MAKESENSECAMPAIGN



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2016 Key Stats



#UnitingVoices used 311* times



13,529 people screened at Early Diagnosis Day clinics across 279 centres



Website relaunch





775* pieces of original coverage generated

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2016 Key Stats

Attendance at ESMO and ECHNO



TTH EUROPEAN CONGRESS ON HEAD AND NECK ONCOLOGY 7-10 SEPTEMBER 2016 InterContinental Hotel, Budapest-Hungary



Development of Make Sense campaign history published in Springer's Trends in Head and Neck Oncology book



'Best practice guidelines in the psychosocial management of HPV-related head and neck cancer' published in Annals of Oncology

Partnerships



10+ national-level partnerships

Over 19 PAGs participated



Executive Summary

The fourth year of the *Make Sense* campaign saw an increase in participation around the world. Patients, patient groups, physicians, industry partners and even students took part in uniting voices to raise awareness of the signs and symptoms of head and neck cancer, ultimately aiming to improve patient outcomes. Campaign activities for 2016 built on the foundation set in 2015, and by using social and digital media to ensure widespread and effective communication about head and neck cancer, we are a step closer to achieving our goal.

To support the Campaign's continued growth, a key activity for this year centred on revamping the *Make Sense* website. In addition to a redesign, the new website included updated content, new information about the role of HPV in head and neck cancer, an interactive map including all activities around the world and real-life patient stories.

The Campaign also developed practice guidelines for healthcare professionals in the importance of psychosocial management of patients with HPVrelated head and neck cancer. Published in the Annals of Oncology, the Campaign highlighted the link between an HPV-related head and neck cancer diagnosis and the emotional impact that it can have on some patients. Lastly, we were pleased to attend both ECHNO in Budapest and ESMO in Copenhagen.

We are beyond grateful for all the support and contributions we have received this year, from Brazil to France to Russia and South Korea (among many others), the participation has been overwhelmingly positive. Great activities, campaigns and lectures were executed throughout the world and we are already looking forward to next year's activities!



Professor René Leemans EHNS President

"I'd like to thank everybody involved in the *Make Sense* campaign for working incredibly hard to make the fourth year of the Campaign so successful. With that said, there is still work to be done. We know that the head and neck cancer landscape is quickly changing, and we will be working together to change just as quickly to ensure we are ultimately improving patient outcomes."



Professor Wojciech Golusiski EHNS Secretary General

"The fourth year of the *Make Sense* campaign was another tremendous year. We have seen a great increase in the number of Early Diagnosis Day clinics and hope that people will become knowledgeable in identifying the signs and symptoms of head and neck cancer. I must congratulate everyone who has worked on the Campaign and we look forward to seeing you participate next year!"

Partnership Spotlight

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.

European Dental Students' Association (EDSA) This year a new collaboration was formed with the European Dental Students' Association (EDSA). EDSA is a student organisation representing 65,000 dental students across Europe. The scope of their activities include designing and running awareness and prevention projects, both in Europe and internationally.

EDSA supported the Fourth Annual Awareness Week by sharing campaign materials and messages via their social media channels. These posts generated over **25,000** views, and enabled campaign messages to reach new audiences. Building up on the *Make Sense* framework, EDSA has designed additional activities to facilitate patient screenings and awareness events at university dental clinics. In the coming months, EDSA will be executing such events in Sweden and will look to additional screenings in other countries next year.



"Collaborating with the *Make Sense* campaign was the perfect opportunity to help us expand our awareness and prevention projects. The Campaign addresses the important unmet need of raising awareness of head and neck cancer among dentists; dentists are at the forefront of early detection of such diseases. As the voice for the generation to come, EDSA has a key role to promote health and best practices to the next European dental professionals."

Valentin Garyga, EDSA Vice-President

European Cancer Patient Coalition (ECPC)

Our collaboration and close partnership with ECPC continued for the fourth consecutive year, as we work together to improve patients outcomes and move head and neck cancer up the European healthcare agenda. This year, in the absence of a parliamentary event, the team shared campaign messaging throughout their **20,000** membership data base, shared successful patient stories for publishing on the website and developed impactful social media posts.

