid or parotid gland. The results
161 demonstrated that those patients who received written information recalled significantly
162 more than those to whom potential complications were only explained orally. Other
163 outcomes, such as anxiety, were not measured. (B)

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

170 A wide-ranging support strategy developed for patients undergoing laryngectomy in
171 England included a comprehensive information pack with material on topics ranging from
172 the procedure itself to support groups and financial benefits. The information pack was
173 used by a CNS to explain the operation and its consequences to patients and their families.
174 85% of patients who were given the pack felt that they had been given as much
175 information and support as they needed on diagnosis, compared with 59% of those who
176 were not. Of the three patients (15%) who had had the information pack yet did not feel
177 they had enough information, one had required emergency surgery which did not allow
178 time for provision of the usual level of support, and another had received more radical
179 surgery than had been anticipated. (B)

180 **Psychosocial issues**

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

185 **Patients' experience of NHS services**

186 The National Cancer Alliance (NCA) survey of head and neck cancer patients' experience,
187 carried out to inform the guidance,⁸¹ revealed that some consultants were reluctant to
188 provide the information that patients wanted. This tended to heighten anxiety.

189 Respondents generally expressed a need to be kept informed; those who had little support
190 or information described a stressful period before treatment, when they felt isolated and
191 fearful. All felt that written information and ready access to support, for example from
192 specialist nurses and counsellors, was needed at this stage.

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

199 An earlier study of patients' experience of head and neck cancer (*Face to Face*⁸²)
200 discusses psychological issues surrounding the diagnosis and confronting the prospect of
201 radical treatment in some detail. The author states emphatically that, "Information and
202 choice were two of the strongest themes to emerge from the patient, carer and professional
203 focus groups." (p.31) Meeting patients' needs for information so that they can participate
204 in decisions about care is a strategy for empowerment for people with cancer and the
205 teams which support them. The information should be designed to meet patients' needs:
206 people with cancer are more concerned to know about the potential effects of treatment on
207 their lives – for example, whether they will be able to eat or speak, the amount of scarring
208 that is likely to result, and how treatment could affect their ability to have children – than
209 technical details.

⁸¹ National Cancer Alliance, *Patients' views of head and neck cancer services and developing national guidance*. National Cancer Alliance, 2002.

⁸² Edwards, D. *Face to Face: Patient, family and professional perspectives of head and neck cancer care*. London: King's Fund, 1997.

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

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

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

223

224 **D. Measurement**

225 **Structure**

- 226 • Written protocols, agreed by all head and neck cancer MDTs in the Network, which
227 specify investigations for each type of presentation of possible head and neck cancer.
- 228 • Specific guidelines for investigation and diagnosis of each form of head or neck cancer,
229 including thyroid cancer.
- 230 • Availability of rapid-access FNAC services for patients with neck lumps or suspected
231 salivary gland tumours.
- 232 • Network-wide systems for monitoring the quality of cytopathology services.
- 233 • Availability of appropriate facilities and staff for discussing the diagnosis with each
234 new patient.

- 235 • Availability of written information for patients about their cancer, proposed
236 interventions, members of the MDT and their roles, and hospital and support services.

237 **Process**

- 238 • Evidence that biopsy samples from possible cancers are sent to a designated pathologist
239 with expertise in identification of head and neck cancer.

- 240 • Audit of accuracy of FNAC.

- 241 • Audit of delay between initial investigation and definitive diagnosis.

242 **Outcome**

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

244

245 **E. Resource Implications**

246 [Note: The section on Resource Implications will be reviewed in the light of the “Analysis
247 of the Potential Economic Impact of the Guidance” – available in draft with the Research
248 Evidence. A summary is included as Appendix 1 in this draft of the Manual].

249

4. Pre-treatment assessment and management

A. Recommendations

Initial assessment

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

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

A CNS should spend some time talking with each patient and carer. She should provide support and information, learn about the patient's values, attitudes and domestic situation, and assess the patient's non-medical needs. She should then liaise with primary care teams and other agencies, such as social services and occupational therapy, as necessary.

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 without delay and patients with addiction problems should also be referred to local smoking cessation services, alcohol dependency or addiction services, as appropriate.

27 **Imaging**

28 All patients with UAT cancers should have chest x-rays. Other forms of imaging are
29 necessary to assess the stage and spread of the tumour, and specialist ultrasound, CT and
30 MRI should be available. If imaging shows possible tumour invasion of the skull, the
31 patient should be referred to an MDT which has specific expertise in treating this type of
32 problem. PET imaging should be used, if available, when it is important to differentiate
33 between benign and malignant lung nodules. It is anticipated that the role of PET will
34 increase over the course of the next decade.

35 **Decision-making about treatment**

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

43 Appropriate members of the MDT, usually a surgeon, oncologist, clinical nurse specialist,
44 dietitian and speech and language therapist, should discuss possible treatment options with
45 the patient. Patients should be offered full information about all potential treatment options
46 and their anticipated effects, so that those who wish to contribute to decision-making are
47 able to do so. The discussion should be carried out in a sensitive way, in a series of
48 meetings if necessary, so that patients do not feel intimidated or overwhelmed by
49 professionals. (See Topic 2, Diagnosis and Assessment.) The patients should be given
50 adequate time to consider the MDT's proposals and raise any concerns before the final
51 plan is agreed.

52 **Dental assessment**

53 Patients whose treatment will affect the mouth or jaw should be examined by a specialist
54 dentist and any dental problems should be identified and treated before cancer treatment

55 begins. Patients who are to have radiotherapy should be treated without delay, to allow
56 time for healing. A dental hygienist should work with these patients to achieve high
57 standards of oral hygiene, to reduce problems after treatment. Patients' dental prostheses
58 should be assessed, along with the denture-bearing ridges, to check that the prosthesis is
59 both comfortable and effective. Those who are to undergo surgery to the jawbone should
60 be assessed by the restorative dentist who works with the surgeon in the MDT.

61 **Preparation for treatment effects on speech, nutrition and swallowing**

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

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

72 The dietitian and SLT should work closely together, sharing responsibility for explaining
73 nutritional issues to the patient and ensuring that he or she is prepared for any
74 interventions that may be required before treatment begins. Patients and carers should be
75 given specific advice on food preparation and diet to maintain adequate nutrition during
76 outpatient treatment and after discharge from hospital.

77 Patients whose treatment is likely to affect their ability to communicate should meet their
78 SLT before treatment begins. The SLT should explain rehabilitation strategies to the
79 patient and carer, describing how she (or he⁸³) will work with the patient to make the most
80 of his or her potential for recovery of speech, voice and swallowing.

⁸³ In the text below, the pronoun "she" is used for convenience to refer to the SLT, although it is recognised

81 **Anaesthetic assessment**

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

84

85 **B. Anticipated benefits**

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

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

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

104 Psychological problems are also more common in these patients than in the general
105 population, and the effects of treatment on social relationships can magnify pre-existing

that the SLT may be male.

106 problems; it is therefore important that these patients' psychological needs are recognised
107 and - as far as possible - met, from the beginning of the process. Alcohol and nicotine
108 dependence are common; recognising and dealing promptly with such addiction can both
109 prevent acute withdrawal problems when patients undergo treatment, and improve longer
110 term outcomes.

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

115

116 **C. Evidence**

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

121 **Prevalence of co-morbidity**

122 A study carried out in a large US hospital found that 21% of 341 patients with head and
123 neck cancer had moderate or severe co-morbidity (other illness, such as respiratory or
124 cardiovascular conditions) – a rate significantly exceeded only by patients with lung
125 cancer, and similar to that for patients with colorectal cancer. Death-rates among these
126 patients were markedly higher than among those with less co-morbidity.⁸⁴

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

⁸⁴ Piccirillo JF. Importance of comorbidity in head and neck cancer. *Laryngoscope* 2000;110:593-602.

131 Nutritional assessment

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

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

153 Dental assessment

154 The evidence review shows that a high proportion of patients have very poorly maintained
155 teeth and many require extensive dental treatment before radiotherapy. One study was
156 identified from the Mersey region of England; this reports on case notes for 1719 patients
157 treated with radiotherapy for head and neck cancers between 1987 and 1990. Only 13% of
158 these records gave information on dental condition and treatment. 250 new patients had
159 dental assessments before treatment in 1990; 65% had not seen a dentist for over three

160 years and their teeth were in a very poor state. 68% required extractions. 21% had full
161 dentures which were over five years old and generally unsatisfactory. (B)

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

169 One study reported on the effectiveness of dental care (careful examination, oral hygiene,
170 atraumatic extractions and use of topical fluoride) before radiotherapy in 528 patients,
171 65% of whom had UAT cancers. In the majority, dental health was preserved after
172 radiotherapy; 3% of patients, most of whom had failed to comply with the recommended
173 dental programme, developed radiation-related caries. (B)

174 **Decision-making about treatment**

175 Research based on focus groups in South East England revealed that more patients wanted
176 to be involved in decisions about their treatment than actually were. In general, younger
177 patients wanted more involvement, whereas some older patients felt that it made no
178 difference as doctors would do as they wanted anyway. Some people were given choices
179 in their treatment but did not have enough information on which to base a choice. Most
180 patients wanted to make a joint decision with the advice of their clinician and have their
181 views taken into account.

