Office for Health Improvement & Disparities

Atlas of health variation in head and neck cancer in England

Introduction

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1. Introduction

What is an atlas of variation?

Atlases of health and healthcare variation are an internationally recognised public health tool developed to identify unwarranted variation in healthcare and outcomes.[4] John Wennberg, who founded the pioneering 'Dartmouth Atlas of Health Care' defined unwarranted variation in healthcare as “variation that cannot be explained on the basis of illness, medical evidence, or patient preference”.[5]

The first 'Atlas of health variation' was produced by the NHS in 2010. The programme was formerly led by Public Health England (PHE) in conjunction with RightCare and is now led by the Office for Health Improvement and Disparities (OHID), part of the Department of Health and Social Care (DHSC), having transferred from PHE in October 2021.

This atlas is the first to look at variation for head and neck cancer in England. It demonstrates the impact head and neck cancer has on society and shows stark inequalities. The data presented can be used to understand these differences and aid the identification of appropriate options for action to reduce healthcare inequalities.

The atlas shows time trends and geographical variation in aspects of head and neck cancer. As well as all head and neck cancers, incidence is broken down by oral cavity cancer, oropharyngeal cancer and laryngeal cancer. There are further breakdowns by age and sex. Also included are indicators on stage at diagnosis, the route to diagnosis as well as head and neck cancer mortality. This atlas also features indicators on risk factors and looks at access to dental services. Data is primarily presented at Integrated Care Board (ICB) level. Data are displayed using maps, box and whisker trend charts, line graphs, bar charts, dot plots and tables.

Additional data and resources are provided to assist local stakeholders in developing and evaluating their service delivery strategies. An explanation of the data presentation is given in the companion document 'Introduction to the data and methods'.

What is variation and why does it matter?

Variations in healthcare are widespread, and their underlying causes are multifactorial, posing challenges for distinguishing whether they are acceptable (warranted) or not (unwarranted). In some cases, it is appropriate that health services vary across the country and within communities with different medical treatment paths followed meeting different levels of healthcare need between areas. However, all patients, regardless of where they live, should receive care of equal quality.

A substantial part of variation in healthcare are health inequalities, which are defined as unfair and avoidable differences in health across the population, and between different groups within society. The causes of health inequalities or disparities are complex but are generally associated with variation in a range of factors that positively or negatively influence our ability to be healthy. This includes individual health-related behaviour, such as smoking and diet; access to services; social deprivation; access to work; education levels; social networks and how much control we feel we have over our lives.

Healthcare services for head and neck cancer varies across the country and within communities, as the total burden of head and neck cancer varies widely and determining locally the cause of the variation, implementing actions to improve where necessary will lead to better outcomes for people.

How should we respond to variation?

The information contained within this atlas is a starting point for ICBs and clinical leaders, to examine their local indicators and the quality of their services, and to benchmark themselves against others and the national average. However, to understand what the variation means and whether it is unwarranted variation, further work will be necessary. It is important not to rely on comparison with the national average, but instead to consider what the appropriate figure or position is based on local need. Where there is concern identified, further analysis of the data and consultation with stakeholders will usually be required to answer the following questions:

- what are the reasons for the variation?
- is this warranted or unwarranted variation?
- is there poorer access for certain groups or is it equal across the whole population?

NHS England has programmes and tools in place that can be used to help address unwarranted variation.

These include a National Healthcare Inequalities Improvement Programme with guidance, resources and dashboard to assist those working to address health and healthcare inequalities across the health system and beyond.

Also available is the Model Health System which uses data to drive a process of continuous improvement to improve patient outcomes and population health. The Model Health System provides hospital provider level benchmarking.

The Getting it right first time (GIRFT) programme is designed to improve the treatment and care of patients through in-depth review of services, benchmarking, and presenting a data-driven evidence base to support change.

The new Head and neck cancer GIRFT workstream will focus on supporting cancer alliances in England to better provide timely, equitable and effective care with the best possible outcomes for patients.

The atlas, National Healthcare Inequalities Improvement Programme, Model Health System and the GIRFT programme demonstrate the importance of using data driven approaches to underpin the identification of unwarranted variation and identify solutions to reduce inequalities in healthcare.