"The European Cancer Patient Coalition has a long history of partnership and collaboration with the *Make Sense* campaign. Our work together at the European level has helped to prioritize rare cancers, including head and neck cancers, in the EU health agenda. We are looking forward to many more years of working together to increase the awareness of this important and complex issue." Lydia Makaroff, ECPC Director

Partnership Spotlight

Merck

For the fourth consecutive year, Merck proudly supported the Campaign via various activities. One of particular excitement was encouraging Merck employees worldwide to unite their voices and raise awareness of head and neck cancer. The companywide campaign "Letting our tongues do the Talking" called for employees to stick their tongues out, and take a picture for head and neck cancer awareness. The campaign, comprised of internal communications,

design collateral and a Merck Group website 'take over', garnered support from 22 affiliate countries and generated over 200 photos of Merck employees sticking out their tongues. This content compiled 4 GIFs, 1 collage and a wrap-up video and contributed to the engaging global social media campaign, which featured on Merck Group and Merck Oncology Franchise channels. The campaign demonstrated Merck's commitment to early detection and optimal management of head and neck cancer.





the tongue can tell what the eye cannot see.

bon't let head and neck cancer silence your tongue.

> know the signs. Take action now!

Uniting our voices for head and neck cancer awareness

The Fourth European Head and Neck Cancer Awareness Week 19-23 September 2016

n initiative of the Make Sense Cempely

Partnership Spotlight

Boehringer Ingelheim (BI)

The Campaign's continued partnership with BI drives healthcare professional (HCPs) education. Activities within this taskforce are focused on ensuring HCPs are aware of the early signs and symptoms of head and neck cancer, and the importance of an MDT approach to treatment.

Through the development of educational leaflets, including this year's focusing on HPV-related head and neck cancers, our active participation at European-wide healthcare professional congresses, and supporting lectures for HCPs and youth, the Campaign works towards sharing useful and memorable information. This year, activities included:

- Attendance at ESMO and ECHNO, with over 21,000 attendees
- Youth Education days held across 2 countries
- HCP Lectures/Workshops held in 7 countries



Country Results

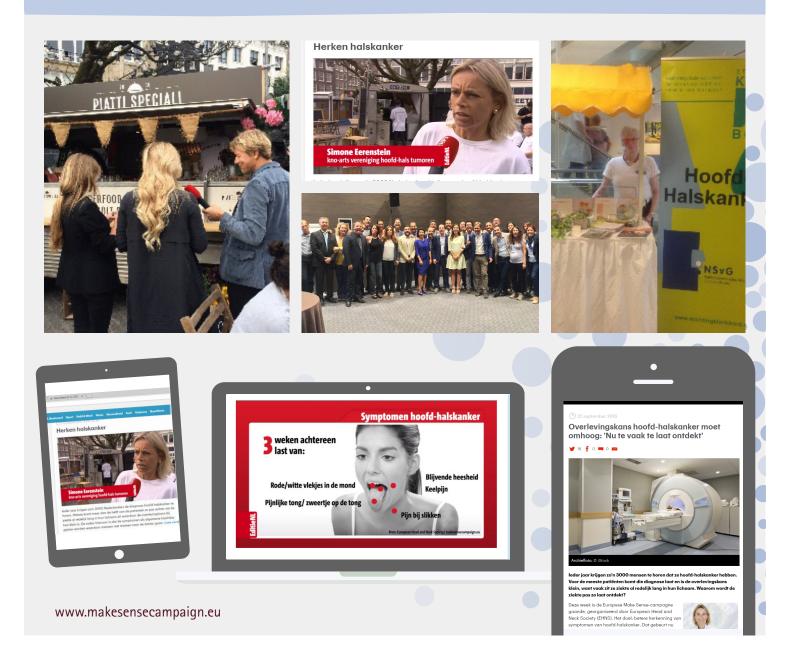


The Netherlands



The Dutch team conducted a number of activities across the Netherlands, with the support of the national patient advocacy group, Patiëntenvereniging HOOFD-HALS and Merck Netherlands.

