

MAKESENSECAMPAIGN

HEAD AND NECK CANCER:

The 'curable' cancer that kills over half of all sufferers – we must continue our efforts to stop this devastating disease

WHITE PAPER

Updated for 2020

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FOREWORD TO 2020 EDITION

Authored by MEP and Chair of the European Parliament Challenge Cancer Intergroup



With over 1.93 million deaths attributed to cancer in 2018, the disease is one of the biggest health challenges facing Europe. Of this total, approximately 72,700 of these deaths were due to head and neck cancer – yet many people remain unaware of this devastating disease. These figures highlight the importance of the *Make Sense* campaign.

Since the inception of the Campaign in 2013, its mission has been to raise awareness of head and neck cancer and ultimately improve outcomes for patients with the disease. The Campaign and its stakeholders must be congratulated for their progress across the three focus areas of awareness and education, encouraging earlier presentation, diagnosis and referral, and improving care of patients. That said, we must do more.

As both a physician and the chair of the newly launched Parliamentary Intergroup on Cancer, I read the recent findings of the *Make Sense* survey with both hope and regret. Hope, that progress is being made, but regret that 73% of people surveyed were still unaware of the disease's signs and symptoms.

Two further points stood out to me on reading this updated White Paper. The first is that although head and neck cancer is considered a preventable disease, with a good prognosis when diagnosed early, rates of this cancer are increasing and diagnosis continues to occur at a later stage. The second is the immense impact this particular cancer has on quality of life for patients and survivors.

I truly welcome this paper and call upon you all to stand up and deliver on the paper's five-point plan. We must not forget that at the very heart of the matter are the lives of those who have, are, or will be affected by head and neck cancer in the future. It is crucial that we join together and take the steps today to put an end to the devastation this cancer causes to patients, survivors, friends and family.

1

CALL TO ACTION TO DRIVE CHANGE FOR HEAD AND NECK CANCER PATIENTS IN EUROPE

There is low awareness of head and neck cancer among the general public and the healthcare community in Europe. As a result, head and neck cancer is often caught in advanced stages of the disease, meaning treatment outcomes for patients are poor and chances of survival are significantly reduced. However, head and neck cancer is curable and preventable. While half of sufferers currently survive, this must be improved, and it is only possible with your help.

Head and neck cancer is the sixth most common type of cancer in Europe. However, there are many different types of head and neck cancer and as a result, many sub-types are classified as rare diseases.

Despite major advances in the treatment of head and neck cancer over the past three decades, patient outcomes vary significantly across Europe and survival remains especially low for those diagnosed at an advanced stage.

Head and neck cancer also places a significant burden on healthcare systems, despite the fact that nearly 80% of head and neck cancers are thought to be preventable. Furthermore, a head and neck cancer diagnosis is often a life-changing experience for survivors and has a significant impact on quality of life.

In regards to COVID-19, it is difficult to foresee the full extent and all of the ways in which the pandemic will have changed the head and neck cancer landscape, however it will undoubtedly have an impact on diagnosis, treatment and care of head and neck cancer patients. At the time of writing this paper, it is forecast that the pandemic will lead to a significant increase in late diagnoses. It will therefore be vital in the coming months and years to closely assess the effect of the pandemic.

In light of the ongoing focus on cancer as a top health priority for the European Union, the Make Sense campaign, in partnership with the European Head and Neck Society (EHNS), the European Cancer Patient Coalition (ECPC) and the Parliamentary Intergroup on Cancer, has set out a five-point plan of action to drive change for head and neck cancer patients in Europe.

