



**MAKE
SENSE
CAMPAIGN**

Engaging local policy makers

Country toolkit

Welcome

Hello!

If you are reading this, you are likely familiar with the aims of the *Make Sense* campaign and know the challenges that head and neck cancer patients face; despite being the sixth most common cancer in Europe, there is low awareness of the disease and its impact among the general public, healthcare community and policy makers in Europe. There is a vital need to change this and for head and neck cancer to continue to be prioritized among these audiences.

We know that policy makers are a vital audience if we want to secure meaningful change. **We are therefore delighted to be sharing this toolkit with you, which is intended to provide you with the information, techniques and tools for you to adapt and use to engage local policy makers.** It is a step-by step guide that will allow you to engage with your policy makers in a meaningful way leading up to the 2021 Awareness Week; from making initial contact through to building more awareness for your key aims.

The *Make Sense* campaign has for some time been advocating moving head and neck cancer up the agenda at a European Parliament level, focusing our efforts primarily on the following key priorities:

- Better promotion of prevention strategies for head and neck cancer
- Support for early diagnosis and referral to qualified healthcare professionals
- Integration of multidisciplinary care as a standardised best practice approach for patients across Europe
- Achieving the highest standards of post-treatment care and ensuring no disparities across Europe
- Dedication of EU and national research and innovation funds to further research on head and neck cancer

It has been deeply encouraging to see the progress that has been made over the last couple of years, such as the inclusion of head and neck cancer in Europe's Beating Cancer Plan, as greater prominence to head and neck cancer is something we have been campaigning for some time. Additionally, the establishment of EURCAN – the European Reference Network (ERN) dedicated for rare adult solid tumours - demonstrates EU commitment to rare head and neck cancers.

However, to continue this momentum and to make the biggest impact, it is crucial that country teams also engage local policy makers. By working together, we can make the biggest impact and have the best chance of getting policy makers to pay attention and take action. With challenges and priorities varying significantly by country, the approach outlined in this toolkit will also allow you to highlight specific priorities and actions that are needed in your country.

Should you have any questions or require further support, please do not hesitate to reach out to the *Make Sense* campaign Secretariat, whose details you will find at the end of this document.

We hope you find this toolkit a useful resource and we very much look forward to seeing your activities!



René Leemans



Lisa Licitra



Wojciech
Golusiński

Professor René Leemans
Make Sense Campaign Chair

Professor Lisa Licitra
Taskforce lead

Professor Wojciech Golusiński
EHNS President

A decade of awareness raising and calling for change at a European level, but what's next?

Head and neck cancer introduced as a topic and action points set out for change, through **launch of campaign White Paper** at EU Parliament

Sept 2013

Written and oral question submitted on care standards for rare cancers, and debated within the Environment, Public Health and Food Safety Committee (ENVI)

Sept 2014

Supporting Survivorship meetings held in EU Parliament, discussing post-treatment care of head and neck cancer patients

Sept 2017 – Nov 2018

Providing an update on head and neck cancer priorities and calling for change with **the launch of second campaign White Paper** at EU Parliament

Sept 2020

Response letter sent to the EU Commission to hold them to account following the **publication of the EU Cancer Beating Plan**

Feb 2021

Launch of Campaign pledge, to be signed by key stakeholders and shared with EU Commission during 2021 Awareness Week

June 2021

Country-level action that seeks to address local challenges faced by people living with head and neck cancer

Read on to find out how to make this a reality...

Overview of toolkit contents

This is intended to be used as a step-by-step guide; we encourage you to action each step in the order they appear.
Click below to go to each section

• Advocates	5
• The importance of advocates	6
• Develop a central policy resource	7
• Approach the right contacts	8
• Hold an introductory meeting	9
• Maintain contact	10
• Awareness	11
• The importance of growing awareness	12
• Host an event	13
• Make an impact on social media	14
• Generate media coverage	15
• Analysis	16
• The importance of analysis	17
• How to measure impact	18
• Useful information and resources	19
• Contact and support	21

