DIGESTIVE CANCERS EUROPE

ADVOCACY POLICY TOOLKIT ON CRC SCREENING

Introduction

Each year, around **500.000 European citizens are diagnosed with colorectal cancer (CRC), and around 250.000 people die from this disease in Europe every year.**[1] CRC is preventable in many cases and treatable if diagnosed in the early stages.[2]

Formal population screening is one of the most effective ways to reduce the burden of CRC. For this reason, in 2003 the Council of the EU introduced the Recommendation on Cancer Screening[3], providing a platform to tackle major cancers, including CRC, through **early and preventative action.** In addition to the Recommendations, there are EU guidelines for quality assurance in CRC screening and diagnosis, which advise how formal population screening should be performed and monitored in order to assure quality and effectiveness.

In some European countries or regions, CRC screening is well-organised, e.g., in Slovenia, the Basque Country in Spain and the Netherlands. In most Member States, however, CRC screening does not follow the EU Recommendations and there is great room for improvement.

Given many scientific developments of the last 20 years, the European Commission is now working on updating the Council Recommendation, which will be presented in 2022, as part of the Beating Cancer Plan implementation. Since 2003, the challenge of several cancers has grown, and we now know that the New Council Recommendation **could set the base for saving hundreds of thousands of lives.**

Raising awareness and engaging with politicians in EU Member States would have a tremendous added value for better policies not only at national, but also at EU level.

About This Policy Toolkit

The purpose of this document is to provide you with counsel and support for engaging with policymakers, media, other patient organisations, and medical societies to raise awareness of key issues and drive change on CRC screening.

Becoming active at the policy level, through providing expertise and resources to policymakers, can be the main contributor to solving healthcare disparities, such as the one of CRC screening. Driving a policy change is also called **advocacy.** The ambition of the policy toolkit is to develop a living resource that will equip you **with practical guidance on how to:**

- Establish your policy advocacy goal, objectives and policy ask
- Reach out to key stakeholders
- Prepare the first engagement with stakeholders
- Achieve constructive collaboration in favour of the end goals

When considering the guidance outlined in this document, adapt the practical tips and language to the specific political, social and cultural context of your country.

[1] Source: ECIS - European Cancer Information System. From https://ecis.jrc.ec.europa.eu, accessed on 04/01/2022. © European Union, 2022.
[2] The process of detecting cancer or precancerous growths in the colon or rectum.
[3] As regards CRC, the document recommends screening for all individuals from 50 to 74 years of age using the faecal occult blood screening test (FOBT).

1. Preparation: Establish Your Advocacy Goal, Objectives and Policy Ask

If you already established your policy goal, objectives & policy ask you can disregard this section and proceed to section 2) Outreaching to key stakeholders.

Establishing your goal and objectives is essential for your advocacy efforts.

Your **goal** is the long-term **desired outcome,** whereas the **objectives** are the **steps** needed to reach the set goal. Based on the goal and objectives, a **policy ask should be developed.** A policy ask is a recommendation aimed at a policy stakeholder with the purpose of achieving your specific goal. The policy ask for policymakers need to be concrete and realistic and be based on the particular situation, in this case, the situation of CRC screening in your country. Below, you can find a simple step-by-step process to establish your goals & objectives.

Step 1:

Analyse the current situation of CRC screening in your country and investigate existing national/regional policies. In case you are aware of the policies that are in place, check if there were any updates, whether these are implemented and what are current practices. Be ready to do google research!

These are the questions that might help you analyse the CRC screening situation in your country:

- What are the incidence and mortality rates for CRC in your country? How do these rates compare to the neighbouring countries?
- What is the percentage of patients with CRC diagnosed at stage 1? And at stage 4?
- Is there a National Cancer Plan and a formal screening for CRC within the Plan?
- Is there a formal population-based CRC screening or a non-population based (opportunistic or pilot programmes)?
- What is the test being used?
- What is the target population (age group)?
- How are citizens invited to participate in CRC screening?
- If FIT is being used, is it sent together with the invitation letter? If not, how/where one can collect it?
- What is the participation/uptake rate?
- What is the colonoscopy compliance rate (percentage of citizens that undergo follow-up colonoscopy out of the number of citizens with positive FIT)
- What is the time-frame for the follow-up colonoscopy to be performed?
- Are the figures from the screening programme publicly available?
- Are the figures regularly analysed to improve the performance of the screening programme?
- Is there an awareness campaign to improve the knowledge of citizens on the importance of early CRC diagnosis?
- What is the official budget of the programme currently in place? What are the estimated economic losses resulting from a lack of screening?

