Jacob, 44, diagnosed with cancer of the larynx

THE RICH PICTURE

PEOPLE WITH HEAD AND NECK CANCER

WE ARE MACMILLAN. CANCER SUPPORT

Understanding the numbers, needs and experiences of people affected by cancer

2017 update

About this 'Rich Picture'

This document is a collation of the key available evidence about the numbers, needs and experiences of people affected by cancer.

Our aim is that the insight within this document will summarise the numbers, needs and experiences of people affected by cancer for Macmillan staff, cancer care professionals, volunteers and other interested parties. It includes data specific to the particular group who are the focus of this Rich Picture, as well as more generic information about all people affected by cancer where specific data are not available or where the information applies to all groups of people with cancer.

The Rich Picture is intended to be accessible to both clinical and non-clinical cancer support staff. Therefore the language and facts included are intended to cater for the information needs of both groups. We have included references to other documents to help with interpretation of some facts included, and a Jargon Buster of some technical terms is included in Appendix A. The information could be valuable in many ways:

- Adding weight and evidence to negotiations with partners and commissioners
- Providing evidence to support campaigning
- Enabling more effective marketing
- Inspiring and engaging supporters to give and do more
- Providing some insight into the lives of people with cancer

This document is not intended to:

- Be a comprehensive collation of all evidence on the group affected by cancer who are the focus of this Rich Picture
- Suggest or recommend that specific action should be taken

For simplicity, the year to which the data in this document relate and the sample size is not always shown in the main sections, however this is shown in the original data linked from the references section.

If you are short on time, a quick read of the summary on pages 2 and 3 will give you a brief outline of the rest of the content of this comprehensive document.

This 'Rich Picture' is one of a suite of documents. To access these documents please visit **www.macmillan.org.uk/Richpictures** or for further information please contact **evidence@macmillan.org.uk**

The legal bit

The information contained in this document is a summary of selected relevant research articles, papers, NHS data, statistics and Macmillan-funded research.

This document intends to summarise in a broad sense the numbers, needs and experiences of people with cancer, it is not an exhaustive systematic review that follows strict scientific community rules governing such types of review. However we have compiled the information using broad quality assessment criteria to ensure that the information presented in this document is largely representative and unbiased. It is worth noting that people with cancer have a very wide range of experiences; therefore the information presented here may not reflect the experiences or profile of everyone within the category presented.

Macmillan or any other organisation referenced in this document claim no responsibility for how third parties use the information contained in this document. We have endeavoured to include all the major data available to us as of July 2017, but a document of this nature (essentially a summary of a large body of evidence) inevitably goes out of date. Macmillan has sought external validation of this document from clinical experts and we aim to regularly update the content of this document.

There may be data that have been released that does not appear in this document and Macmillan is under no obligation to include any particular data source. Any medical information referred to in this document is given for information purposes only and it is not intended to constitute professional advice for medical diagnosis or treatment. Readers are strongly advised to consult with an appropriate professional for specific advice tailored to your situation.

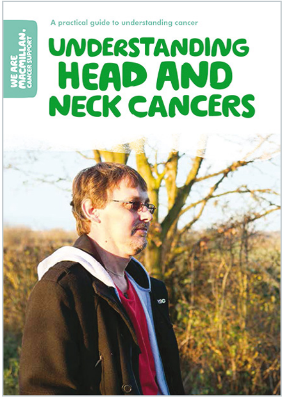
Contents ← →

Guidance on referencing this document

You are free to use any of the data contained in this document, however when quoting any factual data that do not belong to Macmillan, it is best practice to make reference to the original source – the original sources can be found in the References section at the back of this document on page 62.

Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experience of people with cancer. It is not designed specifically with people affected by cancer in mind, although some people within this latter group may find the information contained here helpful. People affected by cancer may find our information booklets more helpful:



Understanding head and neck cancers
MAC11652

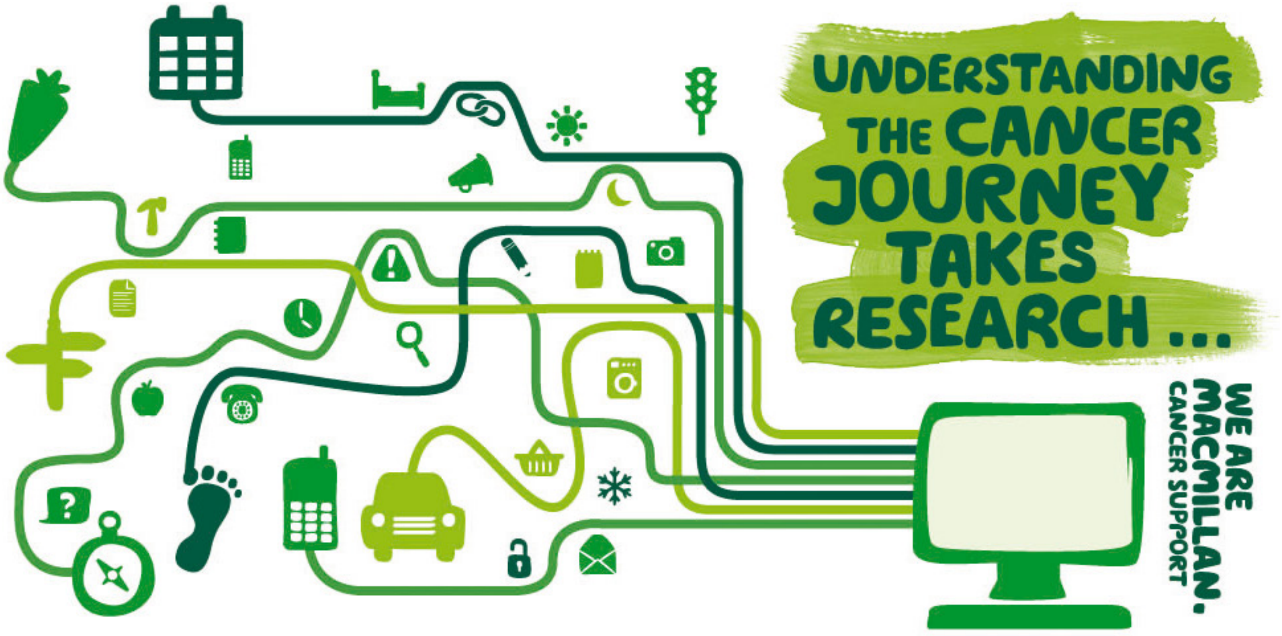
Managing the late effects of head and neck cancer
MAC14270

These titles are available in hard-copy by calling our Macmillan Support Line free on **0808 808 00 00** (Monday to Friday, 9am–8pm), or by ordering online at **www.be.macmillan.org.uk**

A wealth of other resources are also available, all produced by Macmillan Cancer Support and available free of charge.

Find out more about cancer: what Macmillan can offer

Macmillan's own evidence has revealed the story of cancer is changing. We produce a variety of evidence that helps us, and others, understand the needs, numbers and experiences of people affected by cancer.



Our research publications

Our reports and posters
Published Macmillan research and evaluation reports, as well as summaries of commissioned research and research posters, produced either by Macmillan or our partners.

Rich Pictures
Our suite of Rich Pictures describe the needs, numbers and experiences of key groups within the 2.5 million people living with cancer.

Impact Briefs
Our suite of Impact Briefs describe what some of our services do and the impact they have on people affected by cancer.

Our cancer intelligence

Local Cancer Intelligence tool (LCI)
Combining local cancer population data with insight from Macmillan and other sources, LCI is an online tool designed to help you use data as evidence to plan services and influence decisions.

Routes from Diagnosis
Results from first phase of the Routes from Diagnosis study, including outcome pathways, survival rates, inpatient costs and comorbidities associated with some cancers.

Cancer Patient Experience Survey
Macmillan's partnership work to gain insight on how patients feel about their care, what's working and what could be done better.

Contents

SUMMARY OF PEOPLE LIVING WITH HEAD AND NECK CANCER

Key stats

Head and neck cancer is the **eighth most commonly diagnosed** type of cancer, with over 12,000 new cases diagnosed in the UK in 2015.(2,3,4,5)

62,517 people are estimated to be living with head and neck cancer in the UK in 2015.(29)

Head and neck cancer is the **13th most common cause of cancer death**, causing over 3800 deaths in the UK in 2015.(8,9,10)

The lifetime risk of developing oral cancer (one of the cancers classified as head and neck) in the UK is estimated to be **1 in 75 for men** and **1 in 150 for women**.(105)

Laryngeal cancer (one of the cancers classified as head and neck) is much more common in males than in females. The lifetime risk of developing laryngeal cancer is around **1 in 175 for men** and **1 in 800 for women**.(105)

Diagnosis

76% of people with head and neck cancer in England say it took **less than three months** from the time they first thought something might be wrong with until they first saw a GP or other doctor.(26)

In a small qualitative study, the most common complaints reported by head and neck cancer patients preoperatively were pain, anxiety, lack of activity, mood swings and lack of vitality.(57)

A study looking at presentation for different cancers found that only **34% of patients with oropharyngeal cancer and 39% of those with oesophageal cancers presented promptly to their GPs** (within 14 days). This is lower than all other cancer types investigated in the study.(55)

83% of all cancer patients (not specifically head and neck cancer) are, on average, **£570 a month worse off as a result of a cancer diagnosis**.(48)

Treatment

Treatments for head and neck cancer can be damaging to nearby nerves and tissues. Therefore **preserving the function** of the area is very important. Treatments should be planned considering how they might affect how the patient talks, eats and breathes.(80)

Treatment for head and neck cancer can have severe side effects. A total of **53% of patients say their quality of life has decreased** following head and neck cancer diagnosis.(81)

In a small qualitative study, it was found that **pain, functional ability** (swallowing, chewing, speech, and so on), **and problems with social functioning**, were the most common symptoms related to treatment that interfered with patient's daily life after surgery.(57)

Approximately **45% of people with cancer (all cancers) have emotional needs but do not get enough support** for them.(79)

Life after treatment

Tiredness, lack of concentration and difficulties with speech, eating or breathing are barriers for head and neck cancer patients to return to work after treatment.(62)

A study found that amongst patients with head and neck cancer, **39% percent had depressive symptoms and 43% high levels of anxiety**. Also, 12% overall had high scores on the Acute Stress Disorder scale.(67)

Less than 23% of head and neck cancer patients in England said they were **definitely given enough care and help** from health or social services after treatment finished.(26)

Head and neck cancer patients have many psychological needs around **facing body changes as a result of treatment**.(49)

End of life

For head and neck patients with late stage disease, **good nursing care and palliative measures to help them eat and breathe** are crucial.(23)

Patients with head and neck cancer stated that their home was the preferred place of care as it allows them feel a **sense of normality whilst being close to family and loved ones**. However, certain barriers associated with being cared for at home included concern around the impact on family members.(89)

In **12%** of cases, doctors and nurses **did not give a relative or close acquaintance all of the information required** to provide care at home for the person living with cancer.(26)

Lifestyle & perceptions

Patients with cancer undergoing head and neck reconstruction can experience significant distress from **alterations in appearance and bodily functioning**.(54)

Receiving treatment in the area of head and neck can be particularly traumatising. In a 2016 qualitative study, participants reported traumatic responses to a diagnosis of head and neck cancer. These were linked to fear of treatment and potential physical debilitation resulting from it.(47)

INTRODUCTION TO HEAD AND NECK CANCER

What is head and neck cancer?(1)

Cancer can occur in any of the tissues or organs in the head and neck. There are over 30 different places in which cancer can develop in the head and neck area. The most commonly diagnosed head and neck cancers are:

- Cancers of the oral cavity
- Oropharyngeal cancer
- Cancer of the ear
- Cancer of the salivary gland
- Cancer of the eye
- Cancer of the voice box (larynx)
- Cancer of the thyroid gland

About 90% of head and neck cancers are of a type called squamous cell carcinoma. These start in the cells that form the lining of the mouth, nose, throat or ear, or the surface layer covering the tongue.

In rarer instances, head and neck cancers can also develop from other type of cells:

- Lymphomas develop from the cells of the lymphatic system.
- Adenocarcinomas develop from cells that form the lining of glands in the body.
- Sarcomas develop from the cells which make up muscles, cartilage or blood vessels.
- Melanomas start from cells called melanocytes, which give colour to the eyes and skin.

There are a number of risk factors that can increase the chance of developing head and neck cancer. These are:

- Gender – Head and neck cancers are more common in men than women.
- Age – Head and neck cancers are more common in older people.
- Smoking
- Drinking alcohol
- Long periods of exposure to the sun
- A poor diet
- Exposure to chemicals
- Human papilloma virus

Want to know more?

Macmillan produces a wealth of information about what head and neck cancer is, its causes, symptoms and treatment. To find out more, call our Macmillan team on the number below or visit our website.

At Macmillan, we know how cancer can affect everything. But you are still you. And we're here to help you live life no matter what. We'll give you the support you need to hold on to who you are and what's important to you.

From diagnosis, for as long as you need us, you can lean on Macmillan. Call us free on **0808 808 00 00** or visit **macmillan.org.uk**

Life with cancer is still life – we'll help you live it.

‘I was diagnosed with left vocal chord cancer in December 2011 […]. I had 18 months of remission but then in November 2013 the cancer returned to my left vocal chord. At this stage in my life I was married with two young children.

What happened next was a roller-coaster of information overload, life changing choices and major surgery within weeks. I had a partial laryngectomy (or hemi-laryngectomy, meaning removal of half the voice box) in December 2013.’

Jacob

KEY FACTS AND STATS ON HEAD AND NECK CANCER

This section presents some of the key stats and facts relating to people with head and neck cancer. You may benefit from referring to the jargon buster on page 69 for details on some of the terms used in this section. Please note that incidence and mortality data on all cancers exclude non-melanoma skin cancer.