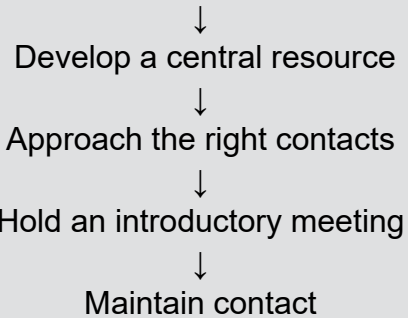
Advocates



The importance of policy maker advocates

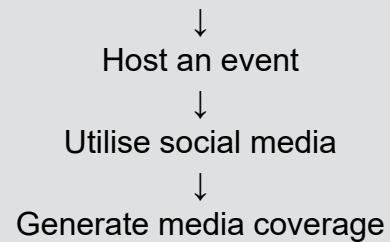
Advocates

The importance of advocates



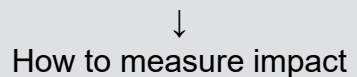
Awareness

The importance of awareness



Analysis

The importance of analysis



Useful information and resources

A vital means of improving outcomes for patients is to create meaningful change at a legislative level. Head and neck cancer is one of the most common cancers throughout Europe, but the burden of the disease, on those directly affected and on the wider healthcare system, is under-recognized. It is therefore crucial that head and neck cancer is on the healthcare agenda and that policy makers understand the need for change, supporting and championing our cause.

To achieve this, we must work with policymakers to ensure they understand the risk that head and neck cancer poses and can act as advocates for our cause.

The information in this section will provide you with guidance and resources for approaching and working with policy makers.

Action Pledge 2021

The Campaign has launched our Take Action on Head and Neck Cancer Pledge, which we are encouraging key stakeholders to sign to demonstrate their commitment to change: [Action Pledge 2021 \(makesensecampaign.eu\)](https://makesensecampaign.eu)

As part of your activities in this section, we encourage you to direct your audiences to sign the pledge. We plan on sharing the signatories of the pledge with the European Commission during the 2021 Awareness Week.

Step 1: Develop a central policy resource (White Paper)

Advocates

The importance of advocates



Develop a central resource



Approach the right contacts



Hold an introductory meeting



Maintain contact

Awareness

The importance of awareness



Host an event



Utilise social media



Generate media coverage

Analysis

The importance of analysis



How to measure impact

Useful information and resources

Before meeting with policy makers, you need to decide what you want to communicate to them and what policy actions and change you are asking for. **It is therefore important to develop a document that sets out your key messages and action points, also known as a White Paper.** This document should highlight the challenges and needs specific to your country, and set out the actions needed at a policy level to address these challenges.

We developed the [2020 Make Sense Campaign European White Paper](#) to outline the key issues at a European level, focusing on incidence, diagnosis, treatment and survivorship, as well as the crucial actions we need policy makers to take (our 'Call to Action').

You can use this [European White Paper](#) as a basis to develop your own country-specific White Paper, adapting any statistics or specific areas of focus as necessary. Resources that may be useful to help develop this are available on page 20. Alternatively, you can create a shorter document or one page highlighting the key actions needed (for example, page 5 of the European White Paper).

Where possible, we recommend developing this paper in collaboration with key local stakeholders including: HCPs across various specialities, patient advocacy groups and industry representatives.

Please email the Secretariat if you would like to upload your country White Paper or resource to the relevant language [Make Sense campaign website page](#), along with any accompanying copy (as needed).

**White Paper
design files**

Click to download

Step 2: Identify and approach the right contacts

Advocates

The importance of advocates



Develop a central resource



Approach the right contacts



Hold an introductory meeting



Maintain contact

Awareness

The importance of awareness



Host an event



Utilise social media



Generate media coverage

Analysis

The importance of analysis



How to measure impact

Useful information and resources

Now that you have outlined your position through your White Paper, you need to identify the best people to share it with. As part of your outreach **we recommend you offer to meet with them to discuss your aims and how you may be able to work together.**

You may already have existing contacts which you can leverage, but if not, you may want to consider:

- Your country representative Members of European Parliament (MEP)
- Members of your national parliament

You can find a list of your national parliament members via Google. A link to the full list of MEPs is available on slide 20.

In the supporting resources, there is further guidance on who to approach as well as template outreach messages that you can adapt.

Template outreach email

Click to download

Key supporting messages

Click to download

Step 3: Hold an introductory meeting to communicate your aims

Advocates

The importance of advocates



Develop a central resource



Approach the right contacts



Hold an introductory meeting



Maintain contact

Awareness

The importance of awareness



Host an event



Utilise social media



Generate media coverage

Analysis

The importance of analysis



How to measure impact

Useful information and resources

During your first meeting with a policy maker, you will want to introduce yourself, your aims and what you are trying to achieve. This meeting can be held either in person or virtually via a platform like Zoom.

The objective of a first meeting is to cultivate a relationship with the policy maker, so they are willing to be an advocate for your cause. Some examples of how they could support you include:

- Join or speak at an event (see Pages 12 and 13 for more information)
- Promote your cause on social media
- Draft a foreword to your White Paper

Before you hold the meeting, it is vital you know what you want to ask them to do.