Step 2:

Based on the analysis, determine the goal of your campaign. What do you want to achieve in the long-term?

Step 3:

Develop your policy ask. General examples could be to:

- Establish a screening programme at regional and national level and implementation plans to achieve the committed goals of 65% participation rate among citizens between 50 and 74 years old as a multidisciplinary and multi-stakeholder effort
- Improve the participation rate
- One of the failures of many screening programmes is that they measure participation as,*having done a FIT test* and not adherence to biennial FIT screening. A single FIT test is not adequate and programmes need to monitor adherence
- Involve patients in awareness campaigns organised by the programmes
- Invest in annual inputs and outcomes metrics as well as in technologies and human resources
- To ensure that total health economic value is measured
- Ensure coherence and consistency of the political vision and health policy approaches at local and national level
- Ensure that regional and national results are monitored and shared at the European level
- Involve every stakeholder and put patients in the centre

Step 4:

Create an action plan including:

- Short-term objectives (e.g. meet with a number of politicians at regional, national and European level and present them your long-term goal; organise an event; speak at a conference).
- A credible and consistent message for your advocacy campaign, based on a list of facts & figures, studies and their outcomes (always reference your data). Remember to link the consistent messages with your policy ask prior to a meeting with a policymaker or other stakeholder.

Some of the good performing CRC screening programmes have the following characteristics:

- Are population-based, screening citizens in the age group 50-74 years using FIT
- Have active invitation/mailed outreach as well as advance notifications informing citizens why it is important to participate in the screening programme and do the test; sometimes, this information is coming from the GP's office
- Include test with the invitation which was very useful during the COVID-19 pandemic
- Send reminders to non-participants
- Have participation rate (percentage of citizens that participate/are tested in the screening programme out of the population invited during a certain period of time) of more than 65%
- Have the waiting time off follow-up colonoscopy of less than 6 months
- Analyse on an annual basis figures that are collected to improve the performance of the screening programme
- Organise awareness campaign to increase the citizens' knowledge on the importance of early cancer diagnosis; these could be organised jointly with patient advocacy organisations
- Have strategies developed to reach out to vulnerable populations such as racial/ethnic minorities and low-income, veteran, and rural populations, exhibit lower screening uptake
- Have sustainable funding

Having a goal and objectives is not enough to achieve the outcome you want. Like so many things in life, careful preparation can be the differentiating factor for reaching your goal. Understand the scope of your goal, the time you have to accomplish it, and any given resources required to help you develop a sound plan to achieve your goal. Once you have your goal & objectives fixed, you can move to the next step: outreach to stakeholders.

2. Outreach to key stakeholders

Now that you have your story straight, you can move ahead with finding and reaching out to the stakeholders that are relevant to your cause. **Below you will find a step-by-step guide on 1) how to identify stakeholders relevant to the topic of screening, and 2) contact them.**

2.1 Identify stakeholders

When it comes to political stakeholders, it is important to find political stakeholders that are receptive to the problem your raise and the corresponding solutions you propose. This will increase your chances of meaningful collaboration. These are political stakeholders that are expressing interest in health through, for instance, their ongoing work, membership in health-related committees within the national parliament, involvement in key legislative files and expressed political interests (events, interviews, social media accounts, and so on).

Ways to find non-political stakeholders (including organisations) are somewhat similar to the ways to find political stakeholders.

Below you can find a table providing you with a simple guide on how to locate CRC-receptive stakeholders.