33

cases of head and neck cancers diagnosed on average everyday in the UK in 2015(2,3,4,5)

62,517

people were estimated to be living with head and neck cancer in the UK in 2015(29)

85%

men in England survive their laryngeal cancer one year after diagnosis. This is one of the most common types of head and neck cancer(7)

67%

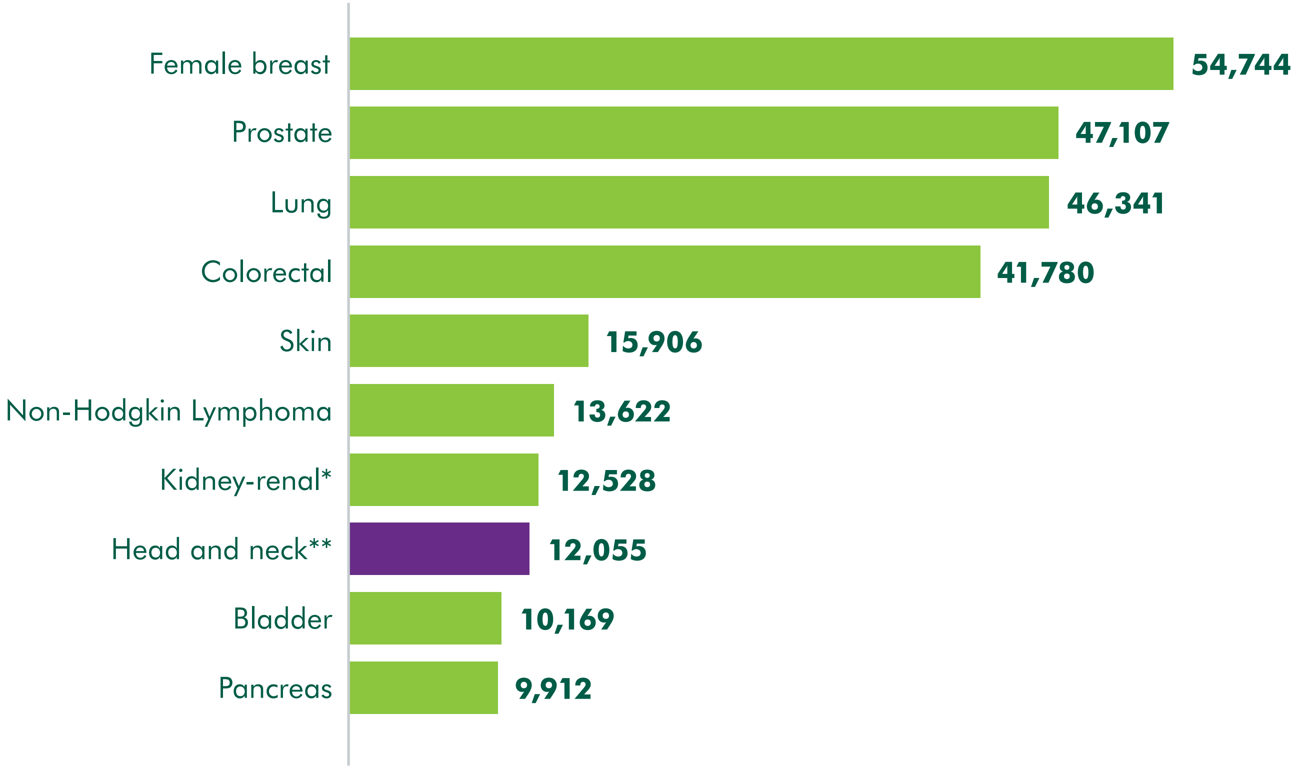
men in England survive their laryngeal cancer five years after diagnosis(7)

11

people, on average, died of head and neck cancer every day in the UK in 2015(8,9,10)

How many people get head and neck cancer per year? (incidence)(2,3,4,5)

Cancer incidence, UK, 2015, top 10 cancer sites

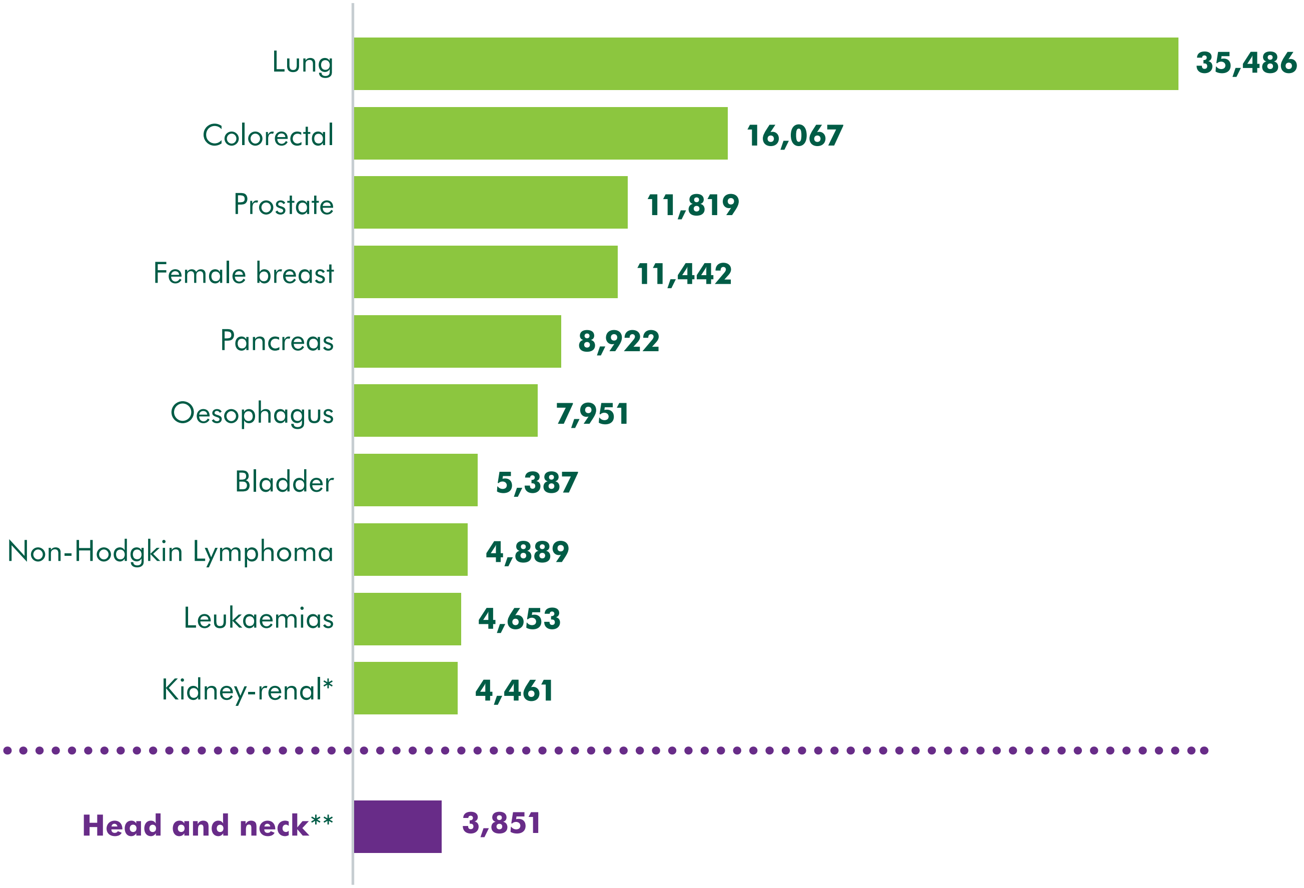


*Calculated using ICD-10 codes C64-66, C68.
**Calculated using ICD-10 codes C00-14, C30-C32.

Head and neck cancer is the eight most commonly diagnosed type of cancer, with over 12,000 new cases diagnosed in the UK in 2015.

How many people die from head and neck cancer per year?(8,9,10)

Cancer mortality, UK, 2015, top 10 cancer sites and head and neck cancer



*Calculated using ICD-10 codes C64-66, C68.
**Calculated using ICD-10 codes C00-14,C30-C32.

Head and neck cancer is the 13th most common cause of cancer death in the UK, causing over 3,800 deaths in 2015.

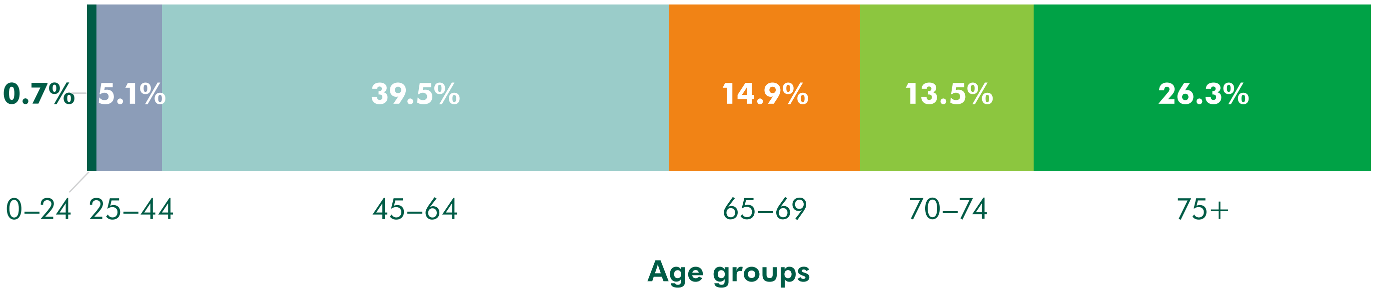
How many people are living with head and neck cancer? (prevalence)(29)

Prevalence, UK, 2015

People estimated to be living with head and neck cancer in the UK in 2015

62,517

20-year head and neck cancer prevalence in 2010 (based on age in 2010 for those diagnosed between 1991–2010), UK(29)



More than half of the head and neck cancer population is aged 65+.

What are the key stats for England?

See data on incidence, mortality and prevalence for England

How many people get head and neck cancer per year in England?(2)

9,722

new diagnoses in England in 2015

How many people die from head and neck cancer per year in England?(8)

3,058

deaths from head and neck cancer in England in 2015

How many people are living with head and neck cancer in England?(29)

50,359

people were living with head and neck cancer at the end of 2010 up to 20 years since diagnosis in England

What is the age-standardised* rate of head and neck cancer incidence in England?(11)

19

new cases of head and neck cancer per 100,000 population in England in 2014

What is the age-standardised* rate of mortality from head and neck cancer in England?(15)

6.3

deaths from head and neck cancer per 100,000 population in England in 2014

*Age-Standardised Rates are used to eliminate the variation in the age structures of populations to allow for fairer comparisons between incidence and mortality rates in different areas (in this case in the four different UK nations). The Age-Standardised Rate is a rate that has been weighted using a standard population (in this case the European Standard Population 2013) to control for differences in populations. Age-Standardised incidence and mortality rates have been expressed here as rates per 100,000 head of population.

What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland

How many people get head and neck cancer per year in Scotland?(3)

1,283

new diagnoses in Scotland in 2015

How many people die from head and neck cancer per year in Scotland?(9)

452

deaths from head and neck cancer in Scotland in 2015

How many people are living with head and neck cancer in Scotland?(6)

7,094

people were living with head and neck cancer at the end of 2010 up to 20 years since diagnosis in Scotland

What is the age-standardised* rate of head and neck cancer incidence in Scotland?(12)

25.3

new cases of head and neck cancer per 100,000 population in Scotland in 2015

What is the age-standardised* rate of mortality from head and neck cancer in Scotland?(16)

9.2

deaths from head and neck cancer per 100,000 population in Scotland in 2015

*Age-Standardised Rates are used to eliminate the variation in the age structures of populations to allow for fairer comparisons between incidence and mortality rates in different areas (in this case in the four different UK nations). The Age-Standardised Rate is a rate that has been weighted using a standard population (in this case the European Standard Population 2013) to control for differences in populations. Age-Standardised incidence and mortality rates have been expressed here as rates per 100,000 head of population.

What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales

How many people get head and neck cancer per year in Wales?(4)

688

new diagnoses in Wales in 2015

How many people die from head and neck cancer per year in Wales?(8)

203

deaths from head and neck cancer in Wales in 2015

How many people are living with head and neck cancer in Wales?(6)

3,366

people were living with head and neck cancer at the end of 2010 up to 20 years since diagnosis in Wales

What is the age-standardised* rate of head and neck cancer incidence in Wales?(13)

22.4

new cases of head and neck cancer per 100,000 population in Wales in 2015

What is the age-standardised* rate of mortality from head and neck cancer in Wales?(17)

6.8

deaths from head and neck cancer per 100,000 population in Wales in 2015

*Age-Standardised Rates are used to eliminate the variation in the age structures of populations to allow for fairer comparisons between incidence and mortality rates in different areas (in this case in the four different UK nations). The Age-Standardised Rate is a rate that has been weighted using a standard population (in this case the European Standard Population 2013) to control for differences in populations. Age-Standardised incidence and mortality rates have been expressed here as rates per 100,000 head of population.

What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland

How many people get head and neck cancer per year in Northern Ireland?(3)

362

new diagnoses in Northern Ireland in 2015

How many people die from head and neck cancer per year in Northern Ireland?(9)

138

deaths from head and neck cancer in Northern Ireland in 2015

How many people are living with head and neck cancer in Northern Ireland?(6)

2,064

people were living with head and neck cancer at the end of 2014, up to 22 years since diagnosis in Nothern Ireland

*Age-Standardised Rates are used to eliminate the variation in the age structures of populations to allow for fairer comparisons between incidence and mortality rates in different areas (in this case in the four different UK nations). The Age-Standardised Rate is a rate that has been weighted using a standard population (in this case the European Standard Population 2013) to control for differences in populations. Age-Standardised incidence and mortality rates have been expressed here as rates per 100,000 head of population.

