HEAD AND NECK CANCER
This working paper has been prepared by Mr D W Patton, Consultant/Honorary Senior Lecturer in Maxillofacial Surgery, School of Postgraduate Studies in Medical and Health Care, Morriston Hospital, Swansea and member of the Cancer Services Expert Group (CSEG). The information has been drawn from advice given by a number of sources acknowledged within the report. The recommendations in this report have been agreed by CSEG. Further information, regarding recommendation priorities and mechanisms for monitoring their implementation, is available from the Project Office.

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1. EXECUTIVE SUMMARY

1. “Head and Neck Cancer” is a non specific term covering a wide range of cancers which vary in their causes and treatment. Over 80% of the cancers of the head and neck, if thyroid, skin and CNS cancers are excluded, are squamous cell carcinomas of the upper aerodigestive tract. Many are tobacco related.

2. Cancer of the upper aerodigestive tract is presenting at an earlier age, increasing the number of life-years lost. The total number of life-years lost to age 75 in Wales from this form of cancer, excluding larynx and paranasal sinuses, for the years 1981-1990 was 9010.

3. On average there are 450-500 new cases of head and neck cancer registered annually in Wales.

4. The overall 5 year survival rate has remained virtually unchanged at 40% over the last 35 years despite major advances in surgical and medical techniques.

5. The survival rate is closely related to the stage at which the disease is detected. The majority of cases present with advanced disease. The greatest impact on the number of life years lost is likely to be achieved by health agencies emphasising the importance of prevention and early diagnosis.

6. The treatment of advanced disease is associated with a high physical and psychological morbidity.

7. In view of the relatively small number of cases, treatment should be concentrated in a small number of centres based on fully supported multidisciplinary surgical and oncological teams. There should be an emphasis on multidisciplinary assessment of new cases in a joint clinic. Commissioning arrangements should take account of the necessity for a number of surgical and medical specialities to come together for the assessment and review of head and neck cancer cases.

8. There should be a greater emphasis on the psychological support of patients undergoing treatment for malignant disease of the head and neck.

9. Surgeons undertaking the management of malignant disease in the head and neck should hold the appropriate postgraduate medical qualifications and have received a formal training in their sphere of cancer surgery in an established centre. In accordance with the Calman report, surgeons undertaking head and neck cancer surgery should be restricting their surgery to the anatomical region in which they have been primarily trained and in which they would normally carry out the majority of their operating in the course of the normal working day.

10. There is an urgent requirement to establish comprehensive databases to collect outcome data for head and neck cancer services in Wales.
2. INTRODUCTION

General
2.01 Head and neck cancer is a commonly used but inaccurate term. By convention in the UK it includes cancers of the head and neck region other than brain cancers and thyroid cancer. These two groups are the subject of short supplementary reports appended to this document. Primary cancers of the facial skin also tend to be considered separately and have been considered under the report on skin cancer.

2.02 If the facial skin, brain and thyroid are excluded, over 80% of malignant tumours of the head and neck are squamous cell carcinomas of the mouth, tongue, pharynx, and larynx. Lip cancers (ICD 140) are also included in this group. Most of the remaining cancers arise in the major or minor salivary glands, or within the bones of the jaws.

2.03 For brevity, other types of local malignant disease in the mouth and pharynx which are less common will not be included in the discussions on epidemiology and aetiology. These include bone (ICD 190), connective tissue (ICD 171), the lymphomas and AIDS related Kaposi’s sarcoma (ICD 200-202).

2.04 Head and neck cancer therefore covers a disparate group of cancers with quite different causes. The treatment required varies widely between the various types of tumour, and the specialities undertaking their management vary depending on their training and anatomical area of interest. Unless otherwise stated, discussion in this report will centre on squamous cell carcinoma of the upper aerodigestive tract, and salivary glands, as these two categories will cover the majority of malignant disease in the head and neck region. In the International Classification of Diseases (ICD) system, 9th revision, this group would come under ICD 140-149 to which ICD 160 and 161 should be added:

ICD-140 Lip
ICD-141 Tongue
ICD-142 Major salivary glands*
ICD-143 Gum
ICD-144 Floor of mouth
ICD-145 Other and unspecified parts of mouth
ICD-146 Oropharynx
ICD-147 Nasopharynx
ICD-148 Hypopharynx
ICD-149 Other and ill defined sites within lip, mouth and pharynx
ICD-160 Nasal cavity, middle ear and accessory sinuses
ICD-161 Larynx

* This would exclude cancer of the minor salivary glands which should be classified either according to their anatomical location, or under ICD 145.9. However, a Welsh Dental Committee report on orofacial cancer has previously reported that many minor salivary gland cancers appear to have been coded under ICD 142.

Epidemiology
2.05 Cancer Research Campaign data for 1988 indicate that there were 6,752 cases of head and neck cancer in the UK, (4,443 male and 2,309 females) in that year (Table 1). With a UK population of 57 million, this gives an incidence 11.8 per 100,000 persons. This figure excludes thyroid cancers, skin cancers and brain cancers. Considering all sites in the head and neck, this is the 8th most common cancer in men and the 16th most common in women. The larynx remains the most common individual site for cancer in the head and neck.
TABLE 1: UK Incidence of Head and Neck Cancer in 1988

<table>
<thead>
<tr>
<th>Site</th>
<th>England</th>
<th>Scotland</th>
<th>Wales</th>
<th>N.Ireland</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Oral Cavity:</td>
<td>1664</td>
<td>294</td>
<td>138</td>
<td>60</td>
<td>2156</td>
</tr>
<tr>
<td>Lip</td>
<td>243</td>
<td>58</td>
<td>24</td>
<td>17</td>
<td>342</td>
</tr>
<tr>
<td>Mouth</td>
<td>805</td>
<td>158</td>
<td>63</td>
<td>27</td>
<td>1053</td>
</tr>
<tr>
<td>Tongue</td>
<td>616</td>
<td>78</td>
<td>51</td>
<td>16</td>
<td>761</td>
</tr>
<tr>
<td>Larynx</td>
<td>1926</td>
<td>243</td>
<td>155</td>
<td>52</td>
<td>2376</td>
</tr>
<tr>
<td>Pharynx</td>
<td>1006</td>
<td>122</td>
<td>82</td>
<td>31</td>
<td>1241</td>
</tr>
<tr>
<td>Totals:</td>
<td>4596</td>
<td>659</td>
<td>375</td>
<td>143</td>
<td>5773</td>
</tr>
</tbody>
</table>