182 Clinicians acknowledged considerable uncertainty about optimum treatment in particular
183 cases, but opinions differed about how much choice patients should be given. Many felt
184 that patients should be involved in choices about rehabilitation and palliative care but the
185 choice of primary treatment should be made by the consultant. Everyone agreed that the
186 patient should have a veto on their treatment but few clinicians presented a range of
187 options with their relative merits, either because of time constraints or for philosophical
188 reasons. “Very often what we do is to make a decision and test with the patient whether

189 that decision is completely unacceptable, which is probably paternalistic. It may be the
190 wrong way round but I suspect that's what we do."⁸⁵

191 **Psychological interventions**

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

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

201 A pilot study of group psychological therapy reported that patients who participated more
202 than once in the group (eight of 25 patients invited) had worse scores on validated quality
203 of life measures at the beginning of the study than controls. After a year, those who
204 participated in psychological therapy showed greater improvements in most areas of
205 functioning than controls who only completed the questionnaires. The greatest benefits of
206 the intervention were in emotional and social functioning, and in global quality of life.
207 Participants particularly valued the opportunity the group gave to talk with other patients
208 about their feelings and reactions to their disease. (B)

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

⁸⁵ Edwards, D. *Face to Face: Patient, family and professional perspectives of head and neck cancer care*. London: King's Fund, 1997, p42.

214 **Practice in the NHS**

215 *Assessment by dietitian and access to SLT*

216 The SWAHNII audit revealed that overall, fewer than half of all patients with newly
 217 diagnosed UAT cancers in the South and West in 1999-2000 saw a dietitian (34%, 46%
 218 and 37% for cancers of the larynx, oral cavity and other sites, respectively).⁸⁶ The locally
 219 agreed standard against which this may be judged was that 95% should have such an
 220 assessment. There was very marked variability between areas; for example, in the Dorset
 221 Cancer Network, no patients with larynx cancer saw a dietitian, in contrast to the “Three
 222 Counties”, where 92% did. It may not be a coincidence that Dorset dealt with much
 223 smaller numbers of these patients than any other Network in the audit.

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

228 *Imaging*

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

235

236 **D. Measurement**

237 **Structure**

⁸⁶ South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001.

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

246 **Process**

- 247 • Evidence that patients who are dependent on alcohol, nicotine or other drugs receive
248 care plans which address their needs for counselling and/or cognitive-behaviour therapy
249 to help them to overcome their dependency before definitive treatment begins.
- 250 • Evidence that every patient with UAT cancer has a chest X-ray or CT scan of the chest.
- 251 • Evidence that every patient whose treatment is expected to affect eating, swallowing or
252 breathing is assessed by a specialised speech and language therapist before treatment
253 begins.
- 254 • Evidence that every patient is assessed by a specialised dietitian before treatment
255 begins.
- 256 • Evidence that patients whose treatment is likely to involve the jaw are referred to
257 appropriate members of the MDT, such as dental specialists, dietitians and speech and
258 language therapists.

259 **Outcome**

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

261

262 **E. Resource Implications**

263 [Note: The section on Resource Implications will be reviewed in the light of the “Analysis
264 of the Potential Economic Impact of the Guidance” – available in draft with the Research
265 Evidence. A summary is included as Appendix 1 in this draft of the Manual].

266

1 **5. Primary treatment**

2

3 **A. Recommendations**

4 **Information for patients**

5 All patients who are to undergo treatment for any form of head and neck cancer should
6 have been given opportunities to discuss information about the potential effects of that
7 treatment with members of the MDT beforehand, so that they know what to expect. They
8 should have clear and accessible information in written form, describing the potential risks
9 of treatment as well as its anticipated benefits, in a language they understand. Such
10 information provided should cover the procedure itself, anticipated time-scales, and short-
11 and long-term effects of treatment. High-quality videotapes are available on
12 laryngectomy; these should be given to patients who are to have this operation. Patients
13 should be encouraged to talk through any issues that may concern them after studying this
14 information with their SLT, CNS, or other appropriate member of the team. When
15 primary treatment is complete, each patient should be offered a candid assessment of its
16 success and given the opportunity to discuss any further interventions that are being
17 considered.

18 **Cancers of the Upper Aerodigestive Tract**

19 *Availability of treatment and support*

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

27 *Surgery*

28 It is anticipated that all surgery for head and neck cancer will be centralised within the
29 next decade. During this period, however, minor surgery to remove early tumours may be
30 carried out by nominated surgical specialists in District General Hospitals. This is only
31 appropriate if these surgeons are active members of the head and neck cancer MDT and
32 can provide adequate post-operative support, aftercare and rehabilitation for their patients.
33 In each case, treatment must be planned by the MDT in a formal MDT meeting at which
34 pathological and imaging data are discussed.

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

41 All surgical modalities, including laser excision and partial laryngeal excision, should be
42 available. Microvascular expertise is essential in reconstructive surgery to minimise the
43 risk of flap failure (failure of tissue grafts used to restore the patient's appearance and
44 function after surgery), which is a major source of morbidity among these patients. There
45 should be 24 hour access to emergency surgery to reverse flap failure.

46 Surgical voice restoration should be available for patients who undergo laryngectomy.
47 This service should be adequately supported, with specialist SLT support on wards,
48 appropriate rehabilitation services and equipment (See Topic 6). The specialist SLT
49 should train nurses and medical staff to carry out basic troubleshooting for these patients,
50 so that they are able to deal with common problems such as leaking or inhaled voice
51 prostheses and breathing and swallowing problems that may occur out of hours. Ongoing
52 rolling training programmes should be planned to allow for staff rotation and changes.

53 Surgery for suspicious or malignant salivary gland tumours, or those which involve the
54 skull, should be carried out only by surgeons with specific expertise in this work after
55 discussion by an appropriate MDT (See Topic 2, Structure of Services). When salivary

56 gland cancer is discovered unexpectedly after initial surgery for what was believed to be a
57 benign condition, the patient should be referred immediately to a head and neck cancer
58 MDT which specialises in salivary gland cancers.

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

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

67 **Radiotherapy**

68 Access to modern radiotherapy facilities, including 3D conformal treatment where
69 appropriate, should be available. Many patients are treated with radiotherapy alone, but
70 those with more advanced disease may require both radiotherapy and surgery or
71 chemoradiation. The interval between surgery and radiotherapy should be as short as
72 possible, ideally less than six weeks. Radiotherapy departments should make every effort
73 to ensure that each patient receives a complete and unbroken course of the prescribed
74 treatment; gaps in treatment must be avoided if at all possible. If radiotherapy is
75 interrupted, the schedule should be altered to minimise the effects of the interruption, as
76 recommended by the Royal College of Radiologists' guidelines.⁸⁷

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

⁸⁷ 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.

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

84 The importance of mouth care and oral hygiene during and after treatment should be
85 emphasised to patients, and appropriate palliative measures should be taken to minimise
86 problems with the lining of the mouth.

87 *Support for patients undergoing radical therapy*

88 Treatment for head and neck cancers can cause problems with eating, swallowing,
89 breathing, speech and voice, and specific support should be provided for all patients who
90 may need it, both during and after treatment. Patients should be educated about adverse
91 effects of treatment before it begins, so that they know what problems may be anticipated,
92 when they are likely to occur, how to minimise their impact, and how long they may be
93 expected to last. They should have access to help and advice from their CNS and other
94 appropriate specialists (such as speech and language therapists, dietitians and
95 physiotherapists) when required, throughout the period of treatment and rehabilitation.

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

101 Patients treated with radiotherapy need access to support over a protracted period, both in
102 their homes and in the radiotherapy centre. Radiotherapy departments should have
103 radiotherapy support clinics, staffed by cancer nurses and/or therapy radiographers who
104 receive education and support from head and neck cancer CNSs and specialised SLTs.
105 Patients should have access to a specialist oncology dietitian and speech and language
106 therapist within the radiotherapy centre, who should liaise closely with their counterparts
107 in the patient's local support team (see Topic 6, After care and rehabilitation). Patients
108 and their carers should be given a telephone number for a radiotherapy helpline so that
109 they have access to advice at weekends.

110 Many patients rely on gastrostomy or nasogastric tube feeding, at least in the short term.
111 They need support from dedicated dietitians before, during and after the period of
112 treatment, to cope with feeding problems and maintain their nutritional status (see Topic 4,
113 Pre-treatment assessment and management). The cancer network should ensure that there
114 are adequate facilities for placement of gastrostomy tubes and local services which can
115 replace nasogastric tubes when necessary.

116 Patients and their carers should be given guidance on the preparation of purée meals
117 before discharge from hospital.

