

State of Mouth Cancer UK Report 2018/2019

A report by the Oral Health Foundation



Table of contents

Chapter one: about mouth cancer

| | |
|--|----|
| What is mouth cancer?..... | 4 |
| The impact of mouth cancer..... | 5 |
| The scale and scope of mouth cancer..... | 6 |
| Where mouth cancer appears..... | 7 |
| The causes and risk factors..... | 8 |
| Survival and early detection..... | 9 |
| Trends over time..... | 10 |

Chapter two: research into awareness

| | |
|--|----|
| Our knowledge about mouth cancer..... | 12 |
| Signs and symptoms..... | 14 |
| Self examinations and dental visits..... | 15 |
| Risk factors..... | 16 |

Chapter three: patient stories

| | |
|-------------------|----|
| Paul Roebuck..... | 19 |
| Laura Taylor..... | 20 |

Chapter four: the future

| | |
|-------------------------------|----|
| Five major challenges..... | 22 |
| Five key recommendations..... | 24 |
| References..... | 26 |

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

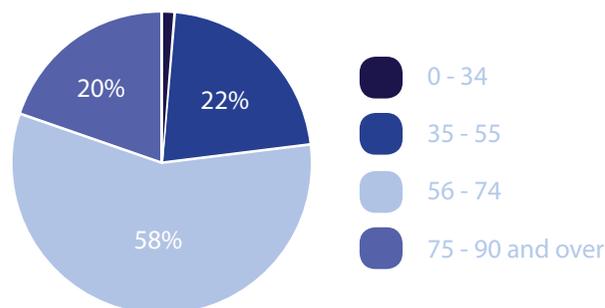
The latest figures show that more than 8,300 people in the UK are diagnosed with mouth cancer each year (8,302). The lifetime risk of mouth cancer currently stands at 1-in-75 for men and 1-in-150 women.¹⁻⁴

Mouth cancer now accounts for just over 2% of all cancers.⁵

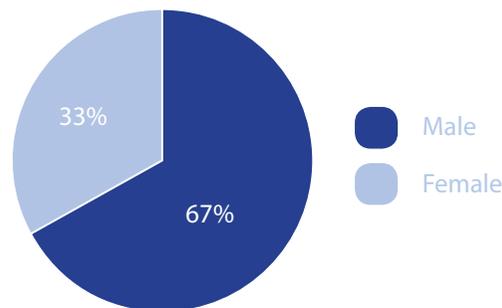
Statistics suggest that men are more likely to have mouth cancer than women. More than two-thirds (67%) of all mouth cancer patients are male.¹⁻⁴ Mouth cancer is now the 14th most common cancer in the UK. For men, mouth cancer is now the 9th most common cancer.⁵

Mouth cancer is also strongly-related to age. More than three in four (78%) of new cases are in those over the age of 55.¹⁻⁴