Please note the former RightCare model of 'diagnose, develop, deliver' (used in previous atlases of variation) has now been incorporated into the wider population health focus of NHS England. RightCare products if still current are incorporated into the GIRFT programme.

Definition of head and neck cancer

Head and neck cancer is a collective term generally used for cancers of the oral cavity, oropharynx, larynx and other sites of the head and neck. The grouping of head and neck cancer is complex as cancers of the head and neck are biologically heterogeneous. The subsites are categorised according to the anatomical location using the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) classification system from the World Health Organization.[1] In this atlas, we report on head and neck, oral cavity, oropharyngeal and laryngeal cancers. We have defined head and neck cancer as all cancers with an ICD-10 code between C00 and C14 or between C30 and C32, which aligns with the scope of the NHS Get Data Out programme.[2] This grouping does not include cancers of the thyroid, eye, bones of the head or lymph nodes. A list of each subsite included in the definition of head and neck cancer in this atlas with the relevant ICD-10 codes is provided below (Table 1.1). A more detailed description of each subsite is included in the appendices.

The rationale for aligning definitions to the Get Data Out head and neck cancer cohort and subsite groupings in this atlas is that they were defined by a multidisciplinary working group with the aim of grouping cancers that have similar incidence, treatments and outcomes.

Table 1.1: Head and neck cancer subsites and corresponding ICD-10 codes

ICD-10 code	Cancer subsite
C00	Malignant neoplasm of the lip
C01	Malignant neoplasm of base of tongue
C02	Malignant neoplasm of other and unspecified parts of tongue
C03	Malignant neoplasm of gum
C04	Malignant neoplasm of floor of mouth
C05	Malignant neoplasm of palate
C06	Malignant neoplasm of other and unspecified parts of mouth
C07	Malignant neoplasm of parotid gland
C08	Malignant neoplasm of other and unspecified major salivary glands
C09	Malignant neoplasm of tonsil
C10	Malignant neoplasm of oropharynx
C11	Malignant neoplasm of nasopharynx
C12	Malignant neoplasm of piriform sinus
C13	Malignant neoplasm of hypopharynx
C14	Malignant neoplasm of other and ill-defined sites in the lip, oral cavity and pharynx
C30	Malignant neoplasm of nasal cavity and middle ear
C31	Malignant neoplasm of accessory sinuses
C32	Malignant neoplasm of larynx

The following definitions will be used throughout this atlas:

- head and neck cancer includes cancers listed in Table 1.1 (ICD-10 codes C00 to C14 or C30 to C32)

- oral cavity cancer includes cancers of the inner lip (C00.3 to C00.5), other and unspecified parts of the tongue (C02 - excluding lingual tonsil C02.4), gum (C03), floor of the mouth (C04), hard palate (C05.0) and other unspecified parts of the mouth (C06)

- oropharyngeal cancer includes cancers of base of the tongue (C01), lingual tonsil (C02.4), soft palate (C05.1), uvula (C05.2), overlapping lesion of palate (C05.8), palate unspecified (C05.9), tonsil (C09) and oropharynx (C10 - excluding anterior surface of epiglottis C10.1)

- laryngeal cancer includes cancers of the larynx (C32) and anterior surface of the epiglottis (C10.1)

Head and neck cancer is a public health concern

Head and neck cancer is the sixth most common cancer group globally and the eighth most common cancer group in the UK.[6] Analyses for this atlas, using data from the National Disease Registration Service (NDRS), shows that in England in 2019, prior to the pandemic, new cases of head and neck cancer had reached 10,735 with 3,313 deaths. Between 2017 and 2019 head and neck cancer accounted for 2% of all cancer deaths in the UK.[7] The associated morbidity and mortality of head and neck cancer is high.[7 8]

Incidence is increasing both nationally and internationally.[9] In the UK this is largely due to an increase in incidence of oropharyngeal cancers[10] which are associated with HPV infection and alcohol consumption.[9 11] Mortality rates are rising, driven by an increase in incidence and unchanging survival rates. [9 12] Head and neck cancer incidence and mortality rates are greatest in people aged 70 years and over and are higher in males than females. There is also a socioeconomic gradient in the incidence and mortality of head and neck cancers with higher rates found in areas of higher socioeconomic deprivation. This variation is not entirely accounted for by behavioural risk factors such as smoking and alcohol consumption.[13]