On Thursday, September 22, the team hosted a surprise event at a food truck in the centre of Amsterdam. Called 'Piatti Speciali', which in English means 'Special Dishes', the truck served special food to the public, highlighting the difficulties that head and neck cancer patients can have with tasting, chewing and swallowing food. Approximately **250** people visited the food truck, and the event was also broadcast on national television. Patiëntenvereniging HOOFD-HALS also organised an event at the Westfriesgasthuis hospital in Hoorn, The Netherlands. The event offered head and neck cancer information, as well as general support for patients. The team garnered media coverage with an approximate reach of over **720,000** impressions and nationwide distribution of campaign leaflets.



Norway

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The focus of this year's campaign in Norway were 2 meetings, hosted by Merck Norway, in collaboration with the Mouth and Neck Cancer patient organisation.

The first meeting took place on Monday, September 19 and brought together oncologists, dentists, nurses, patients and politicians to discuss the current status of head and neck cancer in Norway. The meeting covered a number of topics, including the link between HPV and head and neck cancer and the role of dentists in diagnosis. Those that attended the meeting said that it was educational and provided information that covered an unmet need in head and neck cancer.

The following day, on Tuesday, September 20, another meeting brought together a younger audience to talk about the taboo topics of head and neck cancer, including HPV. The meeting was led by a comedian and sexologist and was streamed live on Facebook, enabling the meeting to be viewed by a far greater number of people who were interested but not able to attend in person.



"I have been to many cancer meetings in my time, this is the very best I have attended."

Karita Bekkemellem, Head of Pharmaceutical Industry Association and former minister in the Norwegian government



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"One does not think that sex can give you cancer. It may give you infections, but not cancer." Student

– Veldig bra møte om munn- og

🖾

halskreft

Dets: 21.09.201

ine uken arrangerte pesielt vellykket fagi

Italy



The Italian team consisting of the Italian Head and Neck Oncologic Society (AIOCC), the Italian Patient Association (AILAR) and Merck Italy held a press conference launching a new online patient platform, 'Persone Che'.

The platform, intended for use by head and neck cancer patients, fosters sharing personal experiences and connects the Italian head and neck cancer patient community together. By uniting voices of patients across Italy, they are truly aiming to improve the quality of life for patients. The Italian team also engaged with media to promote the launch of 'Persone Che', which resulted in **13** pieces of original coverage, and an estimated reach of over **8.6 million** people.



"It's great to see so many people across Europe coming together to raise awareness of head and neck cancer. I am a strong believer in sharing our knowledge and resources with a wide range of people to ensure our messages are reaching those who really need it."

Lisa Licitra, EHNS Member, Italy



Spain



The Spanish team brought together a wide range of people to help raise awareness of head and neck cancer.

The week started off with a press conference, including:

- An ex-footballer and head of the Spanish head and neck cancer patient group, Enrique Castro Quini
- A finalist from MasterChef Spain, Javier Estevez
- Leading oncologists, Yolanda Ramos and Juan Jesus Cruz
- The head of Merck Salud Foundation, Carmen Gonzalez

Throughout the week, 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.

The team also distributed **2,000** leaflets at **10** centres nationwide.



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Kazakhstan



Participating in campaign activities for the first time in 2015, the Kazakhstan team expanded on last year's success and delivered a series of impactful activities.

The team held Early Diagnosis Day clinics at **44** centres across the country, with a total of **1,335** people screened and **183** patients referred. Additionally, the team organised a number of educational seminars in which **530** healthcare professionals participated, including dentists, ENTs and oncologists. The meetings held in **4** cities across Kazakhstan discussed the importance of a multidisciplinary approach in the early diagnosis of head and neck cancer.

The Kazakhstan team also spread campaign messages through a variety of other methods, including billboard advertisement, social media posts and videos, as well as media engagement, which generated **61** pieces of original coverage. Additionally, the team held a press conference dedicated to the Awareness Week results featuring a wide range of people, including Jonatan Weinberg (First Secretary, Economic Department, Germany Embassy), Rogier Janssens (Merck, Head of Biopharma Russia and CIS) and the Kaidarova Dilyara Radikovna (Chief Oncologist of the Republic of Kazakhstan).



Poland

The Polish team had a very successful year, hosting a number of different activities across the country; however, Early Diagnosis Day clinics were the focal point of the campaign.