What is the age-standardised* rate of head and neck cancer incidence in Northern Ireland?(12)

27.1

new cases of head and neck cancer per 100,000 population in Northern Ireland in 2015

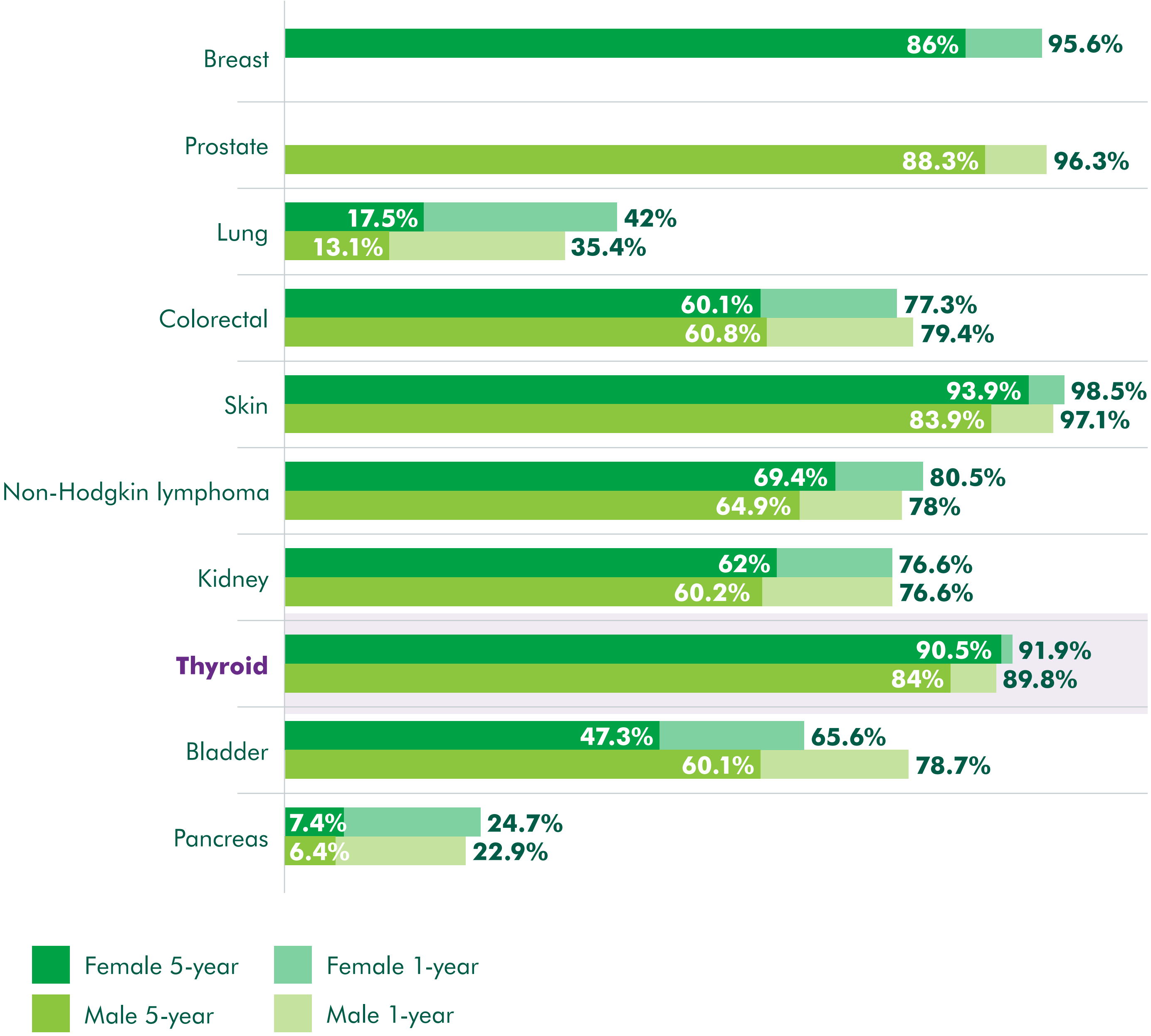
What is the age-standardised* rate of mortality from head and neck cancer in Northern Ireland?(16)

8.8

deaths from head and neck cancer per 100,000 population in Northern Ireland in 2015

How many people survive one and five years after their cancer diagnosis? (survival)(7)

1-year and 5-year age-standardised net survival for the most commonly diagnosed cancers, England, 2011–2015.

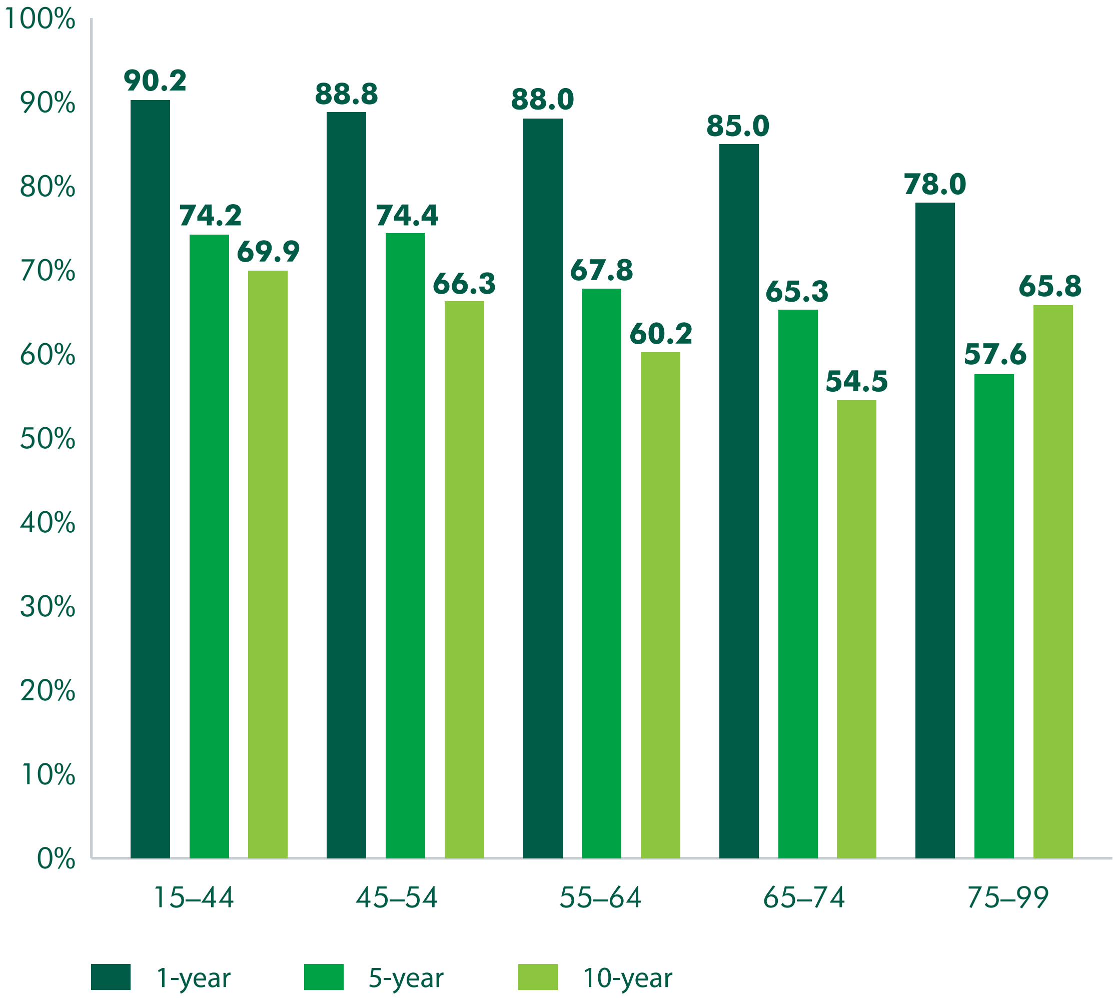


Thyroid cancer (one of the cancers classified as head and neck) has one of the highest 1-year survival rates, with around 92% of women and 90% of men surviving at least one year after their diagnosis.

Looking at the most commonly diagnosed cancers, thyroid has the smallest difference between 1- and 5-year survival rates for both men and women. This suggests that many patients who survive their cancer at least one year are likely to survive also five years post-diagnosis.

How does survival vary with age?(7)

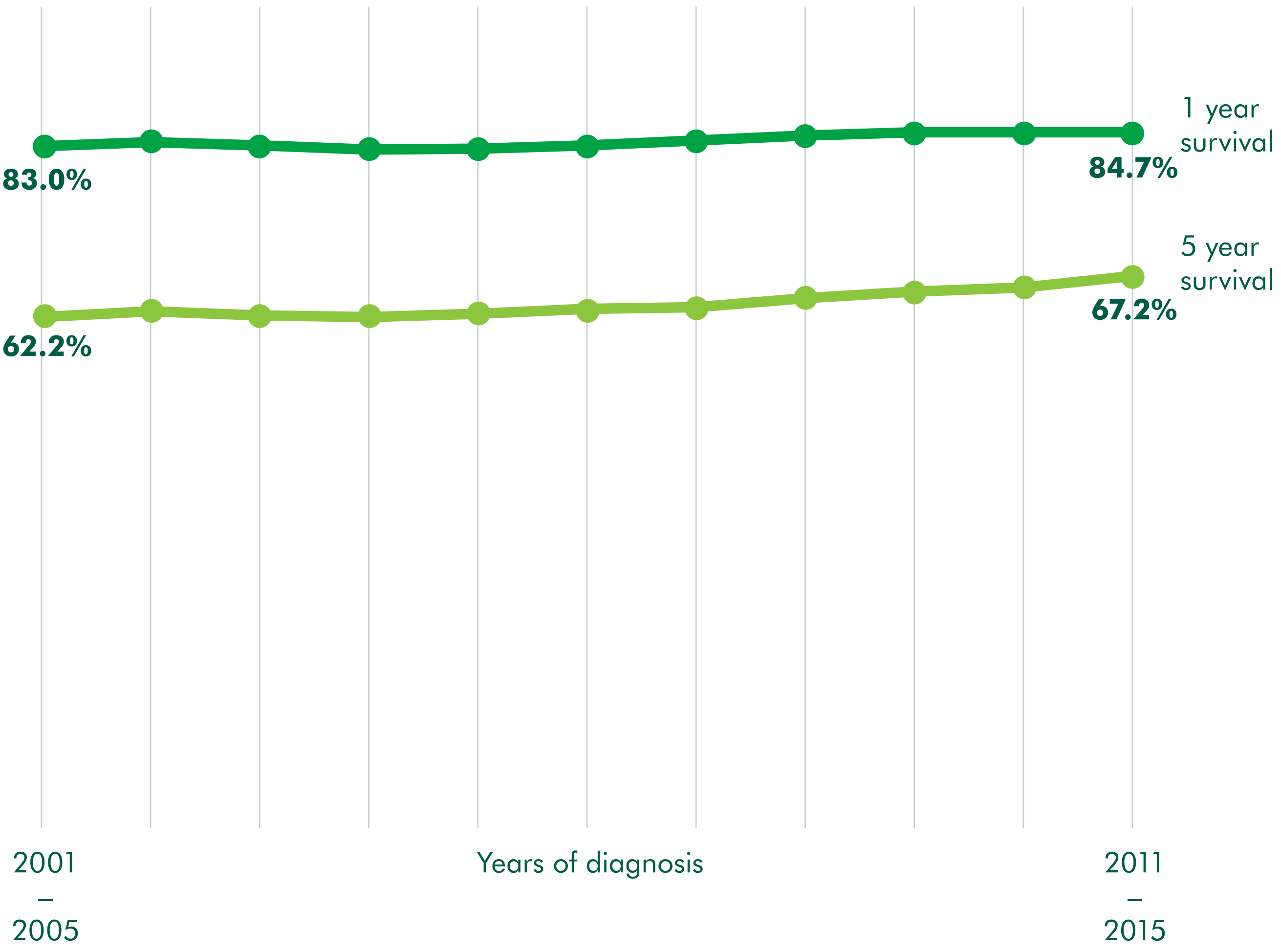
1-, 5- and 10-year age-standardised predicted net survival (%) for men (aged 15 to 99 years) who would be diagnosed in 2016 with laryngeal cancer, England



Predicted survival rates by age show that 5- and 10-year rates for men diagnosed with laryngeal cancer overall decrease with age.

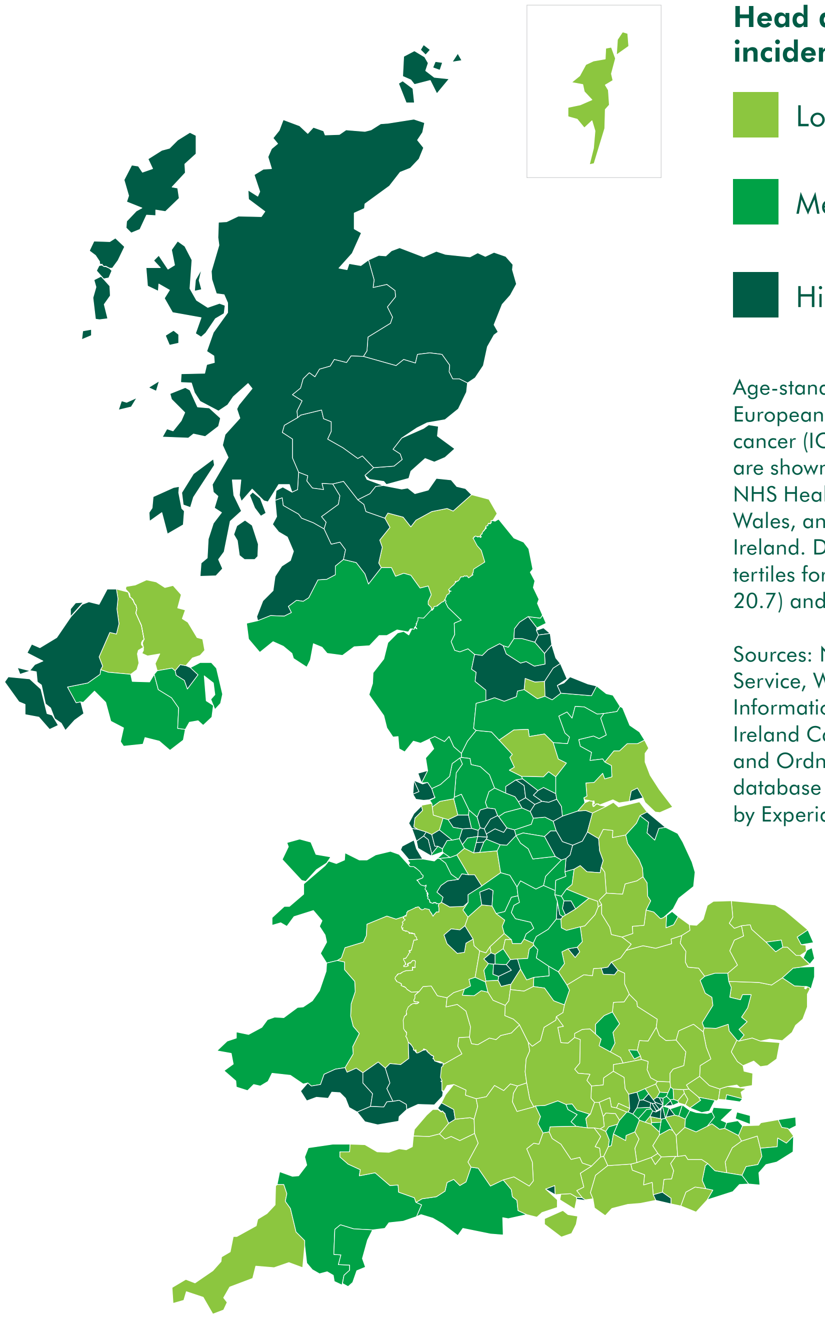
How has survival of laryngeal cancer changed over time?(7)

1-year and 5-year age-standardised net survival rates between men diagnosed in 2001–2005 and 2011–2015, England



In general, both 1-year and 5-year survival rates have increased for laryngeal cancer over the years. 67.2% of men diagnosed between 2011 and 2015 now survive their laryngeal cancer five years after diagnosis. This is higher than for men diagnosed between 2001–2005 (62.2%).