Head and neck cancers are debilitating. They are often diagnosed at an advanced stage when they have a poor prognosis that results in significant morbidity and mortality.[8] Depending on stage, subsite and treatment, people with head and neck cancer experience a significant reduction in quality of life and a multitude of long term and late effects.[8 14 15] People treated for head and neck cancer present with some of the highest post-treatment

morbidity of any cancer groups.[16] Physical changes which may result from surgical and non-surgical treatment include altered anatomy and function including tooth removal, trismus (jaw stiffness), dry mouth, increased risk of tooth decay and risk of osteoradionecrosis (death of bone tissue due to radiation therapy).[14 15] Subsequently, this may cause altered body image due to facial, intra-oral and dental disfigurement and scarring, increased anxiety and depression, social isolation and reduced interpersonal relationships, difficulty eating, speech and voice impairment, sore mouth, pain and fatigue. Treatment of more limited disease is associated with reduced morbidity and better survival.[8]

Head and neck cancers are expensive to treat, requiring multidisciplinary teams (MDT) and with costs of up to £34,000 approximately, per episode of care for very complex procedures requiring critical care. It is not only the costs of the surgical procedures and adjuvant treatments that need to be considered, post-operative rehabilitation, which is complex and costly is often also required to optimise aesthetics, function and patient's overall quality of life.[17]

The COVID-19 pandemic in 2020 resulted in significant disruption to healthcare services nationally and internationally, including head and neck cancer services.[18] Head and neck cancer referrals in the UK decreased during the pandemic, in particular during the first wave. Between March and June 2020, the number of referrals were on average 39% lower than pre-pandemic levels. Referral numbers subsequently increased and were on average 15% lower than pre-pandemic levels between January and February 2021.[18] The pandemic also resulted in reduced face-to-face outpatient appointments and theatre capacity, surgical delays and surgical de-escalation.[18] Although emerging evidence from a Scottish retrospective cohort study suggests that the pandemic did not increase the proportion of head and neck cancers diagnosed at a late stage,[19] its impact on stage of presentation and treatment protocols in England requires further exploration.

The burden of head and neck cancers and inequalities

Analyses for this atlas show that in England between 2013 and 2020 there were 79,583 new cases of head and neck cancer and 25,322 deaths. These comprised 22,490 new cases of oral cavity cancer and 8,142 deaths, 25,932 new cases of oropharyngeal cancer and 5,299 deaths and, 14,575 new cases of laryngeal cancer and 5,292 deaths.

Analyses for this atlas also show that there was variation in the incidence and mortality of head and neck cancer by age, sex and level of socioeconomic deprivation across England implying the existence of inequalities. Other studies have shown inequalities in the incidence of head and neck cancer by ethnicity.[20]

Age and sex

Head and neck cancer incidence and mortality increases with age. Analyses for this atlas show the highest incidence and mortality rates are in people aged 70 years and over. The population of the UK is ageing with the proportion aged 65 years and over expected to increase over the coming decades. Consequently, the number of new head and neck cancer cases in the UK is projected to rise by 3% from 2023 to 2025 reaching approximately 16,300 cases in 2038 to 2040.[6] The increase in incidence of head and neck cancer in older people has been attributed to biological processes associated with ageing and cumulative exposure to risk factors.[6]

In England there is a higher incidence of head and neck cancers in males compared with females.[6] There is a more than 2-fold difference in incidence in males compared with females for head and neck cancers. For oropharyngeal cancer this difference is 3-fold and for laryngeal cancers 5-fold (Table 1.2).

