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Mouth Cancer for Clinicians Part 8: Referral

Abstract: A MEDLINE search early in 2015 revealed more than 250,000 papers on head and neck cancer; over 100,000 on oral cancer; and over 60,000 on mouth cancer. Not all publications contain robust evidence. We endeavour to encapsulate the most important of the latest information and advances now employed in practice, in a form comprehensible to healthcare workers, patients and their carers. This series offers the primary care dental team in particular, an overview of the aetiopathogenesis, prevention, diagnosis and multidisciplinary care of mouth cancer, the functional and psychosocial implications, and minimization of the impact on the quality of life of patient and family.
Clinical Relevance: This article offers the dental team an overview of referral procedures; oral diagnosis is not always simple and a second opinion can be valuable to all concerned in cases of doubt.
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If mouth cancer has been detected early enough, it can usually be treated with a good prognosis and with minimal adverse effects. Thus the patient with any suspicious oral lesion should be referred as soon as possible for a second opinion.

Referral

Generally speaking, the earlier a cancer is found and treated, the better the outcome is likely to be with lesser adverse treatment sequelae. In general, cancer prognosis decreases with advanced disease, advanced age, low SES (Socio-Economic Status), and continuing risky lifestyles. Mouth or oropharyngeal cancer due to HPV, however, is appearing increasingly in younger patients without the 'traditional' mouth cancer risk factor but has a better outlook than in cancers unassociated wih HPV.

If the cancer is small, removal through surgery may be a simple procedure. In some cases the procedure can even be carried out under local anaesthetic. If the cancer is large or has spread, surgery may still be the preferred treatment option, or other treatment modalities in addition to surgery may include radiotherapy and chemotherapy. These days, for such decisions the patient will invariably benefit from the advice and expertise of the MDT (Multi-Disciplinary Team).

Nevertheless, patients frequently delay seeking professional advice, on average for periods up to 3 months after having become aware of any oral symptom that could be linked to mouth cancer. In patients with features suggestive of cancer, investigations in primary care should never be allowed to delay referral. Rapid referral is mandatory. In patients with less typical symptoms and signs that might, nevertheless, be due to cancer, investigations may be necessary but should be undertaken urgently to avoid delay. If specific investigations are not readily available locally, an urgent specialist referral should be made. In the meantime:

- Do not biopsy the lesion;
- Do not tell the patient that they have cancer;
- Tell the patient you are concerned and that they should be seen by a specialist in an MDT;
- Refer to the local MDT.

What should the primary care healthcare worker tell the patient and family?

Primary healthcare professionals should provide culturally appropriate care, recognizing the potential for different cultural meanings associated with the possibility of cancer, the relative importance of family decision-making and possible unfamiliarity with the concept of support outside the family. A cancer diagnosis cannot fail to cause serious concern and patients may find being referred for suspected cancer particularly difficult because of fear, their personal

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circumstances, such as age, family or work responsibilities, isolation, or other health or social issues. The information given to patients, family and/or carers as considered appropriate by the primary healthcare professional should carefully cover, *sensitively*, among other issues:

- Why patients are being referred;
- Where patients are being referred to;
- How long they will likely have to wait for the appointment;
- Who they will be seen by;
- What to expect from the service the patient will be attending;
- What types of tests may be carried out, and what will happen during diagnostic procedures;
- How long it may take to get a diagnosis or test results;
- Whether they can take someone with them to the appointment;
- Other sources of support, including those for minority groups.

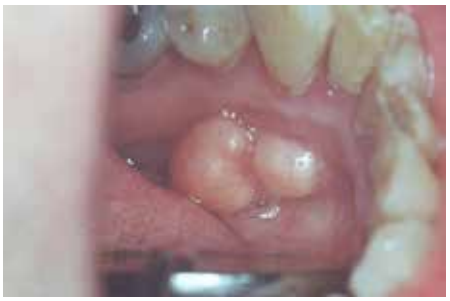

Figure 1. Torus mandibularis – benign.

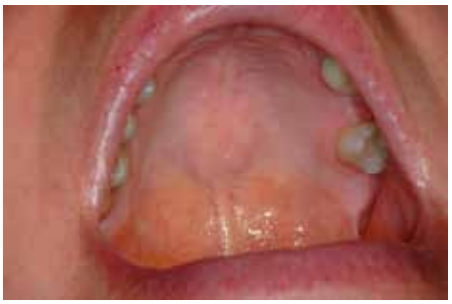

Figure 2. Torus palatinus – benign.