We call on the European Commission to:

1 Actively engage in prevention strategies for head and neck cancer:

- Conduct awareness campaigns on head and neck cancer disease prevention, including tobacco and alcohol use as part of the EU Health Programme 2021-2027, as well as participate and support the Make Sense campaign's annual awareness week in September for a collective approach on education activities
- Support the HPV Action campaign in calling for the implementation of gender-neutral HPV vaccination in national cancer control policies

2 Support early diagnosis and referral to qualified healthcare professionals:

- Fund national screening programmes
- Endorse the early detection and diagnosis of head and neck cancer as part of the EU Cancer Plan

3 Promote multidisciplinary care as a standardised best practice approach for patients across Europe:

- Fund the development of specialised high-volume treatment centres for head and neck cancer
- Advocate for multidisciplinary care to become a legal provision for patients at a national level and for a multidisciplinary team to be in place from the outset and throughout a patient's treatment journey
- Fund education within relevant specialities to ensure patients are receiving the optimal standard of care

4 Advocate for highest standards of post-treatment care:

- Support the development of head and neck cancer-specific survivorship guidelines and integration into National Cancer Plans
- Promote and fund patient rehabilitation and survivorship programmes to drive engagement and increase compliance with ongoing treatment and care

5 Dedicate EU and national research and innovation funds and support further research on head and neck cancer to improve prevention strategies, treatment options, rehabilitation, and survivorship programmes and, ultimately, outcomes, for all patients:

- Foster an environment of data sharing and collaboration across expert centres for head and neck cancers and on an international level to assess quality of care and share learnings
- Encourage the generation of real-world data to better define head and neck cancers
- Drive efforts to better understand the long-term health impact of intensive treatments used for advanced head and neck cancers

2

ABOUT HEAD AND NECK CANCER

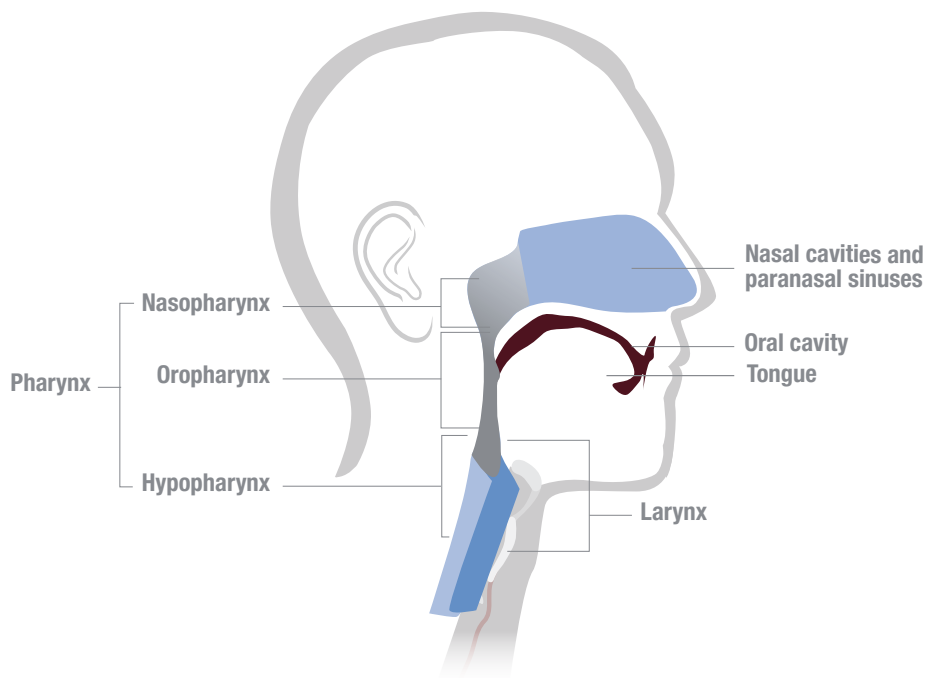


Figure 1: Main sites affected by head and neck cancers.

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 in Europe are mouth (38%) and larynx (25%).¹

Head and neck cancer was the eighth most common cause of death due to cancer in Europe in 2018.² It is also the sixth most common type of cancer in Europe after breast, colorectal,

lung, prostate and bladder cancer, with approximately 160,000 people diagnosed every year. Additionally, while head and neck cancers are relatively common when grouped, there are many different areas where the cancer can present and these types can often be rare depending on the specific sub-site. The rarity of the type of head and neck cancer can have a profound effect on referral, available treatments and quality of care. Despite its severity and increasing prevalence within society, there is little awareness of head and neck cancer and patient outcomes remain poor.

