

# OPPORTUNISTIC ORAL CANCER SCREENING

## The process of oral cancer

### Genetically altered cells

Genetic mutation prompts cells to proliferate instead of rest after their normal cycle of division.

### Dysplasia

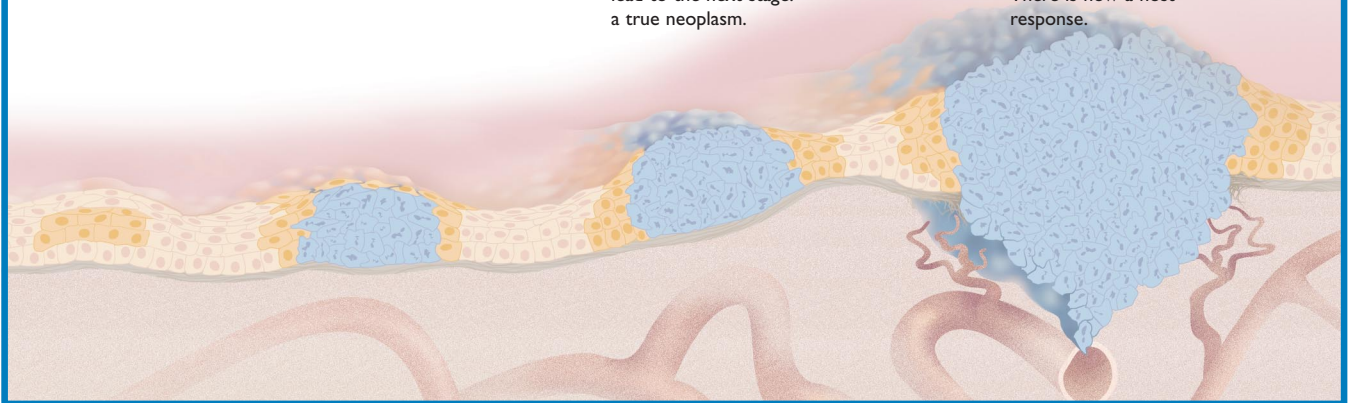
Additional mutations lead to excessive cell proliferation with abnormal cellular features and behaviour.

### Carcinoma in situ

Accumulating cell mutations cause further abnormal growth and appearance, restricted to the epithelium. The lesion may remain unchanged indefinitely or additional mutation may lead to the next stage: a true neoplasm.

### Invasive cancer

Further genetic changes allow the malignant cells to invade underlying tissue and possibly enter the bloodstream or lymphatic systems, resulting in metastasis. There is now a host response.



A management  
strategy for  
dental practice

## OPPORTUNISTIC ORAL CANCER

**SCREENING:** A management strategy for dental practice

Opportunistic screening for oral cancer needs more than just understanding of the signs and symptoms of disease. The process must be managed effectively and handled sensitively. Every team member has a part to play. This paper follows up BDA Occasional Paper 5, published in April 1998 - *Oral cancer: Guidelines for early detection*. It is based on discussions at a multi-disciplinary workshop held under the auspices of the British Dental Association on 22 March 1999 to examine the practicalities of opportunistic screening. The aim was to develop realistic advice for dentists in primary care who now seek to adopt best practice in soft tissue screening. Oral cancer deaths will only be reduced if the disease is recognised earlier and treated sooner. Opportunistic screening can pay big dividends.

## ACKNOWLEDGEMENTS

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“ The FDI World Dental Federation recognises that oral cancer is a major public health issue worldwide, where cancer of the lip, mouth and pharynx combined is the sixth most common site of malignancy.

Oral cancer remains a highly lethal and disfiguring disease. Therefore, a systematic oral mucosal examination, by visual means and digital palpation, should be part of every dental examination procedure and every dentist must be aware of the most rapid and adequate referral pathway for the effective management of these lesions.<sup>1</sup> ”

**FDI  
World Dental  
Federation**

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“ All dentists are advised to review how they screen opportunistically for oral cancer, when patients attend for routine examination. The intra-oral soft tissues should be examined systematically as a matter of course. ”

**British Dental  
Association**

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“ General Dental Practitioners examine around 50 per cent of the population on a regular basis and the Faculty of General Dental Practitioners (UK) strongly encourages a full and systematic soft-tissue examination as part of that routine check. This oral cancer screening strategy clearly lays out such a regime and is wholeheartedly endorsed by the Faculty. ”

**Faculty of  
General Dental  
Practitioners (UK)**

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“ The Commonwealth Dental Association (CDA) puts oral cancer at the top of its list of priorities. Many of the developing Commonwealth countries have a distressingly high prevalence of this affliction and desperately inadequate resources for dealing with the problem. The emphasis on screening and prevention in this excellent document needs widespread encouragement. The CDA will willingly play its part in this process. ”

**Commonwealth  
Dental  
Association**

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“ All dentists should be aware that a number of minority ethnic groups have specific cultural habits which can place them at risk from oral cancer and precancerous lesions. Dentists should ensure that they and their staff have the appropriate training and educational materials to address these challenges and carry out effective routine screening of these patients. ”

**National Centre  
for Transcultural  
Oral Health**

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“ The raison d'être of dentistry is no longer just relief of pain but the saving of a life. Detecting oral cancer early saves lives. This profession has the obligation to save those lives. ”

**Anglo-Asian  
Odontological  
Group**

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“ The British Dental Health Foundation recognises the vital importance of raising awareness of oral cancer and its causes and stressing the need for regular checks, particularly among high risk groups. The Foundation has already been involved in a number of initiatives to promote oral cancer awareness and thoroughly endorses the BDA's occasional paper. ”

**British Dental  
Health  
Foundation**

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## Dental Protection Organisations

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“ Dentists already play a pivotal role in the prevention and early detection of oral cancer. Hygienists, too, play their part in alerting the dentist to suspicious lesions. By increasing knowledge and awareness of risk factors, and by implementing protocols for regular screening, dentists can protect their patients, first and foremost, through an improved quality of care while also minimising the dento-legal risk to themselves.”

**Dental Protection**

**Dental Defence Union**

**Medical & Dental  
Defence Union of  
Scotland**

“ The accurate and timely diagnosis of oral cancer is vital and any reliable and effective method of reducing the incidence of the disease is beneficial. Dentists should bear in mind that:

- Dental inspections should include careful examination of all oral soft tissues and any lesion identified during the course of an examination should be effectively managed.
- Any diagnostic technique for identifying a malignancy should not be used as a substitute for a thorough clinical examination.
- Patients should receive a clear explanation of any technique to be employed, the risks and benefits and any likelihood of any false negative or false positive result, and
- Arrangements should always be in place to ensure that any screening result is provided to the patient in a timely manner.”

**The St. Paul  
International  
Insurance Company**

## Patient Plans

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“ Prevention, screening and subsequent early treatment are the essentials in reducing the incidence of oral cancer.

The routine screening in general dental practice of soft tissues has been considered so essential that it is one of the quality protocols checked by our third party assessors when appraising BUPA DentalCover accredited dentists.

BUPA DentalCover supports any initiative that reduces the incidence of oral cancer throughout the UK.”

**BUPA**

“ The ethos of Denplan is firmly rooted in a preventive approach to all dental care. All Denplan Care dentists are expected to carry out soft tissue screening and record their findings at every examination. Denplan wholeheartedly support the BDA Occasional Paper on Opportunistic Oral Cancer Screening.”

**Denplan**

“ The General Dental Practitioner has a pivotal role to play in contributing to the prevention of oral cancer and helping to reduce the morbidity and mortality from this terrible disease.

The use of a rinse such as OraTest could be of benefit in enhancing the visual examination and detecting the cancers when they are very small.”

**Smilecare**

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# Oral cancer screening obligations and opportunities

Oral cancer remains one of the most debilitating and disfiguring of all malignancies. It presents the whole dental team with important obligations, challenges and a real opportunity to save life. This section introduces the key issues, which are all discussed more fully in later sections:

- Oral cancer deaths are not falling in Britain even though many are preventable
- Patients need to know that certain lifestyles put them at risk of oral cancer

- The dental team has a key role in the prevention of oral cancer deaths
- Practices should review their approaches to opportunistic screening for oral cancer

Finally, on page 28, the paper looks at the practical implementation of a cancer screening strategy.

## How common is oral cancer?

The British Dental Association has adopted a definition of 'oral' cancer largely based on common risk factors. Cancers of the lip, tongue, gingiva, all of the oral mucosa, oropharynx and hypopharynx are included, but not cancers of the major salivary glands and nasopharynx. On this definition, there are currently about 2800 new oral cancer cases a year in the UK and about 1600 deaths. Incidence varies from country to country, with Scotland, Wales and Northern Ireland all having worse oral cancer incidence than England.<sup>2</sup>

The problem is not simply that the number of new oral cancer cases is static or rising, as people continue to put themselves at risk through smoking and excessive drinking. An equal or greater challenge is that oral cancers are not being found early enough for successful treatment. Using England and Wales statistics for convenience, there were

2766 new cancer cases in 1990, and 1307 oral cancer deaths five years later in 1995, giving a 1990-95 ratio of deaths to cases of 0.47. Two years later it was still 0.46, with 2988 new cases in 1992 and 1386 deaths in 1997. Treatment of many cancers is showing impressive improvement in survival but oral cancer continues to have stubbornly high death rates.

The oral cancer challenge is put into perspective in Table 1, which makes comparison with four other much-publicised cancers. Oral cancer, skin melanoma and cervical cancer cause about the same number of deaths each year, but oral cancer has a worse ratio of deaths to cases. Prostate and breast cancer are much more common so there are more deaths and prostate cancer also has a higher ratio of deaths to registrations.

Table 1. Registrations and deaths for various cancer sites, England & Wales

Site	WHO International Classification of Diseases: Code ICD-9	Registrations 1992	Deaths 1997	D:R Ratio
Oral lip, mouth, tongue, pharynx	140-149 excluding 142,147 (major salivary glands & nasopharynx)	2988	1386	0.46
Skin melanoma	172	4151	1378	0.33
Breast	174	31843	11980	0.38
Cervix uteri	180	3400	1225	0.36
Prostate	185	15705	8523	0.54

In the face of the oral cancer challenge, dental professionals have a unique opportunity. Every year about 25 million adults see a dentist for an oral examination. This is where risky lifestyles can be identified, where smoking cessation, nutritional and other advice can be given, and where possible early signs of cancer can be detected. Many people developing oral cancer are elderly but more and more elderly people are dentate and making routine use of primary dental care services.

With new government-led smoking cessation initiatives and a rising media profile for oral cancer - especially following John Diamond's columns in *The Times* - this is the right time for dentists to review practice procedures for:

- medical history-taking
- lifestyle counselling
- undertaking a clinical examination
- recording examination findings
- making specialist referrals.