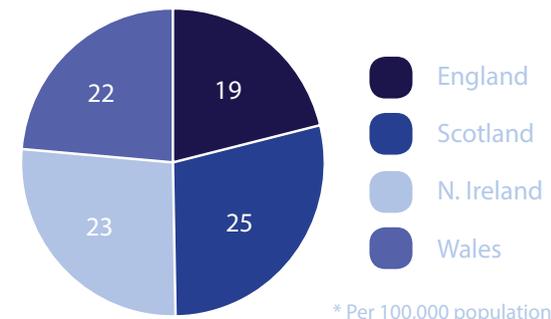
Mouth cancer in the UK by age



Mouth cancer in the UK by gender



Mouth cancer in the UK by AS rate*

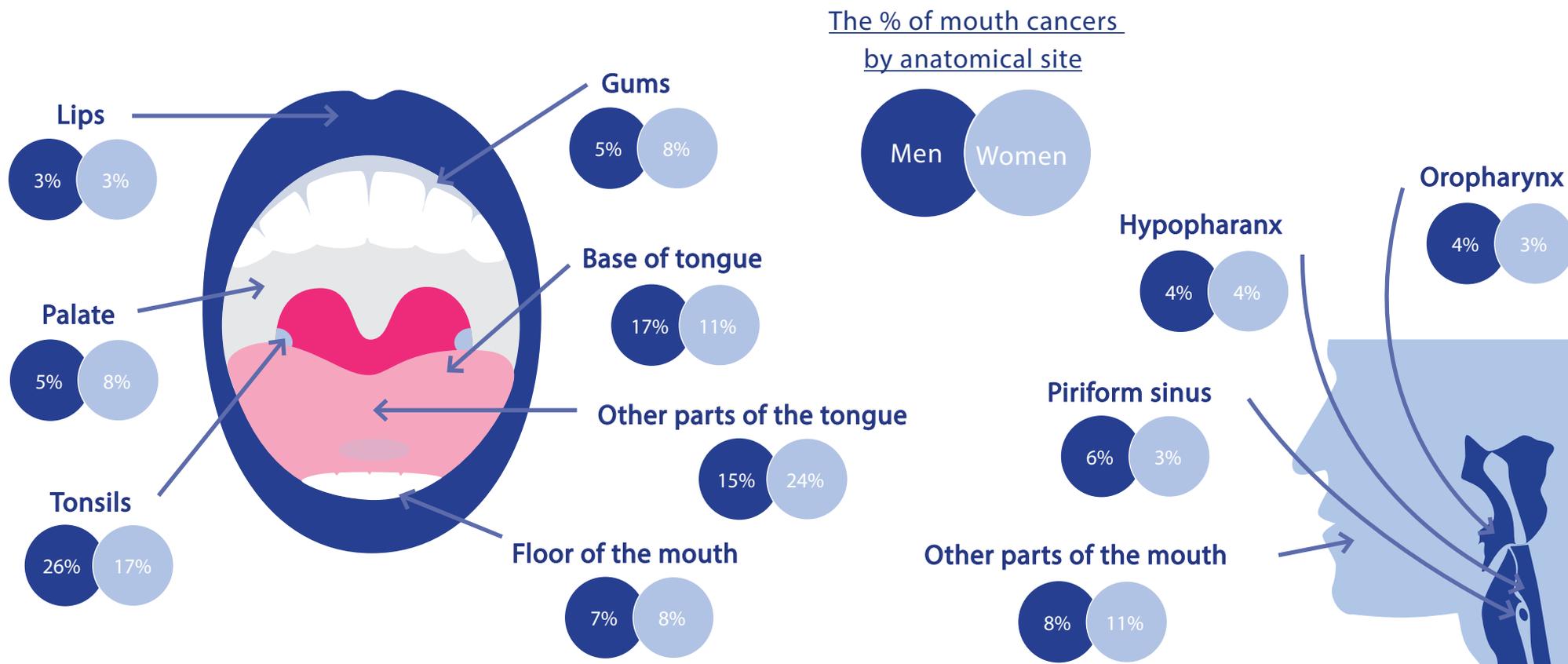


Living in areas of deprivation is also considered to significantly increase the risk of being diagnosed with mouth cancer. In England, mouth cancer rates increase by 135% for men living in the most deprived areas. For women, the increase is 45%.¹⁻⁴

Mouth cancer rates are higher in Scotland compared with the rest of the UK.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. Figures show that a higher number of cases are found on the tongue and tonsil areas, over half of cases (56%).¹⁻⁴



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 one in six (17%) oral cavity cancers are 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.⁷ Those who drink more than 10 units of alcohol a week could be increasing the risk of mouth cancer by 81%.

For those who heavily drink alcohol and also smoke, the risk increases by 30 times.

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, salted fish, formaldehyde, wood dust, over exposure to sunlight, environmental smoke.

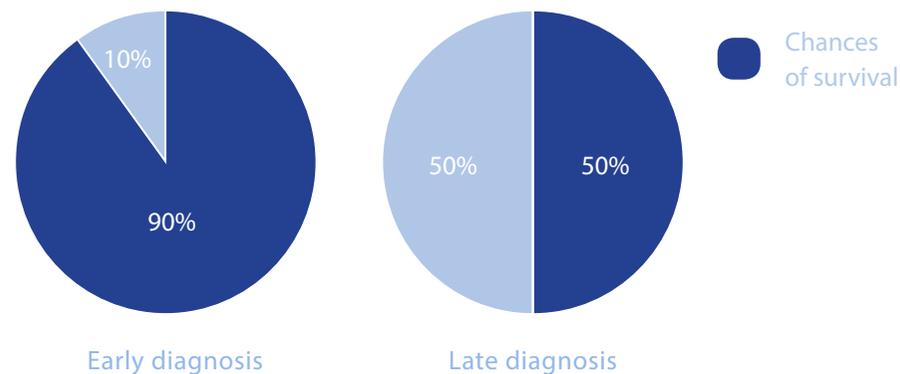
Survival and early detection

An estimated 2,722 people now lose their life to mouth cancer in the UK each year.⁸⁻¹⁰

