

MAKESENSECAMPAIGN

Campaign Toolkit

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Head and Neck Cancer Overview

Head and neck cancer is a way of describing any cancer that is found in the head or neck region, except in the brain, ears, eyes or oesophagus. The cancers usually begin in the squamous cells that line the moist, mucosal surfaces inside the head and neck (e.g., inside the mouth, nose and throat). There are more than 30 areas within the head and neck where cancer can develop.

Head and neck cancer is the seventh most common type of cancer in Europe. It is approximately half as common as lung cancer, but twice as common as cervical cancer.

Despite its severity and increasing prevalence within society, there is little awareness of head and neck cancer, and patient outcomes remain very poor; 60% of people with head and neck cancer present with locally advanced disease at diagnosis and 60% of people diagnosed at an advanced stage die from the disease within 5 years. However, for those patients diagnosed in the early stages of the disease, there is an 80–90% survival rate.

Risk Factors



Smoking



Alcohol



Human papilloma virus (HPV)

Prevalence

- Men are two to three times more likely to develop head and neck cancer than women, though the incidence of head and neck cancer in women is increasing.
- The cancers are most common in people over 40 years old.
- The connection between HPV and head and neck cancers is increasing in a younger demographic.

Signs and Symptoms

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



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About Us and the Make Sense Campaign

MAKESENSECAMPAIGN

The *Make Sense* campaign is a unique and exciting initiative by the European Head and Neck Society (EHNS), led by Prof. Wojciech Golusinski and Prof. C. René Leemans. The EHNS is a multidisciplinary body that brings medical experts together from many disciplines, including head and neck cancer specialists, oral and plastic surgeons, radiation therapists, medical oncologists, imaging specialists and pathologists. The society also brings together other stakeholders, including speech therapists, cancer nurses, psychologists, physiotherapists, dieticians, social workers, basic scientists and patient organisations involved in any aspect of head and neck cancer.

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 by:

- Educating about disease prevention
- Driving understanding of the signs and symptoms of the disease
- Encouraging earlier presentation, diagnosis and referral

Through the campaign, the EHNS hopes to promote the exchange of knowledge between head and neck cancer experts and the general public/other healthcare specialties.



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How to Get Involved



We rely on your support to promote the campaign at the local level and continue the overall success of the campaign! If you are interested in getting involved, or if you are already involved but want to execute a new activity, use this section to find out more information.

Download Posters

Download and print our posters and distribute them at your event(s) or at a variety of locations (hospitals, offices and/or schools)

Download Leaflets

Download and print our leaflets and distribute them at your event(s) to help educate about head and neck cancer

Download Infographics

Download and share our infographics, which provide easily digestible facts and statistics on head and neck cancer – they are available to support any of your awareness-raising activities

Making Meals Make Sense Cookbook

Download, print and share our cookbook, *Making Meals Make Sense*, which offers support for patients, survivors and caregivers by providing information on nutrition and guidance on cooking tasty, nutritious meals

FAQ Discussion Guide

Download, print and share our FAQ Discussion Guide, which features a comprehensive range of questions developed in collaboration with patients, survivors and caregivers to ask doctors and specialists with the goal of providing support following diagnosis





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How to Get Involved



Tweet, share and post about your activities or events to spread the word on the importance of raising awareness of head and neck cancer. You can also follow us on Twitter: [@MakeSenseCmpn](https://twitter.com/MakeSenseCmpn)



Use our suggested social media posts to tweet and/or share on Facebook to raise awareness of head and neck cancer

Hold Your Own Event

You can also host your own event during the annual Awareness Week - a yearly event held in September which acts as the focal point for the campaign's activities. Some ideas to spark your creativity can be found on subsequent pages, but feel free to come up with your own event!

Participating Countries

To find out if your country is participating in the campaign and view the details of planned local events, please see our [global events map](#).

Looking for More?

For further examples of activities in addition to those shown in this toolkit which may serve as inspiration to get involved, please see our [2018 Results Report](#).



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Suggested Activities

Media Engagement

A key aspect of awareness-raising campaigns is successfully engaging with the media. Creating coverage enables the campaign to reach new audiences and tell its broader story. There are so many successful activities taking place across Europe and elsewhere in support of the campaign, so it's pivotal that we get the word out and get it shared on a larger platform.