The evolving medico-legal position is also relevant. There is a parallel with periodontal monitoring in the 1970s, when patient complaints and threats of litigation finally established that it was not enough simply to examine for dental caries. Periodontal monitoring is now accepted as part of the routine dental examination.

Oral cancer screening is following the same course, with case law already establishing that a dentist's duty of care includes an obligation to examine the whole mouth. A typical complaint might allege failure to recognise the possibility of a malignancy having noted swollen gums and loose teeth, for example, with a lack of evidence of adequate medical and social history-taking and delay in making a specialist referral. Dentists need to be sure that they can, if necessary, answer questions like these:

- Did you know that a particular patient fell into an oral cancer high risk group and what did you do in the light of that knowledge?
- Were the medical, social and dental histories taken appropriately?
- Did you investigate the health of soft tissues thoroughly enough?
- Was a decision not to refer the appropriate one in the circumstances?

This paper gives practices a framework for improving screening care of patients while protecting themselves at the same time. Each section of the paper covers ideas that need to be thought about in setting a practice strategy - but the strategy adopted will be down to you. What matters is that oral cancer screening is planned for and integrated into practice working methods. Precisely how you do it is less important than the fact that it is done.

## What can dentists do? And what should they do?

Primary prevention aims to change behaviours known to be associated with oral cancer. Many health professionals and health agencies contribute to health promotion and the dental team may not always have seen lifestyle counselling as part of their role. Certainly, it needs skill and sensitivity if it is to be effective. But dental practices have a great advantage in initiating discussion about smoking cessation, reduced alcohol consumption or good nutrition. The patient is expecting to talk about health with the dentist so all that the dentist needs to do is broaden the

conversation a little. Dental practices with staff trained to advise proactively against tobacco, alcohol and other substance abuse could make a real impact on oral cancer incidence.

Table 2 lists the key health messages for oral cancer prevention, as a check list for briefing the dental team. Several are particularly relevant to the care of ethnic minority groups. Dental professionals need to be aware of and sensitive to the cultural habits and oral health beliefs and practices of different communities.

Table 2. Key messages for oral cancer prevention

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• Don't smoke</li> <li>• Keep within recommended guidelines for alcohol consumption</li> <li>• Cut out use of betel-quid and avoid tobacco use in the quid</li> <li>• Don't sleep with the betel-quid in the mouth overnight</li> </ul> | <ul style="list-style-type: none"> <li>• If you use a quid, rinse your mouth thoroughly afterwards</li> <li>• Discourage children and young adults from chewing betel quid/areca/gutkha/tobacco</li> <li>• Eat plenty of fresh fruits and green-yellow vegetables</li> </ul> |
|--|--|

*Adapted from: Wamukulasuriya and Johnson.<sup>3</sup>*

## The first priority – primary prevention

### Key Points

- Increasing incidence of oral cancer
- High mortality, 5 year survival less than 50% for several sites
- Key role for dentists in early detection of suspicious lesions
- Dentists should identify those patients with a risk factor for oral cancer
- Important role for dental practice team in health education
- Professional and ethical duty of care to opportunistically screen all patients for oral cancer when they attend for routine examination.



## Secondary prevention – catching cancers early

While oral cancer will only be defeated finally through primary prevention, changing habits and lifestyles is difficult and slow. This is what makes the early detection of malignant or potentially malignant lesions through screening so important. The earlier lesions are found the greater the chance of recovery and a good quality of life and function. A major problem is that more than half of all oral cancer cases have already metastasized to regional or distant structures at the time of detection<sup>4</sup> which decreases the 5 year survival rate to less than 50%<sup>5,6</sup> for tongue and floor of mouth cancers.

Screening looks for pre-symptomatic disease. Some screening may be organised proactively, calling patients in for examination at times when they do not have another reason for seeing a health professional. Cervical screening programmes amongst women of specified ages are an example. For oral cancer, however, where large numbers of patients are already seeing a dentist, an opportunistic screening approach is generally advocated. Opportunistic screening is less systematic but very much more cost-effective than population screening. If an opportunistic screening strategy is to be successful, all dentists should carry out the necessary soft tissue examination alongside hard tissue examinations. Screening for oral cancer and pre-cancer becomes part of the routine examination.

*See page 22 for a review of how a head and neck examination is carried out and page 24 for illustrations of suspicious clinical signs.*

## Tertiary prevention – Stopping recurrence and spread

Dentists in primary care also have a role in tertiary prevention – working as part of an oral cancer management team to prevent recurrence and further primary cancers in patients already treated for oral cancer. Table 3 illustrates how multi-disciplinary this can be, and how great the need for good communication with people outside the practice. Communication channels may need to be clarified, as a practice works out its oral cancer strategy.

Treated patients will still have dental needs which dentists will monitor to maintain life quality. There may be special needs as well – prevention of caries by topical fluoride application, dietary advice, help with managing a dry mouth, and prosthetic rehabilitation following surgery and radiation therapy, for example. It can be a great convenience for patients to have an easily-accessible source of dental advice and help, to reduce the need for visits to a possibly remote specialist centre, but if patients are to be helped in this way there must first be good working relationships with the specialists concerned.

Table 3. The head and neck cancer team

### Primary healthcare professionals

Dental practitioners  
Medical practitioners  
Community dental service  
Public health doctors  
Dental hygienists  
Pharmacists  
Health visitors

### Hospital specialists

Oral pathologists  
Oral and maxillofacial surgeons  
Oral physicians  
Ear, nose and throat surgeons  
Plastic surgeons  
Radiation oncologists  
Medical oncologists  
Maxillofacial technologists  
Physiotherapists  
Speech and swallowing therapists  
Dieticians  
Specialist nurses (including Macmillan nurses)  
Occupational therapists  
Palliation and terminal care specialists

### Counsellors

Counselling services  
Chaplaincy and other religious support services

### Others

Epidemiologists  
Molecular biologists  
Biochemists  
Behavioural scientists

*Adapted from: The British Association of Head and Neck Oncologists 1998<sup>7</sup> - Provision and quality assurance for head and neck cancer care in the UK.*



More than a quarter of a million people develop cancer each year in the UK. Complications often occur in the mouth, either as a direct result of the malignancy or as an unwanted effect of treatment. Your practice will probably have some child patients who have or have had cancer, as well as elderly patients. Your medical history-taking will identify them.

Oral complications occur in almost all patients having radiotherapy for head and neck cancers, in 75% of bone marrow transplant recipients and in nearly 40% of patients receiving chemotherapy. These complications can be so debilitating that patients may tolerate only lower and less effective doses of treatment, or even postpone or discontinue treatment entirely. Dental advice at the right time can greatly improve quality of life.

Here are some of the oral complications associated with chemotherapy and radiotherapy:

- Mucositis/stomatitis – can increase risk of pain, oral and systemic infection and nutritional compromise
- Infection – viral, bacterial and fungal
- Xerostomia/salivary gland dysfunction – dryness of mouth due to thickened, reduced or absent salivary flow; increases risk of infection and compromises speaking, chewing and swallowing; increases risk of dental caries

- Gross dental caries and demineralization – as a result of changes in both quality and quantity of saliva following cancer therapy
- Functional disabilities – impaired ability to speak and swallow due to dry mouth, mucositis, trismus and infection
- Taste alterations
- Abnormal dental developments – altered tooth development and/or craniofacial growth in children under 9 secondary to radiotherapy and/or high doses of chemotherapy.

Additionally, with chemotherapy:

- Neurotoxicity
- Bleeding from the gingiva and other body sites

With radiation therapy:

- Radiation caries
- Trismus/tissue fibrosis
- Osteoradionecrosis

Steps to prevent or minimise oral complications are discussed in *Clinical Guidelines: The oral management of oncology patients requiring radiotherapy, chemotherapy, or bone marrow transplantation* by M.J. Shaw.<sup>8</sup> A useful American publication is available – *Oral complications and cancer treatment – what the oral health team can do*.<sup>9</sup>

## Caring for patients with other forms of cancer

Since the objective is opportunistic rather than systematic screening, there is no precise answer to a question about the desirable interval between screenings. Screening takes place when the opportunity arises. In practice, this will normally be at the beginning of each new course of treatment.

The Health Education Authority's (now the Health Development Agency) consensus statement on the Scientific Basis of Dental Health Education says that everyone – child or adult, dentate or edentulous – should have a dental examination at least once a year. This advice is given with both soft and hard tissue diseases in mind.<sup>10,11</sup> Every patient needs tailored advice, however.

Many children would probably be advised to see a dentist more frequently than once a year, based on an assessment of caries risk. Assessment of soft tissue risk can be made in the same way, on adult patients, in the light of lifestyle information, with patients advised to see a dentist again in less than a year if the dentist feels this is appropriate.<sup>10,12</sup>

The patient might still ignore the advice – for example, to have another soft tissue examination after nine months. In that event, the dentist has done all that could be done. A dentist clearly cannot be considered negligent for failing to do something because the patient does not cooperate, provided advice was given and documented.

## Screening frequency

### Key Points

- Opportunity for cooperation with fellow healthcare professionals
- Opportunity for outreach projects
- Important role for dental team in treating dental sequelae in post-treatment patients
- Key role for dental team in preventing recurrence of oral cancer

## Screening techniques – with or without tolonium chloride?

A thorough visual and digital examination has to be the basis of oral cancer screening, but there is also the option, now, of using a tolonium chloride oral rinse adjunctively when examining certain high risk patients. A practice re-considering its screening systems will want to think through the pros and cons of using this method alongside a conventional examination.

Tolonium chloride – ‘toluidine blue’ - has been used in secondary care for many years to help identify dysplastic or malignant mucous membrane. Studies amongst high risk patients have suggested that more asymptomatic lesions are found using tolonium chloride than with a clinical examination alone.<sup>13-16</sup> Studies of normal populations are more difficult to conduct because of the low number of lesions to be found and more research is needed into the usefulness of tolonium chloride in a primary care context. But the technique is becoming accepted as a screening adjunct in primary care, with recent endorsement from the FDI World Dental Federation.<sup>1</sup>

For many patients, a soft tissue examination without tolonium chloride will be completely adequate. And you may, very occasionally, see a lesion which so obviously needs to be referred to a specialist that tolonium chloride would not be used there either. But for high risk patients without obvious lesions, the accuracy of screening may be increased and there is also a possible benefit in the way a disclosing dye raises patient awareness of a risk. Dentists have long used disclosing tablets to help patients who are having difficulty with their oral hygiene. It is not a very large step further to use a disclosing dye on soft tissue which is being abused in some way.