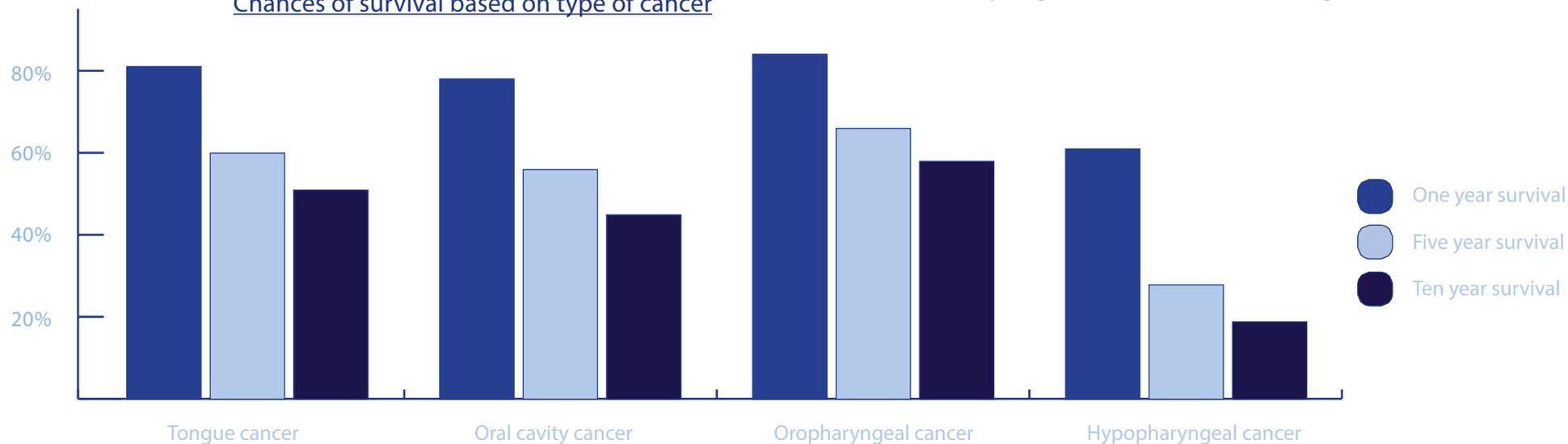
Spotting mouth cancer early is crucial for beating the disease. Early detection boosts our chances of survival from 50% to 90%.¹¹

Depending on where the cancer strikes, the one year survival rate for mouth cancer is between 60% and 83%. This drops to between 19% and 58% after 10 years.¹¹