Why engaging with the media is beneficial:

- Adds credibility to the campaign
- Makes the campaign more memorable
- Increases probability of audience engagement with the campaign

How to Effectively Engage with the Media

1. Review and adapt (as necessary) the *Make Sense* template press release or develop your own to ensure you create a story that will resonate in your region
2. The different types of media to approach can include:
 - a. Print and online consumer/consumer health media
 - b. Print and online medical trade media
 - c. Broadcast media, including television and radio
3. Develop a list of local/national media to approach, including contact details
4. Ensure you have spokespeople that are available for interviews before conducting your outreach. Spokespeople can include: a local key opinion leader or healthcare professional (HCP), a patient, and/or a celebrity
5. Call and/or email the press release, and localised story, offering your spokespeople for interview to your media list. Regular follow-up phone calls and emails may be required to spark interest
6. Alternatively, you can drive coverage by inviting media to your events

Materials available

- Template press release
- Infographics



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Suggested Activities

Media Engagement - Success Stories



Poland

Throughout the past 7 years, the Polish team have successfully worked with the media in a number of ways, reaching an estimated audience of 22 million people in 2015 and 2016 combined.

To launch the fourth annual Awareness Week, in 2016, the team held a press conference at the Polish News Agency in Warsaw, which was attended by national media. A number of leading head and neck physicians, including the EHNS President, Prof. Wojciech Golusinski, have regularly made themselves available for interview, which has driven broadcast coverage over multiple years.

The Netherlands

Taking an innovative approach to talking about head and neck cancer, and how such a diagnosis can affect your life, the Dutch team organised a pop-style food event in the centre of Amsterdam.

The pop-up truck and event, called 'Patti Speciali' served blended food to the public, highlighting the difficulties that head and neck cancer patients can have with tasting, chewing and swallowing food. The Dutch team invited media and the event was broadcast on national television reaching an estimated 668,000 people.



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Suggested Activities

Celebrity Engagement

Celebrity engagement is an exciting and effective way to increase interest and awareness of the campaign, taking it to a new level and reaching an even wider audience that would not otherwise be possible.

Why engaging with a celebrity is beneficial:

- Adds credibility to the campaign
- Captures audience attention and stands out from the crowd
- Makes the campaign more memorable
- A great way of engaging with media
- Increases probability of audience engagement with the campaign

How to reach out to a celebrity:

It's easier than you might think! The steps below are a good start:

1. Look into celebrities who may have a personal connection to head and neck cancer, as they are most likely to be interested in supporting the campaign
2. [break out] Top tip! Make sure to choose a celebrity who will resonate with your target audience
3. Research contact details of their agency or publicist, or utilise any relationships through your contacts
4. Update outreach materials to personalise for the target celebrity and include specific information on your region to engage interest
5. Reach out to the celebrity contact via email

6. If you don't receive an immediate response, don't be discouraged as it's likely they receive a high volume of emails! Follow up by telephone or another email to ensure the request has been received, and to talk through any questions
7. Once a celebrity confirms interest, develop a comprehensive proposal and briefing document
8. Maximise engagement by involving the celebrity in social media activities, marketing materials and campaigns. They can be a media spokesperson, as well as sharing and reposting campaign messaging on their own social media channels

Materials Available

- Template celebrity outreach letter
- Partnership deck outlining potential partnership opportunities



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Celebrity Engagement - Success Stories



Spain

The Spanish team brought together a wide range of people to help raise awareness of head and neck cancer in 2016, including ex-footballer Enrique Castro González and Top Chef finalist Javier Estévez.

The week kicked off with a press conference and the team's activities garnered a lot of media interest, including 55 online articles, 20 print articles and 1 TV broadcast, with an estimated reach of over 7.8 million impressions.



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Suggested Activities

Early Diagnosis Day Clinics

Early Diagnosis Day (EDD) clinics are set up to inform the general public about the signs and symptoms of head and neck cancer. Typically, they are a free activity, and are held at hospitals, clinics or any central location with a lot of foot traffic. It gives people the chance to get screened, learn about the signs and symptoms and risk factors of head and neck cancer, and have a meaningful conversation with a clinician in a more casual setting.