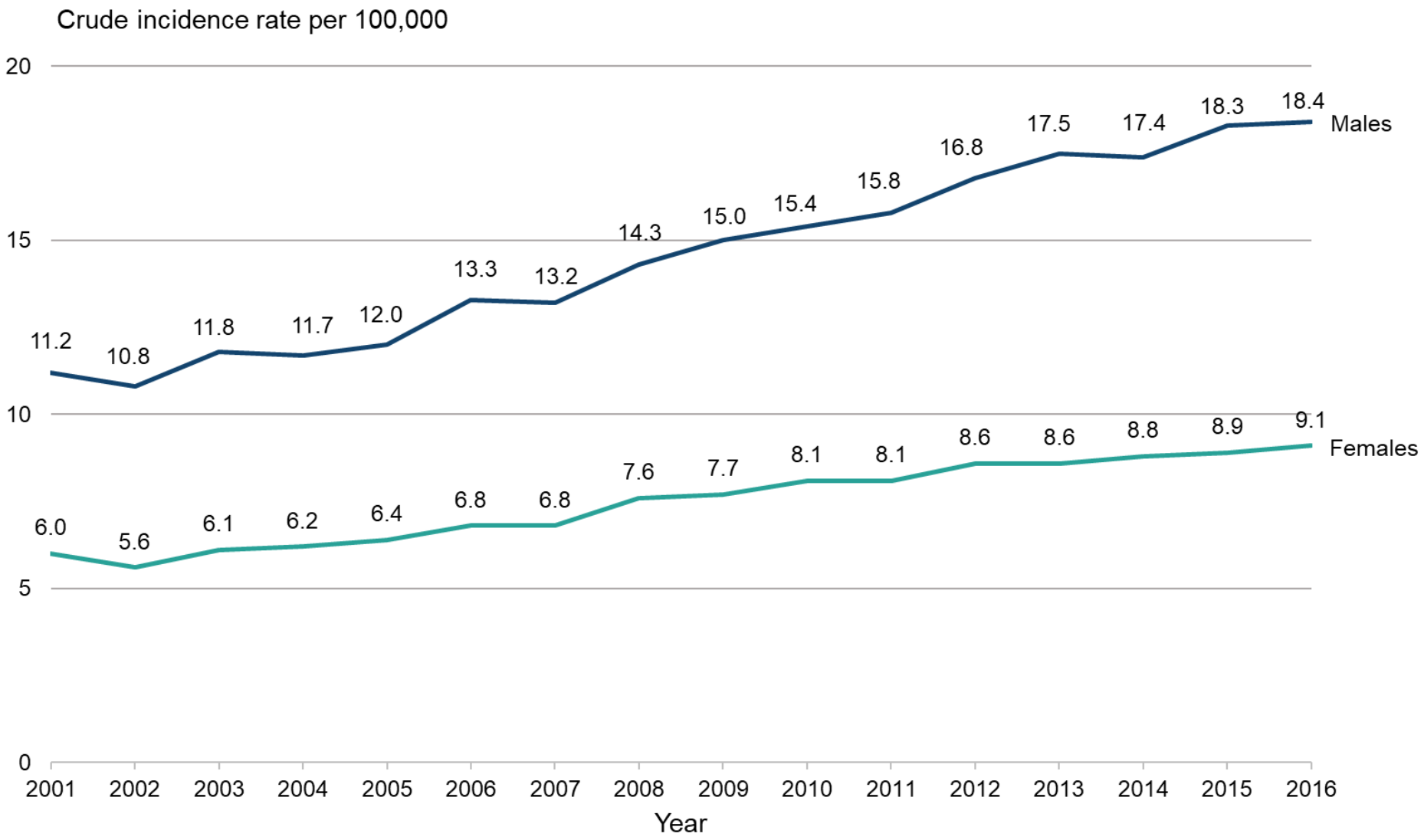
Table 1.2: Incidence rates of head and neck cancer and subsites by sex, in England (2013 to 2020)

DSR per 100,000 population

Cancer type	Males	Females
Head and neck cancer	27.9	11.3
Oral cavity cancer	6.6	4.3
Oropharyngeal cancer	9.6	3.1
Laryngeal cancer	6.2	1.2

Incidence rates of head and neck cancers are increasing in both males and females,[6] which is mostly driven by an increase in the incidence in oropharyngeal cancer. Incidence rates of oropharyngeal cancers increased annually by 7.3% in males and 6.5% in females between 1995 and 2011 and there was a 2.8% and 3.0% annual increase in males and females respectively for oral cavity (excluding lip and hard palate) cancers in the same period.[21] Between 2001 and 2016, the crude incidence of cancers of the lip, oral cavity and pharynx (ICD-10 codes C00 to C14) increased in both females and males, however, the rate of increase was greater in males (Line chart 1.1).[22]

Line chart 1.1: Incidence rate of cancer of the oral cavity, lip and pharynx (ICD-10 codes C00 to C14) by sex, in England (2001 to 2016)[22]



Ethnic groups

In England, head and neck cancer incidences vary by ethnicity and by sex within ethnic groups. The number of cases by ethnic group was estimated for 2013 to 2017 by Public Health England (PHE).[20] Amongst males, head and neck cancer incidence was highest in the white ethnic group followed by the Asian ethnic group. Incidence rates amongst males were lowest in the mixed or multiple ethnic group and the black group (Table 1.3). Amongst females incidence rates were higher in the Asian ethnic group compared with females in the white ethnic group. Incidence rates amongst females were lowest in the black ethnic group.