118 *Other treatment modalities*

119 These are discussed in the context of recurrent disease (Topic 6).

120 **Treatment for thyroid cancer**

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

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

133 Further treatment, such as ablation of residual thyroid tissue using radioactive iodine or
134 external beam radiotherapy (used for locally advanced disease, residual disease after
135 surgery, and some rare forms of thyroid cancer), is likely to require expertise and facilities
136 which are only available in a limited number of hospital sites, mainly Cancer Centres.

137 These include special rooms for patients undergoing radioiodine treatment, to prevent the
138 spread of radioactivity into the wider environment.

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

143 **Research and service development**

144 Because head and neck cancers are relatively rare, collaborative research is essential to
145 improve the effectiveness of treatment and care management. Head and neck cancer
146 MDTs should be actively involved in relevant studies within the NRCN portfolio. Cancer
147 Centres should consider developing academic links to facilitate basic research into these
148 forms of cancer.

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

153

154 **B. Anticipated benefits**

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

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

164

165 **C. Evidence**

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

170 **UAT cancers**171 ***Choice of treatment modality***

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

180 ***Surgery***

181 Major centres report success rates for complex reconstructions after radical surgery in over
 182 90% of flaps for patients with head and neck cancers.⁸⁸ Cigarette smoking and weight loss
 183 of more than 10% before surgery are associated with higher rates of major complications.

184 ***Radiotherapy***

185 There is consistent evidence that minimising treatment time can be crucial to the success
 186 of radiotherapy for head and neck cancers. Awareness of the importance of overall
 187 treatment time has increased over recent decades and conventional radiotherapy schedules

⁸⁸ 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.

188 used in RCTs have been intensified by 4-5 Gy; this corresponds to an increase of over
189 10% in the probability of local tumour control. (A) However, even in RCTs, compliance
190 with the prescribed schedule can be relatively poor. For more than a quarter of patients
191 included in major trials, the time taken to complete treatment exceeded that prescribed by
192 more than five days. (B)

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

201 Further evidence relating outcomes to the length of time taken to complete radiotherapy
202 treatment was reported in a study which found that patients whose treatment was
203 completed in less than 48 days (median duration 45 days) had a 60% chance of survival at
204 two years, compared with 54% survival among those whose treatment took 49 days or
205 more (median 50 days). After adjustment for risk factors assessed before treatment, this
206 translates to a non-significant benefit of 3% for those whose treatment was completed
207 more quickly. (B) A study of split course radiotherapy, used for patients with more
208 advanced tumours, found that interruption of therapy and prolonged overall treatment time
209 was associated with worse loco-regional control and disease-free survival. Multivariate
210 analysis suggests that each day of interruption of treatment increased the hazard rate by
211 3.3% for loco-regional failure and 2.9% for disease-free survival. (B) These figures may
212 not, however, be reliable because of methodological flaws in the study.

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

216 Audit data shows that interruptions in radiotherapy for head and neck cancer are not
217 uncommon. In the UK in 2000, treatment for 37% of patients was prolonged for two days

218 or more. The most important cause of interrupted treatment was machine downtime,
219 either planned servicing or to deal with machine breakdown. In 14% of cases, treatment
220 was interrupted because of adverse reactions to radiotherapy.⁸⁹

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

228 This potential benefit is balanced by more severe acute adverse effects. One study
229 suggested that patients had greater problems with eating and speech a year after
230 accelerated radiotherapy, but gave no details. A Canadian review of a Texan study which
231 examined quality of life outcomes reported significant improvements in some aspects of
232 quality of life after accelerated radiotherapy, but significantly more pain at day 21. In this
233 study, the two-year loco-regional control rate was 54% for accelerated radiotherapy and
234 46% for conventional treatment ($p=0.045$), but survival differences did not reach statistical
235 significance. (A)

236 ***Chemoradiation and chemotherapy***

237 Three meta-analyses of randomised controlled trials comparing radiotherapy alone with
238 radiotherapy and concomitant chemotherapy (chemoradiation) have concluded that
239 chemoradiation can improve survival rates in head and neck cancer. One, based on
240 individual data for 3,727 patients in 26 trials, found a hazard ratio for death of 0.90 (95%
241 CI, 0.85 to 0.94, $p<0.0001$), which corresponds to an absolute survival benefit of 4% at
242 two and five years. Chemotherapy was only beneficial when it was given over the same
243 time-period as radiotherapy. (A)

⁸⁹ 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.

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

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

258 Neoadjuvant chemotherapy – chemotherapy given before local treatment with surgery,
259 radiotherapy or both – does not improve survival in patients with locally advanced head
260 and neck cancer. Meta-analysis of individual patient data from 31 trials (5,269 patients)
261 produced a hazard ratio (HR) of 0.95 (95% CI, 0.88 to 1.01, $p = 0.10$). Pooling data from
262 three trials (602 patients) which compared larynx preservation with surgery (with or
263 without neoadjuvant chemotherapy) showed a non-significant benefit for surgery (HR
264 1.19, 95% CI, 0.97 to 1.46; $p = 0.10$). (A)

265 ***Prophylaxis for oral mucositis***

266 A Cochrane review of randomised trials of prophylactic agents for oral mucositis in
267 patients treated with radiotherapy or chemotherapy included 52 studies ($n = 3,594$). The
268 most effective intervention appears to be ice chips, with an odds ratio of 0.42 (95% CI,
269 0.19 to 0.93). Other interventions, including GM-CSF, antibiotic paste or pastilles and
270 hydrolytic enzymes also reduce the severity of the problem. This review included a
271 variety of types of cancer and treatments and the benefits may not be the same for all. (A)

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

275 ***Interventions for treatment-related xerostomia (dry mouth)***

276 A variety of types of intervention can relieve the symptoms of treatment-related
277 xerostomia. These include pilocarpine, amifostine, topical sprays containing mucin, and
278 various over-the-counter products designed to relieve mouth problems, including
279 mouthwash, chewing gum, toothbrushes and gel. (B) Pilocarpine is effective for patients
280 with adequate pre-treatment salivary function, but produces dose-related adverse effects,
281 particularly increased sweating; these adverse effects are not, however, severe. (A)

282 ***Nutritional support and dietary supervision***

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

289 ***Relaxation therapy for patients undergoing radiotherapy***

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

296 ***Patients' views on hospital services***

297 Focus group interviews with patients and relatives in South East England revealed concern
298 about hospital accommodation, information about side effects, choice, support services

299 and the impact of treatment. Patients who were happiest with their accommodation were
300 those who were nursed in side rooms and those who were on cancer wards. Many who
301 had been in wards with patients having different procedures felt that the nursing staff did
302 not know enough about their condition, and that being on a non-cancer ward reduced
303 mutual support. Patients and relatives understood that their cancers were rare and
304 supported the concept of specialist centres with expertise in head and neck cancer. (B)

305 The NCA report commissioned to inform this guidance manual raised specific concerns
306 about hospital food. All the patients felt that this was a very important aspect of care and
307 for most, it was not well provided. Several reported that their eating difficulties were
308 compounded by poor quality or unsuitable food; but their consultants seemed not to be
309 interested.⁹⁰

310 *Current practice in the NHS*

311 Two recent audits from the South and West of England, SWAHNI and SWAHNII,⁹¹ give
312 figures on the proportion of new patients who receive each major treatment modality,
313 broken down by cancer site and stage. These show that, despite the size of the population
314 base (6.5 million), the number of patients in each sub-group is often quite small.

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

321 Within each cancer site/stage sub-group, there was considerable variability in the form of
322 treatment used. The authors comment that “This reflects continuing uncertainty and lack

⁹⁰ National Cancer Alliance, *Patients' views of head and neck cancer services and developing national guidance*. Oxford: NCA, 2002.

⁹¹ South West Cancer Intelligence Service, *Head and Neck Audit Report, 1997*, and *Second Head and Neck Audit Report, 2001*.

323 of clear evidence based guidelines for most tumours,” and point out the need for research
 324 and audit.⁹² Nevertheless, the overall figure of 65.7% survival at two years compares
 325 favourably with comparable data from other countries.

326 Comparison of the two SWAHN audits shows that waiting times for radiotherapy have
 327 worsened, and cite lack of resources as the most probable reason for this. However,
 328 CHI/Audit figures suggest that there is great variability between radiotherapy centres in
 329 the number of patients treated in relation to facilities, suggesting that the way these are
 330 managed and used may also be important.⁹³

331 A survey of head and neck pathologists, surgeons and oncologists in the UK, carried
 332 out in 2001, revealed that whilst most were aware of the Royal College of Pathology
 333 minimum datasets, only 20% of pathologists produced reports in this form, probably
 334 because many laboratory IT systems did not enable them to do this easily. In general, the
 335 data items that are easiest to record were reported most consistently. Departments with
 336 higher workloads (>1 major resection each fortnight) tended to record a wider range of
 337 data items than those with lower workloads.⁹⁴

338 **Thyroid cancer**

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

⁹² *Ibid*, p51.

