

State of Mouth Cancer UK Report 2022

A report by the Oral Health Foundation



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Chapter one

About mouth cancer

What is mouth cancer?

Most of us have heard of cancer affecting parts of the body such as the lungs or breasts. However, cancer can appear in our mouth, where the disease can be diagnosed in areas like the lips, tongue, cheeks and throat.

In the United Kingdom (and around the world), the number of people with mouth cancer continues to grow at an astonishing rate.

Anyone of us are at risk of mouth cancer, whether we have our own teeth or not.

The signs and symptoms of mouth cancer include:

- A mouth ulcer that does not heal within three weeks.
- White or red patches in the mouth.
- Unusual lumps or swellings in the mouth, head or neck.
- Any persistent 'hoarseness'.

Early diagnosis is vital. It increases our chances of beating the disease, and gives us a much higher quality of life. Self-checks and regular dental visits are extremely important for spotting mouth cancer in its initial stages.

If in doubt, get checked out.

“Mouth cancer is a disease that does not discriminate. It can truly affect any one of us.”

Dr Nigel Carter OBE
Chief Executive
Oral Health Foundation

The impact of mouth cancer

It can be very difficult coping with a diagnosis of mouth cancer, both practically and emotionally.

At first, you are likely to feel very upset, frightened and confused. You may also feel that things are out of your control. It is very important to get the right information and support to help us along the process.

The recovery period can be a difficult time. After treatment, you may have problems with breathing, swallowing, drinking and eating. Speech may also be affected, and occasionally even lost. Facial disfigurement can also occur.

This can lead to other problems such as nutritional deficiency, and depression.

Difficulties in communication, low self-esteem, social isolation and the impact on relationships can cause as much distress as the cancer itself.



The scale and scope of mouth cancer

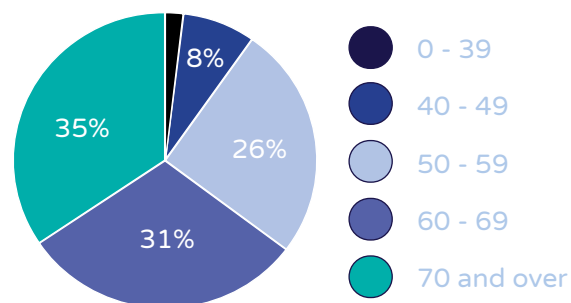
The latest figures show that 8,846 people in the UK are diagnosed with mouth cancer each year. The lifetime risk of mouth cancer currently stands at 1-in-55 for men and 1-in-108 women.¹⁻⁴

In the UK, almost one person every hour is diagnosed with mouth cancer. Mouth cancer accounts for around 2% of all cancers.⁵

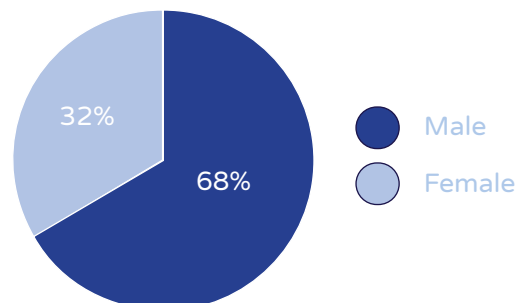
Statistics suggest that men are more likely to have mouth cancer than women. Almost two-thirds (68%) of all mouth cancer patients are male.¹⁻⁴ Mouth cancer is the 14th most common cancer in the UK. For men, mouth cancer is now the 9th most common cancer.⁵

Mouth cancer is also strongly-related to age. More than three-in-four (80%) of new cases are in those over the age of 55.¹⁻⁴

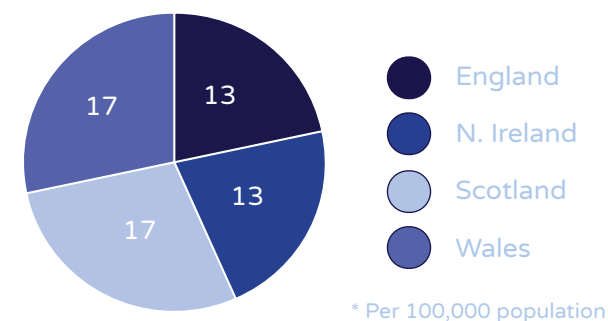
Mouth cancer in the UK by age



Mouth cancer in the UK by gender



Mouth cancer in the UK by AS rate



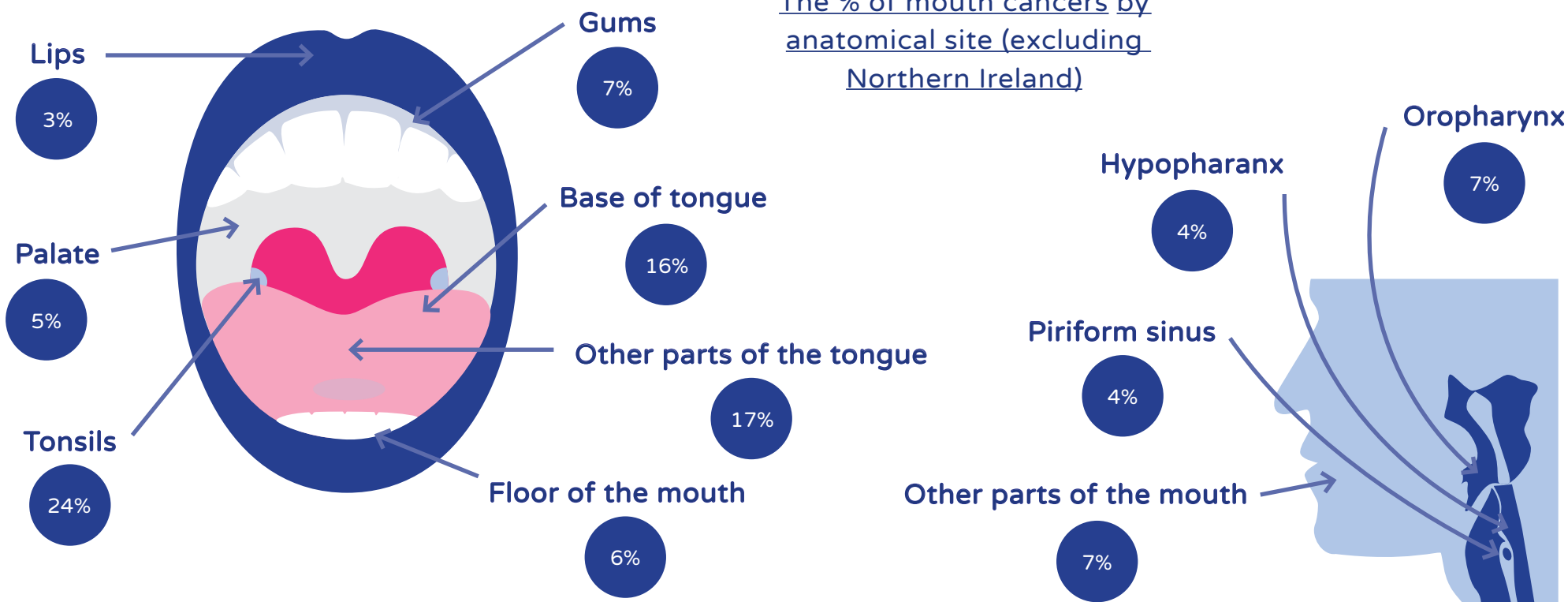
Living in areas of deprivation is also considered to significantly increase the risk of being diagnosed with mouth cancer. In England, mouth cancer rates increase by 68% for those living in the most deprived areas.¹⁻⁴