In setting a practice screening strategy, the use or non-use of tolonium chloride needs to be discussed. Will it be used, and in what circumstances? While dentists in a particular practice may want to approach this individually, it will make more sense to patients if there is a common approach throughout a practice. There could be patient confusion if one dentist in a practice offers tolonium chloride to certain patient groups while a practice colleague says that it is unnecessary.

*See page 26 for information about how tolonium chloride should be used.*

### Key Points

- Tolonium chloride is used as an adjunct to soft tissue examinations and can detect invisible, asymptomatic lesions
- Tolonium chloride test has been shown to improve screening accuracy in high risk patients
- Tolonium chloride may have a useful role in highlighting the potential dangers of an unhealthy lifestyle

# Risk factors

Oral squamous cell carcinoma, the commonest form of oral cancer, is clearly attributable to certain lifestyles. This means that it can be regarded as preventable, even though it will sometimes occur in patients who do not fall neatly into the 'at risk' groups listed here. To manage the primary prevention of oral cancer effectively all

members of the dental team need to:

- understand what usually causes it
- identify patients at increased risk as a result of unhealthy lifestyle
- target advice and counselling on patients in the main risk groups

Table 4 lists two groups of risk factors - those that are well-established as causes of oral cancer and a second group of possibly relevant contributory factors. Age is included as an established risk factor because exposure to the risks listed increases with age but age on its own is not a risk factor. Also, oral cancer is not always

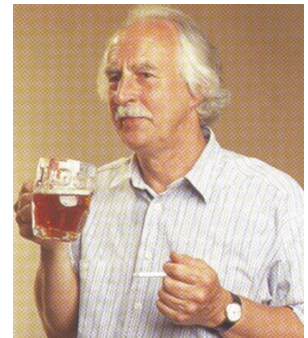
a disease of old age. Clinicians treating oral cancer are concerned that its incidence appears to be increasing in younger age groups.<sup>6</sup>

Currently nearly 6% of oral cancer cases in Southern England, for example, occur in people under the age of 45.

## What causes oral cancer?

Table 4: Risk factors for oral cancer

Established risk factors
Smoking tobacco – cigarettes, cigars, pipes, bidis*
Chewing tobacco – betel quid/pan/gutkha**/pan masala
High alcohol consumption (synergistic with tobacco)
The presence of potentially malignant oral lesions and conditions
Prior history – of oral cavity or other aerodigestive tract cancer
Age, in conjunction with other risks listed
Other possible risk factors
Dietary deficiencies, particularly of vitamins A, C and E and iron, trace elements such as selenium and zinc
Viral infections, e.g. certain types of human papilloma viruses (HPVs)
Candida infection
Excessive exposure to sunlight or radiation (for lip cancer)
Immune deficiency disease or immune suppression
Familial or genetic predisposition
Air pollution and environmental exposure to the burning of fossil fuels
Chronic sepsis in the mouth



\* Bidis are cheap South Asian cigarettes now being imported into the West.

\*\*Gutkha is a form of areca (betel) nut to which chewing tobacco and sugar has been added.

## Key Points

- Dentists and their teams should be aware of risk factors
- Practice systems should identify patients at risk
- Practice teams should target advice and counselling to patients in the main at-risk groups

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## Tobacco & alcohol use



The odds of developing oral cancer increase with frequency and duration of use of tobacco and alcohol, and with combined use of the two.<sup>17</sup> With tobacco and alcohol so well-established as oral cancer risks, it is clearly essential for medical history taking to ask about this. The BDA's model medical history sheet (annexed to this paper) first included questions about tobacco and alcohol use in 1998. It asks:

- How many units of alcohol do you drink each week? (A unit of alcohol is half a pint of lager, a single measure of spirits or a single glass of wine/apéritif)
- Do you smoke any tobacco products or did you, in the past? How many per day?
- Do you chew tobacco, betel quid (pan), use gutkha or supari now, or did you in the past? How many per day?

For both alcohol and tobacco use, some patients may not tell the truth, of course. And in the case of alcohol use, even patients prepared to answer truthfully may find it difficult to gauge intake accurately because of variations in type of alcohol,

quantity and measure size. Current recommendations are that men should not drink more than 21-28 units per week and women should not drink more than 14-21 units. One in four men and one in ten women in the UK are believed to be drinking over the recommended limits, with the number of habitual heavy drinkers estimated at 4 million.<sup>18</sup> The average age at which drinking starts has fallen since the early 1970s from around 17 to around 11, for both boys and girls.<sup>18</sup>

Adolescent drinking is strongly associated with parental behaviour and attitudes, the influence of peer groups, life events, family conflict, and being socially active. Teenagers whose parents either drink heavily or not at all are more likely to drink excessively than teenagers whose parents are moderate drinkers. Young people who are heavier drinkers tend to have friends with similar drinking patterns.<sup>19</sup> We should aim to help our patients stay within safe consumption limits.

*See page 20 for more advice on medical history-taking.*

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## Other risk factors



Other risk factors may be harder for the dental team to address proactively. Ultraviolet light can induce cancer of the lip as well as of the skin generally, so health messages about avoiding too much exposure to sun are relevant to the prevention of oral cancer too. Dentists and the dental team can also advise on diet and nutrition – not only to reduce the frequency of use of fermentable carbohydrates to protect the teeth but also to maximise the efficiency of the body's immune and repair mechanisms and to help prevent diseases like cancers, heart disease and strokes.

Most dental practices will probably decide to major on advice about tobacco and alcohol use and use information about other risk factors in answering patient questions. In this context:

- the antioxidant vitamins A, C and E scavenge potentially mutagenic free radicals from damaged cells. A good natural source is to be found in red, yellow and green fruits and vegetables. Current advice is to eat five servings of such foods a day
- trace elements (e.g. zinc, selenium) and an adequate supply of iron help prevent anaemia
- infections of the oral mucosa may also be important. 'White' patches associated with yeast or hyphae of the fungus *Candida* carry an increased risk of progressing to malignancy
- human papilloma viruses (HPVs) may have a role – this is being investigated

In certain minority ethnic and religious groups, alcohol use is prohibited and smoking tobacco is not accepted. However, chewing tobacco may have greater social approval so tobacco use remains a problem.

Reliable information on tobacco use in the UK's South Asian community is scanty. However, oral cancer in the Indian subcontinent is much more common than in Western Europe, and betel-quid chewing, widespread in the Indian sub-continent, remains a habit in the UK's south Asian community.<sup>20</sup> It is known that the UK's south Asian community has a higher incidence of oral cancer.<sup>21,22</sup>

The Indian tobacco industry has recently introduced gutkha (sweetened areca nut and chewing tobacco) and flavoured bidis (a form of handmade cigarette) both to the market in the subcontinent and countries with significant South Asian populations in

the west. Gutkha is being sold as a mouth freshener and as a positive product for health. It is also being targeted at young people, as confectionery, and can be bought at most Asian corner shops, very cheaply – a cynical way of introducing children to tobacco use. Habitual chewing of pan masala/gutkha is associated with earlier presentation of oral submucous fibrosis than betel quid use.<sup>23</sup>

Based on census estimates, the minority ethnic population accounts for about 6% of the UK's population. Minority ethnic communities tend to be clustered in urban areas. Greater London contains 12.2% of the total population of Great Britain, but nearly half (45%) of Britain's minority ethnic population.

*See page 17 for advice about discussing tobacco use with patients from minority ethnic communities.*

## Special risks in minority ethnic communities



Bidis



Gutkha



Pan Masala

### Key Points

- Practices should be aware of the higher oral cancer risk in minority ethnic groups
- Betel quid, pan masala, gutkha and chewing tobacco are generally linked with this higher risk
- Groups supporting minority ethnic communities may be able to help raise oral cancer awareness
- Minority ethnic groups tend to underuse preventive healthcare services generally
- Consider staff training in transcultural oral health counselling in areas of high minority ethnic density



# Talking to patients about oral cancer screening

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There is clearly a need to raise public awareness towards oral cancer and the risk factors for developing the disease. But telling patients what they need to know, so that they understand without being alarmed, is one of the biggest challenges in opportunistic screening. This section helps practices think through what needs to be said and why, and the different ways of saying it:

- Although there is not a legal requirement for you to give patients detailed information about screening and cancer risks, it will probably increase patient satisfaction if you do.
- Written information can supplement verbal information very usefully but wordings need to be considered carefully.

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## Information for consent

A patient must give informed consent before any procedure is undertaken in the mouth but there is no legal reason why the carrying out of a visual and digital soft tissue examination should be mentioned specifically. If a soft tissue examination is part of every check-up examination, the patient consents when giving general consent to the examination.

A toloum chloride test does need specific consent, however, and a clear explanation. Patients could reasonably expect to be told that:

- The test is an additional check, to be sure that your visual check did not miss anything
- You only offer the test to patients whose tobacco or alcohol habits are increasing the oral cancer risk, though

you might offer it to other patients if you spot something unusual but not unusual enough to refer to a specialist right away

- While the test is very good at detecting cancers and precancers there is also a risk of it picking up trivial inflammations or irritations so it is important not to be alarmed by a positive first test
- Even after two tests there will be a risk - about 1 in 14 - that a positive result is incorrect. Say that you will always refer to a specialist after two positive results but patients should understand that early cancers cannot be diagnosed without further tests, principally biopsy. All you are doing is checking for suspicious lesions which might need further specialist investigation.

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## Information to improve patient understanding

Although a detailed explanation of oral cancer screening is not necessary to gain the patient's consent, the BDA advises that patients should normally be told that an oral cancer check is being carried out. There is plenty of evidence to show that patient satisfaction with clinicians is increased if patients are given information and advice and if they understand what they are told. Also, a patient is less likely to complain that something was not done if told about it at the time.

There are two ways of introducing the subject of oral cancer screening to patients either one to one, in the surgery, or via a letter or other general announcement. In communication terms, the pros and cons of each method are a little like the pros and cons of telling patients individually or as a group about a practice's proposed change of

relationship with the National Health Service. A general written communication has the advantage of openness and clarity.

So writing to at risk patients about oral cancer screening and perhaps about toloum chloride use as well, is a possibility to consider. A letter needs careful wording but it gives patients time and space to absorb the information. Remember that most patients have very limited understanding of oral cancer and research has shown that written explanations must be kept very simple.

If you write a letter, some patients may telephone for more information while others will delay questions until their next visit. Either way, you will need to make sure that all practice members are able to answer follow-up questions at an appropriate level,

using simple language and knowing when to refer on if getting out of their depth.