The supporting resource has an example meeting agenda which you can adapt, as well as some additional information on other attendees you may want to invite to this meeting.

**Template
meeting
agenda and
attendee
guidance**

Click to download

Step 4: Maintain contact

Advocates

The importance of advocates



Develop a central resource



Approach the right contacts



Hold an introductory meeting



Maintain contact

Awareness

The importance of awareness



Host an event



Utilise social media



Generate media coverage

Analysis

The importance of analysis



How to measure impact

Useful information and
resources

Now that you have met with the policy maker, they should hopefully understand your aims and will be happy to participate in your suggested activities.

Remember: The most valuable relationships for creating meaningful change will be those that are maintained long term, so make sure to keep any local policy makers up to date with new opportunities to support the Campaign as they emerge or any key updates on your activities throughout the year.

Ideas on how to keep up contact include:

- Following and engaging with them on social media
- Sending relevant articles of interest/new research
- Keeping them up to date with your activities and news
- Meeting for virtual or real coffee

Awareness



The importance of building broader awareness

Advocates

The importance of advocates



Develop a central resource



Approach the right contacts



Hold an introductory meeting



Maintain contact

Awareness

The importance of awareness



Host an event



Utilise social media



Generate media coverage

Analysis

The importance of analysis



How to measure impact

Useful information and
resources

Now you have created your White Paper and made connections with some key policy makers, you are ready to formally launch your White Paper – ideally during the Awareness Week in September. The activities suggested in this section will help to build awareness for your key messages in two ways:

1. An official launch will ensure the White Paper reaches as many policy makers as possible (beyond your initial advocates).
2. Your activities at a policy level will also provide valuable content for building broader awareness with other audiences, including the public and HCPs.

This section of the toolkit focuses on how to launch your country White Paper and how the launch can be leveraged to reach a wide audience via events, social media and traditional media coverage.

Step 1: Host an in-person or virtual event

Advocates

The importance of advocates

↓
Develop a central resource

↓
Approach the right contacts

↓
Hold an introductory meeting

↓
Maintain contact

Awareness

The importance of awareness

↓
Host an event

↓
Utilise social media

↓
Generate media coverage

Analysis

The importance of analysis

↓
How to measure impact

Useful information and
resources

The most impactful way of launching your White Paper is by holding an event at your local parliament. This is your opportunity to highlight your key messages and build awareness with policy makers of the head and neck cancer burden in your country.

Some recommendations for creating and hosting an impactful event:

1. Partnering with your MEP or a local parliamentarian who you have already identified as a potential advocate to host the event can help with attendance and ensure a smoother process when it comes to the logistics of arranging the event with your local parliament.
2. It helps to host the event at a relevant time – we recommend during the Awareness Week. This takes place every year during the third week of September; in 2021, the dates are September 20-24.
3. Making sure you have engaging and relevant speakers will be vital to creating an event that policy makers want to attend and will help ensure your messages are delivered with impact.
4. If an in-person event is not possible, it can also be hosted virtually (on Zoom, for example).

Our template resources will assist you in organising the event, including guidance on speakers, a speaker invitation and example event agenda.

**Guidance on
event speakers**

Click to download

**Template
speaker
invitation**

Click to download

**Template
meeting agenda**

Click to download

Step 2: Utilise social media to drive awareness of your White Paper

Advocates

The importance of advocates



Develop a central resource



Approach the right contacts



Hold an introductory meeting



Maintain contact

Awareness

The importance of awareness



Host an event



Utilise social media



Generate media coverage

Analysis

The importance of analysis



How to measure impact

Useful information and resources

The launch event for your White Paper with policymakers is a great opportunity to continue building awareness with your other target audiences, too. Sharing content around the event on your existing social media accounts is an effective way of doing this.

Ideas on how to build awareness via social media:

- Create a specific hashtag for the event and make sure everyone involved knows to use this in all posts.
- Share posts ahead of the event to inform your followers about it and build excitement.
- Encourage attendees to also share content on their own channel during and after the event. If possible, it is helpful to provide them with a standard post or graphic that they can use for ease.
- Share live content on your channels during the event. By focussing your social media activities within a specific timeframe – and asking others to do the same– you are likely to make the biggest impact.
- Reach out to your relevant contacts before the event to encourage them to share your content during the event to increase the reach of your messages.
- All social content should direct your followers to find out more – e.g., link to the *Make Sense* website where your White Paper is hosted (see slide 7)
- Targeted paid promotion can further boost the reach of your social content.