Chances of survival based on early and late diagnosis



Chances of survival based on type of cancer



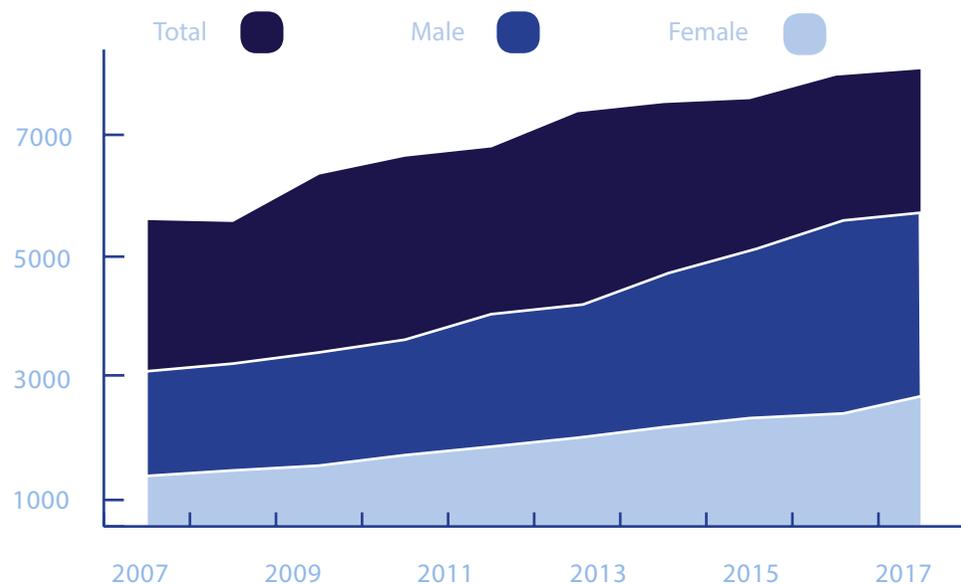
Trends over time

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

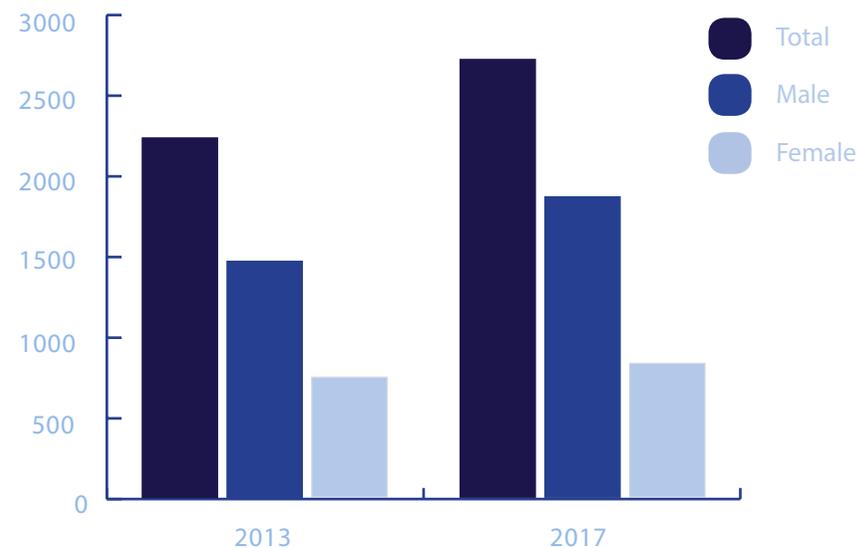
In the last decade, cases have risen by 49% in the UK.¹ Additionally, data shows that mouth cancer has increased by an astonishing 135% over the last 20 years (England data only).¹

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 22% compared with five years' ago.¹¹

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



Mouth cancer deaths in the UK | Five-year comparison



Chapter two

Research into awareness

Our knowledge about mouth cancer

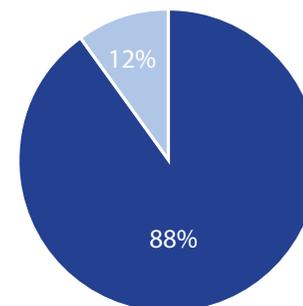
Research suggests that awareness of mouth cancer is improving. Almost nine in ten (88%) British adults have now heard of mouth cancer.

This has increased by almost 45% compared to a decade ago.

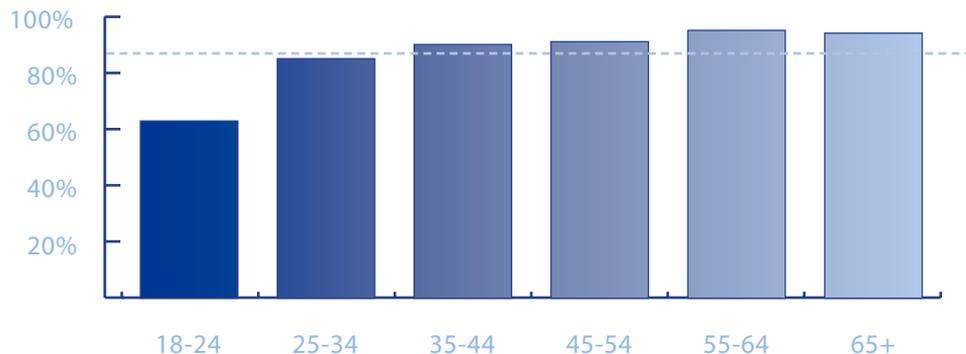
Despite this, and an increase in the number of people being affected by the disease, awareness of mouth cancer still remains relatively low when compared to other cancers.

How many of the UK population has heard of mouth cancer

- Know of mouth cancer
- Not heard of mouth cancer



Awareness of mouth cancer in the UK by age



Although awareness is improving, there is a concerning lack of mouth cancer knowledge in the under 24s. More than one in three (37%) 18-24-year-olds admit to not having heard of the disease.

With many more cases being seen in younger people, this outlook must change.

One in five (21%) of us know someone who has been diagnosed with mouth cancer. These are our parents, grandparents, sons, daughters, brothers, sisters, aunts, uncles, friends and co-workers. The people we are closest to.