Questions will also be asked when a screening examination takes place. It will help to verbalise observations for the attending nurse to record. Over a series of visits, patients will become familiar with:

- The systematic visual examination
- Palpation of the head, neck and soft tissues
- If adopted in the practice, the possible adjunctive use of tolonium chloride

## Information to improve patient understanding

Patients will not only want factual information and advice, but also emotional support to help them deal with even the remote possibility that they might have oral cancer. All team members must be prepared to answer patient questions such as:

- ‘Do I really need oral cancer screening?’
- ‘Why haven’t I had this before?’
- ‘What would you do in my situation?’
- ‘Should I be worried?’
- ‘What do you think it is?’
- ‘Do you think I’ve got cancer?’
- ‘What will happen to me?’

Whether the subject of oral cancer was raised by letter or in chairside conversation there is also a risk that patients will ask ‘why was oral cancer screening not offered before?’ Answers might be:

- ‘We have always screened the soft tissues as part of your routine check-up’
- ‘We are now working to increase your own awareness of the importance of oral cancer screening’
- ‘Evidence suggests that the incidence of oral cancer is increasing and we believe we should be taking a more active role in increasing your awareness of the importance of complete oral health and oral cancer screening’
- ‘We need to keep more detailed records, including information about your lifestyle, so that we can offer you a more comprehensive oral health care service’
- ‘We are extending the range of healthcare provided at this practice’

Difficult questions can be explored usefully with role-play and other training techniques. See page 29 for further discussion.

## Handling difficult questions

Talking to patients is important and verbal information and advice is convenient to give but it often fails because messages are not understood or are forgotten. Written information can then be a very useful supplement. Presentation of written information needs to be careful however and the language must be clear.

Even if the text is understandable, you still need to be confident that the content is accurate and appropriate, as well. It will help to let more than one clinician examine a draft for clarity. Piloting on a small group of patients is then helpful, to test whether anything is confusing or ambiguous. Producing written information for patients will require real time and effort.

Consider the following possibilities:

- Practice information leaflets and newsletters can raise the profile of oral cancer screening, with reminders about unhealthy lifestyles
- Official smoking cessation literature could be made available in practice waiting rooms for patients to take home with them.
- Tolonium chloride testing is explained in a manufacturer’s product leaflet designed for patients.

## Using written information

### Key Points

- Tell patients you are screening for oral cancer
- Supporting literature for patients could be available in the waiting room
- All staff should be trained to answer patients’ questions
- All patients’ questions should be answered fully, truthfully and in simple language



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## Using simple language

Here is an example of simple language use: This text is adapted from a leaflet produced at Liverpool Dental Hospital and carefully tested before use to maximise comprehensibility (Humphris et al, 1999).<sup>25</sup> Note the use of the term ‘mouth cancer’ especially.

### **What is cancer of the mouth?**

It is a malignant growth which can occur in any part of the mouth.

### **What are the signs of mouth cancer?**

Most cancers appear as a painless mouth ulcer that does not heal normally. Less often, however, a white or red patch in the mouth may develop into a cancer.

### **Am I at risk from mouth cancer?**

Anyone can be affected by mouth cancer, whether they have their own teeth or not. Smoking greatly increases your risk of mouth cancer. Heavy drinking is also a risk. If you do both, your chances of getting mouth cancer are much greater. This cancer is more likely to occur in people over 40 years. Also, it is more common in men than women.

### **How many people get mouth cancer?**

In the UK alone about 3000 people get cancer of the mouth each year.

### **Do people die from cancer of the mouth?**

Yes, about 1600 people in the UK die from mouth cancer every year. Many of these deaths could be prevented by early detection of this cancer.

### **How can cancer of the mouth be detected early?**

Mouth cancer can often be spotted during its early stages by your dentist. If mouth cancer is recognised early, then the chances of a cure are good. Many people with mouth cancer go to their dentist or doctor too late.

### **What is involved in a check-up of the mouth?**

The dentist examines the inside of your mouth with the help of a small mirror. Remember, your dentist is able to see parts of your mouth that you cannot see easily yourself. The dentist may also use a special blue mouthwash which helps to identify any malignant growth.

### **Prevention of mouth cancer**

Most cancers of the mouth can be prevented by not smoking or chewing tobacco/areca nut and reducing the amount of alcohol you drink.

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## Lifestyle counselling

This also requires care and sensitivity, from team members directly involved in giving advice and also from people present in a supporting/encouraging role. Advice about smoking cessation or reducing alcohol consumption is best done one-to-one, in a way which leaves the patient feeling in control and able to stop the conversation if it gets too uncomfortable. A stopped conversation is not necessarily a failure - advice rejected on one occasion may be accepted next time, after the issues have been better digested. Keep a note of what happened on the patient record and try again.

Lifestyle counselling can be made more acceptable by helping patients to assess their own levels of risk and identify ways to reduce it.<sup>26</sup> Research suggests that repeated reminders and encouragement to stop smoking have significant success, even if it feels like a thankless task at the time.<sup>27,28</sup> This paper is not intended as a guide to smoking cessation techniques so you will probably want to refer - for example - to the Health Education Authority's 1998 publication *How to stop - advice for the dental team*. However, the following two boxes show some of the arguments that can be used to explain smoking hazards and cessation benefits.

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### Smoking cessation time chart

<b>After 20 minutes</b>	Blood pressure and pulse rate return to normal
<b>After 8 hours</b>	Nicotine and carbon monoxide levels in the blood reduce by half, oxygen levels return to normal
<b>After 24 hours</b>	Carbon monoxide will be eliminated from the body. Ability to taste and smell is greatly improved
<b>After 72 hours</b>	Breathing becomes easier. Bronchial tubes begin to relax and energy levels increase
<b>After 2-12 weeks</b>	Circulation improves
<b>After 3-9 months</b>	Coughs, wheezing and breathing problems improve as lung function is increased by up to 10%
<b>After 5 years</b>	Risk of heart attack falls to about half that of a smoker
<b>After 10 years</b>	Risk of lung cancer falls to about half that of a smoker. Risk of heart attack falls to the same as someone who has never smoked. Risk of oral cancer appears to fall more quickly – close to that of a ‘never smoker’ within ten years

### Coping with cravings – Try the 5 Ds

<b>1. Delay –</b>	Even the most intense craving lasts only a few minutes, remind yourself that the urge is only temporary and will be gone in 3 to 5 minutes at the most
<b>2. Deep breathing –</b>	Take a few breaths, this will help you relax and the extra oxygen will increase alertness
<b>3. Decide –</b>	Think positively. It can strengthen your willpower and increase your confidence. Say to yourself ‘I choose to be a non-smoker’. Repeat this over and over to yourself
<b>4. Drink water –</b>	Have a drink of water every time a craving comes. It will help clean the body. Try to drink 8 glasses of water each day
<b>5. Do something else –</b>	Take a short break from whatever you are doing, go for a walk, talk to someone, do something relaxing or occupy your mind

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Oral cancer is one of the commonest cancers in the Indian subcontinent so first generation immigrants from these countries may have greater awareness than normal and greater fear, too. In addition, marijuana is used by a significant minority of the UK population, including certain minority ethnic groups and heavy use is likely to be linked with oral cancer in the same way as tobacco smoking, particularly when smoked with tobacco.

Team members need to be sensitive to cultural differences of this sort. Practice meetings could be used for sharing experiences and understandings.

As dentists’ opportunistic screening procedures become better known, other health workers dealing with minority ethnic communities will be able to give supporting advice. Generally, people from minority ethnic groups have distinct health problems - more disease and poorer access to services. Problems can be especially acute for women. Health authorities use ‘linkworkers’ and patients’ advocates in some areas to help people access health care.

## Talking to patients from different cultures

### Key Points

- Use simple language in conversation and letters: mouth cancer instead of oral cancer, for example
- Lifestyle counselling of patients should be on a one to one basis
- Counselling should be recorded on patient records
- Obtain literature from health education organisations and make it freely available

## Talking about referrals

Given the incidence of oral cancer, referrals for specialist advice are going to be very rare - on average far less than one a year per dentist. But when a referral happens it is going to be stressful - for the patient, for you and for your nurse - so it will help to have a procedure worked out in advance.

Ideally, arrange a specialist appointment by phone, before the patient goes home. If that is not possible, tell the patient that you will contact the specialist as quickly as possible afterwards and report back, again by phone. You do not want to dramatise but a patient will worry about any sort of specialist referral and you want to keep uncertainties and delays to a minimum. If you have used toloum chloride, there will be an increased need to arrange the appointment quickly because the patient will already have waited 10-14 days for the second test.

You will also need to write to the consultant about what you have found. The letter should be addressed to a named consultant or specialist and give:

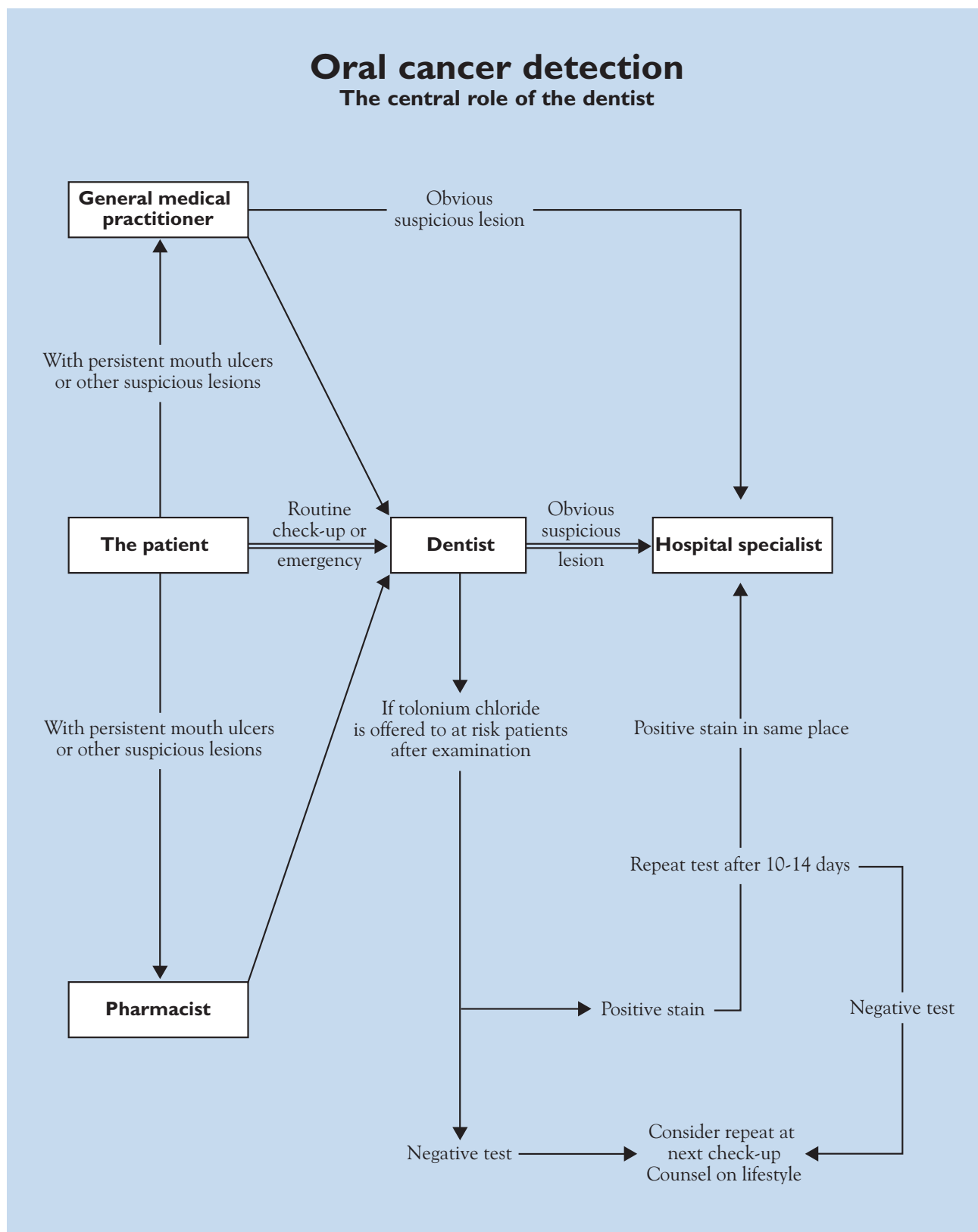
- Patient personal details (age, sex, personal details, occupation)
- Relevant medical history details (or a copy of the medical history record)
- Relevant lifestyle factors
- Brief details of counselling provided and perceived level of patient understanding of the situation
- Brief dental history (attendance patterns, oral hygiene, periodontal condition)
- Details of the suspicious area/lesion (colour, texture, size, position, mobility)
- Whether any regional nodes are palpable
- Copy of completed mouth map
- Copy of previous mouth map if lesion has been under review
- Intra-oral photographs of visible lesion or stained area (if available)
- If applicable, mention use of toloum chloride, with two positive tests being obtained
- Thanks for agreeing to see the patient and a request for an opinion and test results.

You will probably choose to give the letter to the patient to take rather than post it. If you are seriously concerned that cancer may be present, telephone or fax the consultant. Most will then 'fast track' the patient to an earlier consultation.

### Key Points

- If referral is necessary it should be made over the phone before the patient leaves the practice
- Write comprehensive referral letters

# Communication pathways



# Administration

Opportunistic screening is less of a burden the better the supporting administrative systems. Medical history sheets which include lifestyle questions and soft tissue

charts can save a lot of time for dentists and nurses. Mouth maps will help with soft tissue monitoring. It will also help to flag up patients who are 'at risk' on their records.

## Medical history taking

It will help if a practice adopts a common approach to medical history taking – a common form so that a dentist seeing a colleague's patient in an emergency knows what to find in a record envelope and a common way of explaining the form to patients. The BDA model does not have to be followed exactly but the BDA's advice is that all history forms should now include lifestyle questions in some form (see page 12).

Patients can be asked to fill the form in on their own because the answers will always be seen by the dentist who can clarify and ask follow-up questions, if necessary. Nurses

should not assess whether any of the medical history needs to be drawn to the dentist's attention but they can check for omissions and ask for information on tobacco and alcohol use if this is not volunteered.

A practice procedure will also be needed for updating the medical history sheet – showing previous answers to the patient and asking them whether the information is still correct. People who have given up smoking since the last visit can be encouraged and congratulated. People who have taken up the habit can be advised to think again.

## Screening records



A soft tissue examination takes about 3 minutes to carry out, if the oral mucosa is healthy. In that event, all that is needed is a note of negative findings on the patient record. This can be very abbreviated provided there is a practice protocol for ensuring that all practice members know what the abbreviation means and a practice protocol for carrying out the examination. For example, the dentist might list to the nurse the parts of the mouth being examined, in turn and in a particular order. If they are healthy nothing more than a general note need be recorded but it would be clear – and witnessed – that a full examination had taken place. The sequence might be:

- Mucosa – labial/buccal/palatal gingival or alveolar
- Tongue – dorsal/ventral/lateral
- Floor of mouth
- Edentulous areas
- Salivary glands – parotid/sublingual/submandibular
- Pharynx – tonsils/pillars of the fauces
- Neck – lymph nodes

Patient records should also note responses to any lifestyle advice and any commitment – or refusal – to reduce risks. Consider putting identifying 'flags' onto the records of patients found to have suspicious-looking soft tissue lesions.

For some patients you will notice things that are a little worrying – not enough to refer, but something you would like to check up on when the patient next visits. Mouth maps are then helpful. There are two types – either a simplified three-dimensional drawing of an open mouth or a more stylised flat drawing of the oral mucosa around the teeth. The second type of map can also be shown against half centimetre grid markings so that the location of lesions can be shown quite precisely. Mouth mapping, especially using the map opposite, is the simplest way to monitor a soft tissue condition – where it is and how big, so that you can check for any change at the next visit. Also note colour, texture, and mobility.

Data protection laws give patients access to mouth maps as to any other health records.

Tolonium chloride testing should always be recorded. But again, if there is a clear practice protocol for case selection and for carrying out the test, and if the protocol is audited periodically, then the entry on a particular patient's record can be very brief. The protocol would need to cover:

- Confirmation that the patient understands and agrees to the test
- Dates and comments on patient acceptance or refusal of tolonium chloride
- Tests results

- Description of any stained area - texture, size, position, mobility
- Completed mouth map, if any positive stains are found at either first or second test
- Action in the light of a positive second test

Many practices are now using photographic records – digital or otherwise. If available a photograph before and after staining is an excellent record.

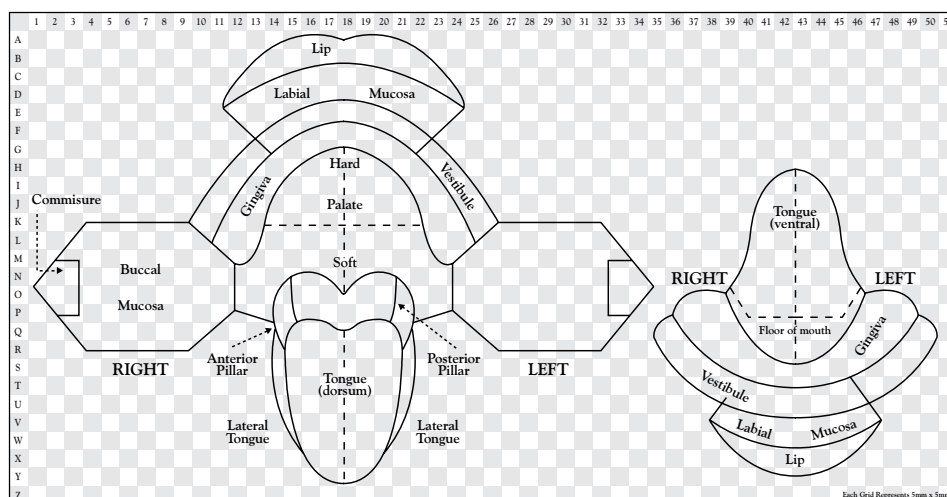
## Record keeping for tolonium chloride tests

Once a practice has a system for targeting patients with smoking cessation or other advice, the advice will need to be reinforced at follow-up visits. This means knowing who the patients are, through an alerting system of some sort. This might be an identifying mark on a paper record card – a 'mucosal alert' sticker similar to a 'medical alert' for patients with a particular health problem. Or an automatic alert might be possible with a computerised record system - think about lifestyle records and an alerting function when choosing a practice computer system. The more dentists

discuss this sort of need with the producers of dental software the more companies will be encouraged to expand their systems to meet it.

The system could also be used to indicate which patients might be offered tolonium chloride testing. All patients should be visually screened, routinely, but the practice may decide to offer additional testing to a group with a specified lifestyle. The smoking and drinking or other risk factor thresholds would be for you to decide.

## Following up on patients at risk



### Key Points

- Dentists should identify those patients with a risk factor for oral cancer
- Use medical history sheets which include lifestyle questions
- Staff to be trained to ensure patients complete medical history sheets fully
- Practice policy on oral cancer screening to be formulated and understood by all staff
- Accurate and comprehensive medical history and dental treatment records must be kept
- Develop procedures to review and update medical history records at each new course of treatment
- Use a mouth map where appropriate
- Negative examination results must be entered in dental treatment records as well as positive

# Examining the head, neck and soft tissue

To ensure completeness, a soft tissue<sup>10</sup> examination needs to follow a pattern. Work out a logical sequence and then stick to it. Since your first step will be a general appraisal of the patient's well-being on entering the surgery, it could make sense to start with soft tissues, before moving on to examination of the teeth and gums. But this is a personal choice - carry out the

examination in an order that you and your nurse are comfortable with and that you find easy to explain to the patient. Use gloved fingers or, preferably, two mouth mirrors to retract the tissues. The visual inspection should be supplemented by palpation of any suspicious area and the submandibular and cervical lymph nodes.

## Extra oral examination<sup>10</sup>

Observe the face for asymmetry, swellings, skin blemishes, moles and pigmentation.

Examine the vermillion border of the lips and corners of the mouth, note any changes in colour or texture (Fig. 1a). Palpate for any enlargement of the lymph nodes of the neck with the fingertips.

The precise group of nodes likely to be affected depends on the location of the primary cancer, but submandibular, then upper, middle and lower deep cervical nodes are most commonly involved with intra-oral lesions: these are often referred to as levels I – IV, level V being the posterior triangle of the neck (Fig. 1b).

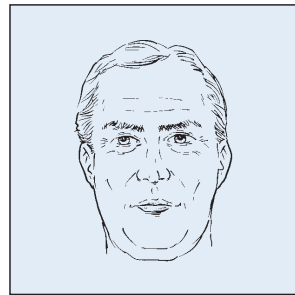


Fig. 1a

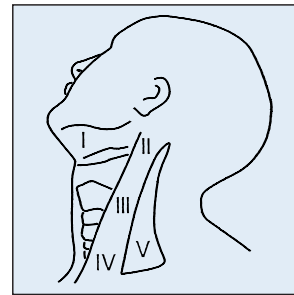
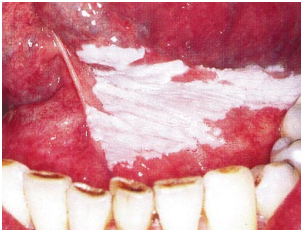


Fig. 1b



# What you're looking for – an overview



Homogeneous leukoplakia in high-risk site.