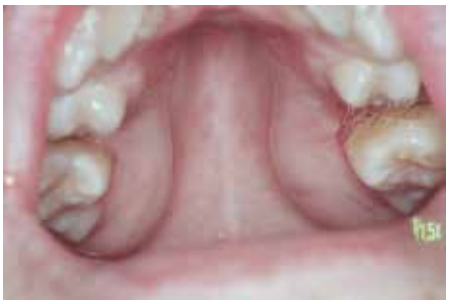

Figure 3. Enlarged maxillary tuberosities.

When is referral warranted?

www.nhs.uk/chq/Pages/910.aspx?CategoryID=68

Anyone can ask for a second opinion. A referral is advice from a second clinician – often a specialist. Often people themselves request a second opinion when they want to try and ensure that they have the best decision for them, for example when any of the following apply:

- A diagnosis is serious, such as cancer, or in doubt;
- Surgery or a certain treatment has been recommended;
- Treatment is not effective or there are complications;
- They do not understand what is being suggested;
- They have communication or other difficulties with their clinician.

There is no legal right to a second opinion, but a healthcare professional will rarely refuse to refer for one. The British Medical Association (BMA) believes that, in most cases, it is best practice for patients to be referred for specialist treatment via their GP. This can be done on the NHS, or privately.

Clinical diagnosis of oral lesions can be very challenging but dental healthcare professionals are usually adept in diagnosing commonplace lumps, such as anatomical features (eg tongue papillae), or torus mandibularis or torus palatinus (Figures 1, 2).

Some other lumps, mostly with a normal surface mucosa, can be due to other benign conditions (Figures 3, 4).

However, lumps on the posterior tongue, for example, can be very difficult to diagnose (Figure 5).

Occasionally, the diagnosis is fairly obvious if there is a clear abnormality likely to represent malignancy, such as persistent cervical lymphadenopathy (Figure 6), or where the lesion has a very characteristic (pathognomonic) appearance (Figure 7).

The causes of other lumps, red lesions or ulcers may be less obvious and may be sinister (Articles 6, 7; Figures 8–12).

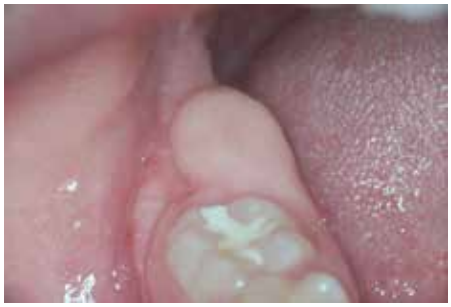

Figure 4. Hyperplasia in mandibular gingiva.

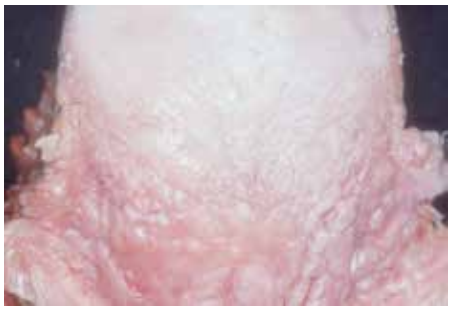

Figure 5. Tongue (post-mortem specimen), to show the vallate papillae and posterior third topographical anatomy which is difficult to visualize fully without endoscopy or examination under anaesthesia.

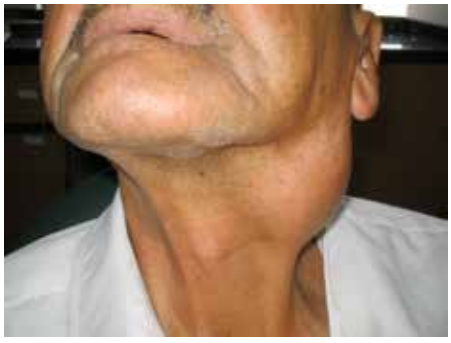

Figure 6. Obvious cervical lymph node enlargement, which is often malignancy or infection.

What are the advantages and disadvantages of a second opinion?

Possible advantages

- If both clinicians are in agreement about the diagnosis and treatment, patients are likely to have increased confidence about their decision.
- The patient may have more confidence with a different doctor.

- A treatment that has not been suggested before, or a newer treatment, may be offered.

Possible disadvantages

- Treatment may be delayed by waiting to see another clinician;
- Patients sometimes are upset or confused receiving the same, or different, information;
- Some patients find it difficult to decide on various options offered;
- If, after the second opinion, the patients decide that they want the second doctor, consultant or specialist to treat them, this will have to be formally arranged with them.