Source: Cancer Research Campaign 1994

2.06 Welsh data for head and neck cancers, as a group, are included in Volume 1 and are summarised as follows:

- Registrations in 1990: 450
- Projected new registrations in the year 2000: not available
- Deaths from 1985-1994: 1,771
- Years of Life Lost for death under 70 years (1985-94): 10,973

Data Sources: see CSEG Report Volume 1; ICD 9 Codes: 140-149, 160,161, 190

2.07 Welsh data for cancer of the oral cavity, pharynx and salivary glands (ICD 140-149), but excluding the larynx, show that the number of cases registered in Wales in 1986 was 250 representing a gradual increase over the previous 10 years. There is, however, a commonly held view that there may have been a degree of under-reporting distorting the data held by the Welsh Cancer Registry. In 1986 168 cases of laryngeal cancer were registered in Wales (ICD 161) and 45 cases of cancer involving the nasal cavity, paranasal sinuses and ear (ICD 160). In 1986 there were a total of 463 new cases of head and neck cancer.

2.08 The average annual registration rate per 100,000 population in Wales for oropharyngeal and salivary cancer in Wales has risen from about 7 to 13 over the period 1974-1989. (This is in men where the registrations have virtually doubled; the number has remained fairly constant in women at 6-7)

2.09 Although salivary glands are included in this data it is important to realise that they are unrelated to the other head and neck cancers in that they are not usually squamous cell carcinomas. The cause of salivary cancer is also unknown. In 1986 45 cancers of the salivary glands were registered.

2.10 The number of deaths from oropharyngeal cancers, excluding larynx and paranasal sinuses, in Wales has remained fairly constant between 1975 and 1990 at about 100 deaths per year. In terms of life lost to age 75, this represents a loss of 9,010 years over the decade 1981-1990.

2.11 The prevalence of cancer of the mouth, pharynx and larynx increases with age. In Western countries 98% of cases are over the age of 40 and men are affected almost twice as often as women. There is, however, evidence of a significant rise in the incidence rate of oropharyngeal cancer throughout Western Europe, including Wales, for which there is no obvious cause. This is particularly true for tongue cancer\(^\text{[6]}\). There is also data suggesting that this form of cancer is occurring at an earlier age especially in males.

2.12 It is interesting to reflect that in 1989 there were 1,716 deaths from oral cancer in England and Wales compared to 1,820 deaths from cancer of the cervix. In 1988 in Wales alone, there were 126 deaths from cancer of the cervix compared to 100 deaths from oral cancer. The number of deaths are therefore comparable and it is perhaps surprising that oral and pharyngeal cancer appears to have received so little recognition from the population at large, or even from some groups of health professionals.

2.13 Of concern is that the overall 5 year survival rate for squamous cell carcinoma of the head and neck remains at about 40%, which is worse than not only cervical cancer, but also breast cancer and melanoma. Moreover, this 40% 5 year survival has not improved over the last 35 years even though there have been significant advances in medical and surgical techniques over this period. The 5 year survival for cancer restricted to the larynx is a little better at 60%.
At every site, including larynx, the survival is related to the stage at which the cancer is diagnosed. In the mouth and pharynx, of those diagnosed with stage IV (advanced disease) only 18% will remain alive at 5 years. The figures for stage III disease are 27%, stage II 65% and stage I (early disease) 77%. Unfortunately the majority of cases present relatively late when treatment carries a high psychological and physical morbidity, resulting in a poor outcome.

Risk Factors and Causes

There is incontrovertible evidence that tobacco in its various forms is the most important cause of cancer in the oral cavity, pharynx and larynx(2,5). The chemical carcinogens present in tobacco, including nitrosamines are well understood. A study by the Office of Population Censuses and Surveys (OPCS)(10) suggests that in general there is a higher incidence of cancer in the less privileged socio-economic groups, and that this is particularly true in cancers where tobacco is a known cause in the mouth, oesophagus, larynx, lung and urinary bladder.

The association of tobacco with cancer of the upper aerodigestive tract may account for the fact that 10% of patients with cancer in the mouth will have, or will develop a second primary cancer elsewhere in the upper aerodigestive tract. Usually this is in the pharynx or larynx, but may, less commonly, be in the lung or oesophagus.

Alcohol has never been shown to be carcinogenic in the head and neck per se but it has been shown to potentiate the effects of other topical carcinogens including tobacco. It is thought for example that the combined effects of tobacco and alcohol account for the relatively high prevalence of head and neck cancer in France.

Other but less important factors in these forms of cancer may be nutritional deficiency (especially iron and vitamin A), certain fungal infections, viruses, and immunosupression. Ultraviolet light is thought to be an important factor in the development of lip cancer, which is particularly prevalent in outdoor workers.

Little is known about the cause of cancer of the salivary glands. Neither alcohol or tobacco have been implicated.

How the Services are Organised at Present

The majority of patients are referred from the primary sector, either from a doctor or dentist. In the study by Cooke and Tapper - Jones in 1977(4) on patients with cancer of the mouth treated in Cardiff, 30% had been referred by their general dental practitioners and 50% by their medical practitioners. In a more recent study by Scully (1986)(3) slightly more patients were referred by dental practitioners than medical practitioners, although the medical practitioners were more likely to suggest the diagnosis of cancer.

