



# Patient **Advocate** Toolkit



Together we have the power  
to end the worldwide suffering  
caused by colorectal cancer.

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**1.4 MILLION**



**NEW CASES**

**DIAGNOSED, AND OVER**

**690,000 DEATHS.**

Colorectal cancer (CRC) is the third leading cause of cancer deaths worldwide. Annually, there are nearly 1.4 million new cases diagnosed, and over 690,000 deaths. The incidence of CRC is expected to nearly double as it is predicted that there will be 2.4 million cases of colorectal cancer diagnosed every year by 2035. There are over 6 million people living with CRC today.

Colorectal cancer is the most preventable major cancer through screening, yet in many countries, there are no formal screening programs, access to treatments, awareness campaigns, or patient voices to effect change. Many cancer patients have little to no support. Nearly 55% of CRC cases occur in more developed countries, and mortality is lower, with more deaths in less developed regions.

Colorectal cancer has a staggering global economic burden, in excess of \$30 billion, and causes immeasurable suffering for millions around the world. Awareness of the disease, its reach, its ability to be prevented, its treatability if diagnosed early, and access to quality care and therapies are the keys to changing the global problem of colon cancer.

#### **GLOBAL COLON CANCER ASSOCIATION**

The Global Colon Cancer Association (GCCA) is the only international nonprofit patient organization dedicated to colorectal cancer. The organization is comprised of the nearly 50 leading CRC patient organizations dedicated in whole, or in part, to colorectal cancer. The vision of the GCCA is to create a global community in which people around the world can unite and fight this disease with one unified voice. The GCCA is an approved 501(c)(3) charity registered in the U.S.

Over the past several years, the GCCA has been an active voice in the patient, healthcare, and regulatory communities regarding education and advocacy related to screening, access to safe and effective therapies, and innovation in CRC diagnosis and treatment. The GCCA has become a leading voice in the advocacy community to effect meaningful change worldwide. We have held multiple regional conferences educating stakeholders about the issues related to CRC.

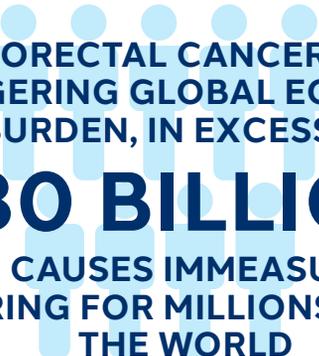
Global Colon Cancer Association members are patient advocacy organizations that are dedicated to prevention, support, advocacy, and other issues related to colorectal cancer. To view the current list of Global Colon Cancer Association members, visit <https://www.globalcca.org/gcca-members>.

#### **GLOBAL COLON CANCER ASSOCIATION PATIENT ADVOCACY TOOLKIT**

The Global Colon Cancer Association is committed to helping patient organizations innovate and leverage the full potential of effecting change.

This toolkit is a resource for existing nonprofit patient advocacy groups that wish to further their impact and for individuals looking to establish new patient advocacy organizations in areas where no colorectal cancer organizations exist.

We understand every country is unique, and what works in one region may not work in another. In some countries, there is a single payor, and in some both private and public healthcare payors. We tried to incorporate general best practices, knowing some information may not always be applicable everywhere.



**COLORECTAL CANCER HAS A  
STAGGERING GLOBAL ECONOMIC  
BURDEN, IN EXCESS OF**

**\$30 BILLION,**

**AND CAUSES IMMEASURABLE  
SUFFERING FOR MILLIONS AROUND  
THE WORLD**

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For additional international resources for starting a nonprofit organization or an NGO, visit: [www.globalcca.org/toolkit](http://www.globalcca.org/toolkit).

This educational resource was made possible in part by





## Section 1: The Fundamentals of Patient Advocacy Organizations

Patient advocates have the power to change the future of colorectal cancer by increasing prevention efforts and access to treatment – ultimately saving lives and improving the quality of life for countless individuals.