How to Identify Stakeholders

Possibilities	Actions
Local, regional and national parliament websites*	Every parliament has a committee that is devoted (entirely or partly) to (public) health. Usually, on the website of your local parliament, you can find the list of members of such committees. Those Members of Parliaments (MPs) that constitute a health-related committee are often focused on healthcare within their parliamentary activities. In some countries, MPs have their website, which can provide useful information in terms of the MPs specific areas of interest. **Check parliaments' websites.**
Following debates in the health committee of the parliaments*	Many committee meetings are open to the general public and can be followed online. The agenda of when such meetings are taking place, including the topics to be discussed, can be found usually on the parliaments' website. Those meetings are likewise great ways to hear about what policymakers think about certain topics and which topics they specifically raise in discussions related to healthcare. **Follow debates and subscribe to RSS newsfeeds if possible.**
Regional and national health authority websites*	Be sure to check regional and/or national health authorities' websites. These websites include the organisation of the authority as well as publications on the latest events and conferences where speakers can be identified. **Check regularly health authorities' websites.**

Twitter	Many stakeholders are active on Twitter. It is a social media (SM) platform used by them to express their interests and priorities, and, as such, for you to find fitting stakeholders for outreach. • **Finding stakeholders through hashtags:** by searching for relevant hashtags (#) in Twitter's search bar, you may come across people who have used that hashtag in their posts. Examples of hashtags to search with would be (translated to your language): #CRCscreening #colorectalcancer #healthscreening #cancerburden #earlydetection • **Looking up stakeholders you previously found:** Twitter can also help in informing you about certain stakeholders that you found elsewhere, such as a parliament website or an event attendee list. Simply look up the name and skim through his or her profile; if he or she is active, you will be able to find some large clues on his or her priority areas and interests. **Follow designated political and non-political stakeholders interested in (CRC) screening.**
LinkedIn	This platform is another SM channel used to express ideas and perspectives on certain issues. To find posts from stakeholders, simply make sure to have a broad network and regularly scroll your feed. Moreover, certain political figures, as well as organisations, have their own dedicated LinkedIn accounts: make sure to find them and follow their activities. If you would like to search in a more targeted way, you can search for key terms in the search bar, e.g. colorectal cancer, cancer screening, and CRC screening. **Connected with designated political and non-political stakeholders interested in CRC screening and follow the pages of the policymakers and organisations.**
List of attendees at relevant events	When attending online/in-person events on healthcare topics, be sure to check the list(s) of attendees of the event. Often, it is easy to identify stakeholders and their affiliations through a publicly available list of attendees of a certain event. **Make sure to always take with you attendees lists of the events you attend.**
Participating in virtual events	By listening in events, you may encounter stakeholders interested in a particular topic. For instance, often events host open discussions sessions (or Q&A sessions), where stakeholders get the opportunity to express their standpoint on how the issues should be addressed. Having been made aware of that person thanks to an event that you attended also provides a nice opening for when you are eventually reaching out to him or her. **When you participate in virtual events, engage with the stakeholders interested in the same topic through the chat option or note down her/his email to reach out after the event.**
Participating in in-person events	In-person events allow you to approach relevant stakeholders. However, be mindful that when having the chance of encountering stakeholders in person, you should have your speaking points (so-called elevator pitch) ready at all times. In the next section (first engagement), you will find more tips and tricks on how to properly prepare such points. **Make sure to practice your speaking points before attending the event.**

* Only for political stakeholders

2.2 Contact stakeholders

Once you have identified the stakeholders you want to approach, it is time to outreach to them: via email, social media and in-person.

VIA EMAIL

Drafting an email is the most common way for outreach because it allows you to craft your message without time restraints. When reaching out to a policymaker or non-political stakeholders, make sure that you create a brief, concise and courteous text, and remember to maintain formality.

Although there are many approaches to writing an outreach email, your communication should include:

- **Introduction:** who you are and why you are writing (briefly explain the issue of concern)
- **Link:** connect your topic of interest to the policymaker/stakeholder activities
- **Ask:** what you want to achieve (for example, the population-based CRC screening, improve screening uptake, enable access for the vulnerable population, lower the waiting time for the follow-up colonoscopy, lower the screening age, e.g. from 55 to 50, etc.)
- **Explanation:** how the issue affects the patient community
- **Next steps:** outline the next steps, e.g. the offer to **meet and provide a specific date and time, confirm that you will set up and share the Zoom or Team link**
- **Team communication:** always include a colleague in the CC of the emails.