⁹³ Commission for Health Improvement/Audit Commission. *NHS Cancer Care in England and Wales*. London: CHI/AC. 2001.

⁹⁴ Helliwell T. Minimum pathology dataset for head and neck cancer. *ENT News and Views*, 2003;12:54-55.

347 A recent audit by the Northern and Yorkshire Cancer Registry (NYCRIS) also found
348 deficiencies in the service. The data were derived from questionnaires, but since the
349 overall response rate was only 60%, the figures can only be regarded as suggestive.
350 Nevertheless, they give cause for concern. For example, they reveal that for more than
351 half of the patients, there is no documented evidence that information was given on the
352 risks of treatment; and only 19% of MDTs and 29% of consultants working outside MDTs
353 gave written information to patients.⁹⁵

354

355 **D. Measurement**

356 **Structure**

- 357 • Agreed guidelines, consistent throughout the Network, describing appropriate treatment
358 of each form of cancer within this group.
- 359 • Evidence that patients are given accessible written information about their treatment,
360 which covers risks and timescales, as well as anticipated benefits.
- 361 • Availability of support for patients undergoing treatment, including access to a CNS, a
362 suitably specialised and experienced head and neck dietitian, and a speech and
363 language therapist with specialist experience in all forms of speech and voice
364 rehabilitation and management of swallowing and eating difficulties.
- 365 • Facilities for a range of forms of enteral feeding (including nasogastric tube and
366 gastrostomy), with adequate support for patients based in hospital and the community
367 who require these forms of feeding.
- 368 • Availability of all surgical modalities (including laser) to each MDT.

⁹⁵ The full reference for this report will be available in time for publication of this Manual.

- 369 • Availability of appropriate rehabilitation for laryngectomees, including primary
370 surgical voice restoration if appropriate.
- 371 • Availability of adequate facilities within each Network for modern radiotherapy,
372 including 3-D conformal treatment. This should include modern linear accelerators,
373 mould room facilities and treatment planning systems, together with adequate
374 personnel such as radiographers and physicists).
- 375 • Arrangements for provision of brachytherapy for selected patients.
- 376 • Facilities for provision of chemoradiation or altered fractionation radiotherapy.
- 377 • Availability of suitably protected rooms for radioiodine treatment.
- 378 • 24-hour availability of facilities and staff with appropriate expertise to provide
379 emergency treatment of flap failure.
- 380 • Availability of specialised wards for patients undergoing surgery.
- 381 • Availability of advice and support at all times (including weekends and outside normal
382 working hours) for patients with breathing or swallowing problems caused by treatment
383 or who have problems associated with surgical voice restoration.
- 384 • Provision of ongoing rolling training programmes for nurses and medical staff,
385 organised by the specialist SLT, in dealing with common problems associated with
386 surgical voice restoration or other effects of treatment on breathing and swallowing.
- 387 • Contract specification for external catering providers, such that the dietary needs of
388 patients with head and neck cancers are met.
- 389 • Agreed guidelines, accepted throughout the Network, designed to encourage
390 recruitment to clinical trials.
- 391 • Evidence of links to academic departments to facilitate research and development.

392 **Process**

- 393 • Audit of congruence between treatment given and Network guidelines.
- 394 • Evidence that patients have been given written information describing the procedures
395 they undergo, and that this information covers risks as well as anticipated benefits.
- 396 • Audit of adequacy of surgery.
- 397 • Audit of free flap failure rate.
- 398 • Audit of delays or gaps in prescribed courses of radiotherapy, and their causes.
- 399 • Audit of delays between surgery and post-operative radiotherapy.
- 400 • Use of prophylactic measures to prevent mucositis in patients treated with radiotherapy
401 or chemotherapy.
- 402 • Evidence that appropriate care and rehabilitation is provided for patients who undergo
403 temporary or permanent tracheostomy.
- 404 • Evidence that surgical voice restoration, and access to appropriate equipment and
405 rehabilitation, is provided for all patients who would be expected to benefit from it.
- 406 • Audit against national guidelines of catering service provision for texture modified
407 diets.
- 408 • Evidence of initiatives to attract both external grant funding and local support for
409 research and development.
- 410 **Outcome**
- 411 • 5-year survival rates for all patients, with information on cancer grade and stage, co-
412 morbidity, age and other features of case-mix, and primary treatment.
- 413 • Audit of failure rates in the neck, osteonecrosis, and surgical mortality.
- 414 • Audit of late complications of radiotherapy.

- 415 • Audit of functional outcomes of surgery.
- 416 • Proportion of patients undergoing laryngectomy who receive surgical voice restoration.
- 417 • Audit of vocal cord palsy, long-term hypoparathyroidism, and other complications of
418 thyroid surgery.
- 419 • Patients' satisfaction with practical, psychosocial and dietetic support during treatment
420 and the recovery period.
- 421 • Patients' satisfaction with food provided in hospital.
- 422 • Audit of feeding-related complications during treatment period.
- 423 • Proportion of patients recruited to clinical trials.

424

425 **E. Resource Implications**

426 Additional resources will be required for Cancer Centres which will treat larger numbers
427 of patients with head and neck cancer. Availability of specialised wards... etc

428 [Note: The section on Resource Implications will be reviewed in the light of the “Analysis
429 of the Potential Economic Impact of the Guidance” – available in draft with the Research
430 Evidence. A summary is included as Appendix 1 in this draft of the Manual].

1 **6. After-care and rehabilitation**

2

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

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

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

17 Surgery to the tongue and mouth can also cause long-term problems with both speech and
18 eating, and these patients need considerable help with communication and nutrition. Not
19 surprisingly, problems with communication and changed facial appearance can lead to
20 psychosocial difficulties.

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

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

30 **A. Recommendations**

31 **Structure of services**

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

38 Every Cancer Unit or Cancer Centre which deals with patients with head and neck cancer
39 should establish a Local Support Team (described below), which will provide services
40 within a defined geographical area. This is a flexible, locally-based team; it is not
41 anticipated that it would have regular formal meetings, although individual members
42 should meet frequently on an informal basis. Local support team members may be shared
43 between units, or work on an outreach basis.

44 Each Local Support Team should have access to the expertise required to manage the
45 aftercare and rehabilitation needs of all of its patients, working closely with Cancer Centre
46 staff and Primary Health Care Teams to provide seamless care. Skilled care should thus
47 be available locally, throughout the Network. The CNS should take responsibility for
48 ensuring that these levels of service work together, for advising health care staff working
49 in the community, and arranging training for such staff when required. (See discussion of
50 the role of the CNS in Topic 2, Structure of Services.)

51 The MDT at the Cancer Centre should establish criteria to be met before patients are
52 discharged from hospital. These criteria should include a written rehabilitation plan,
53 drawn up by MDT members in collaboration with the patient, his or her carers, and the
54 member of the Local Support Team who will take formal responsibility for co-ordinating

55 the care provided by the team for that patient. This individual should be the member of
56 the Local Support Team whose skills are best fitted to meeting the patient's needs, who
57 will then act as the patient's point of contact with the team.

58 Patients and their carers should be taught about wound, mouth and dental care, and
59 management of valves and stomas, and should be given contact numbers for members of
60 the Local Support Team who will help with any problems they may encounter. The Local
61 Support Team should ensure that every patient has access to regular dental care from
62 dentists who are able to deal with the problems that can develop after treatment for head
63 and neck cancer. Routine care may be provided at the primary care level if suitable
64 dentists are available, but arrangements should be made for patients who require specialist
65 care to be treated by restorative dentists in a DGH or dental hospital.

66 **Local Support Team Members**

- 67 • Clinical nurse specialist (CNS).
- 68 • Speech and language therapist (SLT).
- 69 • Dietitian.
- 70 • ENT/maxillofacial nurse practitioner, based in ENT and Maxillofacial outpatient
71 departments, who can provide advanced skills for the management of stomas
72 (tracheostomies and gastrostomies), nasogastric tubes and tracheo-oesophageal valves.
73 This nurse practitioner should work alongside the CNS and SLT, and help to teach
74 local hospital and community nursing teams, thus creating a sustainable and robust
75 seven day service for patients who require help.
- 76 • Dental hygienist.
- 77 • Psycho-oncology, liaison psychiatry or clinical psychology services.
- 78 • Local patients who are willing to provide 'buddy' support and help with group
79 rehabilitation sessions.
- 80 • Physiotherapist.
- 81 • Occupational therapist.

- 82 • Social worker.

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

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

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

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

105 Many patients who have had radical treatment to the neck develop shoulder problems and
106 will require ongoing physiotherapy. These patients are also likely to require the help of
107 occupational therapists.

108 Oral rehabilitation should be provided by the specialist restorative dentist (See Topic 2,
109 Structure of Services) for all patients who require it. This dentist should co-ordinate

110 continuing dental care for these patients and take responsibility for long-term liaison with
111 other dentists who may treat them.