Mouth cancer rates are higher in England and Wales compared with the rest of the UK (17 per 100,000).¹⁻⁴

Where mouth cancer appears

Mouth cancer is a disease that can present itself in a number of ways. We urge anybody who notices anything unusual in or around their mouth, head and neck to seek medical attention from a dentist or doctor as soon as possible. Mouth cancer is most likely to occur in the tongue, this contributes to a third of all cases (33%). This is followed by the tonsil area (24%).¹⁻³

The % of mouth cancers by anatomical site (excluding Northern Ireland)



The causes and risk factors

Mouth cancer can affect anyone. However, there are several risk factors that can increase our chance of developing the disease.

The main causes linked to mouth cancer are:

Smoking

Around two-in-three mouth cancers directly caused by smoking.⁶

The risk of being diagnosed with mouth cancer for a smoker is almost double (91%) that of a never-smoker.⁷

Alcohol

Drinking alcohol to excess is responsible for around a third of all mouth cancers. Those who drink between 1.5 and 6 units of alcohol a day could be increasing the risk of mouth cancer by 81%.

⁸ Mouth cancer is 2.5 times higher in regular drinkers than non- and occasional drinkers,⁹ and for those who heavily drink alcohol and also smoke, the risk increases by 30 times.¹⁰

HPV

The human papillomavirus (HPV) type-16 and 18 are linked to around three-in-four (73%) of oropharyngeal cancers and more

than one-in-ten (12%) oral cavity and hypopharynx cancers. Risk is higher in those with more sexual partners.⁷

Age and gender

As we get older, our cells and DNA become more damaged. This is either biological or from exposure to the other risk factors. We do not know why mouth cancer rates are higher in men, however, it could be due to greater exposure to risk factors.

The other risk factors associated with mouth cancer include: areca (betel) nut, paan masala (Gutkha), chewing tobacco, smokeless tobacco, x-rays and gamma radiation, asbestos, excess body weight, salted fish, formaldehyde, wood dust, over exposure to sunlight, family history of cancer and environmental smoke.

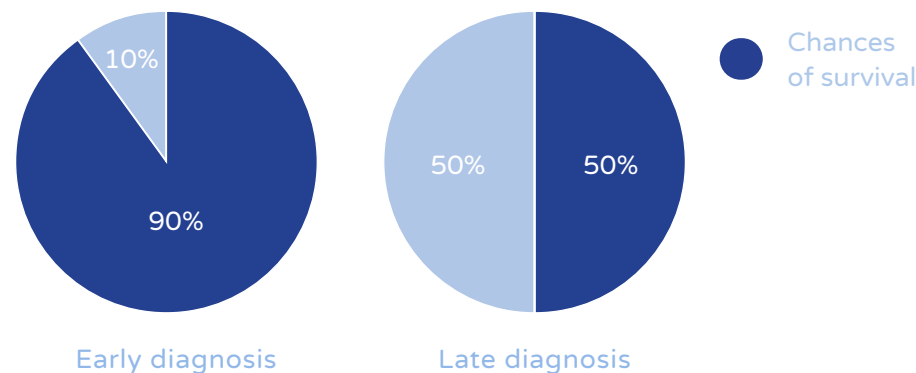
Mortality, survival and early detection

An estimated 3,034 people lost their life to mouth cancer in the UK last year.^{3, 11-13} That's seven people each day.

