

MAKESENSECAMPAIGN



Head and neck cancer:
The ‘curable’ cancer that
kills over half of all sufferers –
it is time to do something about it

WHITE PAPER

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1

Call to action to drive change for head and neck cancer patients in Europe

There is little awareness of head and neck cancer among the general public and the healthcare community in Europe, resulting in the majority of diagnosed cases being late stage. Consequently, treatment outcomes for patients are poor and chances of survival are significantly reduced. This must be changed, but is only possible with your help.

Head and neck cancer is the sixth most common type of cancer in Europe and its incidence is on the rise. In 2012 alone, more than 150,000 new patients were diagnosed.

Despite major advances in the treatment of head and neck cancer over the past three decades, patient outcomes remain disappointingly unchanged.

Earlier diagnosis and referral to specialised healthcare professionals can have a major impact on improving the outcomes for head and neck cancer patients across Europe.

To drive change for head and neck cancer patients in Europe, the European Parliament, in partnership with the European Head and Neck Society (EHNS) and the European Cancer Patient Coalition (ECPC) has set out the following action points and calls on the European Commission to:

1. Actively engage in **awareness campaigns** on disease prevention and highlight the signs and symptoms of head and neck cancer
2. Support **early diagnosis and referral** to qualified healthcare professionals
3. Support a **multidisciplinary treatment approach** for head and neck cancer, by integrating experts across disciplines
4. Provide guidelines at EU level to ensure that **all European citizens have equal access** to the best available treatment, and support the dissemination of best practices in disease management across EU member states

5. Promote **patient rehabilitation** programme to drive engagement and adherence to ongoing treatment and care to ensure best possible health outcomes

6. Encourage further **research** on head and neck cancer to ensure better prevention strategies, treatment options and, ultimately, outcomes, for all patients

About head and neck cancer

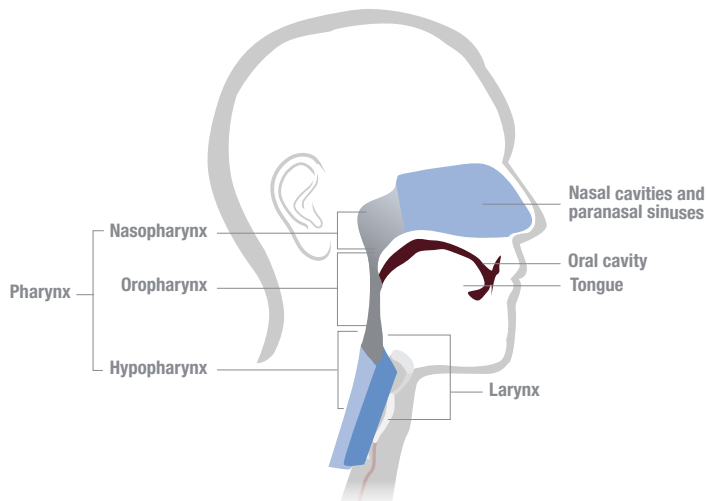


Figure 1: Main sites affected by head and neck cancers.

Head and neck cancer comprises those cancers which form in the head and neck region, not including the brain, eye or the oesophagus. They usually begin in the squamous cells that line the moist surfaces inside the head and neck; for example, inside the mouth, nose and throat. The most common forms of the disease are cancer of the oral cavity, commonly termed mouth cancer (42%) and cancer of the larynx, commonly termed throat cancer (35%).¹

Head and neck cancer is the seventh most common cause of death due to cancer.² It is twice as common as cervical cancer and about half as common as lung cancer.¹ Despite its severity and increasing prevalence within society, there is little awareness of head and neck cancer and patient outcomes remain very poor.

Certain risk factors are associated with head and neck cancer, including:³

- Smoking: Smokers have a higher risk of head and neck cancer than non-smokers
- Alcohol: Men who consume more than three units,* and women who consume more than two units of alcohol per day are at a significantly higher risk of developing head and neck cancer
- Human Papilloma Virus (HPV): The incidence of throat cancer is rising due to certain subtypes of the HPV virus

Incidence data show there are significantly higher rates of head and neck cancer across Eastern Europe, intermediate rates in Central and Southern Europe and lower incidence rates in Northern Europe, the UK and Ireland.⁴ One explanation for the fluctuating incidence of head and neck cancer is the varied exposure to risk factors, which differ based on societal pressures and cultures.

Head and neck cancer affects all ages, genders and ethnicities, but it is most common in males over the age of 40. However, in recent years, there has been a noticeable change in the patient demographic, namely there has been a significant increase in cases of the disease in both younger and female patients. One explanation for this shift is the changing exposure to the aforementioned risk factors.

* **Units of alcohol** are a measure of the volume of pure alcohol in an alcoholic beverage. They are used in some countries as a guideline for alcohol consumption.

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Low awareness of head and neck cancer contributes to late diagnosis

In general, it has been observed that there is a significant lack of awareness of head and neck cancer in Europe. According to a pan-European survey conducted among the general public, 77% of respondents were unaware of the term 'head and neck cancer'.⁵ This survey also highlighted that there is a lack of knowledge among the general public of the risk factors, signs and symptoms of head and neck cancer, demonstrating a clear need for further education.