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

- Smoking: Smokers have a higher risk of head and neck cancer than non-smokers²
- 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 cancer³
- Human Papilloma Virus (HPV): The incidence of throat cancer is rising due to certain subtypes of the HPV virus³

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.² Incidence rates differ across EU countries due to varied exposure to risk factors, often dependent on societal pressures and cultures.² Changes in these incidence rates over time can also be linked to specific risk factors. For example, the decreasing incidence rate of larynx cancers is most likely due to the falling levels of smoking in most countries, while the increasing incidence of oropharyngeal cancers is most likely due to increasing levels of human papillomavirus (HPV) infection.

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, specifically HPV infection. The likely course of the disease and outcome for head and neck cancer patients can also be impacted by known risk factors associated with the specific case. For instance, HPV-related head and neck cancers are associated with better prognosis,³ while smoking is associated with reduced treatment efficacy and higher mortality rates.^{4,5} Inequality also plays a notable role in the epidemiology of head and neck cancer, as rates of these cancers are comparatively high and outcomes poor for patients with a low socioeconomic status.⁶

* **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

3

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 and its signs and symptoms in Europe.

According to a pan-European survey (undertaken in Germany, Italy, Poland, Portugal and Turkey) of the general population conducted in 2020, 38% of respondents said they did not know what head and neck cancer was, while 73% were unaware of the disease's symptoms.⁷ While progress seems to have been made since a 2009 pan-European survey that revealed 77% had not even heard of the term 'head and neck cancer', the results from the 2020 survey revealed there is still an urgent need for better education around the disease.⁸

The 2020 results also demonstrated an alarmingly low awareness of risk factors for head and neck cancer. Tobacco use (57%) and alcohol consumption (31%) were relatively poorly identified as risk factors⁹, despite the fact that 75% of head and neck cancers are suspected to be due to tobacco and/or alcohol use.⁹ Furthermore, only 21% of respondents identified HPV infection as increasing chances of developing the disease, despite the prevalence of HPV-related head and neck cancers steadily increasing in Europe.¹⁰

Another insight from the 2020 survey was that symptoms of head and neck cancer are often not recognized or taken seriously, and consequently medical advice is not sought in a timely manner. Across a list of head and neck cancer symptoms, on average only 46% of respondents would visit a healthcare professional should they experience one of the symptoms for three weeks or longer.⁹

As a result of this lack of knowledge about the symptoms and risk factors, it is unsurprising that approximately 60% of people with head and neck cancer present with locally advanced disease at diagnosis.¹¹ Sadly, if a patient receives a diagnosis when the disease has advanced, patient prognosis is very poor. Current estimates indicate that 60% of people diagnosed at an advanced stage die from the disease within five years. As such, there is a clear need for further education of the general public on the disease, its signs and symptoms and associated risk factors.

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 and moderating alcohol consumption. Additionally, HPV-caused cancers can be prevented by vaccination, ideally before exposure to the virus. However, most countries in Europe are not yet vaccinating both boys and girls, despite evidence of its effectiveness. Countries should therefore adopt gender-neutral HPV vaccination programmes for adolescents.
- Secondly, diagnosis must be made during the early stages of the disease. Therefore, programmes offering free screening that are well publicised and in easy-access locations should be available to all members of the European public. An effective example of such a programme is The National Head and Neck Cancer Prophylaxis Program, which was introduced in Poland in 2018 and is funded by the European Union. The scheme offers free screening in 11 facilities covering 16 provinces in Poland for those most at risk for head and neck cancer. It is estimated that by 2023 the programme will have examined approximately 70,000 people.¹²

Pan-European engagement and education

However, 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%.¹³

The lack of knowledge around head and neck cancer, its risk factors as well as its symptoms demonstrate that there is also a clear need for continuing public education about the disease.

Make Sense Campaign

- Established in 2013, the Make Sense campaign is an awareness initiative spearheaded by the EHNS to drive greater education and best practice management of head and neck cancer across Europe.
- 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



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.

4

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, outcomes for the majority of patients 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, biological agents and immunotherapy

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
- Immunotherapy can be used both alone and in combination with drugs for the treatment of head and neck cancer. Immunotherapy often has fewer side effects than anti-tumour drugs and certain patients have experienced remarkable responses on immunotherapy. However, a clear gap remains for most patients, as the majority of patients with recurrent or metastatic disease do not respond.¹⁴

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.