112

113 **B. Anticipated benefits**

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

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

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

129

130 **C. Evidence**

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

135 **Rehabilitation services**

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

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

145 A study of the effectiveness of speech and swallowing therapy with range of motion
146 (ROM) exercises for patients who underwent surgery for oral or oropharyngeal cancer
147 suggested that these exercises can improve outcomes when they are started early after
148 surgery. Statistically significant differences were found in global swallowing measures in
149 those who received instruction in ROM exercises, compared with those who did not. (B)

150 Swallowing rehabilitation for patients dependent on tube feeding after treatment for head
151 and neck cancer usually takes about three months, according to a Dutch study, although
152 about 20% need help for six months or more and some patients (9 of a group of 82) did
153 not respond to therapy. (B)

154 A recent US study indicated that 27% of patients used oesophageal speech, 21% used
155 tracheo-oesophageal speech, and 48% used an electrolarynx. 89% of patients in the two
156 former groups were satisfied with their means of communication, but satisfaction levels
157 were lower (62%) among those who used the electrolarynx. An older study, also from the
158 US, reported that speech therapy after laryngectomy took an average of five months in
159 patients assessed before surgery, and three months for those reviewed after surgery. 26%
160 of prospectively studied patients used oesophageal speech as the dominant mode of
161 communication, 34% the electrolarynx and 34% communicated by writing. 45% were
162 considered not to be successfully rehabilitated.

163 Patients with problems that make rehabilitation more difficult – such as hearing
164 impairment, previous neurological, pulmonary and gastroenterological disease – can be
165 identified before treatment. These patients require intensive help from a range of
166 professionals.

167 **Restorative dentistry**

168 A number of small studies of the outcome of dental and facial bone restoration using
169 prostheses retained by osseointegrated implants show that these are effective for many
170 patients. The proportion of implants reported lost over five years varies between studies,
171 from 22% to 79% in patients who have been treated with radiotherapy; loss rates are
172 below 20% in patients who have not been irradiated. The probability of success appears to
173 be higher when reconstruction is carried out more than four months after implantation.

174 (B)

175 **Patient support groups**

176 There are well-established support groups for patients who have facial disfigurement, for
177 laryngectomees and for those with dental problems. Details for these can be found on the
178 NHS Direct website (<http://www.nhsdirect.nhs.uk/>) and should be available from members
179 of local support teams.

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

186 A study of a support group for people who undergo laryngectomy in Norway suggests that
187 active membership of a local branch of the Norwegian Society for Laryngectomees, which
188 all patients scheduled for laryngectomy are invited to join, is associated with better quality
189 of life. (B)

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

195 **Patient-held records**

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

200 91% of the 60 patients who returned the questionnaire evaluating the log-book said they
201 had read all of it; 91% had given it to their partner to read and 94% had given it to a
202 professional involved in their care. 47% reported making entries in the book, usually
203 using it as a diary. The most used sections were those explaining what cancer is and social
204 nursing provision. 88% said the book clarified things for them.

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

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

216 (B)

217 **Current services in the NHS**

218 The SWAHNII audit revealed that 80%, 72% and 32% of patients who had surgery to the
 219 larynx, hypopharynx and posterior third of tongue, respectively, saw a speech therapist.
 220 Overall, just 48 of 75 these patients – 64% – saw a SLT, despite an agreed standard
 221 throughout the region covered by the audit that all should do so.⁹⁶

222

223 **D. Measurement**

224 **Structure**

- 225 • Availability of Local Support Teams throughout the Network, constituted as described
 226 above.
- 227 • Systems for provision of specialised advice and assistance at any time for patients in
 228 the community who rely on tube feeding.
- 229 • Streamlined systems to facilitate access to funding for communication aids and
 230 equipment for individual patients.

231 **Process**

- 232 • Evidence that support is available from a Local Support Team for every patient after
 233 radical treatment for UAT cancer.
- 234 • Evidence that patients receive the communication aids or equipment they require within
 235 one month of radical treatment.
- 236 • Evidence of co-ordination of ongoing dental care by a specialist dentist for patients
 237 whose treatment affects the mouth or jawbone.

238 **Outcome**

⁹⁶ South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001, p18.

- 239 • Patients' and carers' experience of local support services.

240

241 **E. Resource Implications**

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

244 [Note: The section on Resource Implications will be reviewed in the light of the “Analysis
245 of the Potential Economic Impact of the Guidance” – available in draft with the Research
246 Evidence. A summary is included as Appendix 1 in this draft of the Manual].

7. Follow-up and recurrent disease

A. Recommendations

Clinical follow-up

Upper aerodigestive tract cancers

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

The main aims of follow-up include:

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

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

26 Follow-up clinics should use regular quality of life screening (assessed with validated
27 tools designed for this patient population), to identify other problems that may require
28 intervention, including complications of treatment. The DAHNO dataset, which should be
29 completed for every patient with head and neck cancer (See Background, page 33)
30 includes the ECOG scale of performance status, to be recorded at one year after treatment.

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

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

37 *Management of patients with recurrent disease*

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

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

48 All patients who are suspected to have recurrent disease or second primary cancers need
49 full assessment and imaging, but previous treatment can make interpretation of images
50 particularly difficult. PET scanning should be available if needed to assess suspected
51 recurrent disease, especially in patients who have previously had radiotherapy. The CNS
52 and SLT should also meet and assess each patient so that they are able to contribute to
53 decision-making about management.

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

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

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

72 ***Thyroid cancer***

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

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

83

84 **B. Anticipated benefits**

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

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

98

99 **C. Evidence**

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

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

105 ***UAT cancers***

106 A study from France found that 30-50% of patients had local or regional recurrences
107 within five years of initial treatment for head and neck cancer, and that the risk of
108 developing a second cancer (most often in the head and neck, oesophagus or lung) among
109 these patients is 10 to 30 times that in the general population. Continued smoking and

110 drinking after initial treatment are both associated with significant increases in risk, but
 111 patients who do not smoke and drink at the time of initial treatment are at low risk of
 112 developing second primaries.⁹⁷ Other studies (tabulated in this paper) suggest, however,
 113 that the incidence of second primaries reported in this study might be unusually high, and
 114 the recurrence rate is generally accepted to be about 3% per year. (C)

115 ***Thyroid cancer***

116 In a cohort of 1,528 patients treated for differentiated thyroid cancer in the US, the
 117 recurrence rate over 40 years was about 35%. The rate of recurrence declined over time;
 118 two thirds occurred during the first decade after initial therapy. 68% of recurrences were
 119 local, whilst 32% were distant metastases, mostly in the lungs. Among adult patients,
 120 recurrence rates and the risk of cancer death are highest in those who are over the age of
 121 60 at the time of initial therapy. Recurrences in younger patients were more often curable,
 122 particularly when detected at an early stage.⁹⁸

123

124 **Diagnosis of recurrent disease**

125 ***PET scanning***

126 Research studies on the effectiveness of PET scanning have been reviewed by the
 127 Intercollegiate Standing Committee on Nuclear Medicine.¹⁰¹ This committee concluded
 128 that PET scanning can be useful for identifying tumour recurrence in patients previously

⁹⁷ Schwartz LH, Ozzahin M, Zhang CN, Tonboul E, et al. Synchronous and metachronous head and neck carcinomas. *Cancer*,1994;74(7):1933-8.

⁹⁸ 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.

⁹⁹ Schwartz LH, Ozzahin M, Zhang CN, Tonboul E, et al. Synchronous and metachronous head and neck carcinomas. *Cancer*,1994;74(7):1933-8.

¹⁰⁰ 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.

¹⁰¹ 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.

129 treated for carcinoma of the oropharynx and larynx, and for assessment of tumour
130 recurrence in medullary carcinoma of the thyroid. (C) There is more reliable evidence for
131 the value of PET scanning for assessment of patients with suspected recurrent thyroid
132 cancer, negative iodine scans and elevated thyroglobulin. (B) Although PET imaging is
133 available in the UK, at the time of writing (Spring 2004), facilities are limited and
134 geographically uneven.

135

136 **D. Measurement**

137 **Structure**

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

142 **Process**

- 143 • Evidence that all patients with suspected recurrent disease are seen promptly by
144 members of the appropriate MDT.
- 145 • Audit of monitoring of thyroid hormones, serum calcium, and thyroglobulin/calcitonin
146 in patients who have been treated for thyroid cancer, and action taken when blood
147 levels of any of these are not within specified limits.

148 **Outcome**

- 149 • Proportion of patients continuing to use alcohol or cigarettes.
- 150 • Survival rates in patients with recurrent disease.

151

152 **E. Resource Implications**

153 [Note: The section on Resource Implications will be reviewed in the light of the “Analysis
154 of the Potential Economic Impact of the Guidance” – available in draft with the Research
155 Evidence. A summary is included as Appendix 1 in this draft of the Manual].