In Wales, head and neck cancer is treated by a variety of surgical and medical disciplines mainly at district general hospital level. This is to some extent dictated by the anatomical location of the cancer and by the individual surgical interests of surgeons. For instance, cancer of the parotid salivary gland is treated by maxillofacial surgeons, ENT surgeons, plastic surgeons, and general surgeons, supported by various oncology services and with varying degrees of ancillary support. There is no data relating to the clinical outcome in cases treated by different surgeons at any particular clinical stage. Indeed there are difficulties in collecting outcome data as the outcome varies considerably depending on the clinical stage and biological characteristics of the tumour. The methods employed at the moment to stage oral and pharyngeal tumours in particular depend on the size and site of the tumour, and whether there has been spread to the regional lymph nodes.

It is however, widely appreciated that tumours of a similar size and site may have very different biological behaviours which cannot easily be measured, but result in a much worse clinical outcome.

Reconstructive surgical techniques are particularly important in head and neck cancer both to replace bone and soft tissue. In modern units the ability to carry out microvascular and microneural surgery is essential. Microvascular flaps are now considered to be the reconstructive technique of choice in several situations, particularly in orofacial cancer. At present in Wales this expertise is generally only available in the Regional Plastic Surgery Unit in Swansea, and in the Maxillofacial Units in Swansea, Cardiff, Newport and Glan Clwyd Hospital in North Wales.
Radiotherapy and oncology services are at present situated at Velindre Hospital in Cardiff, and Singleton Hospital in Swansea. Each holds a variety of joint head and neck cancer clinics with their respective Maxillofacial, ENT, Plastic and General Surgeons. Joint clinics (ENT/Maxillofacial/Oncologist) are held at the Glan Hafren, East Glamorgan, North Glamorgan and Bridgend and District NHS Trusts. These are attended by a Clinical Oncologist/Radiotherapist from Velindre. Radiotherapy services in North Wales are provided by either Clatterbridge or the Christie Hospital in Manchester. Glan Clwyd Hospital holds joint clinics with visiting consultants from Clatterbridge. The Maelor Hospital in Wrexham work more closely with the Christie. However, it is anticipated that a new radiotherapy facility will be completed in North Wales in 2-3 years time. Following that the links with Clatterbridge and the Christie will reduce and eventually cease.

The majority of acute general hospitals provide ENT services. In Swansea, there are joint head and neck oncology clinics attended by an ENT surgeon, maxillofacial surgeon, consultant in restorative dentistry and oncologist. One joint clinic is also attended by the Director of the West Glamorgan Counselling and Bereavement Service. Similarly, in Cardiff there is a weekly joint head and neck clinic attended by ENT, maxillofacial and plastic surgeons and an oncologist with a special interest in head and neck cancer.

A Maxillofacial Unit is co-located with the Welsh Centre for Burns and Plastic Surgery in Swansea. Maxillofacial Units are also based in Glan Clwyd District General Hospital, North Glamorgan, Glan Hafren, University Dental Hospital, East Glamorgan and Bridgend and District NHS Trusts. Peripheral clinics and operating lists are held in the majority of acute general hospitals in Wales by staff from these centres.

There appear to be large variations in the way in which patients receive counselling and psychological support in the different units. In some cases there are formal arrangements for counselling from the time of diagnosis onwards by trained counsellors and groups from the voluntary sector. Nurses play varying roles in counselling. In some units the arrangements for psychological support seem haphazard and depend upon the treating physician. Opinions on the value of psychological support seem to vary widely.

Arrangements for terminal care seem to depend on the local facilities available, and individual circumstances. Most units appear to have access to a hospice and pain control service.

Most units have access to CT and MRI scanning but these may not be in the same hospital. The Carmarthen Hospital NHS trust for instance purchases their MRI service from the Werndale Private Hospital.

Many patients require a variety of prostheses following surgery, to replace eyes, noses, ears, and parts of the upper jaw. Particular dental expertise may also be required to construct dentures in these cases. The facility to insert titanium osseointegrated implants into the jaws or facial bones to secure the prostheses is an integral part of a modern head and neck cancer service, and is important as a quality of life issue. The Maxillofacial Unit at Morriston Hospital provides a regional service for the construction of facial prostheses.

However there is a degree of variability in the access which units have to a Consultant in Restorative Dentistry for the construction of dentures and maxillary obturators. Such consultants are available in Cardiff and Swansea. There is one Consultant in Restorative Dentistry to cover the whole of North Wales. All patients undergoing radiotherapy should be assessed by Restorative Dental Surgeons prior to treatment as poor dental health may lead to significant complications following radiotherapy. Furthermore, a dental hygienist should be available to assist in oral care both before and after radiotherapy involving the mouth.

There is no standardised database for head and neck cancer in Wales. There are however databases administered by individual units within their own particular spheres of interest. The Maxillofacial Units are beginning to use a comprehensive database which it is hoped will be adopted by all the maxillofacial units in the United Kingdom. This was developed by the Regional Maxillofacial Unit at Walton Hospital in Liverpool in co-operation with the British Association of Oral and Maxillofacial Surgeons. There however appears to be no generally accepted format for a minimum dataset in head and neck cancer in Wales. The South Wales Head and Neck Oncology Group are at present trying to reach a consensus on the clinical data which should be collected in each case.
Expected Health Gain from Reorganising Services

There is general agreement that the best service would be based on a multidisciplinary approach in centres with the necessary expertise and equipment. There is no published data to support the belief that this would improve the present poor 5 year survival rate. It is very likely however that the quality of life of patients who have undergone treatment for head and neck cancer would be much improved following treatment in centres well supported by the full range of surgical and medical specialities, and other supporting services such as maxillofacial technologists. There is however very little data on outcome in this area of cancer treatment, other than crude mortality figures, on which decisions could be based. Similarly, there are at present no universally accepted protocols for the treatment of particular head and neck tumours at any stage, based on reliable published evidence.