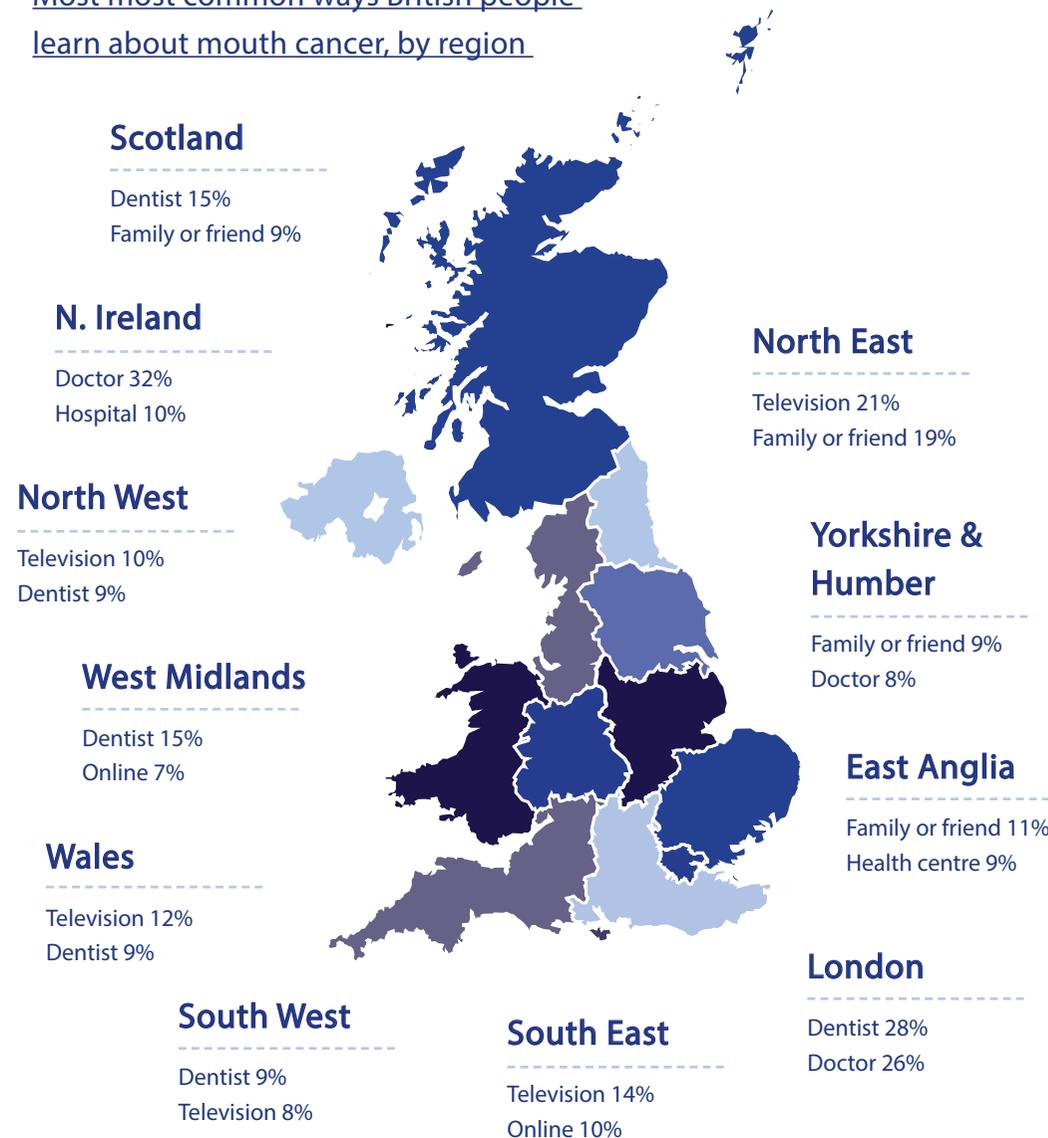
For four in five (80%) British adults, knowing someone with mouth cancer made them think about and assess their own risk.

Less than one in ten (8%) say they feel confident about their knowledge of the disease, including signs and symptoms, risk factors, and where to go if anything unusual is found.

Available information and education about mouth cancer also seems to be extremely hard to come by. Many (68%) do not recall seeing mouth cancer information displayed in dental practices, hospitals, pharmacies etc. A similar number (65%) cannot remember hearing about mouth cancer in other public channels e.g. newspapers, television and social media.

Those living in London are far more exposed to information about mouth cancer than other parts of the UK. People visiting dental practices and GPs in London are more than twice as likely to see mouth cancer education than those in the North East and Scotland. This increases to more than three times when compared to residents in Wales.