156

8. Palliative interventions and care

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

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

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

27 **A. Recommendations**

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

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

39 Possibly as many as half of all patients who develop head and neck cancers eventually die
40 of the disease and will require palliative interventions. Many experience moderate to
41 severe pain, which should be regularly assessed and treated in accordance with the WHO
42 analgesic ladder. In most cases, the cause of death is tumour in the head and neck.
43 Terminal care for these patients can be very difficult. Choking or bleeding to death is
44 particularly feared, and patients, carers and health care staff who deal with them are likely
45 to require considerable practical, psychological and spiritual support.

46 Although hospices may be able to provide the support patients need, some patients will
47 have problems that mandate their return to hospital. General wards in some local hospitals
48 may be unable to offer adequate care and these patients will need to be transferred to a
49 ward which has appropriate resources. Staff in local hospitals should be able to access to
50 expert advice and guidance from specialists based in the Cancer Centre.

51 Surgery, radiotherapy and chemotherapy can all be used for palliation, and all three
52 treatment modalities should be available. Decisions about whether to offer major
53 palliative interventions should be made by the full MDT, and the quality of the patient's
54 remaining life should be the first consideration. Some palliative procedures – for example,

55 surgery to control tumour in the neck – may be appropriate for selected patients, but major
56 resections have the potential to cause great morbidity and distress at the end of life and
57 should be avoided.

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

63 **Management of airway obstruction**

64 Hospitals which deal with patients with head and neck cancers should have systems in
65 place to ensure that patients with anticipated acute airway obstruction can be admitted
66 directly to a ward where staff have the expertise required to deal with the problem.

67 Ambulance personnel, GPs and carers should be made aware that these patients must *not*
68 be taken to accident and emergency departments. Specific training in care for patients
69 with end tracheostomies (neck breathers) should be provided for staff who are likely to
70 deal with these patients.

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

80 **Nutritional support**

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

84

85 **B. Anticipated benefits**

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

92

93 **C. Evidence**

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

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

102 **D. Measurement**

103 **Structure**

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

106 **Process**

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

109 **Outcome**

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

111

112 **E. Resource Implications**

113 [Note: The section on Resource Implications will be reviewed in the light of the “Analysis
114 of the Potential Economic Impact of the Guidance” – available in draft with the Research
115 Evidence. A summary is included as Appendix 1 in this draft of the Manual].

Appendix 1

Economic implications:

Summary

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

The major impacts on costs fall in 5 broad areas. A summary of these costs is given in Table 1.

Table 1: Cost Summary (All costs in £million per year)

Lump Clinics		£ 2.4
Multi-disciplinary teams		
Additional costs of staff time for MDT meetings		£ 3.0
Low scenario		£ 1.4
High scenario		£ 4.3
MDT co-ordinator / data manager for all teams		£ 0.5
Centralisation of Surgery		£ 4.7
Chemo-Radiotherapy		£ 1.0
Patient–Centred Care, including local support teams		£33.2-£47.2
Clinical Nurse Specialists	£ 11.9 - £ 13.2	
Speech and language therapists	£ 5.8 - £ 9.3	
Dietitians	£ 4.7 - £ 7.1	
Nurse Practitioners	£ 3.6 - £ 5.8	
Other Staff	£ 7.1 – £ 11.8	
Of which £18.3 – £36 .6 million are associated with the local support team role.		
Total : Range		£43.2-£60.1

Rapid-Access Lump Clinics

The guidance recommends the establishment of rapid-access lump clinics for patients presenting to their GP with a lump in the neck. Although such clinics exist in the majority of hospitals which deal with head and neck cancer patients, the majority do not have on-site cytological support, which is recommended in the guidance. It has been assumed that such clinics would be run on a weekly basis, and be of length six hours in total (four hours clinic time, plus two hours administration). Coupled with the need for each clinic to have support from a biomedical scientist, the annual cost impact is estimated to be £2.4 million per annum.

Multi-disciplinary Teams

Multi-disciplinary team (MDT) working allows patients to benefit from the expertise of a range of specialists for their diagnosis and treatment, and helps ensure that that care is given according to recognised guidelines. Head and Neck MDTs are already well established in many Trusts. However additional time for meetings will be required and more staff will need to be involved in order that MDTs can function in accordance with the guidance. Thyroid MDTs are generally less well developed. Many MDTs currently suffer from lack of administrative and data management support. The cost of additional staff time for MDT meetings and for ensuring that all MDTs have a co-coordinator/data manager is estimated to be an additional £ 3.5 million per annum.

Centralisation of Surgery

Two scenarios have been assessed in carrying out the economic review of the centralisation of head and neck cancer surgery. Firstly, that under the guidance, all “radical” surgery would be carried out in the Cancer Centres and secondly that all surgery is transferred to the Centres. Data from two sources were used in the analysis, reflecting the uncertainty in the cost of transferring surgery from the Units to the Centres. Using NHS Reference Cost data, the expected costs across the whole of England and Wales under the first scenario of centralising radical surgery would be around £4.7 million (the whole of this cost would be attributable to the Centres), compared with around £6.7

million under the scenario of centralising all surgery. These costs include the cost of the surgical procedure, in addition to the cost of any in-patient stay required. Cancer Centres are also likely to incur costs through the need for additional staff and ward space. The cost at individual Network level will vary depending on the degree to which centralisation has already taken place, and the population base of the Network.

Chemoradiotherapy

The guidance is expected to lead to an increase in the proportion of head and neck cancer patients who are treated with chemo radiotherapy. Through discussions with a number of clinical oncologists, it has been assumed that, of the patients being treated with radiotherapy, 30% of these will be treated with chemoradiotherapy in the future, compared with 20% currently. The costs associated with this include the cost of the chemotherapy drugs, plus the costs associated with patient care, which vary depending on whether patients are treated on an in-patient or an out-patient basis.

It is estimated that this change would lead to an annual additional cost of £1.6 million across the whole of England and Wales.

Patient Centred Care and Local Support Teams

Clinical Nurse Specialists

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

An order of magnitude estimate of the additional number of nurses required was made, based on the CHI report, the preliminary feedback from Cancer Services Collaborative Questionnaire and discussions with a number of clinical nurse specialists. The preliminary

estimate for the cost impact of providing additional clinical nurse specialists is between £11.9 and £13.2 million per annum.

Speech and Language Therapists

A speech and language therapist (SLT) who specialises in head and neck cancer should be available to work with every patient whose primary treatment disrupts the ability to speak, eat or swallow. The guidance will increase the workload for SLTs, particularly within Cancer Centres, where additional posts or part-time posts may be required to allow the duties of existing SLTs to be expanded to a greater volume of patients and to allow cover for attendance at clinics, MDT meetings as well as training, holidays, sickness etc. The role of SLTs within the local support teams is more uncertain and further feedback is being obtained. Preliminary estimates suggest that the cost implications may range between £5.8 to £9.3 million per annum for England and Wales

Dietitians

Dedicated dietitians play an important role throughout the patients cancer journey providing nutritional support, advice on tube feeding and coping with the after-effects of treatment. Discussions with dietitians around the country have confirmed that current levels of input vary considerably between hospitals. It is assumed that as a minimum, Cancer Centres should have between 3 and 4 WTE dedicated dietitians, implying a typical increase of around over 2 WTE per Centre over current levels. It is assumed that Units will require an additional 0.5 to 1.0 WTE. In total this corresponds to an additional 167 to 250 WTE dietitian posts in England and Wales, resulting in an estimated total cost impact of between £ 4.7 and £7.1 million per annum.

Nurse practitioners

The role of the nurse practitioner has been widened to act as a support to the CNS, and based on consultations with nursing staff, it has been estimated that the guidance would required two nurse practitioners per Center and one per Unit i.e. a total of 6 or 7 per Network (depending on the number of Units in each Network), or a total of between 241 for the whole of England and Wales. Currently, this role is often covered by the CNS, with

only a small number of Centres and Units having a full-time nurse practitioner. The cost of providing the necessary additional posts is estimated to be between £3.7 and £5.8 million per annum.

Local Support Teams

The provision of additional staff for post-treatment patient support teams is expected to have significant cost implications. Each hospital which deals with patients with head and neck cancer should establish such a team, and given the current low provision of many of the roles required in the team, this would necessitate the recruitment of a large number of staff. Two scenarios have been used to assess the cost impact, by varying the assumptions made about the extent to which these teams already exist, and the variability in the level of input required between Cancer Centres and Units. The provisional estimate of the cost impact is the range £18.3 - £36.6 million. Further analysis is being undertaken to provide a central estimate of the cost implications for England and Wales and will be presented in the final report. The costs for the roles of CNSs, SLTs, dietitians and nurse practitioners within local support teams are included in the cost estimates above. The cost estimate for local support teams excluding these posts is between £7.1 and £11.8 million.

Appendix 2

How this guidance manual was produced

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

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

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

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

The production of this guidance was funded by NICE, and it has been subject to the full NICE consultation process.

Evidence grading

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

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

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

C. Professional consensus.

The quality of research evidence forms a continuum and there is overlap between these categories. Most of the published research on cancer focuses on clinical evaluations of treatment; little direct research has been carried out on the organisation and delivery of services, issues on which randomised controlled trials

(categorised here as the highest quality evidence) may not be feasible. Research designs which might be regarded as of relatively poor quality for evaluating a clinical intervention may therefore be the most reliable available for assessing the organisational issues.