3. THE CHARACTERISTICS OF A HIGH QUALITY SERVICE

General

3.01 The treatment of squamous cell carcinoma of the upper aerodigestive tract generally involves surgery, radiotherapy or a combination of the two. The role of chemotherapy is more controversial and on the basis of the evidence available should, wherever possible, be used as part of a multicentre trial. Nonetheless, chemotherapy may provide useful palliation in head and neck cancer, particularly when a local recurrence has developed after radical surgery and/or radiotherapy. There is also evidence that certain combinations of chemotherapy and radiotherapy may be more effective than surgery in advanced tumours of the tongue base. As most cases already have advanced disease on presentation, the majority of cases require combinations of both surgery and radiotherapy in a variety of regimes.

3.02 The surgery of head and neck cancer is demanding with operative procedures frequently lasting several hours and requiring a post operative period in an HDU or ITU. Patients are frequently heavy smokers and drinkers, and if drinking excessively or alcoholic will be, by definition, nutritionally deficient. This leads to a higher incidence of both local and systemic complications including infection, particularly chest infections. There may in addition be increased nursing difficulties with alcohol withdrawal and tobacco craving.

3.03 The development of complications may also delay post operative radiotherapy leading to a worse outcome.

3.04 When a “cure” is achieved it is frequently at a high cost to the patient, both physically and psychologically. The patient has to endure the ordeal of prolonged and disfiguring surgery, frequently waking in the unfamiliar surroundings of an ITU or high dependency area, unable to talk because of a tracheostomy, and requiring to be fed by a tube through the nose, side of the neck, or through the stomach wall. After a prolonged hospital stay, and within 6 weeks, the patient has to endure the discomfort of radiotherapy, perhaps with dryness of the mouth and loss of taste. On top of this there may be adjuvant chemotherapy with vomiting and hair loss. Effective psychological support is essential both for the patient and their family. It is perhaps not surprising that a proportion of patients never work again following their treatment and require treatment for a depressive illness, or psychosexual difficulties[7].

3.05 Depending on the type and degree of surgery, there is also a high physical morbidity. Following laryngectomy there is a permanent hole into the windpipe (tracheostomy) and the patient is unable to speak properly. Many are left oral cripples after surgery for mouth cancer, unable to wear a prosthesis or eat anything other than soft foods. There is drooling due to the loss of lip competence and slurring of speech if the surgery has involved the tongue. There may be loss of taste and difficulty in swallowing. Large parts of the upper jaw, nose, ear and face may have been lost leaving the individual with a gross facial deformity.

3.06 A feature of head and neck cancer surgery is the necessity for facial and jaw reconstruction to provide the patient with as good a functional and aesthetic result as possible, leading to good quality survival. The emphasis in surgery is on a one stage resection and reconstruction, to facilitate early post operative feeding and mobilisation, with a reduction in the duration of the admission. This necessitates expertise in a variety of vascularised and non-vascularised bone and soft tissue flaps. In situations where reconstruction may be unsatisfactory, a facial or intraoral prosthesis may be constructed by a Maxillofacial Technician to replace missing tissue. This is commonly necessary to replace an ear, nose, eye socket, or part of the upper jaw. Consultants in Restorative Dentistry working closely with maxillofacial trained Dental Technicians have a major role to play in the cosmetic and functional rehabilitation of these unfortunate patients.
3.07 It is also desirable that in those cases where the radiotherapy field involves the tooth bearing portion of the jaws, a restorative dentist screens the patient for dental disease in order to reduce the chances of later complications such as osteoradionecrosis of bone. Should osteo-radionecrosis of the bone develop, funding should be available for referral to a hyperbaric oxygen unit for treatment. No such unit with the necessary size or medical supervision at present exists in Wales. In South Wales cases are generally referred to the Diving Diseases Research Unit in Plymouth.

3.08 Where part of the jaw bones have been removed, it is frequently impossible for the patient to retain a conventional prosthesis, making eating and speech difficult. It is now possible to insert titanium dental implants into the jaw bones, which fuse to the bone after some months, and to which a denture or dental bridge can be rigidly fixed. The same implants are used to retain facial prostheses replacing ears, noses or eyes.

3.09 The planning of the treatment for head and neck cancer requires a comprehensive radiology service including MRI and CT facilities, with videofluoroscopy for speech and swallowing assessment. Ultrasound scanning is playing an increasingly important part in the staging of head and neck cancer and should be available to the centre.

3.10 It may therefore be seen that the comprehensive treatment of cancers in the head and neck region require a wide range of services and facilities. They fall into three main groups:

- Specialist Medical Services
- Clinical Support Services
- Specialist Nursing Services.

**Specialist Medical Services**

**Surgery**

3.11 The surgery should be carried out by experienced surgeons who have been formally trained in cancer surgery related to a particular anatomical area of the head and neck. No one surgical speciality has the training or expertise to manage every type of head and neck cancer. The surgeon carrying out the surgery should have been trained in the appropriate reconstructive techniques. In a Unit carrying out head and neck cancer surgery there should be at least two surgeons with a major interest in head and neck surgery. These would normally be ENT Surgeons, Maxillofacial Surgeons, or Plastic Surgeons. The ready availability of cardiothoracic, neurosurgical, vascular and ophthalmology surgery services are desirable.

3.12 The principal mode of spread of malignant disease of the head and face is to the lymph nodes in the neck. All surgeons involved in head and neck cancer should be trained in the surgical management of disease in the neck.

3.13 There is no outcome data to support an optimal number of cases to be treated by a surgeon in a year. It should however be his or her principal surgical interest.

**Radiotherapy**

3.14 Clinical oncologists in the unit should have a special interest in head and neck cancer.

**Chemotherapy**

3.15 Should be supervised by accredited medical and clinical oncologists experienced in the management of head and neck cancer.