Lack of response?

Should you not receive a response in the following days, there is no reason to get discouraged. Important stakeholders are often busy and, in many cases, their lack of response is not a sign of disinterest, they might have simply overlooked your email.

A solution for this can be to follow-up: the rule of thumb is to give the stakeholder one week to respond, and after one week you can send another short email, a " Kind reminder", referring to your previous email and asking whether that person already has had the chance to consider it. Another option would be to follow-up by phone in case you have the phone number. This often proves fruitful. Be sure to follow up your phone call by a short email to recap your discussion and write down your request. Keep in mind that this should also be done after a week of no response, to be sure you do not seem too aggressive.

VIA SOCIAL MEDIA (SM)

With the rise of SM, you are given new ways to communicate about your matters; there are several SM channels at your disposal: Twitter, Facebook, LinkedIn or Instagram. The primary social network used by policymakers depends always on the country where you are located – however, in most cases, it is Twitter. Find an account of a policymaker/stakeholder on social media and click 'Follow'.

- Regularly Tweet about your work and actively engage with the chosen accounts by mentioning them in your Tweets (using the '@' sign).
- If a stakeholder tweets about an issue relevant to you, retweet (share) it and mention your work/statement on the issue.
- Send a direct message to ask for an in-person meeting. Keep your message short.

IN-PERSON – AT THE EVENT

You may speak to stakeholders during opportune occasions (events). The direct interaction provides you with the most chances to make your voice heard. Before attending such events, you should:

- Have key points prepared (so-called elevator pitch); the points should be clear and on-point.
- Rehearse your points: either in front of a mirror or, ideally, with a colleague/friend.
- Keep the discussion brief.
- Dress professionally.
- Adjust the discussion to the stakeholder reaction.
- Ensure a follow-up action: send them a thank you email, connect via LinkedIn, follow them on social media accounts, etc.

2.3 First engagement with a stakeholder

Either through direct contact at an event or via a request through email or message, you have now secured a meeting with your targeted stakeholder. Congratulations! Now, it is time to get well-prepared. Below you will find some hands-on tips you can apply during the meeting.

2.4 Meeting preparation

DEVELOPMENT OF A MEETING BRIEF (A SCRIPT)

The key to a successful meeting is the development of a meeting brief: a document that includes the main points you would like to cover (your script) as well as key information about the stakeholder you are meeting with (key parliamentary/stakeholder activities relevant to your cause).

Your script should be brief, concise and powerful. The goal is to help you cover the points you would like to touch upon during the meeting. Here are a few tips that can help you develop it:

- The brief should be not too long and data-heavy (prepare for a meeting of no longer than 15-30 minutes). The brief should also include information about the relevance of the stakeholder. Why would he or she be interested in CRC screening? What have they done in the past on the topic? Any indications you might have for their future interest in CRC screening need to be analysed and acknowledged. Provide successful examples of other countries or regions where a similar strategy was used.
- Make the points in your brief as interactive as possible: prepare a set of questions to ask to carry out the conversation. Link the questions with the interests of the stakeholders.
- Meeting with policymaker: include key policy asks to be considered by the policymaker.
- Meeting with a non-policy stakeholder: explore the common areas of work and include potential ways of collaboration (for example endorsement of your policy ask).

ATTENDANCE

Before the meeting, agree with your colleagues on how many people from your organisation should attend the meeting. The decision should be based on the number of people foreseen to participate from the stakeholder's side: there should be the same/similar amount of people from each organisation.

If you will join the meeting with multiple members from your organisation agree upon who speaks about which aspects.

A FEW MORE TIPS...

Finally, here are a few vital things to put on a pre-meeting checklist to avoid last-minute pitfalls:

<table>
<tr><th>Virtual meeting</th><th>Face-to-face meeting</th></tr>
<tr><td colspan="2">• Rehearse, rehearse, rehearse.
• Confirm meeting time with the official's office (by sending a calendar invitation).
• Get a final list of officials who will be attending.
• Background information should be sent in advance (keep some documents for the follow-up email after the meeting).
• Be punctual and dress professionally.</td></tr>
</table>

• Make sure the calendar invitation is sent to all participants and has the dial-in details (Zoom, Teams, Webex). • Check the technical aspects of the devices you will use for the meeting: internet connection, application download, microphone & sound. • Make sure that you have a neutral background (or a virtual background of your organisation).	• Have a pre-determined and strategic seating chart. • Print and package a dossier and handouts. • Confirm transportation and meeting location with your team. Exchange contact information for last-minute details, changes and emergencies.