Most most common ways British people learn about mouth cancer, by region



Signs and symptoms

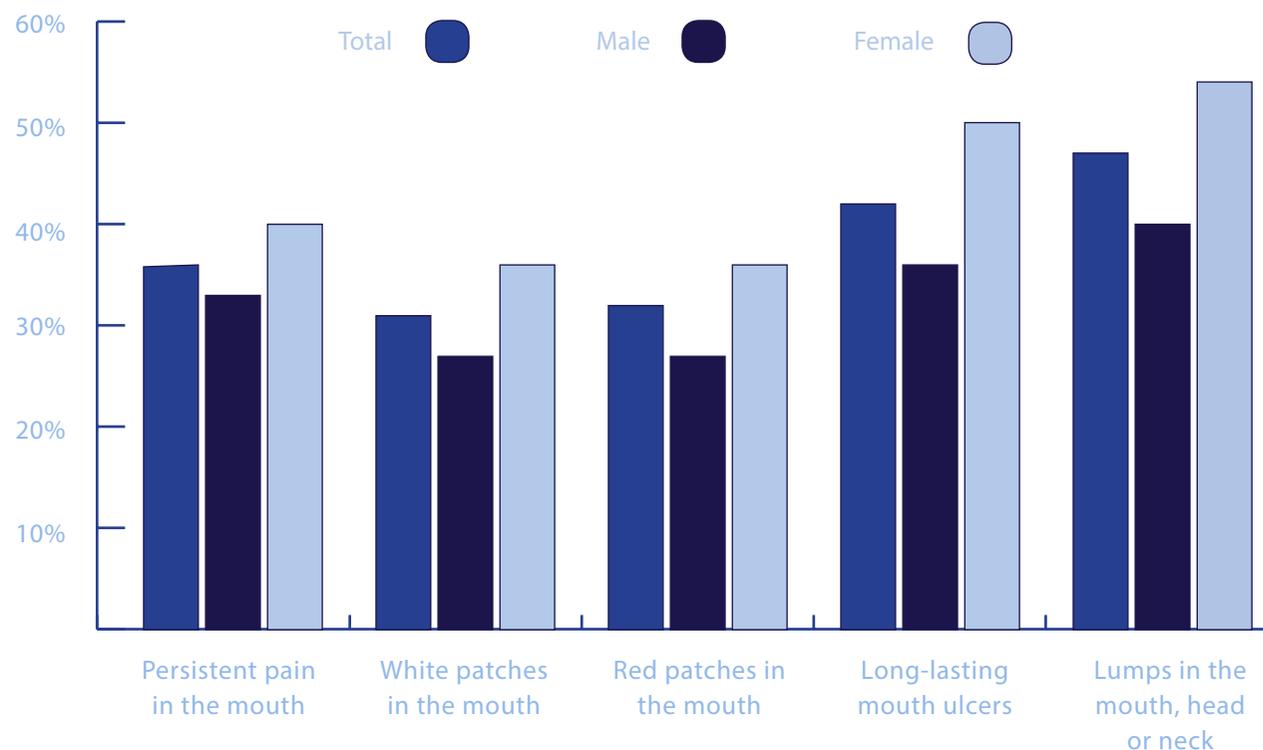
Three quarters (75%) of British adults cannot identify the major signs and symptoms of mouth cancer. More than a quarter (26%) are unable to name just one of the possible signs.

Almost half (47%) correctly identify lumps in the mouth as a symptom of mouth cancer while around four in ten (42%) are aware about the dangers of long-lasting mouth ulcers.

Ability to spot mouth cancer is far lower in men than women. Even more concerning, awareness is extremely low for those who have a higher risk of mouth cancer.

A little over half (53%) know that mouth cancer can appear on the tongue. Under half (46%) know to check the gums and around third (32%) know to look at the lips. Less than one in five (19%) and just over one in ten (11%), say that mouth cancer can appear on the neck and head, respectively.

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



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.

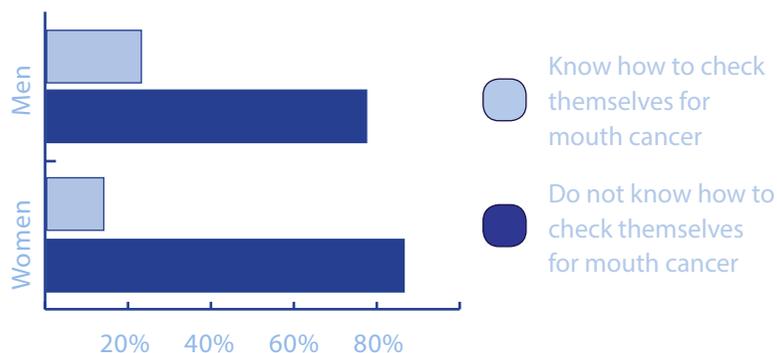
Given the lack of awareness about the symptoms, it is not surprising that more than four in five (82%) of us do not know how to check our mouth for signs of cancer.

If we become concerned about any unusual changes to the mouth, nearly two in three (63%) adults would make an appointment with our doctor while around one in four (28%) would choose to visit a dental professional.

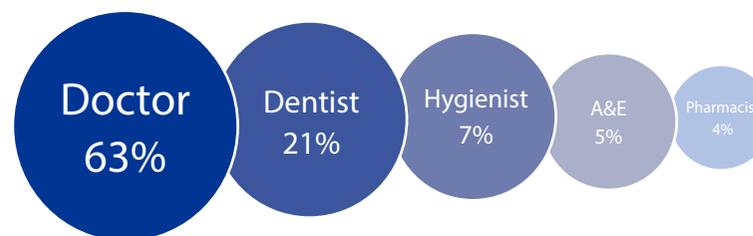
Perhaps that is because only one in four (25%) know that a dentist looks for mouth cancer during a dental appointment.

Just under three quarters (71%) of British adults have never spoken to a dentist about mouth cancer. Less than one in five (17%) say the dentist has brought up the subject of mouth cancer with us. Fewer than one in ten (9%) of us have directly asked about mouth cancer with our dentist.

More than four in five (84%) say we feel comfortable about bringing up the subject of mouth cancer with our dentist.