5

STANDARDISING CARE IN EUROPE

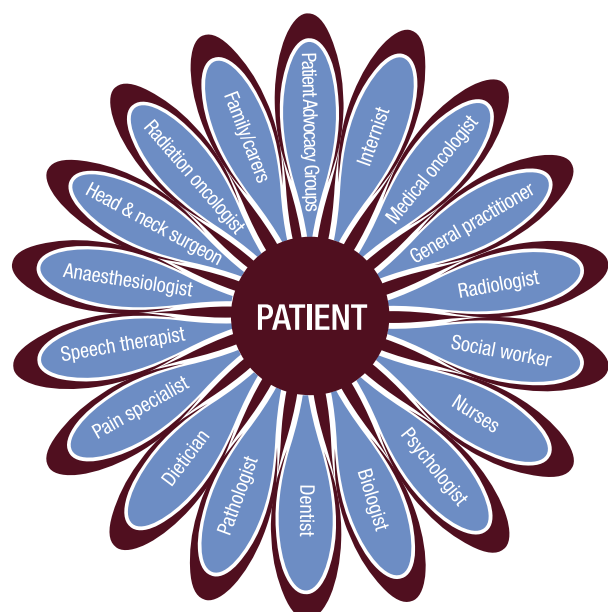
In an effort to standardise care throughout Europe and to encourage equal access to treatment, the European Society for Medical Oncology (ESMO) developed and published clinical recommendations for diagnosis, treatment and follow-up for patients with head and neck cancer in 2009. Eleven years on, there is little sign of uniformity in terms of care across all member states; consequently, patients are not receiving equal access to the best possible. This is especially true of Eastern Europe, where average 5-year survival rates are worse compared to the rest of Europe.¹⁵

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. A 2016 study suggests that in Europe, guidance for implementation of multidisciplinary care is only available in Denmark, Germany, Italy, the Netherlands and the United Kingdom. Even fewer countries have legal requirements on multidisciplinary care (Austria, Denmark, France and Lithuania).¹⁶

The need for multidisciplinary approach to treatment

Appropriate treatment for individual head and neck cancer patients can vary widely due to multiple factors such as age, comorbidities, social issues and need for surgery or radiotherapy.¹⁷ 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.

Who is involved in a MULTIDISCIPLINARY team?



In member states currently offering multidisciplinary care, benefits for both patient and physician have been observed and are outlined below:

- Improved communication, coordination and decision making between healthcare professionals
- Improved accuracy of diagnosis and identification of the stage of the cancer
- 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 access to the most up-to-date treatments
- Improved patient satisfaction
- Improved survival rates

It is worth noting that adherence to the recommended treatment plans devised by a multidisciplinary team (MDT) is associated with improved overall survival in head and neck cancer patients,¹⁸ and reflects the importance of this care.¹⁹ In addition, access to treatment by a MDT is one of the main quality of care indicators for head and neck cancer. These indicators are important for monitoring and improving the quality of cancer care. A 2019 study showed that in countries where multidisciplinary care is more readily available, head and neck cancer patients tend to experience improved outcomes, however quality of care did not reach optimal standards in most countries analysed.¹⁷

Specialised centres and the relevance of international networks

One of the proposed methods for increasing quality of care for head and neck patients is to refer them to specialised, highly-organised, high-volume centres for treatment. As effective multidisciplinary

care requires considerable time, effort and financial resources,¹⁶ it often works best in centres such as these. These centralised high-volume centres have been identified based on predefined criteria, in partnership with patient advocate groups and are associated with better outcomes for head and neck cancers, as quality of care from a specialised MDT is ensured via optimal organisation, facilities, expertise and technology throughout the entire patient journey.¹⁷