Why organising an EDD clinic is beneficial:

- A great way to engage with the general public
- Educational opportunity for the general public
- An innovative way to engage with media

How to hold a successful EDD:

1. Work with a contact at a local hospital, clinic or dental clinic who is interested in head and neck cancer
2. Confirm availability of HCPs, including physicians and nursing staff to conduct the screening and identify and confirm a suitable location (e.g., hospitals, shopping centres, football stadiums, factories)
3. Promote the EDD clinic in advance by using posters, leaflets and traditional and social media (translate if needed)
4. Publicise the day:
 - a. Notify regional media that the EDD clinic will take place at least 1 week in advance. Invite them to attend on the day
 - b. Display posters in primary care facilities to advertise
 - c. Set up a booth in the screening location to encourage members of the public to attend
5. Offer information materials and promotional items to all members of the public who take part in the screening day

Materials Available

- Template posters
- '1for3' Signs and Symptoms leaflet
- Template press release, with space for you to add details of EDD clinics
- Limited number of promotional items as giveaways



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Suggested Activities

Early Diagnosis Day Clinics - Success Stories



Russia

The success of the EDD clinics in Russia can be attributed to holding clinics in multiple cities across the country in a variety of locations, including hospitals and factories. The Russian team also worked tirelessly to promote the clinics with the media, which contributed to the fantastic level of attendance.

From 2013–2018, the team, supported by Merck Russia, disseminated the campaign's message of the importance of early diagnosis through their EDD clinics. During this time, the team managed to screen 66,000 people, with thousands of those screened referred for further examinations.



Poland

In 2018, a national screening programme for head and neck cancer was initiated for the first time in Poland. Prior to the launch of the programme, 20 meetings took place across the country in which 1,030 participants comprised of healthcare professionals, students, politicians and the public discussed head and neck cancer and shared their knowledge. The high uptake and success of the national screening programme was attributed to these informational meetings, with more than 1,200 people referred for care.



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Suggested Activities

Creating Partnerships

Partnerships are the cornerstone to a successful campaign year. They help strengthen and increase the reach of our messages, and are essential to ensuring patients, and the general public, are receiving the information that's ultimately for them.

Why partnerships are beneficial:

- Supports wider distribution of the campaign messages
- Can help the messages reach target audience
- Adds credibility to the campaign

How to reach out to potential sponsors:

1. Identify possible partners who might be able, or are interested in, supporting the campaign. They may have:
 - a. A connection to cancer or health
 - b. A link to the target audience
 - c. Corporate CSR programmes
 - d. Funding available for charity support
2. Research contact details and the best person to reach out to
3. Update outreach materials to personalise for target person/organisation. Include regional information, which may strengthen their desire to get involved
4. Reach out to your chosen contact via email and follow up by telephone phone
5. Explain the campaign, our mission and how their support could help

How Partners can get involved:

- Funding for awareness-raising activities
- Support in distribution of awareness-raising materials
- Online support via social media and websites
- Supporting EDD clinics
- Arranging HCP educational events

Partnerships can vary widely in scope. Different types of partnerships can include professional organisation, patient groups, industry sponsors, and/or corporate sponsorship, etc.

Materials Available

- Partnership outreach presentation
- Partner outreach email
- Campaign posters & leaflets



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Suggested Activities

Creating Partnerships - Success Stories



Portugal

In 2015, the Portuguese team partnered with the Portuguese Football Federation. 151 Portuguese football clubs participated and supported the campaign, with 3,314 campaign t-shirts worn by players and referees, and 115,112 people in attendance at the stadiums during the games.

Social media posts also helped to raise the awareness of the campaign, and a Facebook video from Real Madrid and Portugal footballer, Pepe, pledging his support to the campaign received over 110,000 views.



France

A partnership was established with Office Depot, a large office supply company, in France that has a wide distribution network. Tailored posters were designed, produced and shared with the company for distribution, which were distributed across the country. In total, 30,000 posters were distributed and reached a significant number of people, raising awareness of head and neck cancer.





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Suggested Activities

Young Person Education Day

Holding a Young Person Education Day not only raises awareness of head and neck cancer, but assists in explaining the risk factors and prevention measures. In a disease area where early detection is so important, teaching our youth about the signs and symptoms is key.

Why holding a Young Person Education Day is beneficial:

- Raises awareness of head and neck cancer
- Explains risk factors and prevention measures
- Educates about signs and symptoms
- Promotes engagement with social media activities

How to organise a Young Person Education Day:

1. Confirm participation of suitable HCPs and/or patient advisory groups (PAGs) to lead presentation day
2. Identify school age groups suitable for presentations
3. Reach out to key contact at selected school(s), outlining aims of the Make Sense campaign and proposed topic for the education day
4. Develop presentation and corresponding materials (if necessary)
5. Print campaign materials and order promotional items to hand out
6. Encourage attendees to share their thoughts and experiences on social media at the event

Top tip

To engage the audience and achieve maximum impact, share personal stories or case studies. Choose a presenter who will leave a lasting impression of the impact of head and neck cancer, and inspire them to become involved.