Held at **33** centres nationwide, **2,084** people were screened and **180** people referred.

The Polish team also held a number of smaller scale meetings with a variety of stakeholders, including a meeting with the Association of Patients with Head and Neck Cancer, which showcased the campaign and its successes over the past 4 years. Youth education days also took place at schools and universities across the country, to provide young people with information on head and neck cancer. The team also held a number of meetings/workshops with healthcare professionals throughout the week, including a head and cancer workshop with nurses, a speech therapy workshop for patients and lectures with doctors discussing the latest treatments in head and neck cancer.

The team generated high levels of media coverage surrounding their activities, reaching an estimated audience of **11 million** people.



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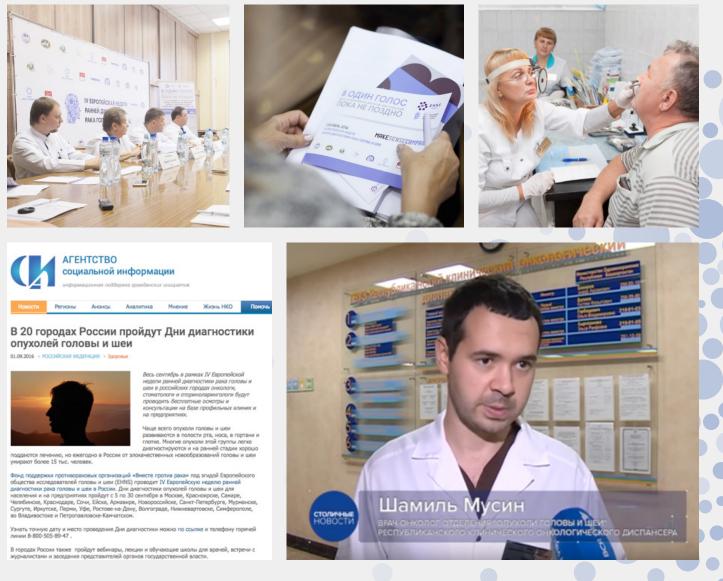
Russia



Clinics took place in **21** cities across the country, in **87** hospitals and **6** industrial plants, with a total of **8,774** people screened. **2,500** people were diagnosed with benign tumours and other pre-cancerous conditions and **570** people referred for further screening. Additional activities included:

- A series of lectures to educate the public on the risk factors associated with head and neck cancer
- Online and face-to-face meetings with HCPs to discuss a number of topics, including the importance of early diagnosis

The team's activities resulted in **96** pieces of original coverage and the distribution of over **28,000** leaflets nationwide.



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United Kingdom



Patient engagement was especially high in the UK, specifically with two organisations very active in raising awareness. In Scotland, newly formed group Head's Up Awareness worked to raise awareness of HPV-associated head and neck cancer.

The three founders, Cath, Sharleen and Kelly – all of who have been impacted by head and neck cancer – are raising awareness of the importance for gender neutral HPV vaccinations. Currently, girls receive the HPV vaccination, not boys. Cath, Sharleen and Kelly conducted a wide range of activities, including: an appearance on Scottish television, fundraising events, as well as a trek across the Great Wall of China. The Campaign has also collaborated with a nationwide head and neck cancer support charity, The Swallows. The Swallows works in various capacities across the UK to support cancer survivors, most notably the group held a head and neck cancer survivorship meeting in Liverpool in November.

The meeting brought together patients and carers to discuss challenging topics surrounding head and neck cancer survivorship. In the coming months, The Swallows will be publishing a support pamphlet and distributing it across Europe and Australia.



"Head and neck cancer is a life changing disease, that has personally impacted Cath, Kelly and I. Support and access to information is essential to being able to get through it, and no matter the person's age social status or background, basic support needs are often very similar. This is why we created Heads Up Awareness, and why we do what we do. We hope that our activities in the UK, along with the Make Sense campaign, can hopefully provide support to survivors."

Sharleen Johnston, Heads up Awareness UK





or head and neck cancer awarene



France



An active participant in the campaign for many years, this year was one of the best for the French team.