Table 1.3: Differences in incidence rates for head and neck cancer (ICD-10 codes C00 to C14 or C30 to C32) in ethnic groups by sex (2013 to 2017)[20]

DSR per 100,000 population

Sex and Ethnic group	Rate	95% lower confidence limit	95% upper confidence limit
Female Asian	11.8	10.9	12.8
Female black	6.2	5.3	7.1
Female mixed or multiple	suppressed	suppressed	suppressed
Female white	10.8	10.7	11.0
Male Asian	19.6	18.5	20.8
Male black	17.7	16.0	19.4
Male mixed or multiple	15.7	13.1	18.3
Male white	27.3	27.0	27.6

Note: Rates standardised to the European 2013 standard population. Rates have been suppressed in groups where there are fewer than 100 cases in total. Cases where the ethnic group is ‘not known’ are excluded from the analysis as the case cannot be allocated to a group. The rates reported are therefore likely to be an underestimate.
Asian includes Bangladeshi, Chinese, Indian, Pakistani, any other Asian background.
Black includes African, Caribbean, any other Black background.
White includes White British, White Irish, any other White background.

Socio-economic inequalities

Analyses for this atlas shows there is a relationship between area deprivation and head and neck cancer. People living in the most deprived quintile have almost double the incidence rate to those living in the least deprived quintile and more than 2.5 times the mortality rate of those in the least deprived quintile.

Deprivation was measured using the Index of Multiple Deprivation (IMD) 2019 national quintiles, with 1 representing the most socio-economically deprived quintile and 5 representing the least socio-economically deprived quintile. More details on IMD can be found in the 'Introduction to the data and methods' supporting document.

A Public Health England (PHE) report on inequalities in oral health, including oral cancer, highlighted research that showed people living in more socio-economically deprived areas were more likely to be diagnosed with oral, oropharyngeal and laryngeal cancers through emergency presentation compared with those in less socio-economically deprived areas.[23] [24] Patients from more deprived areas were found to be more likely to have delayed initial presentation.[25] [26]

The relationship between socio-economic status and head and neck cancer is not entirely explained by risk factors such as cigarette smoking and alcohol consumption.[13] The International Head and Neck Cancer Epidemiology (INHANCE) consortium found low socio-economic status (measured by educational attainment and household income) to be a strong risk factor for head and neck cancer in males and females of all ages. This relationship remained after adjustment for age, sex, country, smoking, alcohol, smoking and alcohol combined, diet and other tobacco use. Only two-thirds of the increased risk of head and neck cancer was explained by behavioural risk factors, such as smoking, alcohol, other tobacco and diet factors. This suggests lower socio-economic status increases the risk of head and neck cancer through alternative pathways or poorly understood risk factors, all of which require further exploration. Similarly, the INHANCE consortium found low occupational socio-economic status was associated with head and neck cancer, but this risk was only partly explained by smoking, alcohol and occupational exposures.[27]

The relationship between alcohol consumption and socio-economic deprivation is complex.[22] Alcohol attributable harms such as alcohol-related hospital admissions are higher in people living in more deprived areas even when few differences are noted in consumption levels; this is referred to as the alcohol harm paradox.[28]

Vulnerable groups

Vulnerable (disadvantaged) groups include people who are homeless, prisoners, travellers, looked after children and refugees.[23] There is currently insufficient evidence to

conclude if there are inequalities in oral cancer in any of these groups and further research is required.[23] The available limited evidence suggests these populations have considerably poorer oral health and face substantial difficulties accessing dental care.[23]

People with disabilities

The PHE report on inequalities in oral health reported on inequalities experienced by those with disabilities. The report concluded that the literature on disabilities and oral health in the UK was very limited, and the heterogeneity in the disabilities under study makes it difficult to summarise the findings. The studies did suggest poorer oral health outcomes and more problems accessing services among disabled people.[23]