How to obtain a second opinion?

The primary care doctor or dentist may need to arrange the referral. The GP/GDP or the current consultant or specialist can refer to another consultant or specialist, either on the NHS or privately. Relatives and carers can also request a second opinion on the patient's behalf, but only with the express consent of the patient. When referred for a second opinion, any relevant medical information will be sent to the new doctor or specialist. If a referring clinician is concerned, they should phone a specialist or fax, e-mail or write for an urgent opinion, always adhering to Data Protection.

For private consultations, usually the health insurance plan must approve the referral. If patients go to the specialist on their own, without referral and prior approval, the health plan may not pay for the consultation. Insurance companies usually require a letter of referral from a GP. Some private insurance companies will accept GPs' referrals to consultants, while others have their own lists of preferred consultants. Patients with private medical or health insurance asking for specialist treatment should check their insurance policy to elicit if:

- They need to contact the insurance company to tell them of the referral;
- The policy covers the treatment needed;
- The insurance company accepts consultant referrals from GPs or has its own list of consultants.

A GP or an NHS hospital doctor may help the patient to complete the form but is entitled to charge for this service. In the case of a claim for treatment under private medical insurance, some parts of the claim form will need to be completed by the doctor who provides the treatment.

Figure 7. Polyangiitis with granulomatosis (formerly termed Wegener granulomatosis) – pathognomonic appearance of 'strawberry gingivitis'.

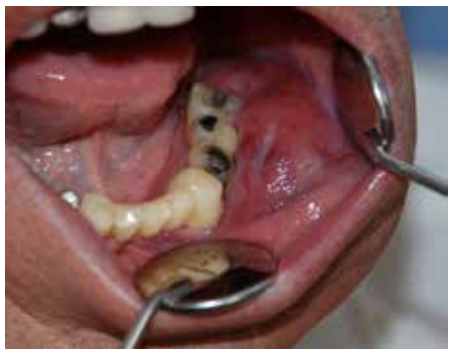

Figure 8. Lymphoma.

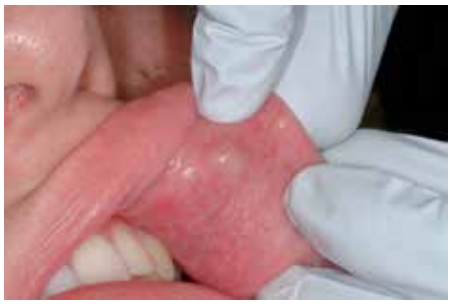

Figure 9. Salivary gland neoplasm.

What are the UK referral guidelines?

The features of mouth or oropharyngeal cancer can be very similar to those of other less serious conditions, particularly PMDs (Article 6), so it can be difficult for GPs/GDPs to decide who may have a cancer and who may have something less serious, and therefore who or when to refer to a specialist. The index of suspicion is best kept high. It is important to remember that:

- General issues such as oral malodour are much more likely to be something less serious than cancer. With such issues, it is perfectly correct that the clinician should ask the patient to wait to see if the problem resolves spontaneously, or responds to treatment such as antibiotics or antifungals since, if they referred everyone to a specialist immediately, the health system could not cope.

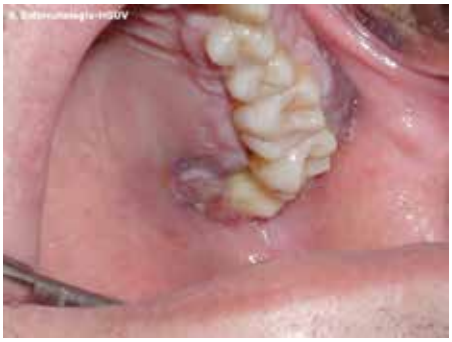

Figure 10. Kaposi sarcoma. (Courtesy of JV Bagan, Valencia.)

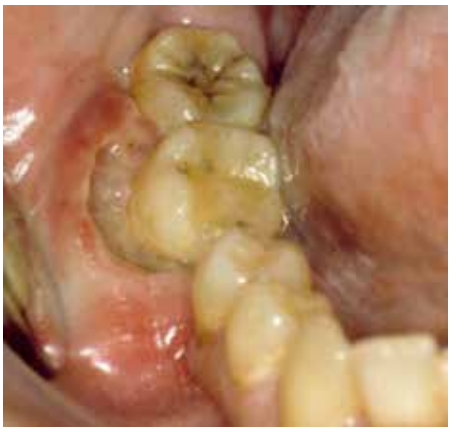

Figure 11. Lymphoma.