The team executed early diagnosis day clinics in 95 clinics around the country! Previous years had 63 and 85 in 2014 and 2015, respectively. Dedicated to ensuring patients are educated about the disease signs and symptoms, the clinics were a huge successes with thousands of people attending to get screened. The team also developed materials and a video to distribute across the country and with doctor surgeries. As a result of their activities, 56 original stories were published in various outlets.

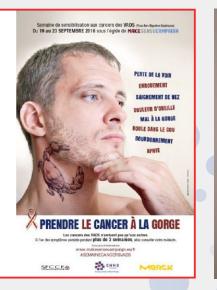
DES CANCERS DES VADS EN PROGRESSION CHEZ LES FEMMES ET LES SUJETS PLUS JEUNES

Video publique

THÉMATIQUES: ONCOLOGIE

Dans le cadre de la semame de sensibilisation des cancers des VADS*, du 19 au 23 septembre, à travers la campagne « Prendre le cancer à la gorge », le Dr Antoine Moya-Plana indique que « les cancers des VADS sont en progression char les femmes à cause d'un tabagisme apparu tardivement et touchent des sujets plus jeunes, entre 40-45 ans, à cause du virus HPV (Human Papilloma Virus). Pour prendre en charge précocement ces cancers, il est important de consulter un méléocin si un symptôme DRL persiste plus de trois semaines. «

* Cancers des voies aéro-digestives supérieures









Noise Digestives Aire Supervises (MADS)

Envoi le 19 Septembre 2016 À **18 273** Personnes :

Ouverture par **11 068** personne: Soit **61% de taux d'ouverture** (en moyenne 25% sur les sujets santé) Suivi de **4746** impressions, soit une taux d'impression de **4**2

CANCERS ORL : LES SYMPTÔMES À CONNAITRE POUR VITE CONSULTER

Article publié par Isabelle Eustache le 20/09/2016



Les signes évocateurs devant mener à consulter

Les **cancers ORL** ou des **voies aérodigestives supérieures** ne touchent pas que les personnes âgées fumeuses et consommatrices d'alcool, mais aussi des plus jeunes et des nonfumeurs. Quels sont les signes qui doivent alerter afin de pouvoir intervenir tôt et les guérir ?

 Des tumeurs aux symptômes non spécifiques qui évoluent rapidement

Portugal



Similar to previous years, the Portuguese team developed and executed a number of events throughout the country over the course of 2016.

Activities included: free screenings in 11 cities during the 78th Portugal Cycling Tour, the launch of a public petition, meetings with members of parliament, distribution of leaflets in supermarket chains and medical centres across the country. The team took every opportunity to engage with the general public, patients and physicians about head and neck cancer. This year's theme showcased that 'there are battles that leave marks"; it showed that head and neck cancer patients go through battle during diagnosis and treatment, and survival leaves marks. They encouraged people to get diagnosed early to help limit the scars that get left behind. Throughout the year, the team engaged media, which resulted in over 160 original articles, including print, broadcast and online.



Non EHNS Country Results



Czech Republic



The Czech team had a very active year with a number of activities taking place across the country, including 3 Early Diagnosis Day clinics, and 4 ear, nose and throat (ENT) clinics, with a total of 150 patients being examined across the 7 clinics.

The team also organised a series of lectures for general practitioners in Brno, Pilsen and Prague with topics covering the importance of early diagnosis in head and neck cancer, the growing incidence of HPVpositive patients and the importance of MDT care during the treatment process. The Czech team also engaged with media by issuing a press release, which resulted in more than 15 pieces of original coverage, including 1 print article, **10+** online articles and **4** TV/Radio broadcasts (TV/radio).



Romania



This year, the Romanian team invested in providing educational materials and resources to raise awareness of head and neck cancer, especially among young people.

Much of the work took place in some of the poorest/ disadvantaged areas of Romania, as they are some of the highest population affected. The Community Health Association partnered with the Romanian team to continuously promote innovative cancer education, support and research that speak to the needs of young people, focusing more on community health delivery systems and their health information systems. ABC Eurodent also joined efforts to help educate individuals to prevent, rather than to treat, by encouraging a simple consult every 6–12 months.