A recent systematic review examining studies of cancer care, not limited to head and neck cancer, for people with disabilities concluded that people with disabilities often experience severe disparities in cancer care with less guideline-consistent care and higher mortality than people without disabilities.[29]

Risk factors

Tobacco and alcohol

Tobacco and alcohol consumption, both separately and in combination, are established risk factors for head and neck cancer.[9] The International Head and Neck Cancer Epidemiology (INHANCE) consortium, a global collaboration of research groups, found the odds of head and neck cancer in tobacco smokers who never drank alcohol was 2 times greater than those who didn't smoke or drink. A similar odds was observed in heavy alcohol drinkers (defined as three or more drinks per day) who never smoked tobacco.[9 30] The combined effect of both smoking and drinking increases the odds for head and neck cancer by a factor of 5 compared with those who only drink alcohol and do not smoke.[9 30]

The magnitude of risk for tobacco smoking and alcohol consumption respectively may vary by cancer sub-site. Tobacco smoking risks appear to be greatest for laryngeal cancers, whereas increased alcohol consumption may have a higher magnitude of risk for oral cavity and oropharyngeal cancers.[9 31]

Higher alcohol intensity (number of drinks per day) increases the risk of oral cavity and laryngeal cancers, while the risk related to duration of drinking appears to be more complex for these subsites.[11] For cancers of the oropharynx, both increased intensity and duration of alcohol consumption were found to increase risk.[11] Mechanisms to explain the association between alcohol intensity and head and neck cancer have been proposed. These include the oxidation of ethanol into alcohol acetaldehyde, a carcinogen, and the local effect of alcohol on cell membranes to enhance penetration of carcinogens, for

example those from tobacco smoking, into the mucosa.[11] This may explain the synergistic effect of smoking and alcohol as risk factors for head and neck cancer.[9] [31] The International Agency for Research on Cancer (IARC) concluded that alcoholic beverages and ethanol in alcoholic beverages are carcinogenic for oral cavity, pharyngeal (including oropharynx) and laryngeal cancers.[32]

There is a dose-response relationship with head and neck cancer and tobacco smoking.[9] [33] Both smoking frequency and duration increase the risk of head and neck cancer. Cigarette, cigar and pipe tobacco smoking are all associated with an increase in risk of head and neck cancer.[33] Tobacco contains 11 agents which have been confirmed as carcinogenic in humans by the IARC, in addition to many agents which are likely to be carcinogenic in humans, given evidence of their carcinogenicity in experimental animals.[34]

Other tobacco usage including smokeless tobacco

The Tobacco and Related Products Regulations (TRPR) 2016[35] states that smokeless tobacco products are tobacco products that are consumed in a way which does not involve a combustion process. These include chewing tobacco, nasal tobacco and tobacco for oral use. Specifically, these are listed as:

- Tobacco products for chewing are usually a highly fermented and liquored form of tobacco. It is consumed by placing the tobacco between the cheek and gum or teeth and is then chewed. There are many varieties but includes paan masala, gutka[36]

- Nasal tobacco (snuff), a dry to semi moist finely ground tobacco product which is mainly used in the nasal cavity. Varieties include Pakistani neswar[36]

- Tobacco intended for oral use, but not to be inhaled or chewed. These are made up of tobacco granules and flavourings designed to be sucked. This product is currently subject to a ban on sale in most European countries and the UK[37]

There is international evidence that smokeless tobacco use is associated with head and neck cancer, particularly oral cavity cancer.[38] [39] Data on the use of smokeless tobacco products within England is limited.[40] The 2004 Health Survey for England focused on the health of ethnic minority groups and questions about the use of chewing tobacco was asked of South Asian (Pakistani, Indian, Bangladeshi) respondents, subsequent national health surveys did not.[41] The use of chewing tobacco was most prevalent among the Bangladeshi group, with 9% of men and 16% of women reporting using chewing tobacco. In 2019, an online survey of 500 people from the south Asian ethnic group by ‘Action on Smoking and Health’ (ASH) found that 9% of males and 7% of females were current users of smokeless tobacco, with 24% of males and 18% of females reporting they had used smokeless tobacco. A limitation of the survey was the findings did not represent those with lower levels of English literacy.[42]