Thematic maps – distribution of head and neck cancer incidence in the UK



Head and neck cancer incidence, UK, 2010–2014

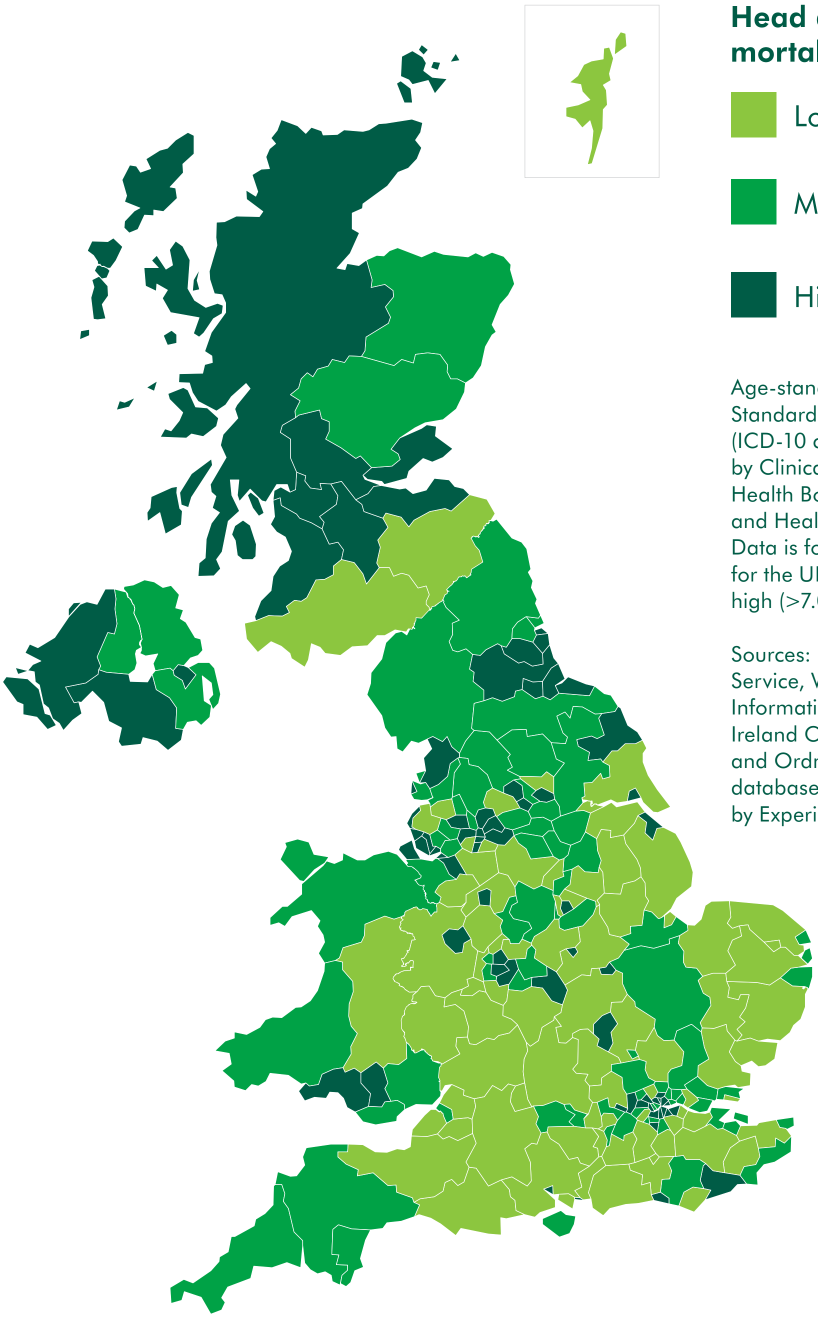
- 🟩 Low
- 🟩 Medium
- 🟩 High

Age-standardised cancer registration rates per 100,000 European Standard population, all ages, head and neck cancer (ICD-10 codes C00-C14 and C30-C32). Rates are shown by Clinical Commissioning Group for England; NHS Health Board for Scotland, Local Health Board for Wales, and Health and Social Care Trust for Northern Ireland. Data is for 2010-2014 period. Data classified by tertiles for the UK combined [Low(<17.7), medium (17.8 to 20.7) and high (>20.7].

Sources: National Cancer Registration and Analysis Service, Welsh Cancer Intelligence and Surveillance Unit, Information Services Division Scotland and Northern Ireland Cancer Registry. Contains National Statistics and Ordnance Survey data © Crown copyright and database right 2015. Additional mapping data provided by Experian.

Head and neck cancer incidence rates are generally higher in parts of Scotland, as well as in some areas across the rest of the UK.

Thematic maps – distribution of head and neck cancer mortality in the UK



Head and neck cancer mortality, UK, 2010–2014

🟩 Low

🟩 Medium

🟩 High

Age-standardised mortality rates per 100,000 European Standard population, all ages, head and neck cancer (ICD-10 codes C00-C14 and C30-C32). Rates are shown by Clinical Commissioning Group for England; NHS Health Board for Scotland, Local Health Board for Wales, and Health and Social Care Trust for Northern Ireland. Data is for 2010-2014 period. Data classified by tertiles for the UK combined [Low(<5.4), medium (5.5 to 7.0) and high (>7.0)].

Sources: National Cancer Registration and Analysis Service, Welsh Cancer Intelligence and Surveillance Unit, Information Services Division Scotland and Northern Ireland Cancer Registry. Contains National Statistics and Ordnance Survey data © Crown copyright and database right 2015. Additional mapping data provided by Experian.

Head and neck cancers mortality rates are higher in Scotland and Northern Ireland. Pockets of high mortality rates can also be found across other parts of the UK.

How do UK survival rates compare internationally?

A large study, EUROCARE, compared survival of many cancer types across European nations in 2000–2007.

It found that five-year relative survival of cancer of the larynx in men in Northern Ireland (75%) is above the average for Europe (59%). Rates in Wales match the European average (59%), whilst England (63%) and Scotland (62%) are slightly above. In women, the survival in England (56%), Wales (59%) and Scotland (54%) are all close to the European average (equivalent data is not available for Northern Ireland).

For oropharyngeal cancer, the five-year relative survival rates in men in England and Scotland (both 44%) are above the European average (36%), same as in Wales. In women, the five-year relative survival rates in England (50%) and Wales (50%) are very close the European average (49%), with Scotland slightly lower (44%).(108,109)

What are the major demographic variations in incidence, mortality, prevalence and survival for head and neck cancer?

Gender

The lifetime risk of developing oral cancer in the UK is estimated to be 1 in 75 for men and 1 in 150 for women.(105)

Laryngeal cancer is much more common in males than in females. The lifetime risk of developing laryngeal cancer is around 1 in 175 for men, and 1 in 800 for women.(105)

Ethnic background

For cancer of the mouth, incidence rates for women aged over 65 years and of all ages in England are higher in Black ethnic groups compared with White ethnic groups. There is also some evidence to suggest that the incidence rate is higher in Asian ethnic groups.

For men in England, there is some evidence to suggest that for all ages Asian ethnic groups have lower incidence rates of mouth cancer, and strong evidence to suggest that for Black ethnic group men of all ages have lower incidence rates for mouth cancer.(110)

What are the major trends? (Incidence/mortality/prevalence or survival)

Head and neck cancer incidence rates have increased by 30% in males and females combined in the UK since the early 1990s. The increase is greater in females, at 40%, compared to males, at 20%. The number of cases of head and neck cancer is set to continue increasing in the UK, with projections suggesting that the incidence rates will rise by 33% between 2014 and 2035, to 20 cases per 100,000 people by 2035.(105)

Head and neck cancer incidence rates in males have increased overall for most of the broad age groups in the UK since the early 1990s, but rates in males aged 70–79 and 80+ have remained stable. The largest increase was for males aged 50–59, with rates increasing by 42% between 1993–1995 and 2012–2014. In females, head and neck cancer incidence rates have increased overall for all age groups in the UK since the early 1990s. The largest increase was in females aged 50–59, with rates increasing by 66% between 1993–1995 and 2012–2014.(105)

Oral cancer mortality rates have remained relatively stable overall in the UK since the early 1970s. This includes a decrease for males and stable rates for females.(105)

‘Whilst I had the opportunity to meet some patients who had a total laryngectomy, the partial option was so rare that there was no one to meet. Also it became evident that some of the people in my health teams including ward staff had no experience treating a person with a partial laryngectomy.’

Jacob

THE CANCER JOURNEY

We know that everyone with cancer has different experiences at different times of their cancer journey. However most people will go through one or more of the four stages of the 'cancer journey'.

The following pages summarise what we currently know about the needs and experiences of people living with head and neck cancer at these stages.

A typical ‘cancer journey’ showing four key stages:

1 Diagnosis

What happens to me when I’m diagnosed with cancer?

This stage of the cancer journey can include different elements, such as:

- Being concerned about health and going for tests
- Receiving a cancer diagnosis
- Cancer coming back – when people are diagnosed with a new cancer after surviving a previous cancer

2 Treatment

What can I expect when I’m being treated for cancer?

This stage of the cancer journey can include different elements, such as:

- Starting and going through treatment
- Finishing treatment and recovering from cancer

3 Life after treatment*

If I complete my treatment for cancer, what next?

This stage of the cancer journey can include different elements, such as:

- Living with consequences of cancer and/or its treatment
- Living well after cancer

4 Progressive illness and end of life

If my cancer is incurable, what might I experience?

This stage of the cancer journey can include different elements, such as:

- Cancer that is treatable but not curable
- End of life

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*This is often referred to as 'survivorship' or 'Living with and beyond cancer'. While Survivorship relates to the time both during and post-treatment, as illustrated by the Recovery Package (p40), this section largely highlights the post-treatment needs and experiences of people living with cancer.

NEEDS AND EXPERIENCES: DIAGNOSIS

What are the top three signs and symptoms of head and neck cancer?[23]

There are over 30 different areas of the head and neck where cancer can develop so signs and symptoms vary. Some of the most common include:

1. Hoarseness persisting for more than six weeks
2. Ulceration of the mouth persisting for more than three weeks
3. Oral swellings persisting for more than three weeks

How good are we at early diagnosis? How aware are people of signs and symptoms?

Head and neck cancers are often diagnosed late, because they can lack any specific symptoms, and patients often present after having developed a second primary tumour affecting their respiratory system, for example in the lungs.(24)

Because head and neck cancers are relatively rare, the average GP would only expect to see a new case about once every six years.(23)

Patients with cancer (not head and neck specific) in the UK tend to present with more advanced disease and have poorer survival rates than many of their European counterparts. Despite overall symptom awareness not differing considerably from other countries, patients with cancer in the UK tend to present with more advanced disease and have poorer survival rates than many of their European counterparts.(21)

General awareness of cancer signs and symptoms is lower in men, those who are younger, and from lower socio-economic groups.(20)

Evidence suggests patients might have a variety of barriers to seeking medical help. Some say they find it difficult to book an appointment with their preferred doctor and/or at a convenient time. Others report being worried about wasting the doctor’s time and/or the outcome of consultation – or just not wanting to be seen to ‘make a fuss’.(20,21,22)

Significant variations are reported for different demographic groups, with younger people, women and people working in non-managerial positions (including full-time students and unemployed) being more likely to report a barrier to seeking help with their symptoms.(22)

If unaddressed, these barriers may lead to late presentation, and consequently to a delay in cancer diagnosis.(21)

Is there any screening available for head and neck cancer?