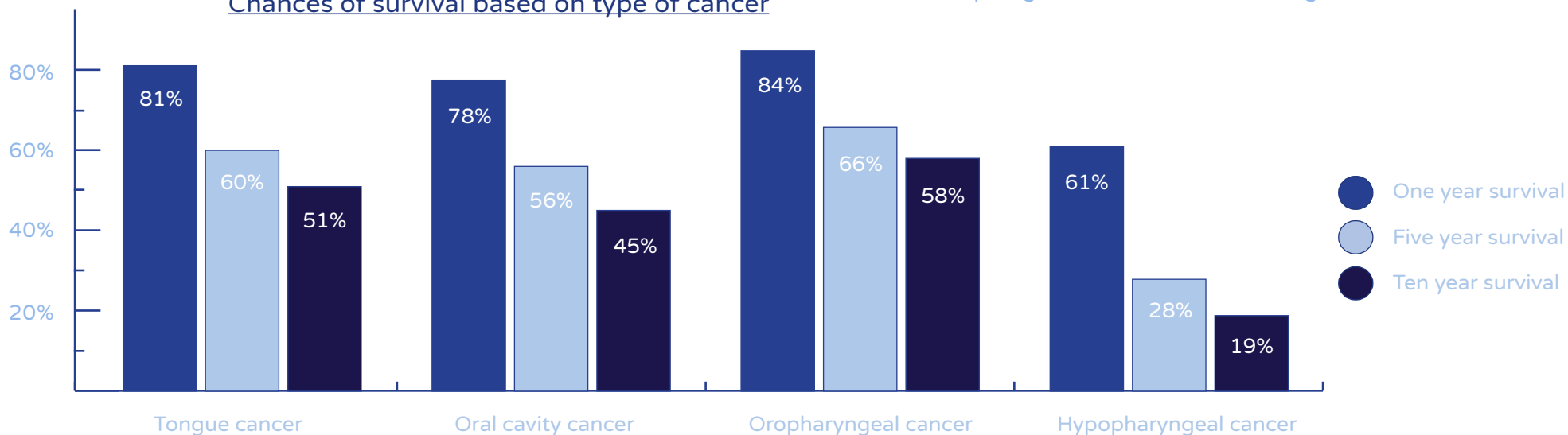
Spotting mouth cancer early is crucial for beating the disease. Early detection boosts our chances of survival from 50% to 90%.¹⁴

Depending on where the cancer strikes, the one year survival rate for mouth cancer is between 60% and 86%. This drops to between 19% and 59% after 10 years.¹⁴

Chances of survival based on early and late diagnosis



Chances of survival based on type of cancer



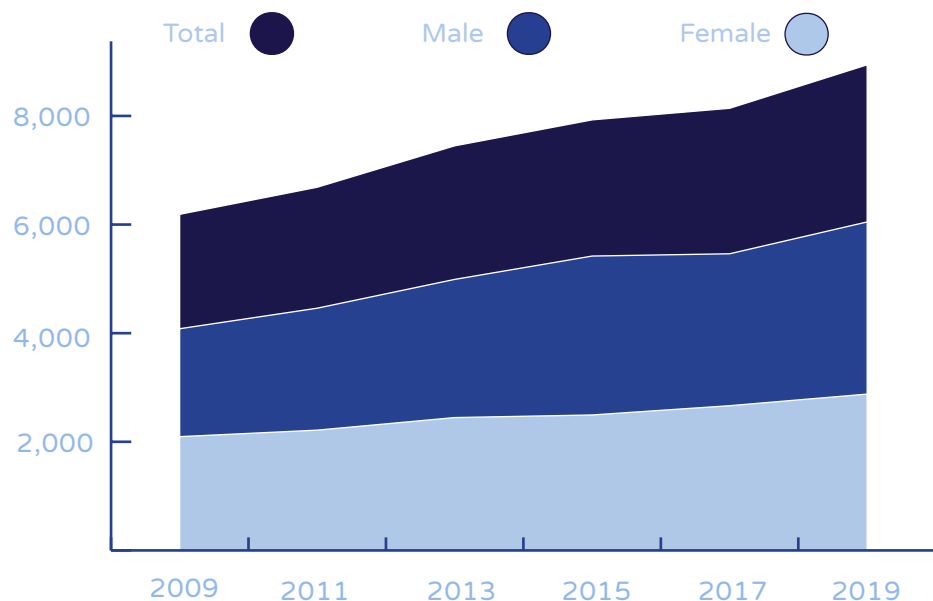
Trends over time

The number of people diagnosed with mouth cancer in the UK continues to increase.

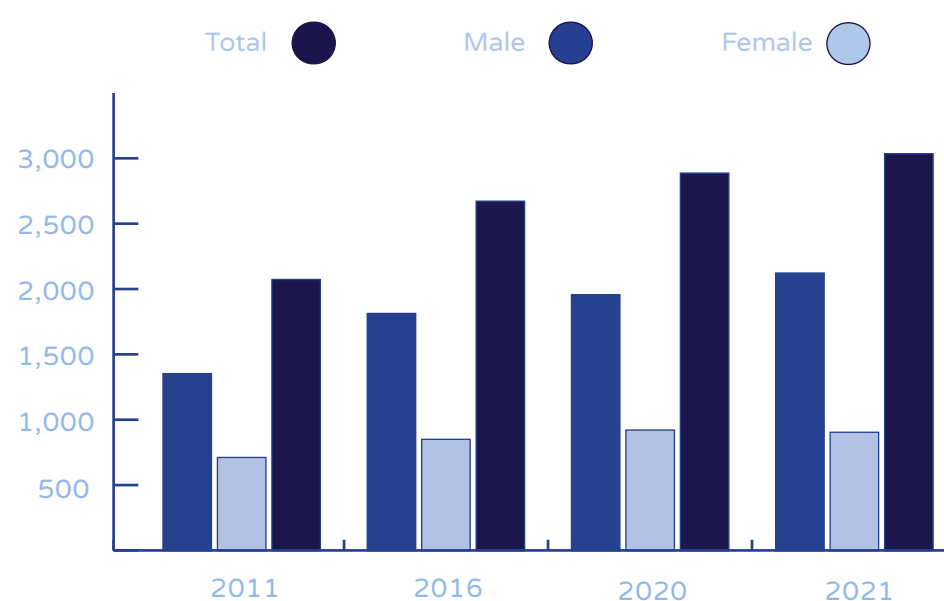
According to the latest annual data, new cases have increased by 1% in the UK. Data shows that mouth cancer cases have risen by 34% over the last decade and by 103% over the last 20 years (England data only).¹

Sadly, the number of people losing their life to mouth cancer has also grown. The latest research says that deaths from mouth cancer have increased by 75% compared with ten years' ago.¹¹

Mouth cancer incidence in the UK | Year-on-year



Mouth cancer deaths in the UK | Ten-year comparison



Chapter two

Research into awareness

Our knowledge about mouth cancer

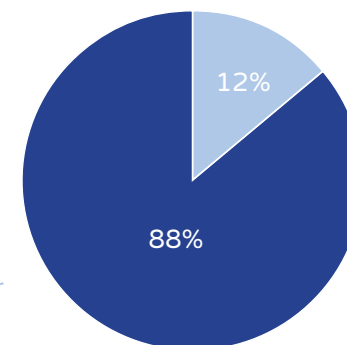
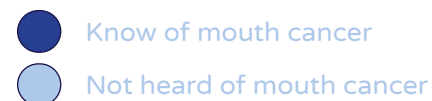
The latest research from the Oral Health Foundation suggests that awareness of mouth cancer is improving.