Waterpipe smoking, more commonly known as 'shisha' or 'hookah', is a method of inhaling tobacco smoke.[43] Users inhale tobacco smoke, which is often fruit flavoured, through a water filled apparatus. Usage has been traditional practice in the Middle East and southern Asia for several hundred years, however, is becoming increasingly popular in western countries and young people in particular.[43] International evidence has found that waterpipe smoking is associated with nearly a threefold increased risk of head and neck cancer (summary relative risk (SRR) 2.97, 95% CI 2.26 to 3.90).[44] Data on waterpipe usage in Great Britain from the ASH Smokefree GB survey found from 2012 to 2016 there was an increase of 11.0% to 12.9% in 'ever' waterpipe use, while 'current' waterpipe smoking remained at around 1%.[43] Pooled analysis of the 2012 and 2013 surveys found there was variation in waterpipe use between ethnic groups, with 32.6% of respondents from mixed or multiple ethnic groups reporting ever use and 4.9% reporting frequent use (at least once or twice a month) and 26.5% from Asian or Asian British ethnic groups reporting ever usage and 6.7% frequent waterpipe use.[43 45]

Human papillomavirus (HPV)

Human papillomavirus (HPV), especially HPV types 16 and 18, is a recognised risk factor for oropharyngeal cancer.[46 47]

The UK Health Security Agency (UKHSA) Green Book, chapter 18a on HPV immunisation, states the estimated attributable fraction of HPV that causes oropharyngeal cancers varies from 6% to 71%; globally 47% has been estimated from a systematic review, and a study in the UK estimated 52%. Several reasons are provided for the lack of certainty of the attributable fraction of HPV in oropharyngeal cancer including the ability to distinguish cancer of the oropharynx and tonsil from other subsites, the competing effect of smoking and chewing tobacco and quality of testing protocols.[47] The prevalence of HPV associated oropharyngeal cancer is lower in females than in males.[47]

There has been an increase in the number of HPV associated oropharyngeal cancers in the last two decades, particularly in males.[47] The rate of HPV negative oropharyngeal cancer has also increased significantly in the same time period.[47] Therefore, although a risk factor for oropharyngeal cancer, the increase cannot be attributed solely to an increase in HPV-associated disease. It has been suggested that behaviours such as sexual practices (number of sexual partners and performing oral sex), tobacco use and alcohol consumption cluster in individuals. Hence the exact nature of the contribution of HPV infection to oropharyngeal cancers is complex.[48]

England has a national HPV immunisation programme. A universal HPV immunisation programme introduced in September 2008 with all girls in school year 8 (aged 12 to 13) offered vaccination against HPV infection, as well as a catch-up programme for girls aged 13 to under 18 years.[47] A targeted vaccination programme for gay, bisexual and other men who have sex with men (GBMSM) up to and including the age of 45 years who attend sexual health services and human immunodeficiency viruses (HIV) clinics was rolled out nationally from April 2018.[47] The national HPV vaccination programme was extended to adolescent boys from September 2019.[47] From September 2023 the vaccination programme moved from 2 to 1 dose for children aged 12 to 13 and GBMSM under the age of 25.[49] This change reflects new evidence from a range of international studies that show that a single dose provides the same level of protection as 2 doses.[50] Eligible GBMSM aged 25 to 45 years will remain on a 2-dose schedule, offered through sexual health clinics.[49] The NHS is looking to improve HPV vaccination rates as part of its pledge to eliminate cervical cancer.[51]

The economic burden of head and neck cancer

The economic burden of head and neck cancer is high and increasing in England. A retrospective analysis of hospital data estimated the total direct costs of treating oropharyngeal, laryngeal and oral cavity cancers in secondary care between the financial years ending 2007 and the financial year ending 2011.[52] The cost was approximately £309 million over the 5-year period (oropharyngeal £115 million; laryngeal £96 million; oral cavity cancer £98 million). Both costs and numbers of people treated increased during the study period suggesting a trajectory for increased costs in future.[25]

The societal and economic burden of head and neck cancers go beyond the direct costs of treatment provided by the NHS.[53] Head and neck cancers incur substantial indirect costs in individuals diagnosed with head and neck cancer and those who care for them. A systematic review of the economic burden of head and neck cancer found no studies assessing the full societal burden, however, individual studies assessing the direct and indirect costs in the USA[54 55] and France[56] suggested that direct treatment costs and indirect costs contributed equally to the economic burden of disease.[53] Further economic evaluation is warranted in England to assess the indirect costs of head and neck cancer.

