Transforming Policy Toolkit

Strategic guidance and resources for colorectal cancer policy advocates

GLOBAL COLON CANCER ASSOCIATION
About GCCA

The Global Colon Cancer Association is a membership-based umbrella organization and a direct patient advocacy organization with more than 80 members in over 40 countries. GCCA is committed to reducing global health disparities, and it is GCCA’s mission to achieve equitable access to quality CRC screenings, testing, treatments, and care. GCCA works towards this goal by amplifying and supporting the efforts of our member patient advocacy organizations, by developing adaptable advocacy and educational materials for our members, and by conducting our own advocacy, education, and initiatives that ensure patients are at the heart of all policy discussions.

GCCA thanks Pfizer for their support of this initiative.
Introduction

Transform policy in your community to fight colorectal cancer.

The global incidence of colorectal cancer is increasing. Worldwide, 1.88 million people were diagnosed with colorectal cancer (CRC) in 2020, and that number is expected to reach 3.08 million in 2040. Mortality is increasing too, with 1.59 million people expected to die from CRC in 2040, compared to 916,000 in 2020. In addition to these devastating human costs, the economic burden of CRC is projected to reach INT$2.8 trillion globally between 2020 and 2050.

There are effective screening tests for colorectal cancer. There are effective treatments for colorectal cancer. But access to these screening tests and treatments is insufficient. The way to address this is through transforming colorectal cancer policy.

The Global Colon Cancer Association (GCCA) Transforming Policy toolkit provides a general guide to effecting colorectal cancer policy change in any community. This toolkit has tips for effective policy advocacy, including how to make the most of social media and how to join efforts with other advocates. It includes a checklist to help advocates organize their policy goals and strategy, from identifying their specific issue to finding the right policymakers to approach. The Transforming Policy toolkit contains a sample letter to policymakers and the Policy Scorecard for Colorectal Cancer, a tool advocates can use to present information to policymakers to support their policy requests.

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people diagnosed with colorectal cancer</th>
<th>Number of people who died from colorectal cancer</th>
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<tbody>
<tr>
<td>2020</td>
<td>1.88m</td>
<td>916,000</td>
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<tr>
<td>2040</td>
<td>3.08m</td>
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SECTION 1

Principles of Transforming Policy
Principles of Transforming Policy

Formulate goals, define your audience, and communicate effectively with policymakers to advance colorectal cancer policy change.

Identify Goals

The first step is to survey the current landscape of CRC policy in your area. First, is the government collecting colorectal cancer data? If not, this is a key place to make change. Data collection is important so the public is aware of statistics such as the incidence of CRC in your region, who is being diagnosed, and at what stage.

Some other features to focus on are whether awareness programs and screening programs exist, whether they are adequately funded, and whether all citizens have access to them. In addition, look at the availability and comprehensiveness of access to testing and treatments. Is there CRC research happening in your country?

As you do this exploration, it should become evident what needs to change. It could be a first step, such as making CRC control a priority for your government, or a further advanced change such as starting a national screening program, increasing research funding, or ensuring the integration of palliative care into CRC treatment programs.

Focus on what is close to your heart. Advocacy is demanding work, and putting your energy into what you feel passionate about will motivate you and will show through in your efforts. Your target audience will respond best to advocacy that has a personal element.

Keep goals focused and specific.
Define Your Target Audience

When it comes to setting colorectal cancer policy, the policymakers you need to target will depend on your advocacy objectives. For example, to advocate for the development of a national CRC screening program, the people you will want to contact are health ministers and other leaders in the health ministry as well as national policymakers like members of parliament, the assembly, or congress. You may well find a natural ally in your health ministry, and they could have guidance for your political advocacy efforts. In addition, seek out medical opinion leaders and healthcare professionals to collaborate and engage. And finally, present your information and goals to members of the local or national media in your country. This can expand your reach exponentially.

If you are not sure who makes CRC policy decisions in your region or country, contact one of your local health officials.

Explain Your Request

You must clearly set forth your goals for your target audience. People are more likely to be responsive to a specific and clear request. If your goal is to increase colorectal cancer awareness among citizens, you might ask for a public statement, an information campaign, or public observation of a CRC awareness day or month. If your focus is on establishing a screening program, your request might be for funding in an annual budget, changes in preventive care guidelines from health agencies, or the creation of a task force to plan the step-by-step program development.

Use the Appropriate Tools of Persuasion

It is important to use the right tool for the job. Different audiences may be moved by different information. An expert at a health agency will likely be most convinced with well-presented statistical data. A campaigning politician may gravitate towards personal stories they can use to connect with constituents.

The first tool in the advocacy toolbox is data. Information about current and future colorectal cancer incidence, mortality, age and stage at diagnosis, and economic burden highlights the importance and impact of CRC in your country.

Be clear and direct in your request.
Policy Scorecards provide context for a country's CRC policy state and support effective communication with policy decision-makers and other stakeholders. The scorecard can help identify gaps, function as a tool to monitor progress, and celebrate and recognize the advances being made. The scorecard was developed by identifying the relevant public policy action areas and their ideal state, including:

- CRC is a national priority and policies exist to address community needs
- Healthcare budgeting for CRC exists
- Programs address timeliness of diagnosis and access to innovative treatments
- Equitable access to diagnosis and treatment exists
- Clinical practice guidelines are developed and updated
- Reimbursement exists for innovative technologies and treatments.

**WISE POLICY SCORECARD™**

—a benchmark of excellence—
developed by Policy Wisdom.