Almost nine-in-ten (88%) British adults have now heard of mouth cancer. This has increased significantly compared to 10 years ago (65%).¹⁵

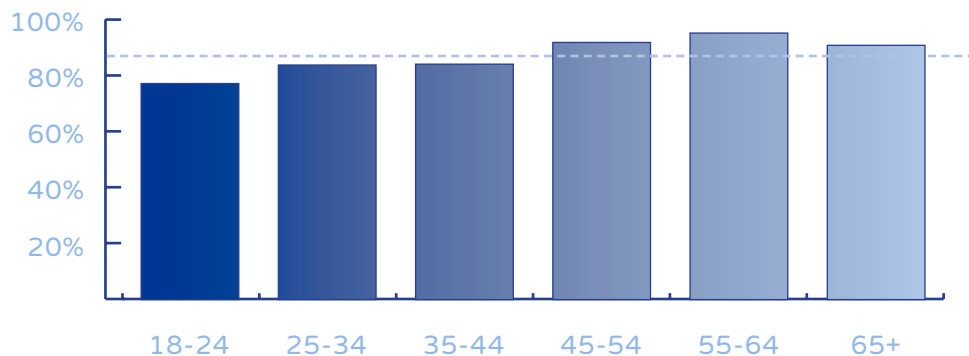
Mouth cancer awareness is generally higher in women, than men.¹⁵

Awareness of mouth cancer improves as we get older. Knowledge of mouth cancer is as much as 21% higher in the over-65s compared with young adults.¹⁵

How many of the UK population has heard of mouth cancer ¹⁵



Awareness of mouth cancer in the UK by age ¹⁵



More than one-in-four (26%) adults under-34 are unaware that cancer can occur in the mouth. This is significantly lower than the national average.¹⁵

As few as one-in-20 (5%) of the adult population have a reasonable understanding about the prevalence of mouth cancer. People are six times more likely to underestimate how common the disease is.¹⁶

Education about mouth cancer also seems to be extremely hard to come by. The majority (80%) of the population cannot recall ever seeing any public health messages around mouth cancer and only around one-in-seven (15%) recall being exposed to information about the disease in the last year.¹⁷

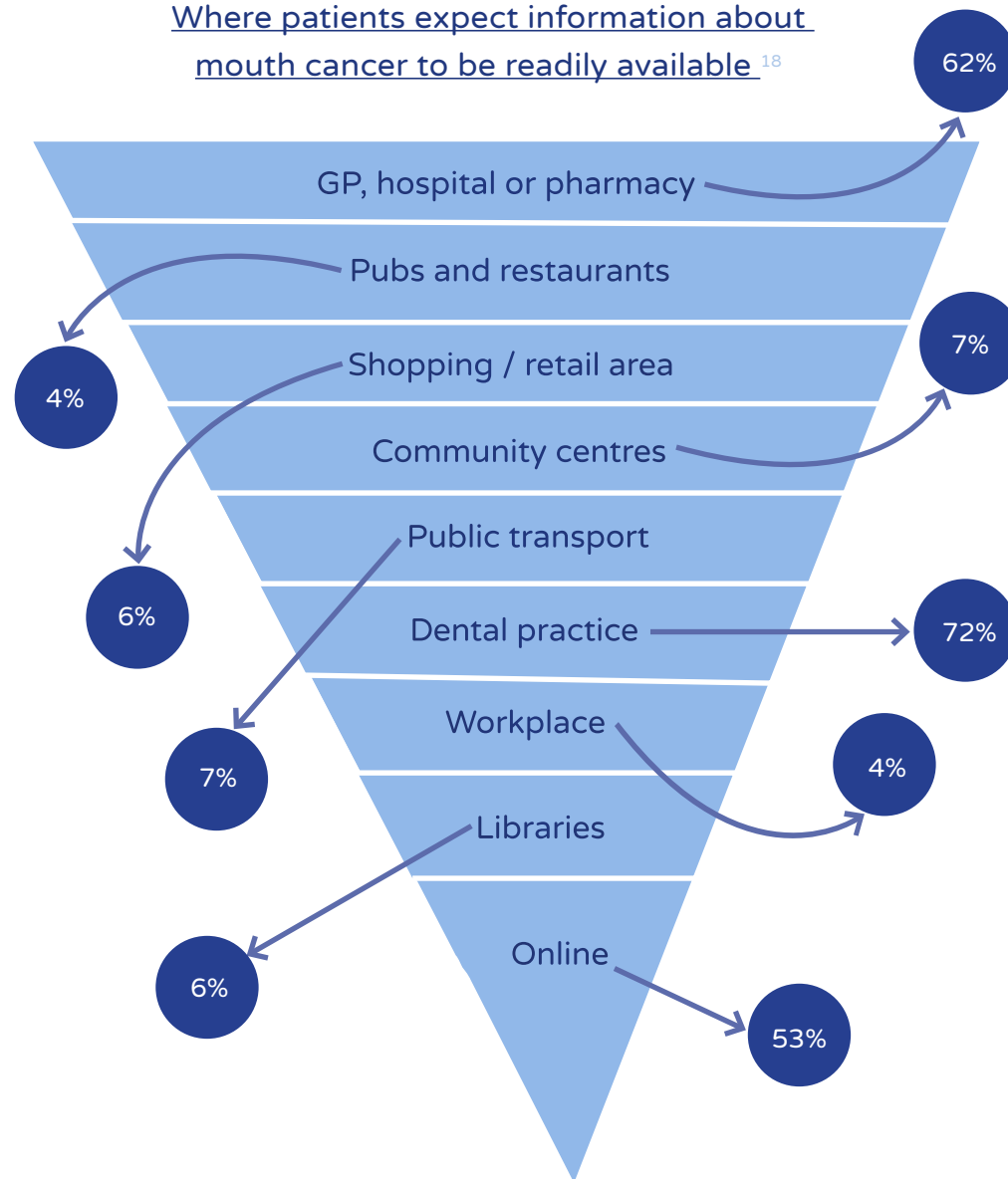
In Scotland and Wales, where incidence rates are highest, nine-in-ten (90%) adults claim they have not seen any education or awareness materials on mouth cancer.¹⁷