Who British adults would see if they noticed anything unusual in the mouth



Risk factors

Although mouth cancer is heavily linked to lifestyle choices, anybody can be diagnosed with the disease.

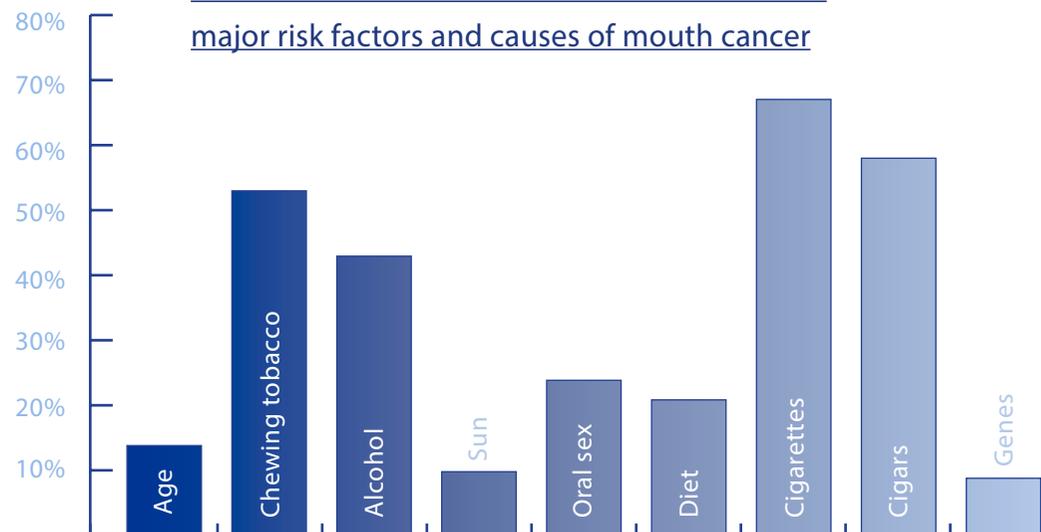
Despite this, two in three (68%) of us do not consider ourselves to have any potential risk. This feeling is more common in Scotland (81%), even though mouth cancer cases per population here are the highest in the UK.

The majority of British adults know that smoking cigarettes (67%), cigars (58%) and chewing tobacco (53%), are causes for mouth cancer. Fewer than half (43%) identify alcohol as a risk factor of mouth cancer. Awareness is less for oral sex (24%), poor diet (21%) and sun exposure (10%).

There is evidence to show that men are less aware of the major causes. For example, 76% of women link smoking with mouth cancer, compared with 59% of men.

In terms of doing the things that could increase our risk of mouth cancer; more than three in four (77%) British adults consume alcohol at least once a week, and around one in seven (15%) smoke cigarettes.

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



UK smoking status

| | |
|------------------|-----|
| Cigarette smoker | 15% |
| Vaper | 6% |
| Ex-smoker | 23% |

UK weekly alcohol intake

| | |
|---------------|-----|
| 1- 4 units | 29% |
| 5 - 9 units | 22% |
| 10 - 14 units | 14% |
| 15 - 19 units | 7% |
| 20+ units | 6% |
| Non-drinker | 23% |

Chapter three

Patient stories



“If you have any doubts,
go and see your dentist,
today. Please.”

Paul Roebuck

Paul Roebuck

Hearing you have cancer is one of the most harrowing experiences a person can have. For Paul Roebuck, it was hearing he may never be able to talk again. Paul (56), a psychotherapist and mind coach from Stratford, has dedicated his life to helping people – something he takes immense pride from.

Last year, while on holiday in Las Vegas with his wife, Kieren, he woke up one morning to find blood in his mouth. On his return to the United Kingdom, Paul immediately sought medical attention.

Paul recalls: “She (the dentist) took one look in my mouth, the look on her face will stay with me forever. She was horrified.”

Mere months later, Paul was faced with the prospect of a mouth cancer diagnosis.

He had one burning question to ask the room full of specialists, who then gave him the news that shook him to his core.

“They told me that you should prepare yourself to be unintelligible,” Paul adds.

Those who are diagnosed with mouth cancer often have challenges with communication. It can lead to feelings of isolation with loved ones and friends. But for Paul, speaking to people was also his life’s work.

It was a day that Paul will always remember and soon later, the father of two underwent surgery to remove the effected area of his tongue.

“I knew something was wrong a few years ago and I just waited and waited. Had I gone years earlier when I should have, I reckon I would have more of my tongue to hold on to. If you have any doubts, go and see your dentist, please, today.”

“She (the dentist)
took one look in my
mouth, the look on
her face will stay
with me forever. She
was horrified.”

Laura Taylor

Many people believe that mouth cancer is a 'old man's disease'. Laura's story serves as a cruel reminder that mouth cancer does not discriminate. We are all at risk.