Non-homogeneous ("nodular") leukoplakia



Erythroplakia in left buccal mucosa.



Lichen planus mimicking leukoplakia



Small carcinoma of lower lip

Cancer may present in the mouth in many ways, but the following clinical signs should be regarded with great suspicion.

Any ULCER of the mucosa which fails to heal within two weeks, with appropriate therapy, and for which no other diagnosis (e.g. major aphthous ulcer) can be established.

INDURATION of any mucosal lesion.

FUNGATION/GROWTH of the tissues to produce an elevated, cauliflower surface or lump.

FIXATION of the mucosa to underlying tissues, with loss of normal mobility.

FAILURE to heal of a tooth socket, or any other wound.

TOOTH MOBILITY with no apparent cause.

PAIN/PARAESTHESIA with no apparent cause.

DYSPHAGIA for which no other diagnosis can be made.

WHITE/RED PATCHES of the mucosa are commonly considered as potentially malignant lesions, but occasionally they may be the clinical presentation of a malignancy.

## Potentially malignant lesions

Lesions of the oral mucosa which are dysplastic, but not frankly malignant, may present in a number of ways, but the clinical signs are likely to be less obvious than those for an established carcinoma. Precancerous lesions are usually well demarcated. Epithelial dysplasia indicates an increased risk of malignant change at that site, it does not mean that the lesion is committed to malignant transformation. Therefore diagnosis, referral, management and follow up of patients with potentially malignant lesions may be life saving.

LEUKOPLAKIA may be defined as a white patch which cannot be rubbed off and can not be characterised clinically or histologically as any other disease.

Oral leukoplakia may be idiopathic or may be associated with carcinogens such as tobacco.

It is not clear what proportion of lesions undergo malignant change but there is a clear association with the severity of dysplasia as determined histologically. Leukoplakia is thus regarded as a precancerous lesion and must be managed accordingly.

**HOMOGENOUS LEUKOPLAKIA** appears as a uniformly white patch of raised mucosa, anywhere in the mouth. The surface may be smooth or cracked; most reveal hyperkeratosis without dysplasia on biopsy. However, an exception to this general finding concerns homogenous leukoplakias involving the floor of mouth and ventral surface of tongue, which are considered high risk lesions.

**VERRUCOUS LEUKOPLAKIA** is a white lesion with a warty, hyperplastic surface.

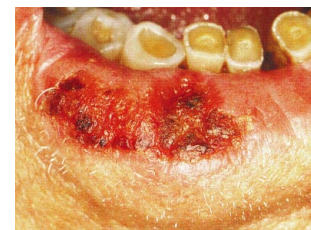
**NODULAR LEUKOPLAKIA** is a white lesion with a granular surface, which may often be associated with *Candida albicans* infection.

**SPECKLED LEUKOPLAKIA** has combined red and white elements in the plaque and has an irregular surface texture.

**ERYTHROPLAKIA** appears as a well defined fiery red, velvety or granular lesion of the mucosa which is usually irregular in outline.

Common sites for erythroplakia are the buccal mucosa and soft palate. Erythroplakia has a greater malignant potential than leukoplakia. Histologically erythroplakia shows changes ranging from mild dysplasia to invasive squamous cell carcinoma.

**MIXED LESIONS** may contain elements of any of the above types and are difficult to classify.



Extensive carcinoma of lower lip

If the patient is wearing dentures, ask for them to be removed.

Examine the labial mucosa and sulcus with the mouth half open (Fig. 2).

With the mouth open wide, retract the cheek on one side and examine the colour and texture of the buccal mucosa. Then with the mouth half open, observe the maxillary and mandibular sulci. Repeat this sequence for the other side of the mouth (Fig. 3). Inspect the tongue at rest and protruded, note any aberrations in colour, texture, distribution of papillae, symmetry or mobility (Fig. 4).

To facilitate inspection of the lateral borders, hold the tip of the tongue with a gauze square and move it to one side, whilst also retracting the cheek. Repeat for the other side of the mouth (Fig. 5).

Examine the floor of the mouth and ventral surface of the tongue with the tip of the tongue raised to the palate (Fig. 6).

Depress the tongue and inspect the hard and soft palate, then request the patient to say 'Ah' and examine the pillars of the fauces, tonsils, uvula and oropharynx.

Patients who have been treated for head and neck cancer will be followed up at regular intervals by their specialist hospital department for at least five years. Beyond this, dental practitioners should examine such patients at six-month intervals.

## Intra oral examination<sup>10</sup>

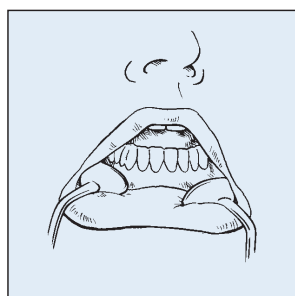


Fig. 2

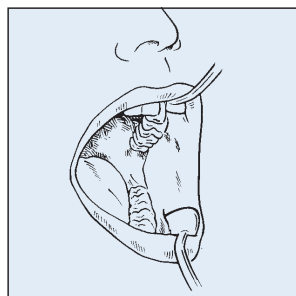


Fig. 3

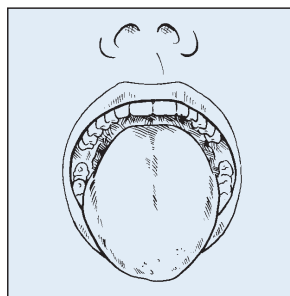


Fig. 4

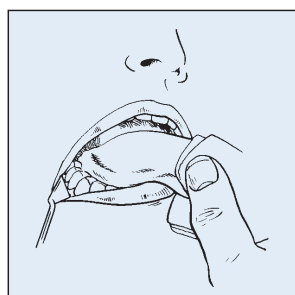


Fig. 5

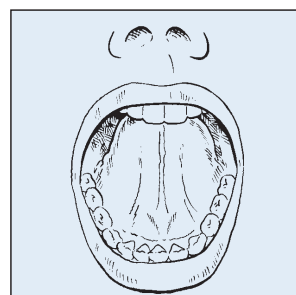


Fig. 6

### Key Points

- This examination should be carried out on all patients as part of every routine check-up exam and at the start of each new course of treatment
- Future check-ups should take account of soft tissue findings, with patients in at-risk groups being seen more frequently

### Potentially malignant conditions

#### CHRONIC IRON DEFICIENCY

ANAEMIA Patterson-Kelly (Plummer-Vinson) Syndrome is the combination of iron deficiency anaemia with dysphagia and glossitis. Mucosal atrophy is often a feature and may be associated with malignant change in the oral cavity and pharynx.

EROSIVE LICHEN PLANUS appears as atrophy, erosion or superficial ulceration of the oral mucosa, in association with white papules, keratotic striae and the characteristic reticular form of lichen planus. Erosive lesions cause pain and discomfort to the patient, especially upon contact with acidic or spicy foodstuffs. Erosive lichen planus must be treated and monitored regularly as a small proportion of lesions, particularly those on the tongue, may become malignant.

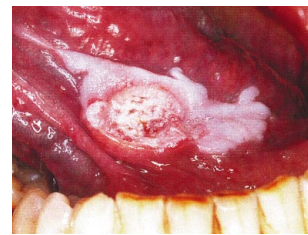
ORAL SUBMUCOUS FIBROSIS presents as a loss of elasticity of the mucosa, with fibrous bands causing limitation of opening of the mouth. The tongue shows loss of papillae, firmness and a lack of mobility. A burning sensation in the mouth or throat may be an early symptom. This condition is most common in Asian patients who chew areca nut, alone or as part of betel quids.

#### DISCOID LUPUS ERYTHEMATOSUS

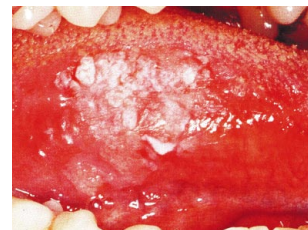
(DLE) of the oral mucosa may or may not be associated with skin lesions elsewhere on the body. Oral lesions appear as an area of atrophy or erosion, surrounded by a white kerotic halo. The buccal mucosa and lips are most likely to be involved in this condition.

TERTIARY SYPHILIS is now rare in the U.K. because syphilis is usually diagnosed and treated early. The keratotic plaque of tertiary syphilis appears on the dorsum of the tongue and may occasionally be associated with the development of oral cancer in the midline of the tongue.

ACTINIC KERATOSIS may be characterised by erosion and white or brown crusting of the vermillion border of the lower lip. It is caused by exposure to ultra-violet light particularly from strong sunlight.



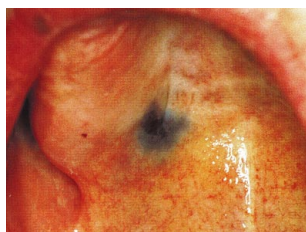
*Carcinomatous transformation in leucoplakia*



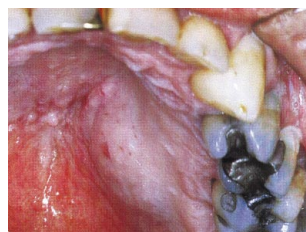
*Carcinoma presenting as leucoplakia*



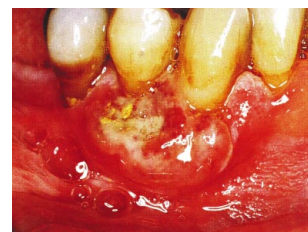
*Extensive carcinoma of the tongue*



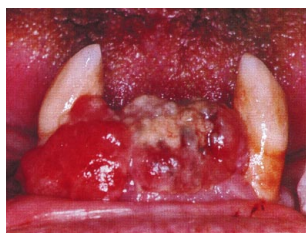
*Malignant melanoma in palate*



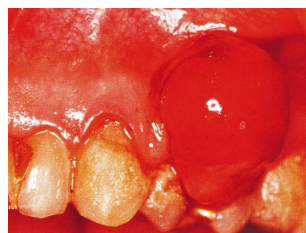
*Salivary gland neoplasm of palate*



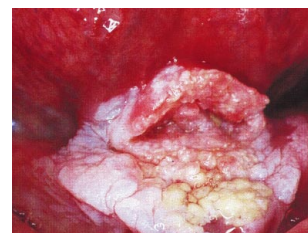
*Gingival carcinoma*



*Gingival non-Hodgkin lymphoma*



*Metastasis from lung carcinoma*



*Verrucous carcinoma of floor of mouth*

### Key Points

- Look for changes or abnormality in oral tissues
- Be aware of differential diagnoses
- Record observations, and consider photographing suspect lesions
- If in doubt review or refer



# Using tolonium chloride

Tolonium Chloride is not a replacement for visual and digital examination, but an extra tool, particularly for people in high risk groups or needing added reassurance or added encouragement to change lifestyle. This section explains how tolonium chloride is used in order that practices can assess whether it has a place in their own screening programmes.