An investigation into awareness within occupational health settings reveals only one-in-three employers (33%) provide their workforce with information about health and wellbeing.¹⁷

Out of these, very few give advice and materials about smoking and smoking cessation (13%), the dangers of alcohol (11%), a healthy diet (8%), and the importance of regular dental visits (11%). Each of these could help either reduce the incidence of mouth cancer or help in early detection of the disease.¹⁷

There seems to be a strong demand for more information about mouth cancer amongst the general public. Two-in-three (66%) UK adults want to understand more about the disease and have access to materials that will help them be more clearly informed.¹⁷

Where patients expect information about mouth cancer to be readily available¹⁸



Signs and symptoms

Almost half (49%) of UK adults do not know that long lasting mouth ulcers can be an early warning sign of mouth cancer.¹⁸

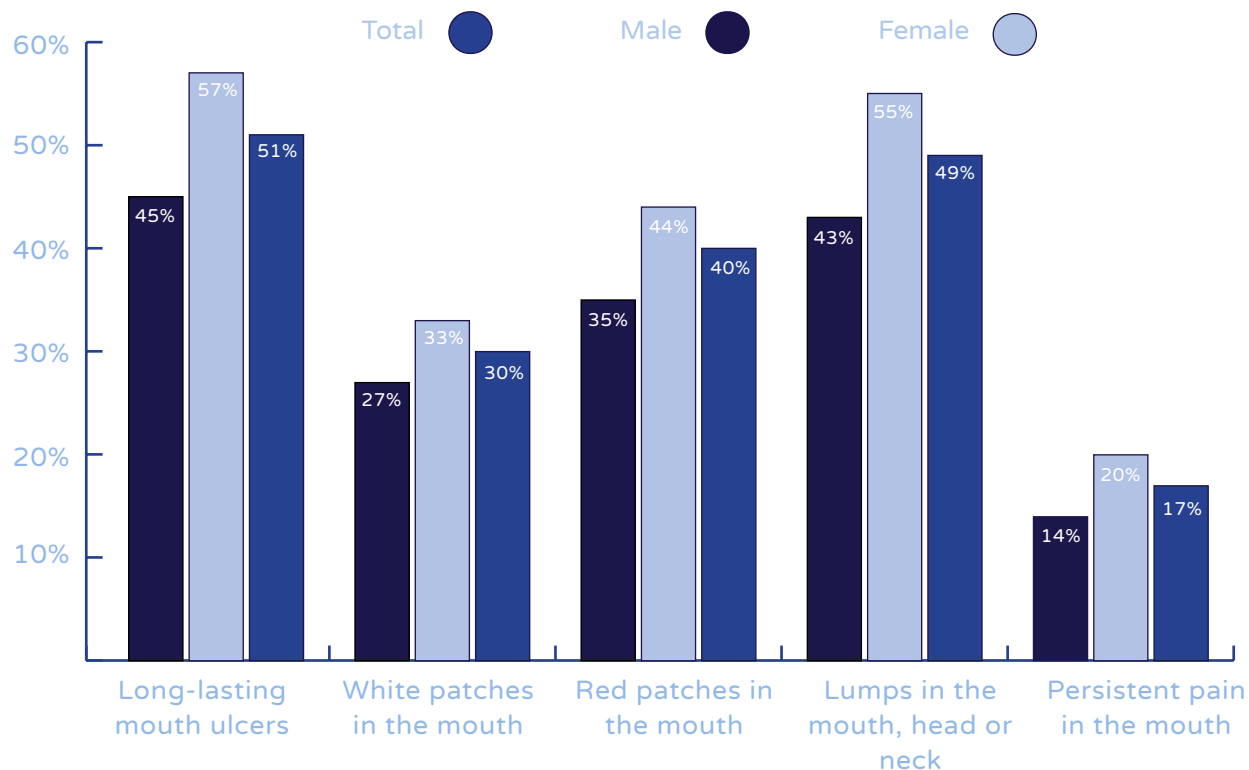
Only a third (30%) identify white patches in the mouth as a possible sign and more than two-in-three (70%) of UK adults do not know that white patches in the mouth, or a loss of taste, could be a sign of mouth cancer.¹⁸

Half (51%) do not realise that lumps in the mouth, head and neck are a symptom of the disease, however, only one-in-five (17%) suspect persistent hoarseness as a sign.¹⁸

A little over half (56%) know that mouth cancer can appear on the tongue and the gums.¹⁸

Almost three-in-four (73%) of UK adults are unaware that mouth cancer can appear on the tonsil. Nearly half of UK adults do not know that mouth cancer can appear on the gums (41%), cheeks (44%), roof (44%) and floor (48%) of the mouth, or the back of the throat (46%).¹⁸

The UK's awareness of the major signs and symptoms of mouth cancer¹⁸



Self-examinations and dental visits

One of the most important factors for early diagnosis of mouth cancer is self-examination at home. The other is to maintain regular dental visits, where visual mouth cancer checks are done as part of the routine check-up.