**Palliative Medicine**

3.16 Supervised by specialist physicians committed to palliative medicine.

3.17 All clinicians involved in the head and neck team should participate in regular teaching and research. They should work to established protocols and undertake regular local and regional interdisciplinary audit. There is a need to give better training to fewer trainees in head and neck cancer. No one speciality is able to give comprehensive training in the management of head and neck cancer. The centralisation of head and neck cancer treatment in Cancer Centres will enable trainees to obtain a fully rounded training with exposure to all the involved specialities including radiotherapy and oncology.
Clinical Support Services

- Diagnostic Pathology Services. This should include a cytology service for the support of Fine Needle Aspiration Cytology (FNAC). The pathologist should have particular experience in the histological features of head and neck cancer including tumour markers.
- Diagnostic imaging service to include Computerised Tomography (CT), Magnetic Resonance Imaging (MRI) and Ultrasound Scanning.
- Speech therapy, videofluoroscopy and assessment of speech and swallowing. There should be a voice rehabilitation programme for patients with laryngeal cancer. Voice restoration after laryngectomy requires multidisciplinary co-operation between a speech therapist and an ENT surgeon. All patients should be offered primary voice restoration at the time of resection. Other methods of voice rehabilitation must also be available from a specialist in Speech and Language Therapy.
- Physiotherapy
- Occupational therapy
- Dietician service for nutritional assessment and post operative nutritional support
- Anaesthesia services for complex airway management
- Maxillofacial technology service for the production of facial prostheses and intraoral prostheses including implant borne prostheses.
- Comprehensive pharmacy service including chemotherapy support
- Access to a hyperbaric oxygen facility
- Photographic services should be available

3.18 The complexity of many head and neck cancer cases dictate that a multidisciplinary approach to management is desirable. This is facilitated by the formation of a joint clinic where opinions may be exchanged and a wide range of clinical expertise brought to bear on the management of individual cases. The organisation of joint clinics needs to be carefully controlled so that they do not become too large and unwieldy. They may be expensive to hold in view of the number of staff involved and may also involve the cross boundary movement of staff. This should be recognised by commissioners. Care must also be taken that the number of clinical staff present does not become intimidating for the patient.

3.19 Standardised databases should be developed for Wales which ideally should reflect data collection in the UK and Europe. This should be centralised in one of the cancer centres. The minimum dataset should probably include:

- Patient identifiers
- Demographic Data including occupation
- Risk factors including alcohol and tobacco consumption.
- Site of tumour
- Histological type and grade of tumour
- Clinical and pathological staging
- Treatment
- Complications of treatment
- Review data for at least 5 years or the death of the patient (to include outcome data)

3.20 Units should work to guidelines developed preferably on a national basis on the basis of the best evidence available. This is complicated by the fact that, in orofacial cancer for instance, there is a lack of consensus throughout the UK and Western Europe on the best management of an orofacial tumour at any particular clinical stage. There may be difficulties in establishing agreement on guidelines and protocols between the clinicians involved in treatment across Wales.

Specialist Nursing Services

3.21 Patients should be cared for by nurses who have experience and training in head and neck cancer. In particular they should have experience in looking after patients who have undergone major ablative and reconstructive surgery. This might include diplomas or degrees in cancer or palliative care together with experience in a cancer centre. Training in the management of the dying patient is desirable.

3.22 Nurses will have received training in ENT nursing, maxillofacial nursing, burns and plastic nursing or intensive care nursing.
The suggested pathway for the management of Head and Neck cancer is found at Appendix 1.

4. ORGANISATION AND ROLES TO DELIVER SERVICES

4.1 This section has been incorporated into Section 3 “Characteristics of a High Quality Service”

5. MONITORING OF PROGRESS AND PERFORMANCE

5.1 There is little available outcome data in Wales for head and neck cancer. What is available is restricted to individual units. There are no centralised databases other than the Wales Cancer Registry. It is essential that comprehensive databases for all forms of head and neck cancer are established, preferably in Cancer Centres or in the proposed Cancer Institute in Swansea. In particular there is a requirement for quality of life data to compare the outcome of differing forms of treatment, as the overall cure rate is so poor and the morbidity associated with treatment so high. The accurate collection of data is central to the development and monitoring of a high quality service.

6. RECOMMENDATIONS

1. There are 450-500 new cases of head and neck cancer per year in Wales. Many are related to tobacco and alcohol abuse and are preventable. There should be an increased emphasis on prevention and health promotion. This should include health education for both the public and primary care professionals.

2. Head and neck cancers are relatively rare. They should be managed in functional cancer centres under the care of a multidisciplinary team of specialists. Ideally there should be at least one ENT surgeon, a maxillofacial surgeon and/or plastic surgeon and a clinical oncologist (radiotherapist and oncologist) who has special expertise in the management of head and neck cancer.

3. The head and neck cancer centre should have ITU and HDU facilities.

4. The head and neck multidisciplinary cancer team should have ready access to surgical, vascular and cardiothoracic services.

5. Nursing expertise should be available to the head and neck multidisciplinary cancer team and should include:
   - Ward nurses trained in head and neck oncology
   - A clinical nurse specialist
   - A palliative care nurse
   - A community liaison Nurse

6. Speech therapy services should be available and a functioning voice restoration programme is essential for the treatment of cancer of the larynx.

7. A head and neck multidisciplinary cancer team should have a maxillofacial laboratory for the construction of facial and oral prostheses.

8. A restorative dentist should form part of the head and neck team. A dental hygienist service is also essential.

9. A maxillofacial service for the construction of implant retained facial and oral prostheses should be available to the cancer centre.

10. Joint multidisciplinary head and neck clinics should be held in the head and neck cancer centre at least every fortnight.

11. There should be ready access to modern imaging facilities including MRI, CT, ultrasound and nuclear imaging. There should be a named radiologist with particular expertise in head and neck imaging.

12. The head and neck multidisciplinary cancer team should have the services of a histopathologist with special expertise in head and neck pathology. There should be a cytopathology and frozen section service.