There is no national screening programme for any form of head and neck cancer and it is unlikely that such a programme will be established in the near future. Screening has been considered for oral cancer but as it is relatively rare the pick-up rate would be very low. There is also little evidence to show that screening would be beneficial for the population as a whole. More research is needed, particularly on screening members of high risk groups.(25)

How is head and neck cancer diagnosed?(27)

Routes to diagnosis, England, 2006–2014

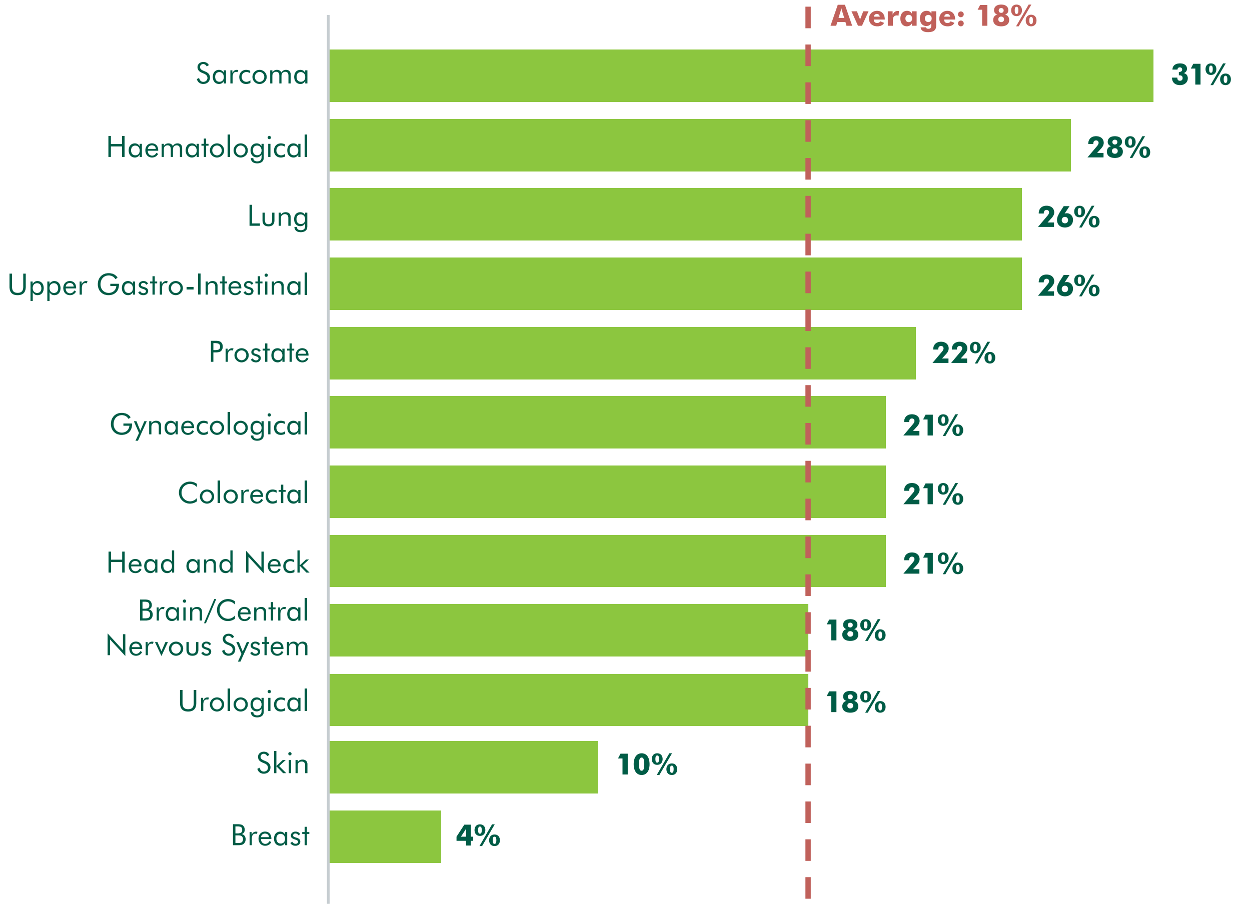
	Emergency	**GP referral**	**2-week wait**	**Other** 'Other' includes in-patient and out-patient routes, 'death certificate only' diagnoses, and 'unknown' routes
Larynx	**10%**	**38%**	**38%**	**14%**
Oral cavity	**6%**	**25%**	**35%**	**34%**
Thyroid	**7%**	**54%**	**17%**	**23%**

Proportions of presentations via the emergency route vary across different types of head and neck cancer, ranging from 10% for laryngeal cancer to 6% for cancer of the oral cavity.

Variations also emerge across other types of presentation. GP referral is by far the most common route to diagnosis for thyroid cancer (54%), but it is the third most common for cancers of the oral cavity (25%). This shows the variation in characteristics of different head and neck cancers.

How many head and neck cancer patients had to see their GP more than twice before they were diagnosed?(26)

More than two GP visits, England, 2016



21% of people newly diagnosed with head and neck cancer had to see their GP more than twice before they were diagnosed compared to 4% of breast cancer patients, and 10% of skin cancer patients.

How is head and neck cancer staged?

Number staging system

Most types of cancer have 4 stages, numbered from 1–4.

The later the stage at diagnosis, the poorer the chances of survival – in other words, early diagnosis and treatment of head and neck cancer saves lives.

Stage 1	Stage 2	Stage 3	Stage 4
Usually means a cancer is relatively small and contained within the organ it started in.	Usually means the cancer has not started to spread into surrounding tissue, but the tumour is larger than Stage 1. Sometimes Stage 2 means that cancer cells have spread into lymph nodes close to the tumour. This depends on the type of cancer.	Usually means the cancer is larger. It may have started to spread into surrounding tissues and there are cancer cells in the lymph nodes in one area.	Means the cancer has spread from where it started to another body organ. This is also called secondary or metastatic cancer.

TNM staging system
Alongside the more common 4 stages of diagnosis, head and neck cancers are also staged using the TNM system. In this case, doctors will assess and rate the size of the tumor (T), whether the cancer has spread to the lymph nodes (N) and whether the cancer has spread to another part of the body (M).(106)

What are the national targets for urgent cancer referrals and treatment?

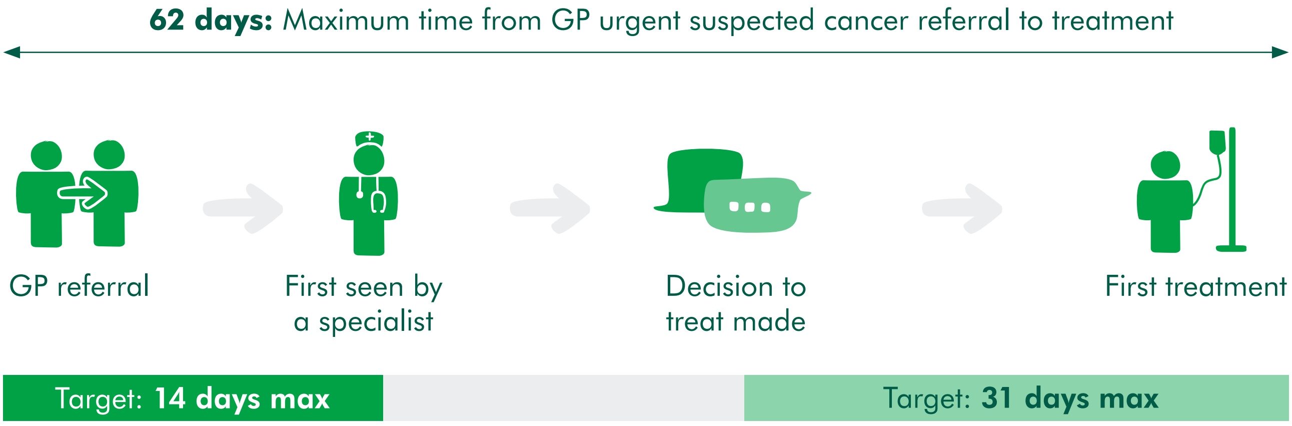
The two-week wait is the route to diagnosis for urgent GP referrals, and is one of many routes to diagnosis including emergency admission and screening.

For England, the NHS aims for maximum a two week wait for patients to be seen by a specialist, after urgent referral for suspected cancer by the GP.

Patients should experience a maximum wait of one month (31 days) between receiving their diagnosis and the start of first definitive treatment, for all cancers.

Following a diagnosis of cancer, patients should wait a maximum of two months (62 days) to begin their first definitive treatment, following an urgent referral for suspected cancer from their GP (therefore via the two week wait).

The exact targets vary across the each of the four nations.(96)



62 days: Maximum time from GP urgent suspected cancer referral to treatment

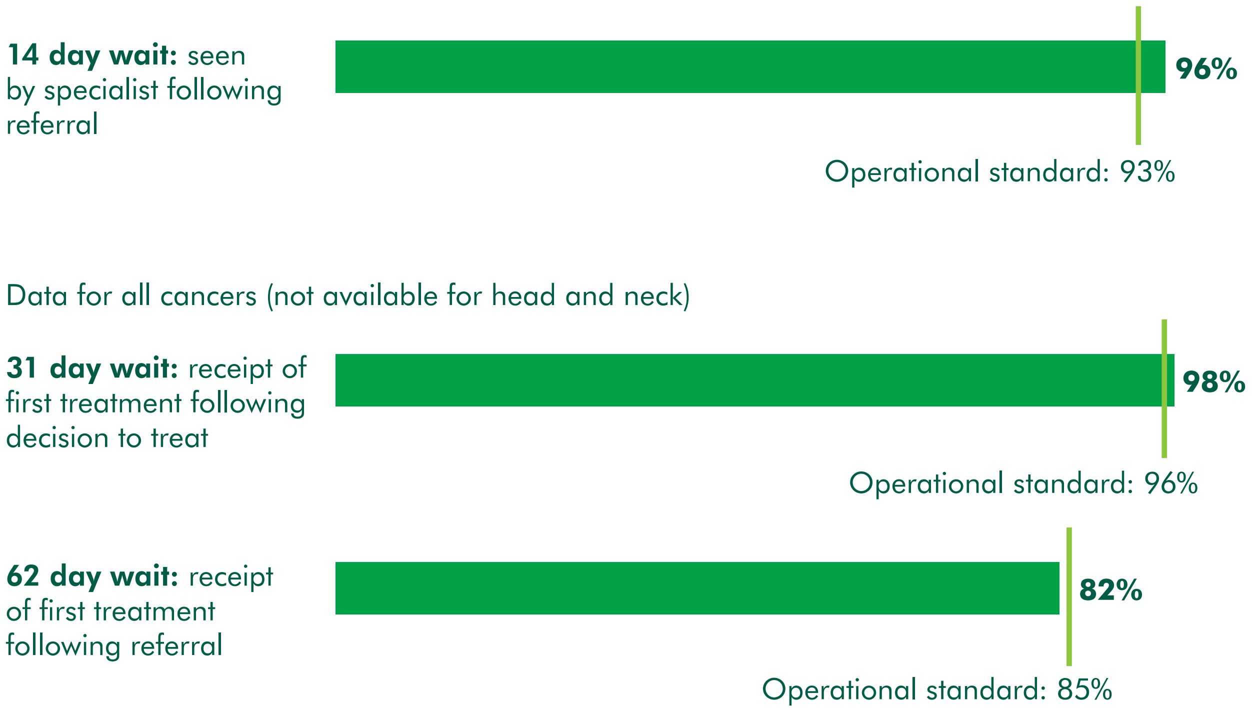
GP referral → First seen by a specialist → Decision to treat made → First treatment

Target: **14 days max**

Target: **31 days max**

How long do people with head and neck cancer have to wait to be referred?(30)

Waiting times for head and neck cancer, England only, 2016–2017



Around 96% of suspected head and neck cancer cases were seen by a cancer specialist within 14 days of urgent referral. This is higher that the average for all cancer types and meets the operational standard set by the NHS.

Data for 31- and 62-day wait are not available for head and neck cancer. For all cancers, we know that 31-day wait performance meets the operational standard, whilst 62-day wait performance regularly does not.

Needs at diagnosis

Physical needs

An international study found that pain, mouth sores, loss of appetite and swallowing problems were considered reasons for observed weight loss in head and neck cancer patients, even before treatment starts.(45)

In a small qualitative study, the most common complaints reported preoperatively by head and neck cancer patients were pain, anxiety, lack of activity, low mood and lack of vitality.(57)

Clinical needs

A study looking at presentation of different cancers found that only 34% of patients with oropharyngeal cancer and 39% of those with oesophageal cancers presented promptly to their GPs (within 14 days of presentation of symptoms). This is lower than all other cancer types investigated in the study.(55)

In England, 79% of patients with head and neck cancer thought that they had their first appointment with a hospital doctor as soon as necessary.(26)

For 76% of people with head and neck cancer in England, it took less than three months from the time they first thought something might be wrong with until they first saw a GP or other doctor.(26)

Practical needs

An international study found that 38% of patients with head and neck cancer identified the need to receive support finding solutions for daily problems.(65)

Not specific to people with head and neck cancer
Cancer patients are found to have mild to moderate concern about cancer affecting their parental role. Cancer symptoms and treatment side effects can sometimes make it very difficult to keep up daily routine, especially for those with children.(56)

Social difficulties are common among cancer patients as a result of their cancer diagnosis. A study found that advance disease, younger age, lower income and poor psychological well-being emerge as some of the factors that made cancer have such a strong impact on the social life of patients.(56)

Financial needs

A third of the head and neck cancer patients in England said they have received information about financial support.(26)

Not specific to people with head and neck cancer
Loss of income alone is experienced by 30% of people with cancer, with those affected losing, on average £860 a month. Additional costs and loss of income arise at different points in the cancer journey, but these figures show the financial strain that a cancer diagnosis can place on many families.(48)

According to a 2013 Macmillan report, 83% of people are, on average, £570 a month worse off as a result of a cancer diagnosis.(48)

The most common additional cost people living with cancer face is getting to and from hospital, or making other healthcare visits.(48)

Costs associated with outpatient appointments hit almost three-quarters (71%) of people living with cancer, and over a quarter (28%) incurring costs for inpatient appointments.(48)

Information needs

In England, 86% of people with head and neck cancer think that they were told they had cancer in a sensitive way.(26)

A study found that some patients perceive the information that they receive at diagnosis to mean that their cancer would be cured if they follow the treatment pathway offered. This perception is more evident in those who receive a diagnosis at an earlier stage of the disease.(58)

Not specific to people with head and neck cancer

The strongest preference for information at diagnosis is information about prognosis. However, there are also many other information needs such as side effects of treatment, impact on family and friends, altered body image, self care and risks of family members developing the disease.(59)

Emotional needs

A significant proportion of people with head and neck cancer are worried about how their diagnosis will affect others, for example dependants, family and friends. A total of 34% of people with head and neck cancer interviewed in a 2015 study felt uncertain about their future.(49)

More than 30% of patients claimed they have issues with anxiety, sadness or depression. Among their fears, that of cancer spreading is the highest psychological need identified for head and neck cancer patients.(49)

Research found that younger people are more likely to need psychological and emotional wellbeing and spiritual support (66%), compared to those aged 65 and over (45%). Women are also more likely to identify issues in these domains than men (64% and 55% respectively).(60)

Not specific to people with head and neck cancer

Cancer affects people physically, emotionally and financially. Although a certain amount of emotional distress is common, particularly around the time of a diagnosis, where it has been found that around half of all people with cancer experience levels of anxiety and depression severe enough to adversely affect their quality of life.(82)