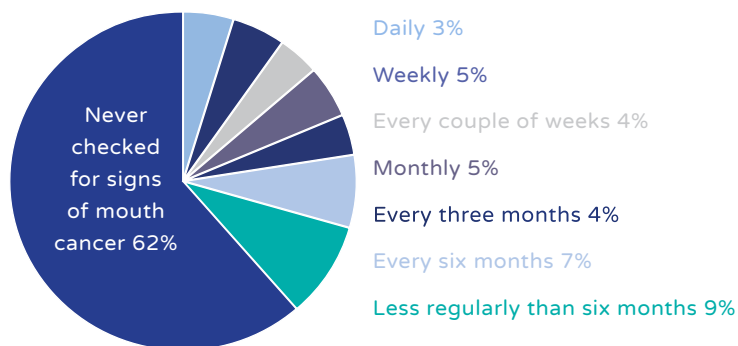
Given the lack of awareness about the symptoms, it is not surprising that nearly two-in-three (62%) have never checked their mouth for signs of cancer.¹⁸ As few as one-in-five (19%) conduct a quick check once a month.¹⁸ Most people (83%) are either not confident about what they are looking for, or do not know what to look for at all. The population are around three times more likely to conduct routine self checks for testicular and breast cancer than for mouth cancer.¹⁷

More work needs to be done to connect mouth cancer to oral health. The number of people who know that a dentist looks for mouth cancer during a dental appointment is low (47%).¹⁸

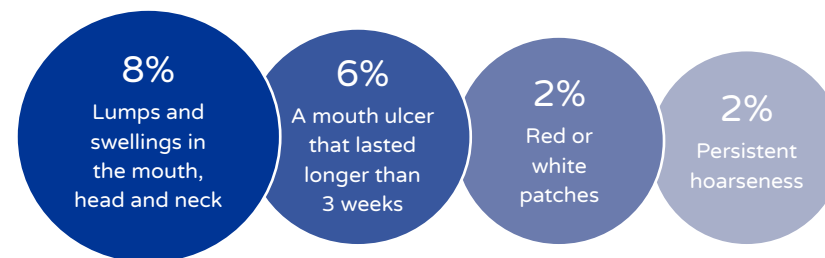
Over half of UK adults (51%) have been unable to see or get advice from their dentist about recent problems and issues with their mouth.¹⁸

Since the start of the pandemic, there have been an estimated 40 million postponed or cancelled appointments. During this time, around one-in-five (18%) people have experienced at least one of the potential early warning signs of mouth cancer and have been unable to seek professional help.¹⁸

How often British adults check their mouth for signs of cancer¹⁸



The % of UK patients with problems linked to mouth cancer who have been able to access a dentist¹⁸



Risk factors

In the UK, awareness of the most common risk factors associated with mouth cancer is poor.

Most British adults know that smoking (65%) can cause mouth cancer. Just over a third (35%) identify excessive alcohol as a risk factor of mouth cancer.¹⁸

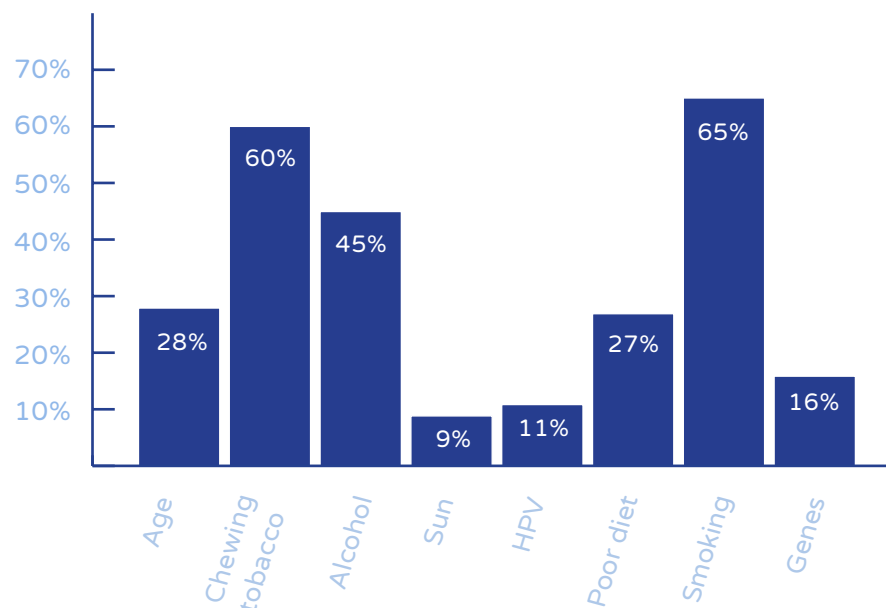
Crucially, awareness of risk factors is low among those who smoke and drink alcohol to excess. Almost half (45%) of cigarette smokers do not know that smoking causes mouth cancer. And, of those who exceed government guidelines of 14-units of alcohol a week, more than a third (65%) do not know that excessive alcohol use is linked to mouth cancer.¹⁹

Four-in-ten (40%) of UK adults don't know that chewing tobacco causes mouth cancer, and 88% are completely unaware of the risks around chewing betel nut.¹⁸

Awareness is also poor for other risk factors, including the human papillomavirus (11%), diet (27%) and sun exposure (9%).¹⁸

Women have a greater understanding about the risk factors associated with mouth cancer compared to men, while awareness over the causes generally improves with age.¹⁸

The number of UK adults who are aware of the major risk factors and causes of mouth cancer¹⁸



UK smoking status

Cigarette smoker	15%
Vaper	6%
Ex-smoker	25%

UK weekly alcohol intake

Non-drinker	25%
Up to 14 units	59%
More than 14 units	21%

Chapter three

Real life stories

Charlotte's story

At 26 years old, Charlotte was given the life-changing news that she had mouth cancer.

The ex-cabin crew member, now training to be a midwife, does not fit the typical mouth cancer patient – being a young woman who's a non-smoker and an active gym goer. But Charlotte represents a growing number of younger people who are being diagnosed with mouth cancer.

Charlotte says: "I had some ulcers for about three to four years before I had my [mouth cancer] operation.

"I wasn't worried about them at first because I do get run down. I was jet-lagged and flying all the time with my job and often ulcers are sign of celiac disease, which I have, so I put it down to that. They came and went but always in the same area, they never fully went but they used to flare up like if I was run down.

"They felt like ulcers do, but just a bigger patch and they started to turn white, and they had like red around them as well, so they looked quite like inflamed.

"I thought maybe it was a bit of an infection or something. My mum kept telling me to go and get it checked so I went to my doctor who sent me for a biopsy.