As a result of this lack of awareness about signs, symptoms and risk factors, it is unsurprising that nearly two thirds of all head and neck cancers are diagnosed at an advanced stage and 10% of patients show metastases at distant sites from the first presentation. Sadly, if a patient receives a diagnosis when the disease has advanced, patient prognosis is very poor. Current estimates indicate a five-year survival rate of only 44% for head and neck cancer patients, versus a 65% five-year survival for cervical cancer patients in Europe.⁶

To combat these worrying statistics, a two-pronged approach must be adopted:

- Firstly, preventative measures should be widely accepted, diffused and practiced among all ages of the European population. These include avoiding tobacco use, moderating alcohol consumption and maintaining low numbers of sexual partners
- Secondly, diagnosis must be made during the early stages of the disease. Therefore, free screening that is well publicised and in easy-access locations should be available to all members of the European public

80-90% is the **survival** **RATE** of **Head&Neck** patients **in the early** **TREATED** **STAGES** of **disease**

Should a patient receive diagnosis and treatment for an early-stage tumour, it is likely that they will remain disease free after single modality treatment. In fact, survival rates of patients who are diagnosed and receive treatment in the early stages are 80–90%.⁷

As part of the efforts of the EHNS and the ECPC to drive best practice in the management of head and neck cancer across Europe, the partnership has taken a stand and is spearheading an awareness initiative called the Make Sense Campaign.

Make Sense Campaign

The Make Sense Campaign aims to raise awareness of head and neck cancer and ultimately improve outcomes for patients with the disease. It will do this through:

- 1. Education on disease prevention
- 2. Driving understanding of the signs and symptoms of the disease
- 3. Encouraging earlier presentation, diagnosis and referral

As part of the Make Sense Campaign, the EHNS, with the support of leading experts from across Europe, developed the One-for-Three definition and is committed to disseminating it to key stakeholders across Europe.



If you have any ONE of these symptoms for THREE weeks...seek medical advice

Sore tongue, non-healing mouth ulcers and/or red or white patches in the mouth	Pain in the throat	Persistent hoarseness
Painful and/or difficulty swallowing	Lump in the neck	Blocked nose on one side and/or bloody discharge from the nose

Primary healthcare professionals should refer a patient to a head and neck specialist if they have any **ONE** of the stated symptoms for **THREE** weeks.

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Treating head and neck cancer

Over the past three decades, great strides have been made in the management and treatment of head and neck cancer. Despite these major advances, patient outcomes remain disappointingly unchanged and subsequently there is still a significant need for research into new treatment options.

Current treatment options

Presently, following a head and neck cancer diagnosis, a patient is likely to receive one of, or a combination of, the following treatment options:

- Surgery
- Radiotherapy
- Drugs, including chemotherapy and biological agents

Prior to a treatment decision, physicians should consider various factors, for example tumour site, extension of the disease, patient preference, comorbidities, expertise of the multidisciplinary team and available equipment.

It is also important to note that all treatments are associated with limitations, which should be considered when deciding on a treatment, namely:

- Surgery is intended to completely remove the tumour, but is sometimes associated with significant loss of function in the area affected
- Radiotherapy can be used alone to treat the disease, although it is more commonly used in combination with surgery, drugs or both. Radiotherapy, especially when combined with other treatment modalities, can result in the loss of function of the affected area after treatment
- Anti-tumour drugs are frequently combined with radiotherapy. These drugs are delivered to improve treatment outcomes in high-risk patients, or are offered to provide greater comfort during the final stages of the disease

While there are a number of associated side effects with each of the treatment options, it must be emphasised that this is a curable disease. The curability depends on the tumour type and size, and also on the treatment delivered.

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Standardising care in Europe

Multidisciplinary care and European clinical recommendations

In an effort to standardise care throughout Europe and to encourage equal access to treatment, the European Society for Medical Oncology (ESMO) developed and published clinical recommendations for diagnosis, treatment and follow-up for patients with head and neck cancer in 2009. Four years on, there is little sign of uniformity in terms of care across all member states; consequently, patients are not receiving equal access to the best possible care.

As part of these guidelines, the need for a multidisciplinary approach to care is highlighted. But again, throughout Europe, only a few healthcare systems currently recognise multidisciplinary cancer care as a standard healthcare provision, namely France, Belgium, The Netherlands and UK.

The need for multidisciplinary approach to treatment

Due to the many factors involved in making an optimal, patient-centred treatment decision and the complex nature of the disease, input and expertise is required from a number of specialised physicians, such as: medical oncologists, radiation oncologists, head and neck surgeons, radiologists, oncology nurses, speech therapists, social workers, psychologists, plastic and/or reconstructive surgeons and dentists with particular interest and expertise in head and neck cancer.