Healthcare variation

Organisation of services

Early diagnosis leads to better outcomes for the patient in terms of survival[57] and psychological impact,[58 59] less complex treatments[58 60] and overall improved patient care.[58 61] Diagnosis, referral, treatment and management of head and neck cancer in England involves a multidisciplinary approach.[61] Primary medical and dental practitioners refer people with suspected cancers to specialist services through the urgent suspected cancer pathway,[58] (previously known as the 'two-week wait' pathway due to the waiting time standard attached to the initial referral pathway) in accordance with National Institute for Health and Care Excellence (NICE) guidance NG12 on the recognition and referral of cancers.[62] NG12 provides guidance to primary care practitioners regarding referral timelines, suggestive signs for oral cancer, laryngeal and suspected thyroid cancers, the diagnostic and referral process, patient information and support. In 2023, the NHS Cancer Programme developed a best practice timed pathway for head and neck cancer to support the ongoing improvement effort to shorten diagnosis pathways, reduce variation and improve patient experience of care.[58] The guidance sets out how diagnosis within 28 days can be achieved for the suspected head and neck cancer pathway to meet the newly implemented 28-day Faster Diagnosis Standard.[58]

Routes to diagnosis

A population-based analysis of the routes to diagnosis for primary invasive head and neck cancer (ICD-10 codes C01 to C14 or C31 to C32) diagnosed from 2006 to 2014 was undertaken.[60] Predictors of routes to diagnosis varied. Older age, males, living in a more deprived area, two or more co-morbidities, ethnic minorities (excluding white minorities) and advanced stage of cancer were associated with higher rates of diagnosis through the emergency route. Patients presenting via emergency routes have lower survival rates.[57] Reasons for the association between older age and emergency presentation included the non-specific nature of head and neck cancer symptoms and the perception of their association with normal ageing and a fear of wasting clinician time with vague signs and symptoms.[60] Increased emergency presentation in ethnic minority groups in England has been linked to barriers to accessing healthcare, lack of trust and discrimination.[60] Reduced health literacy is a proposed common factor for older people, those from deprived areas and ethnic minority groups, consequently further exploration of the association between health literacy and emergency presentation[60] as well as other healthcare access factors, is warranted.

People aged 55 to 64 years, male, of white ethnicity, with cancer of the oropharynx, at stage 3 and 4 disease, with no co-morbidities and residing in an area of higher deprivation were more likely to be referred through the urgent two-week wait referral route.[60] Oropharyngeal cancer often presents as a neck lump thus is more likely to be recognised by patients and primary care clinicians and trigger a two-week wait referral.

People diagnosed with head and neck cancer were more likely to be referred via a dentist compared with all other non-emergency routes if they were aged 65 to 79 years, female, from ethnic minorities (excluding white minorities), had oral cancer, had stage 1 cancer and resided in a less socio-economically deprived area.[60] The cost of a dental examination and treatment and ability to access dental services may be key factors in explaining why people living in more socio-economically deprived areas are less likely to be referred by a dentist.

Data gaps

Ethnicity

The incidence of head and neck cancer sub-sites by ethnic groups are not reported in this atlas. This is because of the small numbers of cases when the cancer sub-sites are also broken down by ethnicity affecting the validity and reliability of age-standardised rates.

Smokeless tobacco

Due to the lack of robust and current data on the use of smokeless tobacco and waterpipe (shisha) in England, data on smokeless tobacco as a risk factor for head and neck cancer is not included in this atlas.

Head and neck cancers attributable to HPV positivity

Between 2013 and 2020 HPV status was not reliably captured in cancer registration data. Therefore, the proportion of head and neck cancers which are HPV positive, in particular oropharyngeal cancers, is not described in this atlas. These data are now routinely collected and can be reported on in the future.

Private dental services

No data is available on access to dental services provided on a private basis and the contribution of private dentistry to the diagnosis of head and neck cancer is unknown.

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