"I went in for the results, and he asked, 'have you got anyone with you today?' I looked at him and said, 'it's not good is it?' he replied 'no, it's not. I'm really sorry, you've got cancer'. I remembering saying to him 'what do you mean? Surely not.' and I think I almost laughed. It was such a shock because I'm otherwise a healthy person.

"There is a stigma against mouth cancer, I was told 'oh, you're too young', 'God it won't be that'. It really can happen to anyone, not just smokers because that's such a stigma – it really annoys me. People think you have to be like a really old man that smokes 50 a day, but you don't."

“ It took this tiny little poster in the clinic for me to say to myself ‘oh my God, that’s mouth cancer’ and by then it was too late.”

Charlotte, Mouth Cancer Survivor



David's story

It was in the wake of his 50th birthday that David Cowan first noticed something was wrong.

A journalist from Dundee, David always felt he was in pretty good shape. He made a conscious effort to keep active and he didn't smoke. And even though he enjoyed a drink in moderation, cancer was far from being on his radar.

Unfortunately, that all changed.

The father-of-two first noticed a small lump on his neck, about the size of a grape.

It was painless but thankfully, David was clued up enough to know that, when it didn't go away, he should get it checked out.

David was diagnosed with tonsil cancer. Speaking about his diagnosis, David says: We were astonished. I was terrified. I was upset, thinking about the kids and our family."

Thankfully however, he had caught it in the early stages. This gave him the best possible chance of beating the disease.

"With cancer, it's inevitable you will have bad weeks but it's important to hold strong and tell yourself that it won't last forever, and you will get better.

"I decided to put my faith in the experts and radiographers. I decided to trust them and put myself in their care. I took all the help that was offered and waited to be fixed. In the end, it all happened as they said it would happen."

Six months later and after radiotherapy, David was given the all clear.

"I'm physically still trying to build my energy up," David adds.

"I lost my sense of taste during the treatment. It's almost back to normal but unfortunately, I still struggle with strong curries and whisky! It did take a big toll on me mentally. It's changed how I think."



“On the upside, I appreciate things in life a lot more now.”

David, Mouth Cancer Survivor

Chapter four

Developing policy

The role of policy in reducing incidences of mouth cancer

Health policy refers any decisions, strategies or actions which have specific health care goals within a society.

In the UK, health policies focus on our priorities and health care needs as a population. They should be chosen and delivered with a long term vision in mind and aim to shape the population's health in a positive way.

Incidence of mouth cancer can be significantly reduced by introducing appropriate health policy. The Oral Health Foundation does not only believe in catching mouth cancer early, our charity wants to prevent mouth cancer from occurring altogether.

Policies that can reduce cases of mouth cancer require support and buy-in across government, health and development partners, civil society and the private sector. By making better use of all available resources for health – we can make strides to eliminate mouth cancer and live longer, healthier lives as a result.

There are several recent examples of policies in the UK that have, or will, reduce the number of people diagnosed with mouth cancer.

- The 2007 smoking ban has contributed to smoking levels falling from 22% to 14%. This number continues to reduce.
- Plain packaging on cigarettes and a ban on tobacco sports advertising have also been influential for fewer people smoking.
- Smoking in cars with children was made illegal in 2015 and will reduce levels of passive smoking - another contributor to mouth cancer.
- The HPV vaccination for girls in 2007 and boys in 2019, will protect 800,000 children a year from HPV-related cancers and diseases.
- In 2018, Scotland passed a bill on minimum pricing for alcohol. Scotland currently has the highest rates of mouth cancer in the UK.

Public support for new policies

The Oral Health Foundation took a series of new policy proposals to the general public. These focused on the three most common causes of mouth cancer; smoking, drinking alcohol to excess and HPV.

Some of the proposals would have a minimal impact on mouth cancer cases while others could significantly change the landscape of the disease.

All the proposals below are talking points for further discussion. It is important that thorough research and evidence-based support is undertaken before any of these are moved forward.

Potential new smoking policies	Public support
A complete and outright ban on smoking	74%
Raising the legal age of buying cigarettes from 18 to 21	63%
Smoking ban in houses with children	48%
Smoking ban in cars	66%
Smoking ban extended to include e-cigarettes	42%
Banning smoking outside where food is served	62%
Banning smoking outside next to children’s play areas	76%

Potential new alcohol policies	Public support
Raising the legal age of buying alcohol from 18 to 21	56%
A cap on how much alcohol people can buy in a single purchase	28%
Pubs to be stricter when serving people who have had too much alcohol	50%
Drinks manufacturers forced to lower the strength of their alcohol products	21%
Plain packaging for alcohol	13%
Drinking guidelines and recommendations on alcohol packaging	71%
Health warnings on alcohol packaging	39%
Having calorie labelling on all alcohol packaging	60%

Chapter five

The future

Six major challenges

1. The rising cost of living

In 2022, inflation in the UK reached a high of 10.1%. With people struggling to heat their homes or feed their families, many are being forced into unfair and unjust choices.

Findings by the Oral Health Foundation show that as many as one-in-five (23%) UK adults have avoided making an appointment at the dentist because of the rise in cost of living. This includes basic check-ups, treatments, as well as the expenses involved in travelling to the dentist. To bring in more household income, one-in-ten (11%) are now working more hours and are unable to find the time to attend the dentist.¹⁸

Rising costs are an increasing barrier to dental attendance – a critical avenue for early mouth cancer diagnosis, a better quality of life and surviving mouth cancer.

2. Dental access

A growing population, coupled with a dwindling NHS dental workforce is leading to a crisis in dental access. In England alone, the number of NHS patients seen in the last 24 months has declined by 26% compared to before the pandemic.²⁰

Those who find it more difficult to access dentistry often include the elderly, people with mobility difficulties, individuals in geographically isolated areas and those from minority ethnic backgrounds. Mouth cancer is strongly related to age and there are also a growing number of cases in South Asian communities.

Dental access is essential for timely referrals and early diagnosis for mouth cancer. Because of this, it is essential that more people are able to access NHS dentistry.