13. A functional head and neck multidisciplinary cancer team should treat at least 80-100 new cases per year. These numbers are not based on outcome data, but are considered necessary to facilitate the provision of a full range of supporting services and to provide research and training opportunities.

14. Thyroid cancer should be managed by a recognised multidisciplinary team with a specialist surgeon and a dedicated clinical oncologist. Ideally an endocrinologist should form part of the team.
Initial work has been undertaken with regard to brain and thyroid cancer however, these will be the subject of a further CSEG study.

**Evidence base:**

- Published papers
- British Association of Head and Neck Oncologists recommendations
- Consensus within Wales.
- Consensus within Wales and wider UK

Consensus is derived from the evidence submitted by those contributing to this task group report.

### 7. REFERENCES/BIBLIOGRAPHY

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### 8. ACKNOWLEDGEMENTS

Mr A Ali, Consultant in Restorative Dentistry, Maxillofacial Unit, Morriston Hospital NHS Trust
Mr A E Brown, Consultant Maxillofacial Surgeon, Queen Victoria Hospital East Grinstead, Council British Association of Head and Neck Oncologists
Mr W Dickson, Clinical Director and Consultant Plastic Surgeon, Welsh Centre for Burns and Plastic Surgery
Dr S El-Sharkawi, Clinical Director, Oncology and Radiotherapy Unit, Swansea NHS Trust
Mr M Fardy, Consultant Maxillofacial Surgeon, University Dental Hospital NHS Trust
Mr C Fielder, Consultant ENT Surgeon and Clinical Director ENT, Swansea NHS Trust
Professor P S Harper, Professor and Consultant in Medical Genetics, University of Wales College of Medicine
Professor A McGregor, Professor of Reconstructive Surgery, Morriston Hospital NHS Trust
Dr I Patterson, Consultant Clinical Oncologist, Velindre NHS Trust (also representing South Wales Head and Neck Oncology Group)
Mr J Phillips, Consultant Maxillofacial Surgeon, Glan Clwyd District General Hospital NHS Trust (in conjunction with Mr C Penfold, Consultant Maxillofacial Surgeon)
Mr G R Shone, Consultant ENT Surgeon, University Hospital of Wales Healthcare NHS Trust
Mr K Silvester, Consultant Maxillofacial Surgeon, Morriston Hospital NHS Trust
APPENDIX 1 - GUIDELINES FOR THE MANAGEMENT OF HEAD AND NECK CANCER

REFERRAL FROM PRIMARY CARE SECTOR

REFERRAL TO APPROPRIATE SURGICAL FIRM.
ENT/MAXILLOFACIAL/PLASTICS

CLINICAL Assessment
Special Investigations
(Biopsy, Endoscopy, MRI, CT, Ultrasound + Fine Needle Aspiration)

DISCHARGE

TREAT BENIGN LESION

NO MALIGNANT DISEASE

MALIGNANT DISEASE CONFIRMED

PSYCHOLOGICAL SUPPORT INITIATED

ASSESS IN MULTIDISCIPLINARY JOINT CLINIC
TREATMENT PLAN

CLINICAL AND RADIOLOGICAL STAGING

DENTAL SCREENING

NO RECURRENCE

POSTOPERATIVE RADIOTHERAPY ± CHEMOTHERAPY

PALLIATIVE THERAPY ± RADIOTHERAPY ± CHEMOTHERAPY

FOLLOW UP

SALVAGE THERAPY

RECURRENCE

PSYCHOLOGICAL SUPPORT

PATHOLOGICAL STAGING

RADIOOTHERAPY ± CHEMOTHERAPY

RADICAL (CURATIVE) SURGERY

PALLIATIVE SURGERY

DENTAL SCREENING

NO MALIGNANT DISEASE

PSYCHOLOGICAL SUPPORT

SALVAGE THERAPY

NO RECURRENCE

DISCHARGE AFTER INTERVAL (GENERALLY 5 YEARS)

*JOINT CLINIC INCLUDES ENT, MAXILLOFACIAL,
ANNEXES TO HEAD AND NECK CANCER

Annex A - Malignant Tumours of the Thyroid Gland (ICD 193)

1. EXECUTIVE SUMMARY

1. Cancer of the Thyroid Gland is relatively rare. Within Wales 80-90 new cases could be expected per year.
2. The small number of cases suggest that the management of these tumours should be limited to a small number of centres in Wales. There is no evidence to suggest an optimal or minimal number of cases which should be treated by one centre in a year.
3. Management should be centred on a multidisciplinary team based on a thyroid surgeon and clinical oncologist and supported by an endocrinologist.
4. There is a requirement for a Welsh and preferably National database for thyroid cancer. The database should include measures of outcome.
5. In view of the small number of cases, audit should be held at both a local and regional level.
6. Protocols and guidelines for the management of thyroid cancer based on published evidence should be produced at least on a regional basis.

2. INTRODUCTION

Epidemiology

2.1 Thyroid malignant disease is relatively rare with an incidence of 4 per 100,000 of the population, accounting for less than 1% of all malignancies in the United Kingdom. The prevalence of palpable thyroid nodules increases with age and is 4-7% in the middle aged population. There were 819 new cancers of the thyroid in the UK in 1985 ranking it as the 28th most common malignant tumour. In the same year there were 398 deaths from the disease.

2.2 Within Wales the distribution of thyroid cancer is fairly even although it may be more common in North Wales. Each new Health Authority in Wales with a population of about 500,000 would, therefore, expect to see about 10 new patients a year with thyroid cancer.

2.3 Welsh Cancer Registry data indicate that in 1990 67 cases of thyroid cancer were registered in Wales of which 18 were in Mid Glamorgan. In 1993/94 there were 79 cases registered in Wales and in 1994/95 88 cases. Outside Cardiff, the greatest number of cases seen by a Trust in 1994/95 in a year was 8 at Swansea NHS Trust. The majority of other Trusts see between 0 and 5 a year.