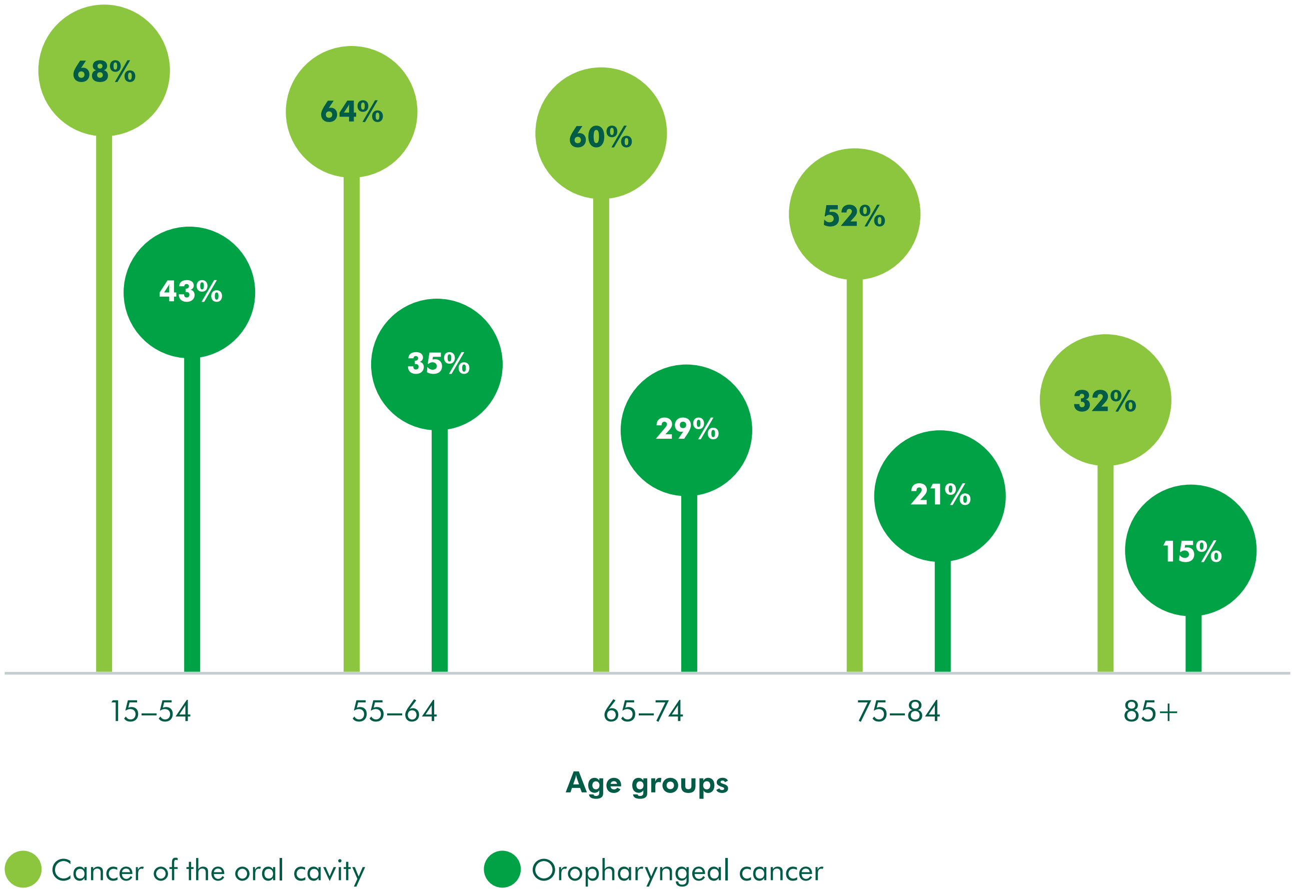
‘Online, surprisingly, I could not find one account from an individual who had undergone a partial laryngectomy, not just the UK but globally! I was determined as I got better to set up a blog as an information resource for other people facing a similar situation to me’.

Jacob

NEEDS AND EXPERIENCES: TREATMENT

How often do head and neck cancer patients have surgical resections?

Percentage of major surgical resection for cancers of the oral cavity and oropharyngeal cancers by age, England, 2006–2010(19)



Surgery is one of the main types of treatment for head and neck cancer. Cancers classified as head and neck can have very different rates of surgical resection. Patients with cancers of the oral cavity tend to receive this type of operation more often, compared to patients with oropharyngeal cancers.

What can a person with head and neck cancer expect from a typical treatment regime?

Surgery is one of the main forms of treatment for head and neck cancers, along with radiotherapy and chemotherapy. Very small cancers can often be treated with a simple surgical operation with no need to stay in hospital overnight. If the cancer is larger, surgery will often involve a hospital stay and an operation under general anaesthetic.(39)

Sometimes the surgery may involve more than one part of the head and neck, and may cause scarring on the face or neck. Some people may need to have plastic or reconstructive surgery to their face.(39)

Radiotherapy for head and neck cancers is usually given in combination with chemotherapy (chemo-radiation). This is known as chemo-radiation. This may be used instead of, or after surgery. Combined treatment is thought to be more effective than using either chemotherapy or radiotherapy alone. However, radiotherapy may sometimes be used alone if a person is not fit or well enough to have chemo-radiation.(41)

What other types of cancer treatment do head and neck cancer patients get?

Radiotherapy

Radiotherapy is an intensive form of treatment that uses high-energy rays to kill cancer cells, while leaving the healthy cells to recover. It is often used postoperatively for head and neck cancer.(31)

The use of radiotherapy varies according to the type of head and neck cancer. It is estimated that in 2014, 52% of patients diagnosed with cancer of the larynx received radiotherapy as first treatment in England and Wales. In comparison, just over 1.6% of patients with tongue cancer received primary radiotherapy.(32)

External beam radiotherapy is the most common way of giving radiotherapy to the head and neck area, but some cancers can also be treated by implanting radioactive material into the tumour and leaving it for several days. This is known as internal radiotherapy, or interstitial radiotherapy.(33)

Chemotherapy

Chemotherapy, a combination of anti-cancer drugs, is normally given at the same time as radiotherapy. This is known as chemo-radiation. Chemotherapy may also be given before chemo-radiation treatment, which is known as induction chemotherapy. Very occasionally chemotherapy is given before surgery to shrink the tumour and make it easier to remove.(34)

Biological therapy

Biological therapies use substances that are produced naturally in the body to destroy cancer cells. Biological therapies, like monoclonal antibodies and cancer growth inhibitors, are sometimes used to treat head and neck cancers, and are currently mainly given as part of cancer research trials.(35)

Photodynamic therapy

Photodynamic therapy (PDT) uses a combination of laser light of a specific wavelength and a light-sensitive drug to destroy cancer cells. In early stage cancer of the head and neck PDT may be used to try to cure the cancer and is usually given as part of research trials. PDT can sometimes be used to shrink an advanced cancer to reduce symptoms, but it cannot cure an advanced cancer.(36)

How many head and neck cancer admissions are there? How long do head and neck cancer patients stay in hospital?

In total, there were over 44,901 admissions to NHS hospitals in England (emergency and non-emergency) for lip, oral cavity and pharynx cancers during 2015–16.(37)

The median length of stay for the same patients who were admitted was 7 days in 2015–16.(37)

What are the challenges of treatment for head and neck cancer?

Cancers affecting the head and neck are uncommon so people with this type of cancer are usually treated in specialist hospitals. This can mean that patients need to travel to receive treatment.

Treatment for most forms of head and neck cancer has permanent effects on organs essential for normal activities like breathing, speaking, eating and drinking. As a result, many patients facing treatment require expert support before, during, and after treatment. Many are likely to need rehabilitation over a sustained period.(23)

Head and neck cancers present special challenges because of the complexity of the anatomical structures and functions affected. A variety of professionals are involved in treating patients with these cancers, as part of a multi-disciplinary team (MDT), including oral and maxillofacial surgeons or ear, nose and throat (ENT) surgeons, speech and language therapists, dietitians, and dentists or oral hygienists.(23)

How many people with head and neck cancer have access to a head and neck Clinical Nurse Specialist (CNS)?(46)

In 2014, there were 133 head and neck cancer nurse specialists in England, who make up 5% of all Clinical Nurse Specialists in England.

Macmillan CNS in head and neck cancer make up more than half of the head and neck specialist nurses across the UK.(38)

In England, 85% of people with head and neck cancers were given the name of a Clinical Nurse Specialist who would be in charge of their care. This is compared to 92% of people with breast cancer.(26)

What does this mean for patients?

Patients with a Clinical Nurse Specialist are more likely to be positive about their care and treatment than patients without a CNS. This is particularly the case with regards to verbal and written information, involvement, information on financial support and prescriptions, discharge information and post-discharge care, and emotional support.(26)

Clinical Nurse Specialists play a vital role in supporting people with head and neck cancer. They can carry out crucial interventions to aid patients' recovery, as well as signpost patients to the most appropriate type of support.(52)

Research suggests that Clinical Nurse Specialists can influence head and neck cancer treatment by helping patients manage with the physical, psychological and social consequence of their disease and treatment.(40)

What other health conditions do people with head and neck cancer have? How does this affect their treatment, survival, long-term effects or experiences?

Patients who present with some of the most common head and neck cancers often have underlying health problems, linked to smoking and alcohol consumption. Co-morbidities linked to smoking and alcohol can complicate how these cancers are managed, as fitness prior to treatment can be a key issue in determining treatment options. Continuing to smoke and drink during and after treatment can also have an impact on recovery, and long-term survival.(23)

Needs during treatment

Physical needs

Side effects of treatment for head and neck cancer can include sore and sensitive skin, a sore mouth and throat, loss of taste and a hoarse voice.(50)

A study found that weight loss of more than 10% during and directly after radiotherapy for head and neck cancer may have a significant impact on quality of life. This in turn has reported effects on social eating and social contact.(51)

In a small qualitative study, it was found that pain, functional ability (includes swallowing, chewing and speech), and problems with social functioning, were the most common symptoms related to treatment that interfered with a patient's daily life after their operation.(57)

Clinical needs

Treatments for head and neck cancer can be damaging to nearby nerves and tissues. Therefore preserving the function of the area is very important. Treatments should be planned considering how they might affect how the patient talks, eats and breathes.(80)

Osteoradionecrosis (ORN) is a severe and understudied complication of radiotherapy for head and neck cancer, characterised by devitalised bones following treatment. Although rare, some evidence suggests ORN incidence is between 2–22%.(53)

Practical needs

Treatment for head and neck cancer can have severe side effects. A small study in England found that 53% of participants said their quality of life decreased following a head and neck cancer diagnosis.(81)

Only 7% of head and neck cancer patients in England said that they did not receive practical advice and support on dealing with the side effects of their treatment.(26)

Not specific to people with head and neck cancer
75% people with cancer who have practical or personal needs say these are caused by their cancer or cancer treatment.(79)

Help with mobility and practical tasks is reported as crucial for some patients during and after treatment. On average, 1 in 3 people with cancer need help with getting out of bed and using transport. 31% of cancer patients also need assistance in tasks around the house and grocery shopping.(79)

Approximately 31% of patients who have practical needs say they do not get enough support. Around 1 in 7 patients had an emergency hospital visit due to lack of social and practical support.(79)

The majority of people with practical needs receive support from their friends and family, but around 3 in 10 receive formal support through their local authority or the NHS.(79)

Financial needs

Not specific to people with head and neck cancer
33% of people with cancer spend an additional £24 a month on household fuel bills as a result of their cancer and/or its treatment.(48)

The cost of travel to and from appointments affects 69% of people with cancer and costs them, on average, £170 a month.(48)

A quarter of patients incur costs for help around the home or garden due to experiencing fatigue during treatment. This adds up to around £34 a month.(48)

Patients that had recently undergone chemotherapy or surgery would likely have taken time off work which would have accentuated the effect of increased costs during the treatment period.(48)

Information needs

In England, 78% of head and neck cancer patients say they were given written information about their operation and that it was easy to understand.(26)

In England, 58% of head and neck cancer patients discussed with hospital staff or were given information about the impact cancer could have on their day to day activities, such as work life or education.(26)

Emotional needs

A small study found that concerns around mood and appearance, as well as anxiety, were the most commonly reported post-operative emotional symptoms for head and neck cancer patients.(57)

Not specific to people with head and neck cancer

A small study found that patients undergoing treatment were more likely to be open to seeking help to deal with emotional issues, compared to those who hadn't undergone treatment yet.(100)

Approximately 45% of people with cancer have emotional needs but report that they do not get enough support for them.(79)

NEEDS AND EXPERIENCES: LIFE AFTER TREATMENT

What do we know about needs of cancer patients after treatment (not just head and neck)?

The current system for cancer patients after the end of treatment concentrates on medical surveillance, and looking for recurrence. However, we know that this does not address all of people's needs:

- An estimated 500,000 people living with and beyond cancer have at least one physical or psychosocial need.(69)
- At least 350,000 people are living with chronic fatigue.(69)
- At least 350,000 people are living with sexual difficulties.(69)
- At least 240,000 people experience mental health problems such as anxiety, depression and symptoms of PTSD.(69)
- 200,000 people are living with moderate to severe pain.(69)
- Other common problems include urinary and gastrointestinal problems and lymphoedema.(92)
- Fear of cancer recurrence is a common psychosocial problem. Cancer treatments can also increase the risk of other long-term health conditions such as osteoporosis and heart disease.(69)
- 40% of people with cancer with emotional difficulties had not sought medical help or other support.(69)
- 23% of people with cancer lack support from friends and family during treatment and recovery.(93)
- One in six people (17%) who were diagnosed with cancer more than 10 years ago have not been visited at home by a friend or family member for at least six months.(93)

Cancer survivors have greater health needs than the general population

- A 2014 study has shown that less than 25% of cancer patients have received a holistic needs assessment and a care plan. Both of these are essential in providing personalised care for cancer patients and their carers.(107)

Macmillan and NHS England are working to implement improved aftercare for people with cancer.

The National Cancer Survivorship Initiative (NCSI) was a partnership between the Department of Health, Macmillan and NHS Improvement. In 2013, NCSI published documents to support commissioners and the health system to deliver services to improve the long-term quality of life of cancer patients. This included tested interventions which can address the needs of people after cancer treatment, including the Recovery Package.

In 2015, an Independent Cancer Taskforce published 'Achieving world-class cancer outcomes: a strategy for England 2015–2020'. The strategy recommended that everyone with cancer has access to personalised care and support after their treatment ends. To help achieve this, it recommends that NHS England commission services 'for patients living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the Recovery Package by 2020'.

The Government and NHS England have since committed to delivering on these recommendations. The provision of the Recovery Package for cancer patients was included in the NHS Five Year Forward View, and reiterated in the 'Next Steps on the Five Year Forward View', published in 2017. To help deliver these commitments, the NHS Operational Planning and Contract Guidance for 2017–2019 included commissioning all elements of the Recovery Package within it's 'must-dos' for cancer.