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

Appendix 3

People and organisations involved in production of the guidance

- 3.1 National Cancer Guidance Steering Group**
- 3.2 Participants in the proposal generating event**
- 3.3 People/organisations invited to comment on original proposals**
- 3.4 Researchers carrying out literature and economic reviews**
- 3.5 Members of focus groups**

Guidance synthesis and writing

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

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

Professor M R Baker, Director/Lead Clinician, Yorkshire Cancer Network, Leeds
 Mr G J Cox, Consultant ENT/Head and Neck Surgeon, Radcliffe Infirmary, Oxford
 Ms T Feber, Macmillan Nurse Specialist, Yorkshire Centre for Clinical Oncology, Leeds
 Dr C Gaffney, Consultant Clinical Oncologist, Velindre Hospital, Cardiff
 Dr G Harding, GP/Medical Director, St John's Hospice, Doncaster
 Dr T Helliwell, Consultant Histopathologist, University of Liverpool
 Ms J Machin, Speech and Language Therapist, Surrey
 Mr P Madeley, Patient, Cottingham, East Yorkshire
 Dr J Olliff, Consultant Radiologist, Queen Elizabeth Hospital, Birmingham
 Dr N Slevin, Consultant Clinical Oncologist, Christie Hospital, Manchester
 Mr D S Soutar, Consultant Plastic Surgeon, Canniesburn Hospital, Glasgow
 Mr E D Vaughan, Consultant Maxillofacial Surgeon, University Hospital Aintree, Liverpool

Mr J C Watkinson, Consultant Otolaryngologist/Head & Neck Surgeon, Queen Elizabeth Hospital, Birmingham

Mr P Williams, Patient, Amersham, Bucks.

People/organisations invited to comment on drafts of the guidance

National Cancer Guidance Steering Group

Focus Groups

Various professional organisations

Department of Health

NICE Stakeholders; the drafts were subject to the full NICE consultation process

Economic reviews

School of Health and Related Research, University of Sheffield

Project support

The Northern and Yorkshire Cancer Registry and Information Service

Appendix 3.1

Membership of the National Cancer Guidance Steering Group

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

Chairman

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

Vice Chairman

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

Members

Dr J Barrett Consultant Clinical Oncologist and Clinical Director, Four Counties Cancer Network

Mrs G Batt Section Head, Cancer Policy Team, Department of Health, Wellington House

Mr A Brennan Director of Operational Research, School of Health and Related Research, University of Sheffield

Ms A Eastwood Senior Research Fellow, NHS Centre for Reviews and Dissemination, York

Dr J Hanson Cancer Services Project Co-ordinator, Welsh Office

Dr G Harding GP and Medical Director, St John’s Hospice, Doncaster

Professor P Littlejohns Clinical Director, National Institute for Clinical Excellence

Professor R E Mansel Chairman, Division of Surgery, University of Wales College of Medicine, Cardiff

Dame G Oliver Director of Service Development, Macmillan Cancer Relief

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

Dr J Verne Consultant in Public Health Medicine/Director, South West Public Health Observatory

Appendix 3.2

Participants in the head and neck cancers proposal generating event

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

Professor N W Johnson	Professor of Oral Medicine and Pathology, Guy's, King's and St Thomas' Dental Institute
Dr R J Johnson	Consultant in Diagnostic Radiology, Christie Hospital, Manchester
Ms G Jones	Macmillan Head and Neck Clinical Nurse Specialist, Royal Berkshire Hospital, Reading
Dr J Kabala	Consultant Radiologist, Bristol Royal Infirmary
Ms A Kelly	Speech and Language Therapist, The Royal National Throat, Nose and Ear Hospital, London
Dr C G Kelly	Consultant Clinical Oncologist, Newcastle General Hospital, Newcastle upon Tyne
Miss J Lees	Cancer Services Manager, Greenwich District Hospital, London
Mr A G Leonard	Consultant Plastic Surgeon, The Ulster Hospital, Belfast
Professor A McGregor	Professor of Reconstructive Surgery, Welsh Regional Burns and Plastic Surgery Unit, Morriston Hospital, Swansea
Mr K MacKenzie	Consultant ENT Surgeon, Glasgow Royal Infirmary
Professor K MacLennan	Professor of Cytopathology and Histopathology, St James's University Hospital, Leeds
Ms H McNair	Superintendent Radiographer, The Royal Marsden Hospital, Surrey
Mr P Madeley	Patient, Cottingham
Mr I Martin	Consultant and Senior Lecturer in Oral and Maxillofacial Surgery, Sunderland Royal Hospital
Dr D Morgan	Consultant Clinical Oncologist, Nottingham City Hospital
Dr R Neal	GP, University of Wales College of Medicine, Wrexham
Dr P Norris	GP, Kingston upon Thames
Ms K Radford	Speech and Language Therapist, Birmingham City Hospital
Dr M Robinson	Consultant Clinical Oncologist, Weston Park Hospital, Sheffield
Mr S Rogers	Consultant Oral and Maxillofacial Surgeon, University Hospital Aintree, Liverpool
Mrs L Rushworth	Patient, Bradford
Dr D Salvage	Consultant Radiologist, Hull Royal Infirmary
Professor C Scully	Dean and Director of Studies and Research, Eastman Dental Institute for Oral Healthcare Sciences, University College London
Ms C Shaw	Chief Dietitian, The Royal Marsden Hospital, London
Dr M J Shaw	Consultant in Restorative Dentistry, Birmingham Dental Hospital and School
Mrs I Theabould	Patient, Bradford
Mr Nigel Towler	Patient, Thirsk
Dr B Walker	GP, Seascale
Dr S Warnakulasuriya	Reader and Honorary Consultant in Oral Medicine, King's Dental Institute, London
Mrs E Waters	Chief Oncology Dietitian, Clatterbridge Centre for Oncology, Merseyside
Mr J C Watkinson	Consultant Otolaryngologist/Head and Neck Surgeon, The Queen Elizabeth Hospital, Birmingham

Ms W White	Macmillan Head and Neck Clinical Nurse Specialist, Queen Alexandra Hospital, Portsmouth
Professor J Wilkinson	Professor of Public Health, North East Public Health Observatory
Professor S Williams	Professor of Dental Public Health, The Oral Health and Ethnicity Unit, The Leeds Dental Institute
Ms H Woods	Speech and Language Therapist, Christie Hospital, Manchester
Mr G Zaki	Consultant Oral and Maxillofacial Surgeon, Queen Alexandra Hospital, Portsmouth
Dr I Zammit-Maempel	Consultant Radiologist, Freeman Hospital, Newcastle upon Tyne
Facilitated by:	
Dr J Barrett	Consultant Clinical Oncologist and Clinical Director, Four Counties Cancer Network
Professor R A Haward	Professor of Cancer Studies, University of Leeds

Appendix 3.3

Referees of the head and neck cancers proposals

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

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

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Appendix 3.4

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i) Literature Reviews

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

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ii) Patient views of head and neck cancer services

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iii) Economic Review

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Appendix 3.5

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Appendix 4

Glossary of terms

3D conformal radiotherapy

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

Adenocarcinoma

Adenocarcinomas are cancerous growths of glandular tissue.

Aetiology

The origins or causes of disease.

Altered fractionation regimens

See *hyperfractionated radiotherapy*.

Anaplastic thyroid cancer

See *thyroid cancer*.

Areca or betel nut

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

Atraumatic extraction

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

Audit

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

Betel nut

See *Areca nut*.

Biochemical evidence

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

Biopsy

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

Brachytherapy

Radiotherapy delivered within an organ.

Calcitonin

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

Cancer networks

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

Cardiovascular

Having to do with the heart and blood vessels.

Cervical lymphadenopathy

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

Chemoradiation

Treatment that combines *chemotherapy* and *radiotherapy*.

Chemotherapy

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

Chronic lymphocytic thyroiditis

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

Clinical oncologist

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

Cognitive and behavioural interventions

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

Colostomy

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

Community

Non-hospital based services.

Computed tomography (CT)

An x-ray imaging technique.

Cranial neuropathies

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

Cytologist

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

Cytology

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

Cytopathologist

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

Cytopathology

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

Dysphagia

Difficulty with swallowing.

Electrolarynx

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

Endocrine

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

Endocrinologist

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

Endolaryngeal

Within the *larynx*.

Endoscope

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

Endoscopy

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

End tracheostomy

See *tracheostomy*.

Enteral feeding

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

Epidemiology

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

Epiglottis

The lidlike structure overhanging the entrance to the *larynx* which prevents food from entering the *larynx* and *trachea* whilst swallowing.

Epithelial cells

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

Epstein-Barr virus

A viral infection which may be connected to cancer of the *nasopharynx*.