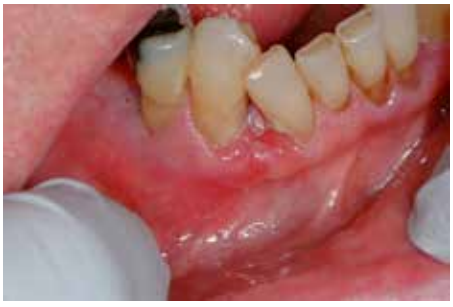

Figure 12. Metastasis with the appearance of periodontal disease.

- Mouth and oropharyngeal cancers are uncommon – there are about 6,500 cases diagnosed each year in the UK and there are few cases diagnosed in people under 45 years.
- A number of risk factors affect the chances of developing a mouth or oropharyngeal cancer. Patients could be more at risk if they are a long-term smoker (especially if they drink alcohol as well), or if they chew tobacco (or betel quid, paan, gutkha) although, with HPV-related tumours, the risk groups are changing.

Nevertheless, the index of suspicion is best kept high. Cancer Research UK issues guidance (**publications.cancerresearchuk.org/downloads/product/GP1.pdf**).

What are the guidelines for *urgent* referral?

The UK National Institute for Health and Clinical Excellence (NICE) has produced guidelines to help clinicians decide which patients need to be seen urgently by a specialist. The NICE guidelines indicate a need for an *urgent* referral to a specialist for possible mouth and oropharyngeal cancer if there is:

- A sore area or ulcer that does not resolve in 3 weeks;
- Mouth swelling that does not resolve after 3 weeks;
- Red and white patches in the mouth which are painful, swollen or bleeding;
- An unexplained sore or painful throat that has lasted longer than it should;
- An unexplained neck lump;
- Unexplained pain on one side of the head or neck for more than 4 weeks, with ear ache for no apparent reason;
- Any other signs or symptoms affecting the mouth that cannot be explained and have lasted for more than 6 weeks.

A clinician may also want to refer to a specialist urgently if there is a loose tooth for more than 3 weeks, for no apparent reason.

What are the current NICE guidelines covering mouth cancer?

Current NICE guidelines (2005; under revision 2015) are that a patient with symptoms of head, neck or thyroid cancer should be referred to a specialist or to a neck lump clinic (Figure 13). According to these NICE guidelines, the patient should ideally get an appointment within 2 weeks if cancer is suspected.

The NICE guidelines are found at:

www.nice.org.uk/guidance/cg27/chapter/1-guidance#head-and-neck-cancer-including-thyroid-cancer (accessed 1 January 2015) and are verbatim here, stating:

'1.11 Head and neck cancer including thyroid cancer

General recommendations

1.11.1 A patient who presents with symptoms suggestive of head and neck or thyroid cancer should be referred to an appropriate specialist or the neck lump clinic, depending on local arrangements.

1.11.2 Any patient with persistent symptoms or signs related to the oral cavity in whom a definitive diagnosis of a benign lesion cannot be made should be referred or followed up until the symptoms and signs disappear. If the symptoms and signs have not disappeared after 6 weeks, an urgent referral should be made.

1.11.3 Primary healthcare professionals should advise all patients, including those with dentures, to have regular dental checkups.

Specific recommendations

1.11.4 In a patient who presents with unexplained red and white patches (including suspected lichen planus) of the oral mucosa that are:

- painful, or
- swollen, or
- bleeding

an urgent referral should be made. A non-urgent referral should be made in the absence of these features. If oral lichen planus is confirmed, the patient should be monitored for oral cancer as part of routine dental examination.

1.11.5 In patients with unexplained ulceration of the oral mucosa or mass persisting for more than 3 weeks, an urgent referral should be made.

1.11.6 In adult patients with unexplained tooth mobility persisting for more than 3 weeks, an urgent referral to a dentist should be made.

1.11.7 In any patient with hoarseness persisting for more than 3 weeks, particularly smokers aged 50 years and older and heavy drinkers, an urgent referral for a chest X-ray should be made. Patients with positive findings should be referred urgently to a team specialising in the management of lung cancer. Patients with a negative finding should be urgently referred to a team specialising in head and neck cancer.

1.11.8 In patients with an unexplained lump in the neck which has recently appeared or a lump which has not been diagnosed before that has changed over a period of 3 to 6 weeks, an urgent referral should be made.