2.5 DOs and DON'Ts for during the meeting

You have spent a lot of time and effort developing a message that will be effective in motivating stakeholders to support your ideas and requests. It is now key to deliver this effectively. Please note that there are some important "Advocacy DOs and DON'Ts" to be aware of:

DOs	DON'Ts
✓ Start with a tour de table – who are you, who are your colleagues. ✓ If appropriate in your country, take the lead in the meeting. ✓ Focus on your goals and key points. ✓ Focus on the future rather than dwelling on the past. ✓ Be constructive. ✓ Be clear but brief when presenting your arguments/benefits. ✓ Stick to the roles assigned. ✓ Respect the time allotted to you. ✓ Take notes of key points discussed. ✓ Be sure to capture action items. ✓ Take note of any specific follow-up information you have promised. ✓ Be polite, yet firm.	✗ Do not get side-tracked on minor issues. ✗ Do not argue about facts. Present your 'benefits' as their solutions. ✗ If possible, do not let the stakeholder take over the meeting to discuss issues important only to him/her. ✗ Do not lose track of time. ✗ Do not make promises you cannot keep. ✗ As always, the last-minute details can make or break your credibility and how well you are perceived in your readiness and expertise. This initial perception can be the difference between the success and failure of your team's efforts.

2.6 What to do after the meeting

Always follow up after the meeting, to maintain contact and build a strong relationship with the stakeholder.

Below are a few steps to be taken right after the meeting:

Organise a short call/meeting with your team to compare impressions, notes and the action points taken from the meeting. Jointly agree on who will prepare and send a thank you email.

WRITE A THANK YOU EMAIL

After the debrief, the thank-you note should be drafted and reviewed by the team. It should include:

- Your appreciation for the meeting.
- A summary of key points, including the main agreed next steps.
- Confirm the actions to be done by your organisation.
- Additional information requested by the stakeholder.

If the meeting was a success and there has been positive action in response to your request(s), be sure to praise the official for his/her actions. It can be done via:

- A follow-up phone/email to personally thank them.
- Mention the support of the stakeholder in your social media messages by tagging (@) them or during various events you attend/speak at.

ORGANISE A FOLLOW-UP MEETING

Stay in touch! Do not let your interaction fade after the first encounter. Keeping the momentum and opportunities stemming from your meeting is key.

There are several ways you can ensure a proper follow up:

- Every once in a while, send emails with updates and information on relevant developments, to keep stakeholders in the know of the problem.
- If your organisation is (co)-organising an event, do not forget to send your stakeholders an invitation. Make sure to personalise it. If applicable, you can propose the stakeholder speak at the event or join the open discussion should they wish to do so.

2.7 Achieving constructive collaboration

It is key to provide the stakeholder with regular updates. The stakeholder should start considering you increasingly more like the expert on CRC and screening specifically. Thanks to such updates, a strong relationship can be created where the stakeholder can consult you on the topics he or she is working on. Below you can find a list of compiled resources on CRC screening you may consider sharing with various stakeholders with who you interact:

- Roadmap for Colorectal Cancer Screening
- White Paper: Colorectal Screening in Europe: Saving Lives & Saving Money
- Roadmap for the Prevention and Treatment of Colorectal Cancer in Europe
- Factsheet: The costs of colorectal cancer
- The latest information on CRC figures of the European Cancer Information System: Link
- Quality assurance guidelines for CRC screening (which will be updated)
- European Commission's guidelines for quality assurance in colorectal cancer screening and diagnosis (The guidelines will be updated)
- Council Recommendation of 2 December 2003 on cancer screening
- I Colorectal Cancer Screening Summit Report
- II Colorectal Cancer Screening Summit Report