Trends in Outcome

2.4 The majority of patients with thyroid malignancy have differentiated thyroid cancer; papillary and follicular cancer, but a minority have anaplastic cancer, lymphoma or medullary cell carcinoma of the thyroid. The mortality from differentiated thyroid cancer has fallen over the last few decades. There has been a gradual and significant improvement in five year survival rates for thyroid cancer of all types. Although a number of factors may be responsible for this improvement, it is likely that early diagnosis and more effective initial management accounts for much of this improvement.

The Present Service in Wales

2.5 Services in South Wales are at present centred on two thyroid clinics, one at the University Hospital of Wales and one in the Swansea NHS Trust. Both clinics are multidisciplinary and have a full range of supporting services. Cases are also treated in other District General Hospitals in South Wales. The Cardiff unit receives referrals on both a regional and supra-regional basis.

2.6 In North Wales, a service for thyroid cancer is provided by a General Surgeon and a Physician in Wrexham. Radiotherapy support is at the Christie Hospital. A similar service is provided at Glan Clwyd Hospital with radiotherapy services at Clatterbridge Hospital. Thyroid cancer cases are also treated in other District General Hospitals in North Wales.
Expected Health Gain from Reorganisation of the Service

2.7 An emphasis on multidisciplinary teams working in established units with comprehensive supporting services may lead to improved outcomes both in terms of survival and quality of survival. We are unaware of any outcome data, other than mortality, for carcinoma of the thyroid in Wales which could be used as a baseline to assess any changes in organisation of the service.

3. CHARACTERISTICS OF A HIGH QUALITY SERVICE

3.1 The management of thyroid cancer should be carried out by multidisciplinary teams treating an appropriate number of cases with full supporting services. The teams should be committed to research and teaching, and participate in local and regional audit. A multidisciplinary clinic should be staffed by or have easy access to a:

- Thyroid Surgeon
- Endocrinologist
- Medical Physics Unit
- Cytology Service
- Pathology and Biochemistry Service
- Imaging Services
- Oncologist/Radiotherapy Service
- Psychological Support Services
- Palliative Care Services
- Genetics and Molecular Biology Support Groups

3.2 In general the initial management of a case following diagnosis should be discussed in a multidisciplinary joint clinic. The initial management of the case has been shown to influence outcome and determine follow up strategies and subsequent management\(^6\).

3.3 Thyroid nodules are common, and the initial management must be to identify those small number of patients who have malignant disease. This is achieved with Fine Needle Aspiration Cytology (FNAC). This is a safe and inexpensive technique and by using it the number of patients undergoing surgery is reduced with no reduction in the number of cancers diagnosed\(^3,4,5\). A thyroid unit must therefore have access to an FNAC/cytology service. It would also be desirable to have the facility for carrying fine needle aspiration of thyroid lumps under ultrasound control\(^8\). The majority of benign thyroid disease will continue to be treated in District General Hospitals. Where a thyroid nodule, initially felt to be benign, is removed and found to be malignant, the patient should be referred to a Cancer Centre for further management.

3.4 In the area of medullary thyroid cancer and the inherited syndromes the optimum management and screening of family members requires co-operation between the clinician and a genetics and molecular biology service.

3.5 Patients who have received treatment for thyroid cancer should be followed up for 5 years by an experienced clinician who is capable of detecting any early recurrence of the disease. It is generally held that this follow up should be undertaken within the hospital service, probably on a joint clinic basis.

4. ORGANISATION, ROLES AND FUNCTIONS TO DELIVER SERVICE

Principal Personnel

- Thyroid Surgeon
- Endocrinologist (Physician)
- Oncologist/Radiotherapy

Affiliated Personnel

- Histopathologist/cytologist
- Radiologist with a head and neck imaging interest
- Genetic Support
- Palliative care services
Volume and Outcome
There is no current evidence to suggest the optimal number of cases which a surgeon should treat in a year. No outcome data appears to be available other than mortality figures.

5. MONITORING OF PROGRESS AND PERFORMANCE

5.1 Database centralised on a Cancer Centre. The information recorded to include the number of patients undergoing investigation, the number requiring surgery, and the numbers undergoing surgery found to have thyroid cancer.

5.2 Outcome data to include recurrence and survival information related to the histological type and staging of the tumour.

5.3 Audit at both local and regional level.

5.4 Monitoring of quality of life issues.

6. ACKNOWLEDGEMENTS

Dr R Davies, Director, West Glamorgan Counselling, Bereavement and Training Service
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Mr JS Waters, Consultant Surgeon, Swansea NHS Trust
Mr M Wheeler, Consultant Surgeon, University Hospital of Wales Healthcare NHS Trust

7. REFERENCES/BIBLIOGRAPHY

2. CRC Factsheet 3, Mortality in the UK 1989
ANNEX B - Brain Cancer

1. EXECUTIVE SUMMARY

1. Brain cancers are relatively uncommon and their treatment as at present should be limited to established neurosurgical centres working in conjunction with radiotherapy/oncology units.
2. There would seem to be no evidence to support changing the present arrangements for the provision of the service.
3. The developing field of craniofacial access for inaccessible intracranial or skull base tumours makes the addition of a Maxillofacial Surgeon to the team desirable.

2. GENERAL

Epidemiology
2.01 In 1985 there were 3,116 brain cancers registered in the UK with a ranking of 18th in the sites of cancer in the UK. (1,766 male and 1,350 female). This equates almost exactly to the number of melanomas registered over the same period (3,119)
2.02 In 1988 there were 2,940 deaths from brain cancer in the UK (1,660 male and 1,280 females) ranking 13th in the causes of death in the UK from cancer. European data (Eurocare study) in cases of brain cancer between 1978 and 1985 (13,318 cases) show that the 5 year survival is only 14% in men and 15% in women.
2.03 1644 cases of brain cancer in children (<15 years) were registered between 1978 and 1985. The 5 year survival of 50% is much better than the adult survival.
2.04 Welsh Cancer Registry data indicates that in 1990 there were 193 registered cases of brain cancer in Wales. There is no indication as to which of these were primary tumours and which were metastases.