Materials Available

- Campaign posters & leaflets



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Suggested Activities

Young Person Education Day - Success Stories



Poland

The Polish team had a very successful year in 2016, hosting a number of different activities across the country, including Young Person Education Days. Educational days took place at schools and universities throughout the country to engage and educate young people on head and neck cancer.

Portugal

In 2014 and 2015, the Portuguese team held Young Person Education Days in schools across the country, educating children on early signs and symptoms. To support the lectures, the team collaborated with the Portuguese Head and Neck Study Group to develop an animated video and accompanying booklet to increase the awareness among children on the importance of oral health. Specialists then used the video and booklet when speaking at elementary schools across the country.



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Suggested Activities

Healthcare Professional Education Events

Communicate the 1for3 signs and symptoms to ensure timely referral rates for patients. It can also help physicians become better equipped to have difficult conversations with patients.

Why holding a HCP education event is beneficial:

- Highlights the importance of early detection and becoming wary of head and neck cancer
- Provides an opportunity for HCPs to connect on best practices
- Encourages a multidisciplinary approach to patient care
- Engages HCPs in the Make Sense campaign and garner support
- Educates on clinical updates in head and neck cancer care to ultimately improve patient outcomes

How to hold a HCP education event:

1. Identify an opportunity or unmet need where a HCP education event would be beneficial
2. Collaborate with partners and healthcare providers to plan a programme and define objectives
 - a. Potential topics can include: Identifying the signs and symptoms of head and neck cancer, the multidisciplinary team approach to patient care, and survivorship
3. Reach out to potential presenters and confirm
4. Finalise details of the event and promote via partners, social media and any other available channels
5. Create materials and/or key takeaway messages for participants to share with colleagues following the event

Materials Available

- HCP leaflets
- Template presentations



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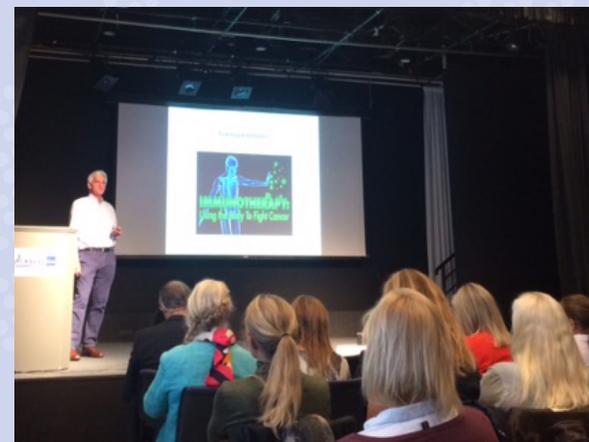
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Suggested Activities

Healthcare Professional Education Events - Success Stories



Norway

The focus of the 2016 campaign in Norway were two HCP meetings, hosted by Merck Norway, in collaboration with the mouth and neck cancer patient organisation.

The first meeting brought together oncologists, dentists, nurses, patients and politicians to discuss the current status of head and neck cancer in Norway. A number of topics were covered, including the link between HPV and head and neck cancer, and the role of dentists in diagnosis. Feedback was positive, with attendees appreciating the education and information provided that covered an unmet need in head and neck cancer.



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Suggested Activities

Engaging with Parliament

Raising the profile of head and neck cancer in parliament is vital to increase the chance of improving head and neck cancer patient care through policy updates.

Why engaging with Members of the European Parliament (MEPs) is beneficial:

- Raises the profile of head and neck cancer in parliament
- Regional MEP support can translate to EU Parliament activities
- Improves potential of improving head and neck cancer patient care through policy updates

How to reach out to MEPs:

1. Identify target MEPs who might be interested to support the campaign. They may have:
 - a. A personal connection
 - b. Interest in head and neck cancer or rare cancers
 - c. Interest in health
2. Health ministers, or those with a history of supporting health or cancer policies, may be a good start
3. Research contact details
4. Update outreach materials to personalise for target MEP and include regional information that may strengthen their desire to get involved
5. Explain the campaign, our mission and how their support could help us
6. Reach out to chosen MEP contact via email and follow up by telephone

Top tips for engaging with Parliament:

- Engage a local PAG/professional group to improve chances of confirming a meeting
- Utilise relationships between contacts and MEPs to organise meetings – strong relationships are critical for success!
- Identify Parliament-focus topics/agenda items and target campaign accordingly
- Don't be disheartened if three or less MEPs attend your meeting, this is still a fantastic result

Materials Available

- White Paper
- Oral Question
- Campaign materials
- Template outreach letter



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Social Media Posts

Topic hashtags: #SupportingSurvivorship #MakeSenseCampaign #HNCSM #HeadandNeckCancer #Cancer #CancerAwareness

Make our voices heard...