The Recovery Package consists of:

- Structured Holistic Needs Assessment and care planning
- Treatment Summary to provide good communication to primary care including information about treatment, and the potential short and long-term consequences
- Education and support events, such as Health and Wellbeing Clinics, which give patients information about lifestyle choices, signs and symptoms of recurrence, getting back to work, benefits and financial support
- The Cancer Care Review carried out by the GP six months following a diagnosis of cancer

Further key interventions include:

- Offering appropriate information including information about work support needs onwards referral to specialist vocational rehabilitation services and financial support
- Offering advice on physical activity, weight management and how to access appropriate programmes.

Needs after treatment

Physical needs

A small study found that early post-treatment, head and neck cancer survivors find swallowing unpredictable and have to adapt the way they eat by reducing their portion sizes and restricting their food to what they could swallow. Six months after treatment, patients still report problems with swallowing, stating that food would get stuck in their throat.(90)

Other problems reported after treatment involve changes to salivating and mouth dryness. Some people find that their appetite has been severely reduced which may lead to missing meals.(90)

Clinical needs

Treatment for head and neck cancers often has permanent effects on basic activities like breathing, speaking, eating and drinking. Patients undergoing any treatment often need specialist support and may need rehabilitation over a sustained period.(23)

Not specific to people with head and neck cancer

A US study identified the need to be informed about and receive clinical support for possible late effects of treatments as important for cancer survivors.(60)

Cancer survivors can experience treatment-related pain long after treatment and during survivorship. In these cases, prolonged pain is likely to have effects on the psychological wellbeing of cancer survivors. Reducing pain becomes crucial to help alleviating other symptoms.(61)

Practical needs

Less than 23% of head and neck cancer patients in England said they were definitely given enough care and help from health or social services after treatment has ended.(26)

Not specific to people with head and neck cancer
A study of cancer patients after treatment found that cancer patients felt the need for more community-based programmes, and better linking and partnership between community teams, secondary, primary and social care as well as voluntary sectors.(63)

Evidence suggests that older people tend to have high needs at transition from treatment to survivorship. Key concerns are around rehabilitation and maintaining independence.(64)

Financial needs

Tiredness, lack of concentration and difficulties with speech, eating or breathing are barriers for head and neck cancer patients to return to work after treatment.(62)

A small study found that the rate of employed head and neck cancer patients drops from three-quarters before diagnosis to one-third around 67 months after diagnosis.(88)

A study involving head and neck cancer patients in England found that there was a financial burden on 20% of participants due to loss of earnings, change in the type of food required and home heating. Transport costs were the most frequently reported cost.(87)

Not specific to people with head and neck cancer
Financial difficulties following treatment are widely recognised as a major worry for cancer survivors. These are linked to concerns around adjusting back to normal life, as well as readjustments of life standards for themselves and their partners or dependents.(49)

Information needs

Many head and neck cancer patients have unmet information needs relating to support for fear of recurrence, sadness and other psychological factors.(65)

Only 30% of head and neck cancer patients in England have received a care plan.(26)

Not specific to people with head and neck cancer
A German study found that many cancer patients have high levels of information needs. Those less satisfied with the information they received tend to have higher levels of depression and anxiety, as well as lower quality of life.(66)

Emotional needs

Head and neck cancer patients have many psychological needs around facing body changes as a result of treatment.(49)

A study found that among patients with head and neck cancer, 39% percent had depressive symptoms and 43% high levels of anxiety. Also, 12% overall had high scores on the Acute Stress Disorder scale.(67)

Fear of recurrence is the most commonly reported emotional concern for people with head and neck cancer patients after treatment. A study found that anxiety, depression, low mood and self-esteem were the most commonly reported needs selected alongside fear of recurrence.(68)

Not specific to people with head and neck cancer
Cancer survivors can experience a variety of long-term emotional and psychological side effects of cancer and its treatment. These can include depression, anxiety and symptoms of post-traumatic stress disorder (PTSD).(69)

‘Miyuki [the Macmillan nurse who looked after Jacob] was with me from my second diagnosis, present when discussing surgical options and then throughout my stay at hospital. She acted as liaison with different health teams and was there to soak up my mood swings in the early days post-operation. She was at all times so helpful, considerate and optimistic despite the situations and challenges.’

Jacob

NEEDS AND EXPERIENCES: PROGRESSIVE ILLNESS AND END OF LIFE

What is the impact of giving patients palliative care?

The National Institute for Clinical Excellence (NICE) has defined supportive and palliative care for people with cancer. With some modification the definition can be used for people with any life-threatening condition: 'Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.'(44)

Where do cancer patients (all cancers) prefer to die?(8,83)

Preferred place of death in the UK, all cancers, 2017

Own home	Hospice	Hospital	Care Home	Elsewhere
64%	18%	1%	1%	2%

With the right support, 64% of people with cancer would like to die at home and just 1% would like to die in hospital.

Where do people with head and neck cancer actually die?(43)

Actual place of death in England, head and neck cancer, 2003–2012

Own home	Hospice	Hospital	Care Home	Elsewhere
26%	22%	41%	10%	2%

41% of all deaths for head and neck cancer in England happen in hospital. We know most cancer patients prefer to die at home, however only 26% of head and neck cancer deaths happen at home.

Needs at end of life

Physical needs

Not specific to people with head and neck cancer
The most common symptoms experienced by more than half of people during their last two weeks of life include shortness of breath, pain and confusion.(70)

About 1 in 3 carers help the person they look after to wash, dress, eat and use the toilet.(94,95)

As terminally ill cancer patients become weaker and less able to do things, just carrying out ordinary daily activities such as getting up can lead to exhaustion and the need to rest or sleep more during the day. During this time, it is common for people to lose interest in things that were previously important to them.(96)

Clinical needs

For head and neck patients with late stage disease, good nursing care and palliative measures to help them eat and breath are crucial.(23)

Not specific to people with head and neck cancer
1 in 10 patients dying from cancer in England experience poor care at end of life.(99)

The most frequently reported unmet need for those receiving palliative care is effective communication with healthcare professionals. Where this communication was lacking, participants in a survey reported adverse effects on both patients and carers.(84)

Practical needs

Patients with head and neck cancer stated that their home was the preferred place of care as it allows them feel a sense of normality whilst being close to family and loved ones. However certain barriers associated with being cared for at home included concern on what the impact of that would be to family members. Other concerns were that the carers themselves had limited medical skills and there may not be access to specific equipment at home that can effectively manage pain.(89)

Not specific to people with head and neck cancer
Those who are older, male, not married, or socio-economically disadvantaged are all less likely to access community palliative care services.(71)

Cancer patients make up 88% of palliative care users in England, Wales and Northern Ireland, despite cancer accounting for only around 29% of deaths.(71)

Financial needs

Not specific to people with head and neck cancer
More than 1 in 5 carers (28%) say they help manage the finances of the person they care for.(94,95)

People with a terminal diagnosis who wish to travel may have their travel insurance cover refused by insurance companies, or be offered cover at prohibitively high premiums, stopping them from fulfilling their wishes.(97)

According to a 2010 Macmillan report, 36% of all people with terminal cancer did not claim the benefits they were entitled to. This amounts to over £90m.(98)

Information needs

A study looking at end of life care for head and neck cancer patients showed that they were acutely aware that any decisions they make with regards to their care would have to take into account the impact would be on their family. Other patients found that family were taking control of their decisions.(89)

12% of patients in England say that doctors and nurses did not give a relative or close acquaintance all of the information required to provide care at home for the person living with cancer.(26)

Not specific to people with head and neck cancer

Cancer patients and their families often want information about how long they may have to live after hearing that their cancer is terminal. However, around 1 in 3 doctors tend to overestimate the survival times of terminally ill cancer patients.(73)

Following hospitalisation in end of life care, patients reported feeling that here was a discrepancy between their priority problems and the palliative intervention determined by professionals. For example, a lack of time for conversation about their own assessment of issues created barriers.(74)

Emotional needs

Not specific to those with head and neck cancer

A small study in part of England showed that cancer patients at end of life have poor quality of life and high levels of depression.(75)

Being diagnosed with cancer that cannot be cured can trigger a wide and complicated range of emotions. People receiving such a diagnosis may feel anger, depression, resentment, or a sense of injustice. Some find it helps to talk to professionals from support organisations.(76)

In a small qualitative study in England, both patients and carers rated trust in professionals as the most important factor in coping with advanced cancer.(77)

In the same study, patients and carers indicated a desire for individual, personal mentors, with lived experience of cancer, to help them through coping with advanced stage cancer.(77)

> **‘Well 12 months on I have rebuilt myself, I’ve learned to swallow and eat again and took up running. I am about to embark on my first half marathon and I am committed to running races to fundraise for those organisations that helped me get back on my feet, Macmillan being one. Life has changed but I don’t see the loss of most of my voice as an overly debilitating one, it is more victor than victim’.**

Jacob

LIFESTYLE AND PERCEPTIONS

This section attempts to give an indication of the typical profile of people living with head and neck cancer, although we know that there is huge variation within the population. This section also provides insight into perceptions about head and neck cancer.

What is the profile of the average person living with head and neck cancer?

There is some dissimilarity in the profile of the average person living with different types of head and neck cancer. Both cancer of the oral cavity and laryngeal cancer, the two most common types of head and neck cancer, can affect men and women, but both are more common in men.

There are twice as many new cases of oral cancer in men than women at a ratio of 2:1.(85) Oral cancer incidence is strongly related to age, though the patterns by age are quite different for men and women. Oral cancer is most common in men between the ages of 60–69, before falling in the over 70s, whilst in women it is most common in those aged over 85.(85)

Laryngeal cancer is rarely diagnosed in people under 40, but incidence rises steeply thereafter, peaking in people aged 70–74.(85)

What do people living with head and neck cancer think about their cancer?

Patients with cancer undergoing head and neck reconstruction can experience significant distress from alterations in appearance and bodily functioning.(54)

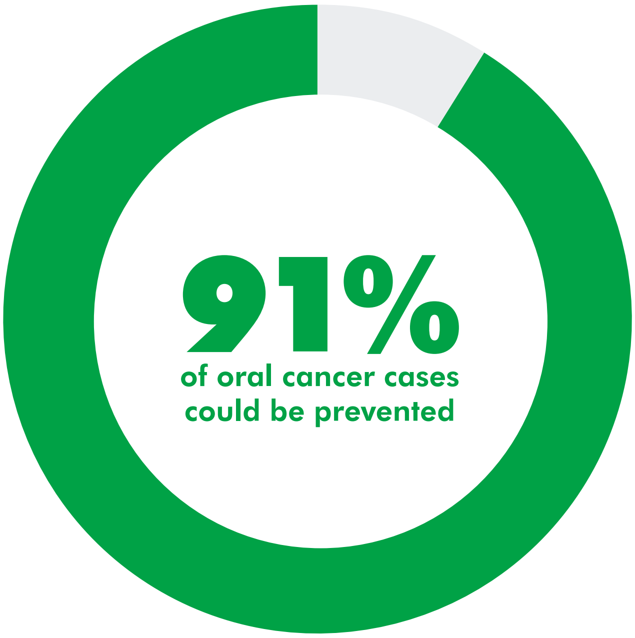
International studies have identified that these alterations can lead to anxiety and depression for patients treated for head and neck cancer(46). Thus, knowledge relating to specific body image issues can be used to guide psychosocial assessments and intervention to enhance patient care.(54)

Head and neck cancer is associated with particularly high levels of stigma. A 2016 qualitative study found that participants' traumatic responses to head and neck cancer diagnosis were linked to fear of treatment and the potential physical debilitation resulting from it. Self-acceptance and the right level of support can allow patients to grow psychologically and redefine themselves positively after head and neck cancer treatment.(47)

Can head and neck cancer be prevented?

Percentage of preventable oral and laryngeal cancers, UK, 2011(86)

Oral cancer



This includes:

65%

cases linked to tobacco smoking(101)

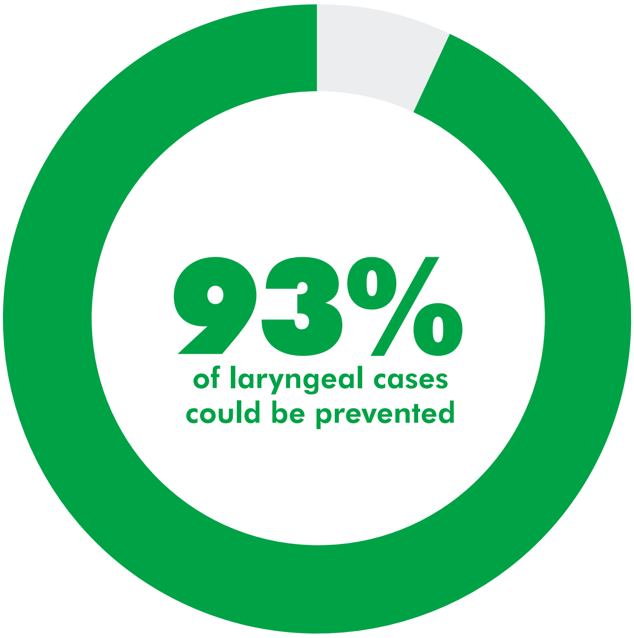
30%

cases linked to alcohol consumption(102)

8%

cases linked to human papillomavirus (HPV) infection*(103)

Laryngeal cancer



This includes

79%

cases linked to tobacco smoking(101)

25%

cases linked to alcohol consumption(102)

11%

cases linked to human papillomavirus (HPV) infection*(103)

*HPV is a probable cause of oral cancer based on limited evidence

A large percentage of cancers cases classified as head and neck in the UK are considered to be preventable, as they are linked with modifiable lifestyle factors. Smoking is the factor with the highest impact.

How does prevalence vary according to deprivation?

20-year head and neck prevalence in 2010 (based on diagnosis between 1991–2010) by deprivation quintile, England(29)*

* Based on the Income Domain of the Index of Multiple Deprivation at time of diagnosis.

The levels of deprivation are usually split into quintiles, going from least deprived (Quintile 1) to most deprived (Quintile 5).

Head and neck cancers appear to have a slight link with socio-economic status. 22% of people living with this type of cancer are in the most deprived quintiles, compared to 18% in the least deprived quintile.

‘I have just had to adjust and adapt but in general I am continually moved by people’s response when I explain my whisper. I get a positive “well done” reaction when they see how well I have overcome my challenges.’

Jacob

What are people affected by head and neck cancer saying about their lives with cancer?

Diagnosis and treatment

‘The treatment may seem brutal and barbaric but it can be done, I know, I've done it. And believe me when I say that while it certainly wasn’t pleasant, I regarded it as a bit of an adventure, a weird journey that I would rather not have done but as I had to do it, well, let’s get on with it.’