In the four member states currently offering multidisciplinary care (France, Belgium, The Netherlands and UK) benefits for both patient and physician have been observed and are outlined below:

- Improved communication, coordination and decision making between healthcare professionals
- Reduced time to diagnosis and treatment
- Improved adherence to guidelines
- Improved consideration for inclusion in clinical trials
- Increased access to knowledge about support groups
- Improved patient satisfaction

Centres of Excellence

Currently, there is a project underway in Europe that is looking to change how and where head and neck cancer patients receive treatment. Fundamentally, this project aims to ensure that all treatment is delivered in Centres of Excellence. As part of this project, criteria are also being devised, including details of the optimum number of patients that should be treated at any one time, the types of technologies and treatments that should be available and types of physicians that should be employed as part of the multidisciplinary team. The criteria will also include details of how to report patient outcomes.

The implementation of these 'Centres of Excellence' and dedicated treatment guidelines will have a huge impact on the way head and neck cancer patients are treated in Europe. It will also change the way medical knowledge and best practices are transferred. Most importantly it will have a drastic impact on the way patients are diagnosed and treated, and the benefits will be seen through greatly improved patient outcomes and better quality of lives.

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Life after diagnosis

The right to care throughout the patient journey

Life following a cancer diagnosis means starting a long and complex path. A cancer diagnosis forces a drastic change on a patient's life and on those around them. Head and neck cancer has a profound effect on a patient's quality of life as it affects the functionality of organs located in the head and neck region and can also lead to visible deformities.

Following diagnosis, treatments for head and neck cancer often lead to undesirable consequences that have a marked effect on both physical and psychosocial aspects of the patient's life. The impact of the functional and visual changes of surgery or treatment to a patient can transform their daily lives. Head and neck cancer does not only alter the appearance and the personal functions of a patient, but it forces a patient to reconsider their outlook on life, their role within a family, their professional life and their future. Moreover, even for a survivor, the ongoing effects of the disease have such overpowering psychological and relational consequences that many will never regain the quality of life they previously experienced.

Consequently, it is vital that head and neck cancer patients receive care from a multidisciplinary team throughout their entire journey with the disease. Again, herein is further evidence in support of the need for a standardised multidisciplinary treatment approach from diagnosis through to treatment, follow-up and beyond. As part of this care, an efficient rehabilitation programme should be offered, including psychological care to ensure greater adherence to ongoing treatment and support for patients through lifestyle changes caused by their illness.

This rehabilitation may also be offered by head and neck cancer patient advocacy groups (PAGs) and not only by the multidisciplinary team in the hospital setting. A rehabilitation project fundamentally means investing in the patient's future. Conversely, a non-rehabilitated patient requires more health care over time, and becomes a cost burden on the economy. A patient who undergoes rehabilitation is able to recover personal relations faster, reintegrate into society and get back to work much faster with fewer problems. The impact this has upon not only the patient and their family, but also the economy must be considered.

The role of patient advocacy groups

The role of head and neck cancer PAGs vary across the member states. PAGs aim to play a role at the very centre of the patient experience and are working hard to move away from the subsidiary role that they have previously played to the public healthcare system. Their role in a person's journey with the disease is crucial. In fact, they are integral to a patient's recovery in a number of ways, as they can:

- Assist patients from the time of diagnosis, offering support through the treatment decision stage right up to and during the rehabilitation process following treatment
- Co-operate with other associations on new disease prevention programmes to increase education and awareness
- Provide and share warnings about tobacco, alcohol and HPV risks in schools and other networks
- Spread hope in the effectiveness of the suggested treatment
- Train 'survivor patients' to offer real-life advice to patients
- Provide updates on new treatment options, research programmes and clinical trials in progress

In order for PAGs to continue their crucial work, it is necessary for them to be formally acknowledged by healthcare providers and public healthcare systems.

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Conclusion

Driving change for head and neck cancer patients in Europe – let's take action!

Head and neck cancer is a curable cancer, yet it continues to kill over half of all sufferers. Therefore, there is an urgent need, not only to raise awareness of the signs and symptoms of the disease, but also to educate the general public and healthcare providers on the importance of prevention and regular screening.

Whilst treatments have improved for head and neck cancer patients in recent years, there continues to be a significant lack of effective, non-toxic treatments available. Hence, it is imperative that funds are made available to continue research to identify new and more efficacious and tolerable treatments.

Uniform care across the European member states must become the norm. This can only occur if guidelines are communicated and enforced from a parliamentary level. In addition, in order for patients to receive optimal care, multidisciplinary care in Centres of Excellence is critical. As part of this care, rehabilitation is needed throughout the patient journey and it must be formally acknowledged that PAGs play a fundamental support role.

Without support and implementation of our call to action by the EU Commission, we will only continue to see a rise in incidence, further late diagnoses and consequently multiple unnecessary deaths due to head and neck cancer. So we challenge you, why not do something about it?

To do something about the unnecessary deaths, visit our website <http://makesensecampaign.eu/petition> and show your support by signing our petition. All signatures will be put to the European Commission, alongside the aforementioned call to action points, by Darciana Sarbu, MEP with the intention of driving change for head and neck patients in Europe.

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