Tolonium chloride may be used:

- To detect invisible, asymptomatic lesions
- To confirm a suspicious lesion identified visually
- On a regular basis for patients at special risk, or as an occasional check
- For educative reasons or to give additional reassurance to a concerned patient

## Reliability

After explanations, the test takes about five minutes to carry out. It involves looking for tissue which tolonium chloride stains blue.

A false negative result is the real worry with any screening test - a result which suggests that there is no problem when there is in fact something wrong. The tolonium chloride test has been shown to compare very favourably in sensitivity with other cancer screening tests. For example, the cervical smear test has sensitivity in the range 52-64%<sup>29</sup> compared with 94% for tolonium chloride. If a patient has oral cancer then tolonium chloride is very likely to find it.

There is, however, a possibility of inflammation and irritation taking up the stain, so that the test carries a risk of false positives. If the first test is positive the recommended protocol therefore includes a second test 10-14 days later, to give inflammatory lesions an opportunity to heal. Using this procedure the false positive rate for benign lesions is reduced to about 7%.<sup>16</sup> In other words, few referrals after a positive result using the two rinse protocol would result in negative biopsies.

## Acceptability

Patient acceptability is important. A test which frightened patients and risked the possibility that they gave up examination even of teeth and gums would be unfortunate. There is however, accumulating evidence that the test has

good acceptability in primary care if its purpose and context is clearly explained.<sup>30</sup>

*See page 14 for more advice on how to handle patient explanations.*

## Chairside protocol

The test is carried out after visual and digital examination and before scaling or other instrumentation of soft tissue. The patient's face and clothing will need to be protected from staining through spills or splashes. Apply petroleum jelly to the patient's lips to reduce staining. Ask the patient to expectorate into a large cup, to be disposed of in an infectious waste container or poured into the centre of the spittoon with water running. Then:

- The patient rinses and gargles with pre-rinse solution for 20 seconds, followed by water
- The patient rinses and gargles with tolonium chloride for 20 seconds
- The patient rinses and gargles with post-rinse solution for 20 seconds, repeats, and rinses with water

- The dentist examines the oral cavity for stain. Stain retained by the dorsum of the tongue is normal and not positive. Any other retention of stain that cannot be removed with the application of a pre-or post-rinse solution on a cotton bud, is considered positive.
- To reduce false positives, local aetiological factors are eliminated and the patient with positive stain is retested in 10-14 days, after which any inflammatory lesions have healed. A second positive stain makes biopsy mandatory.
- Any suspicious lesions that do not stain should also be referred for second opinion and possible biopsy.

The following illustrations show how tolonium chloride can highlight suspicious lesions:

## Interpreting test results



Fig 1a  
Early asymptomatic squamous cell carcinoma, floor of mouth



Fig 1b

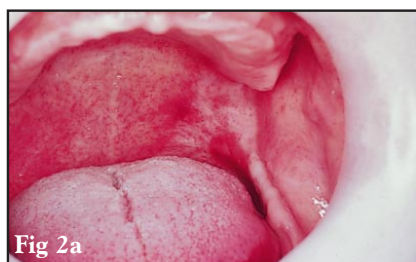


Fig 2a  
Early asymptomatic squamous cell carcinoma found on routine follow-up exam for leukoplakia, oropharynx



Fig 2b



Fig 3a  
Early asymptomatic squamous cell carcinoma found on routine follow-up visit for asymptomatic leukoplakia, tongue



Fig 3b

Clinical slides courtesy of Professor Sol Silverman, Jr.

In high risk populations, tolonium chloride has been shown to be 90-100% sensitive in detecting squamous cell carcinoma, which accounts for 90% of all oral cancer cases:

- In 1981, Mashberg reported a false negative rate of 5.9% (94% sensitivity) and a false positive rate of 7.4% (92.6% specificity) for tolonium chloride rinse.<sup>16</sup>
- In 1994, Warnakulasuriya and Johnson reported a trial of tolonium chloride rinse in 102 patients with mixed lesions. Biopsy confirmed that the stain recognized clinically apparent carcinomas with 100% accuracy. In addition, the tolonium chloride stained seven clinically unsuspected lesions that were confirmed histologically as dysplasias.<sup>15</sup>
- In 1997, Epstein et al. reported 100% sensitivity for tolonium chloride in the identification of carcinoma in situ or new invasive malignant lesions with no false-negative findings in a cohort of patients with upper aerodigestive tract cancer. Unaided clinical examinations of the same patients resulted in only 78% of the lesions being identified.<sup>14</sup>
- In 1998, Feldman et al reported 100% sensitivity in a trial of tolonium chloride among 367 patients with a previous history of upper oro-pharyngeal squamous cell carcinoma. Visual exam sensitivity was 41%. Ten lesions histologically identified as carcinoma or carcinoma in situ were not detected by visual exam.<sup>31</sup>

## Research summary

### Key Points

- Tolonium chloride may be used as an adjunct to soft tissue examination to highlight any invisible, asymptomatic lesions
- The tolonium chloride test is well accepted by patients
- Tolonium chloride is also used to delineate surgical sites for biopsy or excision

# Putting screening into practice

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Opportunistic screening for oral cancer will only produce results if used consistently throughout a practice, in a visible and coherent way, so that patients receive a clear message and respond to what the dental team are saying and doing. This section suggests ways of setting a practice strategy which has full team support. The strategy will need to specify:

- Roles and responsibilities
- Initial and ongoing training support
- Methods of introducing and explaining screening to patients
- Use of supporting leaflets to maintain patient awareness
- The screening processes to be used
- Record keeping
- Referral procedures to specialists
- Liaison with other local health professionals
- External communication about the practice and its oral cancer screening initiative

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## Managing the debate

Screening can be approached in many ways. In some practices, dentists might discuss screening first, to try out the agenda, and then broaden the discussion so that everyone has a chance to have a say, ask questions, and test the solutions being proposed. Other practices might start with a practice meeting to set some broad principles and then ask a smaller group or an individual to work out the detail, for discussion at a subsequent meeting. There are no right and wrong methods. There will be a need for leadership and a need for

input from the dental team. Nurses, practice managers, receptionists and hygienists will all have good suggestions to make about how to explain screening to patients in a way that does not alarm them, about the efficient management of at risk registers, and maintaining good communications with other health professionals. All that matters is that a practice ends up with an agreed approach to opportunistic screening which gives everyone a clear understanding of their part in the process and produces a clear message for patients.

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## Agreeing the approach

This paper has suggested that effective screening for oral cancer is clinically simple but organisationally and psychologically complex. The barriers are less to do with the ability of dentists to carry out a proper head and neck examination and more to do with lack of integration of screening into practice thinking and working methods. Nurses may not be sure when to expect a head and neck examination, and where and when to record findings. Primary care dentists may not be confident enough of their right to be commenting on patient lifestyle beyond the familiar dietary messages. Issues such as these need to be talked through in the practice before a strategy is decided. For example:

- Does anyone in the practice smoke?  
Is this appropriate in a practice committed to oral cancer prevention?  
How can the practice help its colleague to give up? How could the colleague be rewarded for giving up?
- Is everyone familiar with nicotine replacement systems to help smoking cessation - the different types available, what they cost per week, the number of weeks of use probably needed, and the cost of smoking, as a comparison?  
Think about sending a practice member to the local pharmacy to check up on prices and report back.
- We all understand what smoking and drinking mean – but how familiar are practice members with tobacco chewing? Is there anyone in the practice who could explain how chewing tobacco products are used and what they look and taste like? Could you borrow a member of a nearby practice to explain to a practice meeting if your own practice does not have a member who can do this?  
Might the local postgraduate centre be persuaded to organise a briefing session for local practices if this is a general need?

- Try talking through the pros and cons of opportunistic screening and population screening programmes (such as are used for cervical screening, for example) with practice staff. Look at the pros and cons from the point of view of patients, including patient convenience and cooperation.
- Discuss screening techniques. Is there a simple routine that all the dentists can agree on and which nurses and other staff can then explain? How will findings be recorded? And will the routine include toloum chloride or will it rely on conventional methods of clinical examination?
- Do all practice staff understand what a dentist is doing when undertaking a head and neck examination? Try using the explanations and illustrations in this paper to brief nurses and other staff.
- Think about the practice's role in the care of patients who have been identified as having oral cancer or precancer. Are there currently any such patients in the practice? Which consultants is the practice working with and who else, outside the practice, is involved in their care? Are channels of communication good enough with other members of the oral cancer management team?

Once you have decided what to do, you have to organise yourselves to do it - making maximum use of everyone's skills. A nurse might have very good communication skills, for example, and be made a first contact point for questions from patients who phone or are in a waiting area. However duties are organised, training will be necessary but that can probably be organised within the practice through discussion and role play. Clearly, team members' confidence in their own awareness and understanding of oral cancer screening must be very good before the subject is introduced to patients. You need to get the facts right if patients are not to be alarmed.

There is nothing quite like being put in someone else's place to appreciate and empathise with their concerns and difficulties. Role play can be a useful training method. Describe some two player scenarios on cards, divide into pairs, and then ask each pair to draw a card at random and act out the scenario with the rest of the practice team watching. Then discuss how it went, as a team, looking for good and not-so-good points and drawing lessons out of the role play for everyone. See the box for some scenario ideas.

## Making the most of your resources

- Woman patient phones to ask for more information about oral cancer screening; she is very worried (but has no known risk factors)
- Young couple with poor oral hygiene dismiss the importance of oral cancer screening when they visit the practice for their annual check-up
- Single parent, heavy smoker with a young child; very anxious that she may have oral cancer; her own mother died of cancer
- Obese middle-aged male patient, suspected alcoholic, loudly protests in the reception area that oral cancer screening is an invasion of privacy
- Male patient, previous smoker is desperate to check he doesn't have cancer, but is very scared of accepting a toloum chloride test
- Professional female accepts the toloum chloride test, a positive stain appears on the lateral border of the tongue

## Ideas for role play

### Key Points

- Develop understanding of the issues and commitment from the entire dental team
- Team members' confidence in their own awareness and understanding of oral cancer screening must be complete before the subject is introduced to patients
- Ensure that a team training programme is initiated, undertaken and periodically reviewed
- Appoint oral cancer screening advisers to liaise with patients



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## Auditing your screening systems

Once a practice has agreed an approach to screening it will help to put it down on paper, to ensure that everyone follows it in the same way and to help the later training of new staff, who were not present when the approach was worked out. A clear statement of what is intended to happen also helps in the auditing of whether it does in fact happen. Think of some audit tests which will let the practice demonstrate to itself how performance is improving. For example:

- What proportion of patients have given information about their alcohol consumption and tobacco use? How will better social history taking procedures improve this, and what

might the target for improvement be, over the coming year?