1.11.9 In patients with an unexplained persistent swelling in the parotid or submandibular gland, an urgent referral should be made.

1.11.10 In patients with unexplained persistent sore or painful throat, an urgent referral should be made.

1.11.11 In patients with unilateral unexplained pain in the head and neck area for more than 4 weeks, associated with otalgia (ear ache) but with normal otoscopy, an urgent referral should be made.

Investigations

1.11.12 With the exception of persistent hoarseness (see recommendation 1.11.7), investigations for head and neck cancer in primary care are not recommended as they can delay referral.'

Referral should therefore be as soon as possible, and within 3 weeks. The UK national target for urgent referrals, however, is currently 2 weeks. The UK guidelines for treating cancer are no longer than 62 days from urgent referral to treatment, or 31 days from diagnosis to treatment. These have significantly expedited the time taken from referral to first outpatient appointment.

What are neck lump clinics?

Neck lump clinics are one-stop outpatient clinics providing all the tests needed to check for cancer in a neck lump, usually:

- Ultrasound scan (US);
- Fine needle aspiration (FNA) and/or needle (core) biopsy;
- Nasoendoscopy.

Neck lump clinics often give the results on the same day.

An *urgent* referral should be

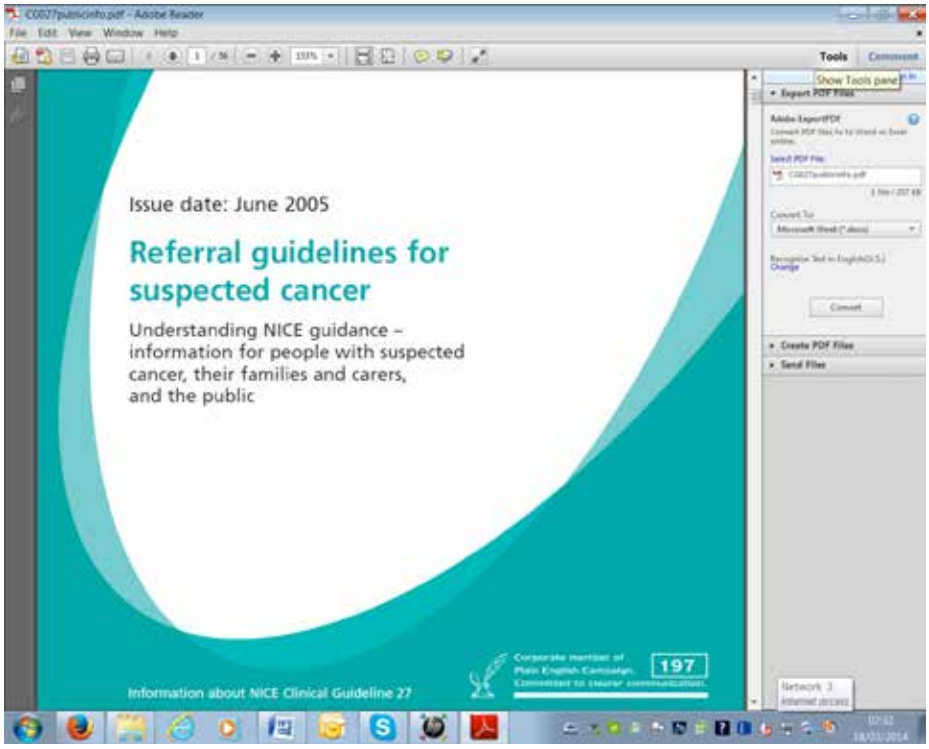

Figure 13. NICE referral guidelines.

made in patients with:

- An unexplained lump in the neck which has recently appeared or a lump which has not been diagnosed before that has changed over a period of 3 to 6 weeks;
- An unexplained swelling in the salivary glands;
- An unexplained, persistent sore or painful throat;
- An unexplained pain in one side of the head and neck area for more than 4 weeks, and ear ache, but with normal results on ear examination;
- Unexplained ulcers or a lump in the mouth lasting for more than 3 weeks; unexplained red and white patches inside the mouth that are:
  -painful, or
  -swollen, or
  -bleeding.
  (If these patches are not painful, swollen or bleeding, a non-urgent referral should be made.)
- Persistent undiagnosed symptoms in the mouth lasting longer than 6 weeks.

According to the NICE guidelines, patients should ideally receive an appointment within 2 weeks if symptoms could be due to cancer.