One of the simplest and most effective means of communicating our campaign is through social media.

Why using social media is beneficial:

- Increases awareness of the Make Sense campaign and head and neck cancer in a younger audience
- It is a simple and free tool that we can use to increase distribution of campaign messages
- Provides a link between everyone participating in the campaign and an opportunity to interact with others
- Acts as a platform for all countries to share activities and campaign messaging
- Provides a simple and easy partnership opportunity for third-party organisations (e.g., television shows, not-for-profit organisations, and PAGs) by allowing them to support and engage in social media activities – e.g., tweeting, or posting comments in support of the campaign

Top tips for social media:

- Identify your audience and adjust the tone of your messaging accordingly
- Use a free link-shortening service (e.g., bitly.com) when inserting links into posts
- Posts with images are more engaging – always include a photo or visual element
- Keep messaging concise and to the point to engage audience's attention

How to incorporate social media into your campaign:

- Update campaign materials to include information on social media
- Identify opportunities to include information on the social media campaigns in your activities
- Raise social media opportunities with partners to seek their involvement
- Prepare for launch of activities and reach out to networks to secure their involvement
- Direct donations towards the crowdfunding account – (to be set up on Kickstarter)

Unrecognisable digital campaign

To find out about our visually striking digital campaign and how you can get involved, please see the [Unrecognisable toolkit](#).

- Ensure to use any relevant hashtags (e.g., #HNCSM) and use Twitter handles to tag others
- Utilise tweet scheduling tools, such as Hootsuite or TweetDeck, so you may plan your posts in advance
- Encourage others to share your posts
- Interact with followers and engage them in conversation online



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Social Media Posts

We've put together some tweets below – use these to spread the word or create your own:

 #DYK 80-90% of head and neck cancer patients survive when treated early #HNCSM? Know the symptoms & speak to a doctor if you are at risk!

 Over 130,000 patients were screened for #HNCSM in 2016. Join us this week to find out how you can spread the word #SupportingSurvivorship

 September marks head & neck cancer awareness week. Stay tuned to find out more about the symptoms, diagnosis & treatment of #HNCSM

 #HNCSM is a group of cancers affecting cells that line tissues or organs in the head & neck. >600,000 people are diagnosed each yr worldwide

 Today we are offering free early diagnosis sessions at centres across Europe. Are you getting checked? #SupportingSurvivorship

 686,000 people are diagnosed with head & neck cancer every year. Raise awareness & make a difference! #HNCSM

 Lifestyle choices can increase the risk of #headandneck cancer. Watch Ed's story to find out more bit.ly/2bcef4C #knowtherisks

 Head & Neck Cancer Awareness Week starts today. Find out how YOU can participate! #HNCSM bit.ly/2bYm0qZ

 Early Diagnosis Day clinics are set up around Europe today. Find one near you #HNCSM bit.ly/2bYm0qZ

 Infection with HPV can increase your risk of developing head & neck cancer #HNCSM #knowtherisks

 #DYK who's involved in #HNCSM patient's treatment journey? Watch to find out!

 Early #HNCSM diagnosis can save lives. Watch our video to learn about signs & symptoms @cancereu

 Monday is the 5th @MakeSenseCmpn Awareness Week. What you are doing to participate? #SupportingSurvivorship bit.ly/2bWZ4wn

 Youth Education Days help increase awareness of risk factors for head & neck cancer. RT to raise awareness #HNCSM

 #DYK about the link between #HPV & head & neck #cancer? Watch our video to find out more and RT to raise awareness!

 Awareness of symptoms can save lives. Do you know the #HNCSM symptoms? <http://bit.ly/2cMCnYD> RT to spread the word!

 RT to show your support of improved care for patients with head & neck cancer #HNCSM @cancereu



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We are looking forward to having you take part in the campaign. For more information or questions, please contact us: secretariat@makesensecampaign.eu.