3. Late diagnosis

Late diagnosis of mouth cancer is all too common and has a severe effect on a person's quality of life and their chances of survival.

Nearly two-in-three (63%) patients are diagnosed in stages III and IV. Overall, just under half (53%) are diagnosed in stage IV, when the cancer is at its most advanced.²¹

Public awareness of the signs and symptoms remains exceptionally poor. Also, given the nature of mouth cancer, even health professionals have difficulty spotting the disease before visual symptoms present themselves.

4. The protection of public health policies

A large proportion of mouth cancers are linked to causes and could be prevented with a change in lifestyle choices.

The two of the most common and destructive risk factors linked to mouth cancer are tobacco and drinking alcohol. When combined, these two causes triple a person's mouth cancer risk.

For many people, tobacco use, and excessive alcohol intake is not a choice, it is an addiction. As a result, the government has a duty of care to protect the population from harm.

In recent months there have been worrying noises coming out of government regarding important public health policies such as Smokefree 2030 pledge. Diluting or removing such policies would be a disaster for mouth cancer rates.

5. HPV vaccinations

In the UK, schoolboys and schoolgirls are eligible for the HPV vaccination. The vaccine is the most effective route for protecting people against HPV cancers and diseases, including mouth cancer.

WHO have set a global coverage target of 90% for one dose, however, a newly published report shows the UK falls well short of that. School closures and child absences following COVID-19 has meant that coverage in some regions of the UK is as low as 67% (East of England).²²

The two-dose vaccination uptake has also decreased from 84% before the pandemic, to 57%. It means that 317,581 children in year 9 went without a second HPV vaccine dose last year while 147,337 have gone completely unprotected.²²

6. Tax on cancer

In addition to the overwhelming emotional and psychological impact that mouth cancer can have, survivors can also be challenged with several oral health issues. Chronic toothache, tooth loss and dry mouth are just some of the common problems that require long-term dental care.

Frequent dental treatment is often a necessity for mouth cancer victims. With NHS dental charges ranging from £23.80 to £282.80 in England, the recurring costs over the course of a year can soon mount up.

We estimate that mouth cancer sufferers can expect to pay up to £1,500.00 over five years for dental treatment, significantly higher than average.

Six key recommendations

1. Improving education and awareness

Despite the number of mouth cancer cases continuing to increase, mouth cancer awareness remains extremely low. Awareness around the causes of mouth cancer is as low as 9% while around half have no knowledge around the early warning signs.¹⁸

Mouth cancer receives little or no national attention when it comes to cancer awareness programmes. Future campaigns focusing on the risk factors and how to spot mouth cancer should receive greater support from policymakers, media outlets, celebrities and influencers.

This year, the Oral Health Foundation has become a founding member of two new coalitions – the Head & Neck Cancer UK Coalition and the HPV Coalition. With the support and backing of more like-minded organisations and charities, these coalitions have the ability to transform how much the public knows about mouth cancer.

2. Boosting HPV vaccine uptake

Coverage of HPV vaccinations in schools must increase in-line with, and even beyond that of, before the pandemic. With significant regional and local variations in uptake, there must be a priority towards increasing vaccination in populations with low coverage.

To help increase vaccination uptake, all parents of Year 8 and Year 9 children should receive information about HPV and the HPV vaccination, including when and how their child's vaccinations will take place. This information must also be made available to children and young people who do not attend schools (e.g., home schooling).

Invitations and reminders about the HPV vaccination must be sent out routinely. This could involve other health and social care providers that are in contact with the family to help gain consent where contact cannot be made through the school. Incentives for returning consent forms has also been proven to be successful for increasing vaccine uptake.

3. Free dental check-ups for mouth cancer patients

The current NHS dental contract arrangements do not allow all patients recovering from mouth cancer to receive free restorative treatment on the NHS. Many of these patients will have complex and expensive restorative needs for life.

This issue is made even worse by the fact that generally patients must pay for the privilege of asking their dentist for a potentially life-saving examination to detect the cancer in the first place.

In our opinion, there would be a public outcry if patients with any other type of cancer were asked to contribute to the cost of their reconstructive treatment and lifelong care.

It is an issue that needs to be put right to ensure that mouth cancer sufferers do not have the financial burden for returning their lives to normal and recovering from their condition, which often involves major facial surgery.

Free dental checks for mouth cancer patients after their treatment has strong support. Nearly four-in-five (78%) of the general public and nine-in-ten (90%) dental professionals support the proposals.^{17, 23}

4. Training for health professionals and carers

Many people are now seeing doctors and pharmacists about problems with their mouth. This includes symptoms of mouth cancer.

Mouth cancer is recommended Continuing Professional Development (CPD) for dental professionals but very little is taught about the disease in wider healthcare. Mouth cancer information and education should be routinely given to non-dental health professionals.

Care home, nursing staff and other carers must also be trained to look for signs of mouth cancer, in addition providing effective oral hygiene and oral health care and support.

5. Investing in NHS dentistry

NHS dentistry continues to perform a remarkable service, despite being continually underfunded by successive governments.

The current dental contract needs a major overhaul. Reforms to remove the current UDA payment system and replace with a capitation-based contract would go a long way in restoring NHS dentistry and making it fit for purpose.

There also needs to be a committed plan from government to address the workforce issue –the UK simply needs to train more dentists.

In the Autumn, Rishi Sunak vowed to restore NHS dentistry if he was made Prime Minister. He now must honour this pledge by increasing funding, encouraging dentists to stay part of the health service and having a much stronger focus on prevention.

6. Reinforcing health policies

Legislation is the most effective route for reducing incidence and mortality of mouth cancer.

There are a number of smoking and alcohol policies that could be adopted. The Oral Health Foundation supports an outright ban on smoking and urges the new Secretary of State for the Department of Health and Social Care, Steve Barclay, to prioritise public health by reinforcing tobacco control policies and alcohol legislation.

Smokefree 2030 must not be softened or abandoned while health warnings on alcohol packaging and minimum unit alcohol pricing should also be brought in.

We also recommend extending the powers of pharmacists, so they are able to issue referrals for mouth cancer.

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