What to do if there is difficulty getting a referral for a second opinion

When referring patients with suspected cancer to a specialist service, primary healthcare professionals should assess the patients' need for continuing support while waiting for their referral appointment. The Patient Advice and Liaison Service (PALS) in the local hospital may be able to help obtain referral.

What should the secondary care doctor tell the patient about mouth cancer tests?

Some questions for which the patient might want answers include how to obtain further information about the type of cancer suspected and, in relation to investigations:

- What tests are needed to establish the diagnosis firmly?;
- How soon should the tests be done?;
- What are tests looking for?;
- Are any tests painful?;
- Is an anaesthetic needed for any tests?;
- Do any tests have adverse effects?;
- How long will the results take?;
- Who will give them the test results?

Figure 14. Macmillan Cancer Support information.

When is an *urgent* chest radiograph indicated?

The NICE guidelines indicate the need for an urgent chest radiograph if the patient has had a hoarse, husky, or quieter than normal, voice for more than 3 weeks, particularly if they are:

- A smoker aged 50 or over;
- A regular heavy drinker.

When is a *non-urgent* referral indicated?

Red or white patches in the mouth that are not painful, swollen or bleeding and other lesions that are not suspected as being malignant, can perhaps wait for a non-urgent referral.

www.nice.org.uk/guidance/cg27/chapter/key-priorities-for-implementation

What information is available for patients and families?

Good up-to-date information is available from numerous sources (Figure 14; Tables 1, 2).

Further reading

1. **www.nice.org.uk/guidance/NG12/chapter/1-**

Resource	URL	Remit
Citizens Advice Bureau (CAB)	**www.citizensadvice.org.uk/**	Free, confidential, independent advice on a variety of issues including financial, legal, housing and employment
Citizens Advice Scotland	**www.cas.org.uk**	Similar
Macmillan	**www.macmillan.org.uk/Home.aspx?gclid=CMatqvni8MICFeISwwodZngA3w**	Patient and family support
NHS Choices	**www.nhs.uk/Pages/HomePage.aspx**	Advice on medical issues
Patients Association	**www.patients-association.com/**	Represents interests of patients to government, professional bodies and the media. It advises individual patients on their rights, access to health services, self-help groups and complaints procedures via a patient helpline

Table 1. Useful resources and organizations.

Organization	Known as	URL
American Cancer Society	ACS	**www.cancer.org/treatment/treatmentsandsideeffects/emotionalsideeffects/copingwithcancerineverydaylife/a-message-of-hope-for-spouses-families-friends**
British Association of Head and Neck Oncologists	BAHNO	**www.bahno.org.uk/**
Cochrane Collaboration	Cochrane	**www2.cochrane.org/reviews/en/subtopics/84.html**
Cancer Research UK	CRUK	**www.openuptomouthcancer.org/index.htm**
Macmillan Cancer Support	Macmillan	**www.macmillan.org.uk/Home.aspx?gclid=CMatqvni8MICFeISwwodZngA3w**
Merseyside Regional Head and Neck Cancer Centre		**www.headandneckcancer.co.uk**
Mouth Cancer Foundation	MCF	**www.mouthcancerfoundation.org/?gclid=CIbuvIu_8MICFSfLtAod2GUA7w**
National Institute of Health and Clinical Excellence	NICE	**www.nice.org.uk/Guidance/CSGHN**
National Institutes for Dental and Craniofacial Research	NIDCR	**www.nidcr.nih.gov/oralhealth/topics/oralcancer/detectingoralcancer.htm**
Oral Cancer Foundation	OCF	**www.oralcancerfoundation.org/**

Table 2. OSCC detail from various UK/USA bodies.

recommendations#head-and-neck-cancers

2. **www.clevelandclinicmeded.com/medicalpubs/diseasemanagement/hematology-oncology/head-and-neck-cancer/**
3. **www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/index.html**
4. **www.isdscotland.org/Health-Topics/Cancer/**

Publications/index.asp
5. **www.wales.nhs.uk/sites3/page.cfm?orgid=242&pid=59080.**
6. **www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/**
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8. Diz Dios P, Scully C. Cancer of the mouth for the dental team. Oral cancer: comprehending the condition, causes, controversies, control and consequences 7. Staging and diagnostic clinical aids. *Dent Update* 2011; **38**: 354–356.
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20. Webb CJ, Benton J, Tandon S, Jones TM, Roland NJ. Head and neck cancer waiting times. *Clin Otolaryngol* 2007 Aug; **32**(4): 293–296. PubMed PMID: 17651275.