It is also agreed that European Reference Networks (ERNs), launched in 2017 by the European Commission, are emerging as essential tools to facilitate multidisciplinary head and neck cancer care.¹⁶ ERNs are virtual advisory board networks created to improve the management of rare diseases across Europe by encouraging communication across medical specialities. Of the 24 ERNs created, three are concerned with rare cancers, with head and neck cancers represented in ERN EURACAN. In addition, the Joint Action on Rare Cancers (JARC) framework, created to maximise efforts of the EU commission, EU member states and stakeholders to advance quality of care and research on rare cancers, is vital. As part of its efforts, the JARC aims to optimise the creation, effectiveness and growth of the ERNs. Simultaneous and integrated international collaboration from networks such as these are paramount to reducing disparity in care and advancing research in rare cancers across European countries.¹⁶

Centralisation for many rare cancers, including head and neck cancer, is limited in many European countries.¹⁷ The implementation of these specialised high-volume centres, alongside establishing and utilising essential novel networks such as ERNs, will have a huge impact on the way head and neck cancer is treated. As such, this healthcare policy should be prioritized to ensure patients across Europe receive optimal care and experience improved outcomes and better quality of life.

6

LIFE AFTER DIAGNOSIS

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; by impacting eating, drinking and speaking, it attacks the cornerstones of social life. Due to these consequences following treatment, head and neck cancer patients are at an increased risk of experiencing loneliness,²⁰ which has been recognised as a public health issue and is linked with poor mental and physical health and worsened quality of life.^{21,22,23}

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. Compounding the problem, survivors may experience stigma and certain levels of discrimination, such as when seeking employment.

Many patients and survivors do not always receive the psychosocial support they need throughout their recovery process and beyond. 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.

European Guidelines

It is vital that head and neck cancer patients receive care from a multidisciplinary team throughout their entire journey with the disease. However, there is currently no European-specific guidance in place that advocates for optimal patient care and a standardised multidisciplinary treatment approach for head and neck cancer survivors. Care practices therefore vary across Europe and survivors often do not receive the support they need.

As part of the care that survivors receive, 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. As a component of this, it is important that support is available to prevent survivors from experiencing loneliness. While some options do exist, more research is needed to identify the best interventions to achieve this.

Self-management in survivorship care

Self-management is a key component of sustainable survivorship care. That said, many cancer survivors need support to self-manage their quality of life and care.²⁴ Behavioural intervention technologies (BITs) use digital media to target behaviours, cognitions and emotions in support of physical and mental health.

Studies have shown that BITs can be effective and possibly cost-effective to support head and neck cancer survivors to improve health-related quality of life and reduce distress and the burden of several head and neck cancer-specific symptoms. Although the European Commission has funded some specific research in this area, such as the BD4QoL project, further research and funding is still needed to improve access to these technologies for patients.^{25,26,27}

Furthermore, routine survivorship care provided to cancer patients falls behind that provided to patients of other chronic diseases in terms of incorporation of proactive self-management support (SMS). This is despite the fact that cancer is often a very complex disease, with high-risk treatments that cause worse side-effects and the potential for long-term disability versus other debilitating chronic diseases.²⁸ This leaves the cancer patient population potentially vulnerable to worse health status, long-term disability and poorer survival. This lack of adequate SMS is particularly detrimental in the case of head and neck cancer, where the inherent emotional and lifestyle-related consequences of the disease are already severe, and highlights the need for improved SMS systems and resources for patients as a standard component of survivorship care.

Rehabilitation may also (partly) 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
- Represent the needs of patients at a national and European scale, such as by supporting the identification and evaluation of high-volume centres for treatment and participating in the EURACAN ERN

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.



CONCLUSION

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

Head and neck cancer is a preventable and curable cancer, yet it continues to kill half of all sufferers. Awareness of the disease is alarmingly low; 73% of the general population in a 2020 pan-European survey were unaware of the disease's symptoms. Early diagnosis and referral save lives. 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.

While treatments have improved for head and neck cancer patients in recent years, it is crucial to continue funding for research to identify new and more efficacious and tolerable treatments.

Finally, we must continue to highlight, and respond to, the critical need for multidisciplinary treatment and survivorship care to ensure that once diagnosed, patients receive the best possible chance of a positive outcome.

Head and neck cancer has a devastating impact on patients and their loved ones, and places a severe burden on European healthcare systems. It is paramount that we take action now. Without support and implementation of our five-point 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.

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