Template social content

Click to download

Our template resource will guide you on what to post on social media.

Step 3: Generate media coverage using the launch of the White Paper

Advocates

The importance of advocates



Develop a central resource



Approach the right contacts



Hold an introductory meeting



Maintain contact

Awareness

The importance of awareness



Host an event



Utilise social media



Generate media coverage

Analysis

The importance of analysis



How to measure impact

Useful information and resources

Media engagement is another effective way of using the launch of your White Paper and your parliamentary event to reach a broader audience with your key messages on the importance of taking action against head and neck cancer.

Firstly, you will need to identify the media outlets and contacts that would be interested in the story. Types of outlets to consider are:

- Health reporters at national newspapers
- Specific local magazines or online outlets that cover politics/policy
- Regional outlets that cover the area where your parliament is based (e.g., The Brussels Times)

Secondly, you will need to decide on your pitch angle. Ideas for story angles include :

- Key action points from the White Paper
- Information about the event and participants, and why it's taking place
- A patient's experience
- HCP testimonial

Our template resources will guide you on how to position your story and how to reach out to media.

Template media pitch note

Click to download

Supporting information

Click to download

Analysis

The importance of analysing your impact

Advocates

The importance of advocates



Develop a central resource



Approach the right contacts



Hold an introductory meeting



Maintain contact

Awareness

The importance of awareness



Host an event



Utilise social media



Generate media coverage

Analysis

The importance of analysis



How to measure impact

Useful information and
resources

Measuring the impact of your activities will be important to track your progress and to demonstrate to policy makers the value of your activities in order to maintain momentum in the future.

The next slide contains some suggested metrics that you can use to measure the impact of the actions outlined earlier in the toolkit.

The *Make Sense* Secretariat also consolidates a results report after each Awareness Week, and we would love to showcase your successes in this document; please do get in touch to share your results and any accompanying images with us! Our contact email is at the end of this document.

How to measure your impact

Advocates

The importance of advocates



Develop a central resource



Approach the right contacts



Hold an introductory meeting



Maintain contact

Awareness

The importance of awareness



Host an event



Utilise social media



Generate media coverage

Analysis

The importance of analysis



How to measure impact

Useful information and
resources

Below are some suggested metrics you can use to track the impact of your activities once they have been completed.

White Paper

- Number of views/downloads (*if hosted on the Make Sense website, please reach out to the Secretariat for these details*)
- Any tangible next steps taken in Parliament

Launch event

- Number of attendees, highlighting any notable networks or influential individuals
- Number of policy makers reached

Social media

- Number of posts
- Number of impressions, shares, likes etc.
- Notable posts or interactions, highlighting any specific individuals who engaged

Media coverage

- Number of articles
- Page views/ outlet reach
- Article shares online

Useful information and resources

Useful information sources to support your activities

Advocates

The importance of advocates



Develop a central resource



Approach the right contacts



Hold an introductory meeting



Maintain contact

Awareness

The importance of awareness



Host an event



Utilise social media



Generate media coverage

Analysis

The importance of analysis



How to measure impact

Useful information and
resources

These resources may be helpful to support your activities:

- [Full list of current MEPs](#)
- [Global Cancer Observatory](#)
 - For epidemiological data that can be sorted by country, as well as information on cancer causes, future trends and other graphics
- [Europe's Beating Cancer Plan](#)
- [RARECARE: Information Network on Rare Cancers](#)

Each year, the Make Sense campaign creates a number of resources aimed at the EU parliament. We strongly urge you to leverage these and share them with your local policy makers, to raise awareness of the key issues and as a way of maintain contact (see page 10 for further ideas).

Existing *Make Sense* campaign policy materials include:

- [White Paper](#) (Sept 2020)
- [Europe's Beating Cancer Plan: Letter of Response](#) (Feb 2021)
- [Make Sense Campaign Pledge](#) (2021)
- [European Parliament Event Factsheet](#) (Nov 2019)
- [European Parliament Event Call to Action](#) (Nov 2019)

Contact and support

The *Make Sense* Secretariat is here to help!

We are on hand to support you! Please do keep us in the loop about your plans and get in touch should you require any feedback or advice on your activities and materials. We also love to see your results, and will usually be in touch following the annual Awareness Week to hear about your activities.

Should you require any assistance or have any questions about the activities described in this toolkit, as well as any general enquiries about the Campaign, please do not hesitate to contact the Secretariat!



secretariat@makesensecampaign.eu

WWW

www.makesensecampaign.eu



Make Sense Campaign



@MakeSenseCmpn