Organisation of Services at Present in Wales
2.05 The treatment of brain and other central nervous system cancers in South East Wales are treated by the Neurosurgical Team at UHW in conjunction with the Oncologists at Velindre. The service for paediatric CNS tumours in South East Wales seems to run well. There is a close liaison with two paediatric oncologists at Llandough Hospital. One paediatric oncologist has a particular interest in paediatric neuro-oncology. The team is also strengthened by a Consultant Paediatric Neurologist.
2.06 A Consultant Maxillofacial Surgeon has recently been appointed in Cardiff who besides working with the neurosurgical team in the management of craniofacial trauma, also carries out facial access osteotomies to facilitate the neurosurgical approach to difficult skull base tumours.
2.07 In South West Wales, the Neurosurgical Unit in Swansea (Morriston) treats brain cancers in conjunction with the radiotherapy unit at Singleton Hospital.
2.08 In addition to the joint neurosurgical / oncology clinics, joint neurosurgical / maxillofacial clinics are held for the management of skull base tumours. Ophthalmological assessment of patients has in the past been carried out at Singleton Hospital. This service will shortly be provided on site at Morriston Hospital.
2.09 There is a combined neuro-endocrine clinic involving neurosurgeons and endocrine physicians predominantly for the management of pituitary tumours. Pituitary tumours are also treated by ENT surgeons.
2.10 Acoustic Neuromas: The number of such tumours is relatively small, and may present a difficult challenge to the neurosurgeon. They are generally managed in a small number of supra-regional centres where collaboration between a neurosurgeon and neuro-otologist offers the best prospect of a favourable outcome. There is currently no such service available in Wales. The catchment population of South Wales would probably be sufficient to justify the development of such a service in one of the two centres in South Wales.Until then, such patients will be referred outside Wales.
2.11 Paediatric Brain Tumours are referred from the Swansea Centre to Cardiff.
2.12 The neurosurgical centre in Swansea is staffed by 3 Consultant Neurosurgeons. It is intended that a fourth consultant with a special interest in neuro-oncology will be appointed over the next two years.
There is currently no service available in North Wales for the treatment of brain cancers. These cases are referred to the Regional Neurosurgical Centre in Walton Hospital in Liverpool, where they are treated in conjunction with the radiotherapy service at Clatterbridge Hospital. There is no indication at present as to how the service might change once the new radiotherapy service becomes available in North Wales.

**Anticipated Health Gain from Reorganisation of the Service**

The treatment of brain cancer will continue to be centred on neurosurgical centres with a full range of supporting services. In South Wales therefore it is likely that the service will continue to be provided in the two neurosurgery/radiotherapy centres. The service in North Wales may change following the construction of the new radiotherapy centre in Clwyd.

It seems unlikely that, in the foreseeable future, there will be any change in the numbers of patients being referred, or in the biological behaviour of the lesions themselves. The prognosis following treatment of brain cancers has changed little over the last three decades, and it is unlikely that re-organisation of the service would change this. The morbidity and peri-operative mortality has however been reduced by the introduction of stereotactic surgical methods and the use of peri-operative steroid therapy.

There may however be scope for improvements in the pastoral care of patients following treatment.

### 3. CHARACTERISTICS OF A HIGH QUALITY SERVICE

#### 3.1
Brain cancers may present in a variety of ways. They may present as headaches, visual disturbances or behavioural changes for instance. Cases may be referred from a number of sources including medical practitioners, ophthalmology units, neurology units, endocrinology units and from other head and neck specialties.

#### 3.2
It is essential that a good head and neck radiology service is available with CT and MRI facilities. The radiologist should be a neuro-radiologist.

#### 3.3
Management of the cases requires a multidisciplinary approach based on a neurosurgical unit and radiotherapy centre. Such units should hold joint clinics and engage in regular local and regional audit. A common database should be set up in one cancer centre to record all the data for Wales. As far as possible units should work to an agreed national or international protocol or guidelines.

#### 3.4
The outcome following treatment for brain cancer in adults is generally poor, and may carry a high morbidity. The support of clinical psychologists and palliative care services is essential. Ophthalmology services should be available.

#### 3.5
The support of a Maxillofacial Unit is desirable to gain transfacial or transoral access to tumours in difficult anatomical locations.

### 4. ORGANISATION, ROLES AND FUNCTIONS TO DELIVER SERVICE

#### Principal Personnel

- Surgeon
- Oncologist

#### Affiliated Personnel

- Neuro-radiologist
- Maxillofacial Surgeon
- Endocrinologist
- Ophthalmologist
- Clinical Psychologist
- Palliative care services
- Rehabilitation services
5. **MONITORING OF PROGRESS AND PERFORMANCE**

5.1 Database centralised on a Cancer Centre. The information recorded to include the number of patients undergoing investigation, the number requiring surgery, and the numbers undergoing surgery found to have brain cancer.

5.2 Outcome data to include recurrence and survival information related to the histological type and staging of the tumour.

5.3 Audit at both local and regional level.

5.4 Monitoring of quality of life issues.

5.5 Patients with CNS malignant disease should be followed up for 5 years in neurosurgical clinics or by the radiotherapists involved.

6. **REFERENCES/BIBLIOGRAPHY**


7. **ACKNOWLEDGEMENTS**

Mr Colin Fielder, Consultant ENT Surgeon, Swansea NHS Trust

Dr T Joannides, Consultant in Radiotherapy/Oncology, Swansea NHS Trust

Mr J Martin, Clinical Director, Neurosurgical Unit, Morriston Hospital NHS Trust

Mr R Redfern, Consultant Neurosurgeon, Morriston Hospital NHS Trust

Mr B Simpson, Consultant Neurosurgeon, University Hospital of Wales Healthcare NHS Trust