Colin

‘I am one week on from the end of treatment. I am finding that the pain in the mouth and throat is just starting to ease a little, but that the coughing up and retching on the phlegm is very painful. I am really struggling to swallow anything at all, even water, so I know I have to try really hard to get back to doing that.’

Alison

‘I think we all put too much pressure on ourselves to try to feel like we did before diagnosis. I don’t know if you ever can.’

Sue

Life after treatment

> **‘I don't suppose any of us ever get back to exactly the life we had before, but I think over time I’ve learnt to adapt and manage my energy levels so I can do everything I want to. If I'm having a busy day or a late night I just make sure I keep the next day quiet and that seems to work for me.’**
>
> Margaret

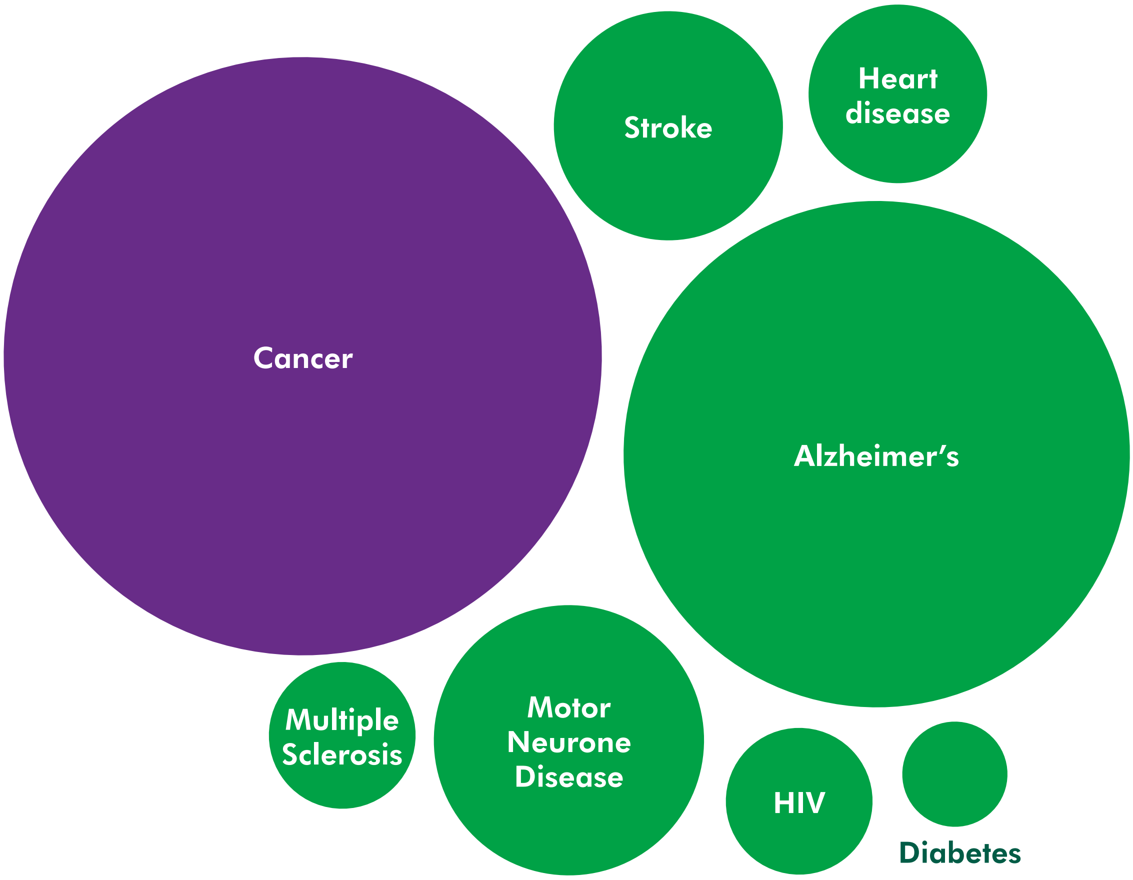
> **‘I lost my taste buds following 35 radiotherapy sessions (I had cancer of parotid gland). I mainly ate salmon and softer foods like shepherds pie as it was more about texture. I couldn’t taste a thing, it took about two months and things gradually got back to normal but it was over a year until I enjoyed a cuppa.’**
>
> Victoria

> **‘I have just finished radiotherapy a couple of weeks ago. My eating is now almost normal, and taste is returning.’**
>
> Laurence

What are people's perceptions of cancer compared to other illnesses?(42)

A 2011 study by Cancer Research UK surveyed people's fear of certain cancer types. However, head and neck cancer was not included in the research.

The same study looked at people's fear of cancer compared to other illnesses.



Overall, 35% of people said cancer (not head and neck cancer specific) is the illness they fear getting the most. This is higher than other conditions including Alzheimer's (25%), stroke (5%), heart diseases (3%) and diabetes (1%).(42)

The Macmillan website hosts guest blog posts from Online Community members, which are a great source of information on the different experiences of people living with cancer.

The post below was written by Paul, who was treated for throat cancer.

I'm learning to live with having a future again
It was about 11 months ago that I discovered a lump in my neck. Thanks to prompt referral by my GP, a month later I had my diagnosis and treatment plan in place. Cancer has taken away close family and friends, and I am determined not to be the next one.

So here I am, seven months after my treatment for throat and neck cancer was completed, currently free of cancer and hoping to remain so.

Check-ups feel far from routine
Check-ups, whilst routine in many ways, feel far from routine when you undergo them. My initial check-ups with the oncology team were a blur of thinking "what will they say?", "what is the process?"; and then the pure elation of finally being told I am currently cancer free...

For the first check-up I was still off sick, recovering from my treatment and had two weeks where it loomed large in my mind. I was rattling about at home some of the time fretting and others keeping myself busy and getting fatigued. For the second, I worked until a week before and kept busy by having a week away before the appointment.

As I headed towards the appointment my mind naturally turned to thoughts that I might get bad news. Yet throughout my journey I have been mostly optimistic that I will be cancer free and remain so at the end of treatment. This is how I am at the moment, enjoying life again and thinking that I have a good chance of remaining cancer free pretty much all of the time.

I was only looking as far as the next appointment
I am mostly positive, even though I do have some dark days. It is only normal to have doubts when you go for a post-treatment check-up, so I don't beat myself up about this – I accept them as only thoughts and move on to other thoughts.

I am still fairly new into this experience and learning to live with having a future again. Whilst I was never told I had a terminal diagnosis (in fact the opposite), I was very aware there was always the chance the treatment would be ineffective and I could be one of the 20% who didn't survive five years or more.

Until recently I was seeing my life in six-week to two-month blocks, this being the time between appointments. Anything beyond was hazy, felt unreal and it was too far in the future to think about or make plans for. I am now beginning to be able to think about further into the future.

I'm taking time to enjoy the good things in my life
Returning to work has helped with this, as I have to think about future all the time. For personal stuff, I do feel now that it is OK to think about next year and what I could be doing. Looking back to my treatment, I found it hard to even think about the immediate future, doing a week's shopping seemed like long-term planning. Now I am definitely planning for the mid-term and soon I expect to be making longer-term plans. Some may be the same as before diagnosis and some will have changed, but this is normal – life happens and we adapt.

So, 11 months on, I am now nearly back to making future plans much as I was before. This very much feels like rediscovering my future, something that was very absent for the eight months of treatment and immediate post-treatment recovery.

In some ways, it has been easy to reconnect with my future, as it is always there waiting. In others, it has been the hardest thing I have ever done, a leap of faith, but I have managed it. What has helped me make the reconnection is being kind to myself, taking time to enjoy all the good things in my life, however small they might be. Each day is a bonus and I intend to make the best of my bonus time. Life is better when you notice the good bits.

What our head and neck cancer online Macmillan Community members are saying…

How the media* portrays head and neck cancer…

*UK national daily newspapers.
Note: these 'word clouds' give greater prominence to words that appear more frequently in the source text.

What does this tell us about people's perception of head and neck cancer?

Macmillan hosts online discussions on its website; we have analysed the frequency of words used in the discussions relating to head and neck cancer compared to the frequency of words used in the UK media articles where head and neck cancer is the subject. The results are summarised here:

References to treatment and side effects are predominant in the online community. The presence of words such as 'eat', 'food', 'weight' and 'talk' shows how issues specifically related to this type of cancer are an important topic of conversation for members of the community. Words such as 'need', 'information', 'advice' and 'support' also suggest that receiving and accessing information is a potentially very important area of need for head and neck cancer patients.

The media seem to focus more on drawing the link between head and neck cancer and physical wellbeing, suggested by the prominence of words such as 'obesity', 'wellness' and 'fitness'. The healthcare system is also an area of interest for the media, as shown by the presence of words such as 'treatment', 'disease' and 'service', as well as references to medical research.

References, sources, notes and caveats

Photo and quotes

The photo on the front cover and quotes on pages 5, 21, 33, 45, 51 and 55 are from our cover star Jacob, who has kindly agreed to be featured in this publication.

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Appendix A: Jargon Buster

Not sure of some of the terms used in this document? Our handy jargon buster should help you out.

(i) Health data terms

Incidence: When we talk about 'cancer incidence' we mean the number of people who are newly diagnosed with cancer within a given time-frame, usually one calendar year. The data can be 'cut' in a number of ways, for example by cancer type (breast, prostate, lung, colorectal, etc) or by gender, age, etc. The latest data we have is for 2015, and we know that over 350,000 people are newly diagnosed with cancer in the UK every year. Incidence can sometimes be given as a rate (per head of population).

Mortality: When we talk about 'cancer mortality' mean the number of people who die from cancer within a given time-frame, usually one calendar year. The latest data we have is for 2015, and we know that over 160,000 people die from cancer in the UK every year. Mortality can sometimes be given as a rate (per head of population).

Prevalence: When we talk about 'cancer prevalence' we mean the number of people who are still alive and who have had, within a defined period, a cancer diagnosis. It equates to the number of people living with cancer. Any prevalence figure is for a snapshot (set point in time). The latest snapshot we have was made in 2015, and we estimate that there are 2.5 million people living with cancer in the UK. Some data are only available and presented for 20-year prevalence (i.e. anyone with a cancer diagnosis within a 20 year period). Prevalence can sometimes be given as a rate (per head of population).

Survival: When we talk about 'cancer survival' we mean the percentage of people who survive a certain type of cancer for a specified amount of time. Cancer statistics often use one-year, five-year or ten-year survival rates. Relative survival (the standardised measure used) is a means of accounting for background mortality and can be interpreted as the survival from cancer in the absence of other causes of death. Survival rates do not specify whether cancer survivors are still undergoing treatment after the time period in question or whether they are cancer-free (in remission).

(ii) Other terms

Co-morbidities: This means either the presence of one or more disorders (or diseases) in addition to a primary disease or disorder, or the effect of such additional disorders or diseases.

Curative treatment: When we talk about curative treatment for someone with cancer, we talk about treatments intended to cure the cancer; this usually mean the removal of a cancerous tumour. It works best on localised cancers that haven't yet spread to other parts of the body, and is often followed by radiotherapy and/or chemotherapy to make sure all cancerous cells have been removed.

Palliative treatment: Palliative treatment is only used to ease pain, disability or other complications that usually come with advanced cancer. Palliative treatment may improve quality of life and medium-term survival, but it is not a cure or anti-cancer treatment. However palliative treatment can be given in addition to curative treatment in order to help people cope with the physical and emotional issues that accompany a diagnosis of cancer.

For further support, please contact
evidence@macmillan.org.uk

Notes

Full suite of the Rich Pictures

This document is one of the twenty in the full suite of Rich Pictures summarising the numbers, needs and experiences of people affected by cancer. See a full list below:

Overarching Rich Picture

The Rich Picture on people with cancer	MAC15069_14

The Rich Pictures on cancer types

The Rich Picture on people living with cervical cancer	MAC13846_11_14
The Rich Picture on people living with breast cancer (2017 update)	MAC13838_17
The Rich Picture on people living with prostate cancer	MAC13839_11_14
The Rich Picture on people living with lung cancer	MAC13848_11_14
The Rich Picture on people living with cancer of the uterus	MAC13844_11_14
The Rich Picture on people living with non-Hodgkin lymphoma	MAC13843_11_14
The Rich Picture on people living with rarer cancers	MAC13847_11_14
The Rich Picture on people living with malignant melanoma	MAC13841_11_14
The Rich Picture on people living with head & neck cancer (2017 update)	MAC13845_17
The Rich Picture on people living with colorectal cancer	MAC13840_11_14
The Rich Picture on people living with bladder cancer	MAC13842_11_14

The Rich Pictures on age groups

The Rich Picture on people of working age with cancer (2017 update)	MAC13732_17
The Rich Picture on children with cancer	MAC14660_14
The Rich Picture on older people with cancer	MAC13668_11_14
The Rich Picture on teenagers and young adults with cancer	MAC14661_14

Other Rich Pictures

The Rich Picture on people at end of life (2017 update)	MAC13841_17
The Rich Picture on carers of people with cancer (2016 update)	MAC16275_10_16
The Rich Picture on people with cancer from BME groups	MAC14662_14
The Emerging Picture on LGBT people with cancer	MAC14663_14

All these titles are available in hard-copy by calling our Macmillan Support Line free on **0808 808 00 00** (Monday to Friday, 9am–8pm), or by ordering online at **be.macmillan.org.uk**

A wealth of other resources are also available, all produced by Macmillan Cancer Support and available free of charge.

Contents ← →

At Macmillan, we know how cancer can affect everything. But you are still you with a life to lead, friends to see, family who need you and people to love.

Macmillan is here to help you get on with your life no matter how cancer affects you. We can give you the practical, emotional and genuinely personal support you need to hold on to who you are and what's important to you.

We can be there for you during treatment, help with work and money worries and give you the time you need to talk about your feelings or whatever's troubling you. Whether it's everyday things like the cost to park at hospital during treatment or big stuff like explaining cancer to your children, we'll do all we can to support you.

We'll be honest: cancer can be tough. But we've helped millions of people through it and we can do the same for you. To us you're always a person, never just a patient. Life with cancer is still your life and we will help you live it.

From diagnosis, for as long as you need us, you can lean on Macmillan. Call us free on **0808 808 00 00** or visit **macmillan.org.uk**

Life with cancer is still life – we'll help you live it.

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