Fine needle aspiration cytology (FNAC)

A fine needle is inserted into tissue to withdraw cells which are then examined for the presence of cancer cells.

Flap

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

Follicular thyroid cancer

See *thyroid cancer*.

Gastroenterological

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

Gastrostomy

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

Goitre

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

Glottis

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

Grade

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

Gutkha

A form of chewing tobacco.

Herpes simplex

A viral infection which causes watery blisters on the skin or mucous membranes and may be implicated in some head and neck cancers.

Histopathologist

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

Histopathology

The study of microscopic changes in diseased tissues.

Hospice

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

Human papillomavirus

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

Hydrolytic enzymes

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

Hyperbaric oxygen

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

Hyperfractionated or accelerated radiotherapy

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

Hyperthyroidism

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

Hypoparathyroidism

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

Hypopharynx

The lower part of the *pharynx* which lies below the upper edge of the *epiglottis* and opens into the *larynx* and *oesophagus*.

Hypothyroidism

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

Laryngectomee

A person who has had their *larynx* removed.

Laryngectomy

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

Larynx (voice box)

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

Laser excision

The use of a laser to remove tissue.

Local recurrence

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

Lymph nodes

Small organs which act as filters in the lymphatic system.

Lymphoma

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

Lymphoma of the thyroid

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

Magnetic resonance imaging (MRI)

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

Maxillofacial

Having to do with the jaws and face.

Medullary thyroid cancer

See *thyroid cancer*.

Meta-analysis

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

Metachronous

Occurring at different times.

Metastases - metastatic disease

Spread of cancer away from the primary site.

Microvascular

Having to do with very small blood vessels.

Monoclonal antibody treatment

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

Nasal cavity

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

Nasogastric tube

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

Nasopharynx

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

Neo-adjuvant treatment

Treatment given before the main treatment.

Neurological

Having to do with the nervous system.

Oesophageal speech

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

Oesophagus

The gullet.

Oncologist

A doctor who specialises in treating cancer.

Oncology

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

Ophthalmologist

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

Oral

Having to do with the mouth.

Oral cavity

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

Oral mucosa

The mucous lining of the mouth.

Oral mycosis's

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

Orbit

The bony cavity which contains the eyeball.

Oropharynx

The middle part of the *pharynx* which lies between the soft *palate* and the *epiglottis*.

Osseointegrated implants

Surgical implants which become integrated into the surrounding bone.

Osteonecrosis

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

Otalgia

Earache.

Otolaryngologist or otorhinolaryngologist

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

Palate

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

Palliative

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

Palliative Care

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

Pan

Also known as paan or pahn. See *Areca nut*.

Papillary thyroid cancer

See *thyroid cancer*.

Parotid gland

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

Partial laryngeal excision

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

Percutaneous gastrostomy (PEG) feeding

Feeding by a tube which is passed through the wall of the abdomen directly into the stomach.

Periodontal disease

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

Pharynx (pharyngeal)

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

Photodynamic therapy

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

Pilocarpine

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

Positron emission tomography (PET)

An imaging method which reveals the level of metabolic activity of different tissues.

Prophylaxis

An intervention used to prevent an unwanted outcome.

Prosthesis

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

Protocol

A policy or strategy which defines appropriate action.

Psychosocial

Concerned with psychological influence on social behaviour.

Pulmonary

Having to do with the lungs.

Purulent

Containing, consisting of, or being pus.

Quality of life

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

Radical treatment

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

Radioiodine

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

Radioiodine ablation

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

Radiologist

A doctor who specialises in imaging.

Radiotherapy

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

Randomised controlled trial (RCT)

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

Recurrence

The return of cancer. See *local recurrence*.

Resection

The surgical removal of all or part of an organ.

Salivary glands

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

Serum calcium

Level of calcium in the blood.

Sinuses

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

Squamous cell carcinoma

A common type of cancer which originates in superficial layers of tissue (squamous epithelium).

Staging

The allocation of categories defined by internationally agreed criteria. Staging helps determine treatment and indicates prognosis. The TNM staging classification system is based on the depth of tumour invasion (T), lymph node involvement (N) and metastatic spread (M).

Stoma

A surgically created opening (see *tracheostomy*).

Stridor

A harsh vibrating sound heard during breathing caused by obstruction of the air passage.

Supportive care

Care that helps the patient and their family and carers to cope with cancer and its treatment throughout the cancer journey, and in the case of the family and carers, into bereavement. It aims to help the patient maximise the benefits of treatment and provide the best possible quality of life.

Synchronous

At the same time.

Thyroglobulin

A protein made by the normal *thyroid* gland. However, thyroglobulin can also be produced by papillary or follicular *thyroid cancer* cells. If high levels of serum thyroglobulin (thyroglobulin in the blood) are found following *thyroidectomy* and *thyroid ablation therapy*, this may indicate residual or recurrent *thyroid cancer*.

Thyroid

A small butterfly shaped gland situated in the front of the neck just below the *larynx*. Its chief function is to produce the hormones which control the body's rate of metabolism.

Thyroid ablation therapy

Treatment to destroy *thyroid* tissue. See *radioiodine ablation*.

Thyroid cancer

There are four main types of cancer of the *thyroid*. Papillary cancer is the most common and develops in cells that produce *thyroid* hormones containing iodine; it most commonly affects women of child-bearing age and tends to grow slowly. Follicular cancer also develops in cells that produce iodine containing hormones, but is much less common and tends to occur in older people. Medullary cancer is rare and develops in cells that produce the hormone *calcitonin*; it is known to run in families. The rarest thyroid cancer is anaplastic cancer which tends to affect older people and can be confused with thyroid lymphoma; it grows rapidly and can be difficult to treat.

Thyroidectomy

Surgical removal of the *thyroid* gland. A partial thyroidectomy is where only part of the *thyroid* is removed.

Thyroxine

The main active ingredient of the hormone produced by the *thyroid* gland. This hormone is one of the most important in the body and controls the rate of metabolism. The body needs a regular supply of iodine to produce thyroxine.

Tonsils

Masses of lymphoid tissue that lie on each side of the back of the throat.

Trachea

The windpipe.

Tracheoesophageal valve

A valve which fits in the surgically created opening between the *trachea* and *oesophagus* preventing food from entering the *trachea*.

Tracheostomy

A surgically created opening in the lower part of the neck which allows air to be breathed in following a *laryngectomy* or other type of surgery where it was necessary to divert the *trachea*.

Trusts

In the context of this guidance, Trusts are organisations responsible for managing and/or delivering health services. There are a variety of Trusts, the two most common being primary care trusts (PCTs) and NHS Trusts. PCTs are local organisations responsible for managing health services in a given local area. NHS Trusts manage hospitals, but can also provide services in the *community*.

Ultrasound

High-frequency sound waves used to create images of structures and organs within the body.

Upper aerodigestive tract

The mouth, lip and tongue (*oral cavity*) and the upper part of the throat (*larynx* and *pharynx*).

Vocal cord palsy

Paralysis of the *vocal cords*.

Vocal cords

Two vocal cords are contained within the *larynx*, which vibrate together when air is passed over them to produce the sound to be turned into speech.

Xerostomia

Deficiency of saliva - dry mouth.

Appendix 5

Abbreviations

AC	Audit Commission
BAHNO	British Association of Head and Neck Oncologists
BAOHNS	British Association of Otorhinolaryngologists and Head and Neck Surgeons
BAOMS	British Association of Oral and Maxillofacial Surgeons
CHI	Commission for Health Improvement
CI	Confidence interval
CNS	Clinical nurse specialist
CT	Computed tomography
DGH	District general hospital
ENT	Ear, nose and throat
EQA	External quality assurance
FNAC	Fine needle aspiration cytology
GM-CSF	Granulocyte macrophage colony stimulating factor
Gy	Gray (unit of absorbed dose of radiation)
HPV	Human papilloma virus or human papillovirus
HR	Hazard ratio
HSV	Herpes simplex virus
IARC	International Agency for Research on Cancer
ICD	International classification of disease
IT	Information technology
MDT	Multi-disciplinary team
mg	milligrams
MRC	Medical Research Council
MRI	Magnetic resonance imaging
NCA	National Cancer Alliance
NCRN	National Cancer Research Network

NICE	National Institute for Clinical Excellence
NNT	Number needed to treat
NYCRIS	Northern and Yorkshire Cancer Registry and Information Service
ONS	Office for National Statistics
PEG	Percutaneous gastrostomy
PET	Positron emission tomography
PTA	Polymyxin E, Tobramycin and Amphotericin B
RCT	Randomised controlled trial
ROM	Range of motion
RR	Relative risk
RT	Radiotherapy
SLT	Speech and language therapist
SWAHNI	South and West Head and Neck Audit Report
SWAHNII	Second South and West Head and Neck Audit Report
T	Tumour
TNM	Tumour invasion, lymph node involvement and metastatic spread
UAT	Upper aerodigestive tract
UKCCCR	United Kingdom Co-ordinating Committee for Cancer Research
WHO	World Health Organisation