Policy Wisdom is a public health policy consulting company founded in 2010 with the ambitious goal of playing a role in every worldwide public health policy. It provides organizations with the strategies, tools, and vision necessary to achieve their public health policy goals. It also shapes public health policies by working with the full spectrum of individuals —from policy makers to those who guide their thinking —at governmental and non-governmental organizations and in the public and private sector.

With its evidence-based approach and methodology, Policy Wisdom developed the **WISE SCORECARDS**, a tool that supports policy decision-making and helps to systematically measure the current state of policies and actions against the ideal or optimal state of such policies. With **WISE SCORECARDS**, users can confidently navigate their decision-making process, ensuring policies align with their desired outcomes.
Intermediate steps toward each ideal were chosen as indicators, and publicly available information from reliable sources was used to determine the country’s current status on each indicator. A score was given to each indicator status, and results were calculated for an overall score.

The policy scorecard was developed to be used with policymakers, policy influencers, and policy advocates. It provides a way to celebrate the progress towards achieving the ideal policy environment. It also provides valuable information to guide the policy conversation and communicate the path forward.

Data by itself can seem abstract. It is key to make a connection between statistics and the real experience of people. Personal stories from patients, survivors, and families can serve as a catalyst to the movement for CRC policy change. Personal experiences are simple to understand, and tend to be remembered and repeated, which can multiply their impact.

One of the most important advocacy tools is engagement with others, forging partnerships, and joining voices. Advocacy is more powerful in numbers and with the right partners. Whether through a campaign of letters from multiple advocates or organizations, partnership with a local celebrity or media outlet, shared efforts with healthcare providers, or through social media publicity, it helps to increase the number of stakeholders behind your request for change in CRC policy.

Gather support for your cause by using colorectal cancer and regional policy #hashtags on social media to help a broad range of people see your posts.
SECTION 2

Transforming Policy Checklist
Transforming Policy Checklist

This checklist can be used to help you narrow down your objectives, find your target audience, clarify your request, and map out a strategy to achieve your goal.

What is your goal?
- Gather and utilize CRC data
- Start a public awareness campaign
- Increase CRC awareness and education for healthcare providers
- Establish a CRC screening program
- Ensure access to innovative treatments for CRC
- Increase availability of targeted treatments
- Increase CRC research in your country
- Ensure existing patients have support
- Ensure a policy environment exists to spur investment in innovative screening, testing, and treatments for CRC

What is your request?
- Public statement
- Budget allocation
- Support for or against a specific law or policy
- Task force to address CRC
- CRC screening/awareness program
- Ensure access to innovative treatments

Which persuasive tools are you using?
- Data to support the importance of your goal
  - Policy Scorecard for your country
  - Global Cancer Observatory data for your country
  - Data from other countries showing the success of investment in CRC
  - Brief printed summary of the issue and the request to leave with policymakers
- Personal stories to make a human connection
- Increase your reach and your strength in numbers
  - Social media
  - Healthcare providers and hospital systems
  - Other advocates and advocacy organizations
  - Patients, survivors, and families
  - Media
  - Corporations and employers
  - Celebrities or other well-known or well-respected figures
- Election or political cycle timing

Who will help you achieve this goal?
- Local policymakers (governors, state or provincial leaders, etc.) and their staff
- National policymakers (members of parliament, assembly, congress, etc.) and their staff
- Health ministers and health ministry staff
- Community leaders
- Other NGOs
- Media
- Likeminded citizens who have been affected by CRC

- [ ] _______
SECTION 3

Sample Letter to Policymaker
Sample Letter to Policymaker

The following sample letter can be used as a template for your colorectal cancer policy advocacy efforts. You may need to adapt it for your organization, and tailor it for your issues and for your country.

[DATE]
[Policymaker Name and Title]
[Address]

Dear [Policymaker Name and Title],

As a colorectal cancer [patient/advocate/advocacy organization, etc.], I am/we are writing to ask for your support of [a CRC awareness program, a CRC screening program, expanded coverage of CRC treatments, a reduction in waiting times for CRC diagnosis and treatment, etc.].

As you may know, colorectal cancer incidence and mortality rates are increasing. In our country, [include information about country incidence, mortality, economic burden]. Policy Wisdom, in collaboration with the Global Colon Cancer Association and sponsored by Pfizer, developed the Policy Scorecard, which provides a comprehensive overview of the state of CRC policy within our country. This scorecard also facilitates a comparative analysis with other countries in the region. The scorecard’s foundation rests on various critical factors, including national priorities and policies, healthcare budget allocation, equitable access to timely diagnosis and high-quality treatments, the presence of up-to-date clinical practice guidelines, and reimbursement for innovative technologies. The results from our country’s scorecard reveal areas within our colorectal cancer policy that require enhancement and improvement.

Behind the data reflected in this policy scorecard are real people. [Include one or more personal stories from CRC patients. Find stories of patients who have benefitted from a program for which you are advocating continued or increased funding, or of those who have suffered from the lack of a policy or program you are trying to implement. Use names and facts about their lives and families to increase personal connection.]

Because of people like [names of patients], it is imperative that our country do better. [ORGANIZATION NAME] urges your support for [policy change] and asks that you [include request].

Thank you for your time and consideration of this important request. I am available to meet with you personally to discuss this further.

Sincerely,

[Name]
[Organization]
SECTION 4

Resources for Transforming Policy
Resources for Transforming Policy

These data resources can help you make a convincing appeal to policymakers.

Policy Scorecard

Current and projected incidence and mortality of CRC by country, age group, and sex from the International Agency for Research on Cancer’s Global Cancer Observatory.


Become a GCCA member to get access to all GCCA programs including educational materials, awareness campaigns, mentorship from experienced patient advocates, and networking opportunities with other CRC advocates and organizations.