- What recording conventions are followed now for soft tissue screening? Are all dentists able to understand each other's recording methods? How can consistency of recording be improved?

Once there are agreed procedures for carrying out oral cancer screening, they can become part of the practice's clinical governance system. Clinical governance is about ensuring that patients get the care they need and that there are no accidental gaps. That's what this paper has been all about, too.

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## Working with other health professionals

The first priority will be for local oral and maxillofacial surgeons to understand what the practice is planning and what its policies on referral will be. Investigation of suspect lesions will be treated as urgent when the referrals arrive but the specialists will want to be sure that the practice sieve is effective and that an oral cancer screening strategy is not going to result in unnecessary work. A phone call to discuss plans at an early stage would probably be helpful and welcomed by most specialists. If you will be using tolonium chloride tell them. Check up on the arrangements for making appointments too, and make it someone's responsibility to keep telephone numbers up to date.

Once a practice has an administratively workable screening system in place, then other health professionals locally ought to know about it too. Think about telling medical and pharmacist colleagues because they will deal with patients asking about

mouth ulcers and other soft tissue conditions.<sup>32,33</sup> It could help them to reassure patients if they could fully understand and explain that regular mouth checks by dentists are looking even for things like oral cancer and are not simply confined to the examination of teeth for decay or gum disease.

Also, find out about smoking cessation or other relevant health promotion programmes being run locally. Your practice cannot do everything and some patients will need to be referred to other support systems. There is now plenty of evidence to show the effectiveness of smoking cessation programmes<sup>26,27</sup> and it is important to know where to send patients for counselling, where the practice feels that additional expertise is needed to help a particular patient.

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## The key to success – everyone with a clear role

As for any task, each team member should have a clear role which they understand and see as contributing to an effective and well-managed oral health service. Roles may be distinct but there should also be interchangeability so that holiday and sickness absences can be covered. Each practice needs to work out how roles and responsibilities fit around the staff available but the following framework may be a useful starting point:

## Team roles and responsibilities

### Everyone in the practice should:

- Understand the risk factors and problems of oral cancer, and the importance of oral cancer screening
- Understand the practice oral cancer screening policy, and the full oral cancer screening procedure
- Help raise patient awareness and understanding for the need and importance of oral cancer screening
- Be able to answer patient queries at an appropriate level
- Be able to offer or support lifestyle counselling to reduce the oral cancer risk.

### Each dentist is responsible for:

- Adopting an approach to oral cancer screening which is consistent with current medico-legal advice from defence organisations and the BDA
- Ensuring that the approach is followed consistently, and consistently documented
- Ensuring that team members are trained for and understand their contributions to oral cancer prevention, while still taking responsibility for team actions and advice
- Establishing and confirming specialist referral arrangements
- Deciding whether to use tolonium chloride testing and, if using it, defining the groups to be offered the test

### Dentists collectively in a practice should consider:

- Adopting a common approach to oral cancer screening so that patients receive a clear message and to aid flexibility and team support within the practice
- Setting up a common audit system
- Using common documentation
- Having a common training policy for staff about oral cancer screening
- Producing written information to explain the practice's screening approach to patients
- Communicating the practice's screening approach to other health professionals in the area
- Talking to other local practices to develop a common approach

### Hygienists should:

- Monitor the oral mucosa for signs of change, referring back to the dentist if necessary
- Investigate sources of trauma and refer all suspicious lesions to the dentist
- Record soft tissue conditions found and advice given, according to conventions agreed with the dentist
- Take note of lifestyle information from the medical history sheet and advise, if necessary
- Be aware of the specific oral care needs in general practice for patients already treated for an oral cavity or aerodigestive tract cancer

### Nurses should:

- Understand the medical history sheet and be able to help patients experiencing difficulty in answering the questions
- Make accurate notes of the dentist's observations during head, neck and soft tissue examination, using agreed conventions
- Confirm in patients' records that a visual and palpatory examination has been carried out
- Assist with tolonium chloride tests, if used, and be able to answer patients' questions about the test
- Support patients emotionally during oral cancer screening

### Reception staff should:

- Answer patients' queries on the telephone and in the reception area
- Know about leaflets available and be able to answer questions about the leaflets, if necessary

### Practice managers should:

- Help develop practice training policies to support oral cancer screening, including refresher training
- Arrange cover for holidays and sickness
- Maintain stocks of any documentation decided on
- Organise regular audits of systems for medical history taking, screening, record keeping and recording

## Key Points

- Create an audit system to monitor the implementation of your screening programme
- Develop contacts and expand working relationships with fellow healthcare professionals
- Ensure that each member of the team has a clear understanding of the issues and a defined role to play

# For more help

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## Medical history sheets and mouth maps

BDA model medical history sheets and mouth maps are available.

To order: contact Education and Science Department 0207 935 0875 extension 18

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## Leaflets on alcohol and tobacco cessation for patients

### Health Development Agency

Trevelyan House  
30 Great Peter Street  
London SW1 2HW  
Tel 020 7222 5300 Fax 020 7413 8900

The Health Development Agency (which has taken over from the Health Education Authority) has a wide range of information materials for the general public:

- Think about Drink – explains the Department of Health's new sensible drinking messages in a way that is understandable and interesting.
- Drinking for Two – advice on alcohol consumption for women who are trying to become pregnant, are at any stage of pregnancy or are breast-feeding.
- Advice for Parents and Young People – encouraging them to talk to one another about drinking alcohol.

### The Portman Group

2a Wimpole St  
London W1M 7AA  
Tel 020 7499 1010 Fax 020 7483 1417  
email: portman-group@compuserve.com

The Portman Group is funded by companies selling alcoholic drinks. It aims to encourage responsible use of alcohol and produces 'ALCULATOR', a guide to how much alcohol is in various drinks, as well as various sensible drinking fact sheets.

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## Helplines

A number of Government-funded helplines offer recorded message or one-to-one telephone advice:

### Don't give up on giving up:

0800 169 0 169

### Quit:

Victory House, 170 Tottenham Court Road,  
London W1P 0HA

England Quitline: 0800 002200

Scotland Smokeline: 0800 84 84 84

Northern Ireland Quitline:

Tel 028 9066 3281 Fax 028 9066 0081

Wales Helpline: Tel 0345 697 500

Fax 029 2064 1045

### Asian Quitline – Weekdays 1-9pm:

Bengali: 0800 00 22 44

Gujarati: 0800 00 22 55

Hindi: 0800 00 22 66

Punjabi: 0800 00 22 77

Urdu: 0800 00 22 88

### Drinkline All UK: 0345 320202

11am-11pm. Calls charged at local rates.

Monday to Friday

Dial and listen Freecall 0500 801802

Dial and listen 24hours 0990 143275

### AL-ANON Family Groups:

Tel 020 7403 0888

Alcoholics Anonymous: Tel 01904 644026

Fax 01904 629091

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There is a large network of support agencies for cancer sufferers, who will also give advice to practices developing patient communication strategies about oral cancer:

**British Association for Counselling:**

1 Regent Place, Rugby,  
Warwickshire CV21 2PJ  
Tel 01788 550899 Fax 01788 562189

**Cancer BACUP Counselling Service:**

3 Bath Place, Rivington Street, London  
EC2A 3JR

London: Tel 020 7696 9000

Fax 020 7769 6002

Glasgow: Tel 0141 553 1553

**Cancerlink:**

17 Britannia Street, London WC1X 9JN  
London: Tel 020 7833 2451  
Fax 020 7833 4963  
Edinburgh: Tel 0131 228 5557

**Asian Cancer Information Line:**

Tel 0800 590 415

**Let's Face It:**

14 Fallowfield, Yateley, Hants GU46 6LW  
Tel 01252 879630

**Changing Faces:**

1 & 2 Junction Mews, London W2 1PN  
Tel 020 7706 4232 Fax 020 7706 4234

## Counselling and support services

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*Smoking cessation: evidence based recommendations for the healthcare system*

Martin Raw, Ann McNeill, Robert West.

BMJ Vol.318. 16 January 1999. (182-185)

An article that summarises the new Smoking Cessation Guidelines for Health Professionals, as previously published in full in Thorax (1998: 53: supplement 5(1):S1-19)

*Report of the Scientific Committee on Tobacco and Health (SCOTH)*

Chairman: Professor D. Poswillo.

Department of Health.

Available from: The Publication Centre  
PO Box 276, London SW8 5DT  
Telephone orders: 020 7873 9090  
Fax orders: 020 7873 8200

*Helping smokers to STOP – a guide for the dental team* – Richard Watt and Mary Robinson

Health Education Authority, 1999.©

ISBN 0 7521 1466 2

All the information you need brought together into one document.

An excellent and informative publication – a must for every dentist's bookshelf.

*What is gutkha?*

BDA News. Vol. 12 No.4 April 1999.

*C Because Cowards Get Cancer Too*

John Diamond

ISBN 0 09 181664

## Further reading

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**Web Sites:**

**Department of Health**  
[www.doh.gov.uk](http://www.doh.gov.uk)

**Health Education Authority**  
[www.hea.org.uk](http://www.hea.org.uk)

**FDI World Dental Federation**  
[www.fdi.org.uk](http://www.fdi.org.uk)

**British Dental Association**  
[www.bda-dentistry.org.uk](http://www.bda-dentistry.org.uk)

**Cancer Research Campaign**  
[www.crc.org.uk](http://www.crc.org.uk)

**The Portman Group**  
[www.portman-group.org.uk](http://www.portman-group.org.uk)

**International Union Against Cancer**  
[www.uicc.ch](http://www.uicc.ch)

**National Cancer Institute - USA**  
[www.nci.nih.gov](http://www.nci.nih.gov)

**America Cancer Society**  
[www.cancer.org](http://www.cancer.org)

**National Oral Cancer Awareness Programme - USA**  
[www.oralcancer.org](http://www.oralcancer.org)

**National Oral Health Information Clearing House**  
[www.aerie.com/nohicweb](http://www.aerie.com/nohicweb)

## General information resources

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**Zila Europe**

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