One year ago, Laura noticed a lump under her tongue and immediately made an appointment with her doctor.

Beforehand, Laura did some research and found her symptoms were similar to that of a mouth cancer patient, so she posed a scary question to her doctor.

'Could it be mouth cancer?'

Sadly, she was laughed at and told "you're 23, you cannot get mouth cancer".

It took six more visits for Laura to be finally referred to a specialist who diagnosed her with cancer of the tongue in November 2017.

Laura says: "The whole point of my story is EARLY DIAGNOSIS is key! Check your mouth. If you notice anything abnormal get it checked out, visit the dentist more.

"Age is just a number. I'm 23-year-old non-smoker and don't drink alcohol, yet I still got mouth cancer. It only takes 45 seconds to check your mouth, do it!".



"I was only 23, I should be hearing about my son's day at nursery, not cancer."

Laura Taylor

Chapter four

The future

Five major challenges

1. Lifestyle choices

A large proportion of mouth cancers are linked to risk factors and could be prevented with better lifestyle choices.

Despite heavy government investment in education-based campaigns, smoking and excessive alcohol consumption remains too high.

British adults are eating less fruit and vegetables than 10 years ago and around three in four do not have their 'five-a-day'.¹³

There is also a lack of research into the long-term effects of e-cigarettes, an avenue which has proved successful for smoking cessation.

2. 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 (62%) patients are diagnosed in stages III and IV. Overall, just under half (45%) of all mouth cancers are diagnosed in stage IV, when the cancer is at its most advanced.¹⁴

Public awareness around 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.

3. Dental access

Despite the vast improvement in access of dental care, certain groups in the UK still struggle to seek the help they need.

Those who struggle with access to dentistry include the elderly, people with mobility difficulties, individuals in geographically-isolated areas and those from ethnic backgrounds.

Mouth cancer is strongly-related to age and there are also growing cases in South Asian communities.

Greater access for these groups is a severe challenge in addressing late diagnosis of mouth cancer.

4. On-going costs associated with mouth cancer

A study carried out by the Oral Health Foundation has found cancer diagnoses leaves us 'afraid', 'concerned', 'scared' and 'angry', with financial worries playing a significant role in these feelings.¹⁵

Mouth cancer survivors are usually left with permanent and complicated oral health side-effects because of their cancer treatment.

This often leads to expensive dental treatment which they are expected to finance themselves. We estimate that mouth cancer sufferers pay £1,500.00 over five years, more than five times the average.

5. HPV vaccinations

In July 2018, the Joint Committee on Vaccination and Implementation (JCVI) recommended that British boys be included in the national HPV vaccination programme.

Since then, Scotland, Wales and England have all announced their plans to go ahead but there has been no verdict in Northern Ireland.

A swift and effective implementation is required across UK governments and a positive decision must be reached in Northern Ireland.

There remains poor public awareness of HPV and its role within mouth cancer. This could affect the rate of take-up.

Five key recommendations

1. Education and national exposure

Despite the number of cases continuing to increase, mouth cancer receives little-to-no national attention when it comes to raising awareness of cancer.

Future campaigns focusing on the risk factors and how to spot mouth cancer must receive greater support.

Broadcasting agencies and media outlets have a responsibility to share messages around mouth cancer, and other lesser-known cancers.

Channel 4's Stand Up To Cancer, ITV's Real Full Monty, soap operas and celebrity editions of quiz shows, are all effective at raising the profile of cancer. These platforms need a greater representation of mouth cancer.

2. Community dentistry

There is a need for improved access and investment in community dental services across the whole of the United Kingdom.

There is a growing elderly, multicultural and homeless population, all at higher risk of mouth cancer. These groups have the right to access dental services.

Central government and local authorities can reduce health inequalities and late mouth cancer diagnoses by introducing more mobile dental clinics, home visits, as well as visits in nursing and care homes.

The current services that exist must be more widely signposted.

3. Free dental work 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.

4. Training for health professionals

A growing number of people are seeing doctors and pharmacists about problems with their mouth. This includes symptoms of mouth cancer.

Mouth cancer is core 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 and nursing staff must also be trained to spot for signs of mouth cancer, in addition to being effective in oral hygiene education.

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.

5. HPV catch up programme for boys

The Joint Committee on Vaccination and Immunisation (JCVI) has taken six years to recommend a gender-neutral HPV vaccination programme. During this time, more than two million British boys have gone unprotected and are at risk of HPV-diseases.

Following the implementation of the boys' HPV vaccine (hopefully in 2019), there must be a catch-up programme for those who have missed out. Campaign groups need to lobby together to make sure this happens quickly and effectively.

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For more information about mouth cancer and November's Mouth Cancer Action Month, please visit

www.mouthcancer.org
#mouthcanceraction



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