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### WHAT IS ADVOCACY?

Advocacy is the active promotion of a cause. The goal of advocacy is to create change around a particular issue. There are several types of advocacy, including individual, community, and legislative.

Advocacy can be an individual or group advocating for one particular concern or it can be a collective voice speaking for a large community of people around a number of issues.

*Examples of types of advocacy:*

**Self-advocacy for a particular issue:** An individual's insurance company has denied a treatment-related procedure. The patient becomes a self-advocate by contacting the insurance company and pushing them to approve their ability to receive the procedure. Additional steps may include sharing this issue on social media, and contacting government officials and the mainstream media.

**Advocating on behalf of a group on a particular issue:** An upcoming piece of legislation threatens to limit patients' access to a critical treatment. A patient advocacy organization creates a statement on how this will negatively impact the colorectal cancer community at large and lobbies for patients to continue to have access to this important treatment option. While individual stories may be used to put a face to the issue, the organization is lobbying for an issue that impacts a group of individuals.

### WHAT IS THE ROLE OF PATIENT ORGANIZATIONS IN ADVOCACY?

To be an effective patient advocacy nonprofit, it is critical to be the voice of the stakeholders impacted by the cause. As a nonprofit, your organization is representing the needs of the community. Regularly engaging with your community will ensure that your organization is accurately advocating around the areas of need and critical issues that the community faces.

*advocacy*

Common advocacy activities to consider:

- Building awareness about colorectal cancer
- Increasing access to lifesaving screenings
- Establishing and distributing policy positions on a variety of colorectal cancer issues
- Lobbying policy makers and governmental agencies

**TIP:** *Create a clear call to action in all advocacy efforts. “Contact your doctor to get screened,” “Call your local representative,” “Share your story on social media,” “Sign and distribute this petition.”*



### WHAT IS A PATIENT ADVOCATE?

A patient advocate is a person or an organization that lobbies for change on behalf of an individual, a particular issue, or a problem that affects a community at large.

Many individuals who create patient advocacy organizations have already been acting as a patient advocate. Patient advocates identify a need in the patient community and are moved to action. The specific need may vary and impact patients, families, or entire communities. Patient advocacy organizations, once properly established, are recognized as nonprofits and are a part of the non-governmental organization (NGO) sector.

### WHY BECOME A PATIENT ADVOCATE?

Patient advocates are often personally affected by the disease or cause. Whether they are a patient, caregiver, or work in the medical community, they are moved to make a difference and inspire others to do the same.

By becoming a patient advocate, you can make a positive impact on individuals affected by colorectal cancer. Patient advocates have the power to change the future of colorectal cancer by increasing prevention efforts and access to treatment — ultimately saving lives and improving the quality of life for countless individuals.

# Section 1: The Fundamentals of Patient Advocacy Organizations

How will we know that we were successful in achieving our goals?

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## CREATING A PATIENT ADVOCACY ORGANIZATION

Starting a patient advocacy organization can be a rewarding venture that can save lives and provide critical support to those in need. It can also be a challenging undertaking, tackling everything from identifying where and how to form your organization to building renewable revenue streams. **Prior to establishing a nonprofit, research what organizations or resources exist in your community. Collaborating with existing organizations or resources can maximize your impact.**

This toolkit will provide you the framework necessary to identify what your patient advocacy organization aims to achieve and how your organization will succeed in reaching its goals.

## GROUNDWORK FOR SUCCESS — STRATEGIC PLANNING

A strategic plan enables a nonprofit to establish their most critical objectives and plan to meet their goals. **A strategic plan is particularly important for a new nonprofit.** Strategic plans identify what the

organization wants to accomplish in the next 3 to 5 years. A strategic plan can be a complex series of documents that not only establish goals but also the roadmap on how these goals will be accomplished.

Starting with big-picture questions can be helpful in establishing the major goals that a patient organization aims to achieve in its strategic plan.

### Global Questions to Consider

What is my **organization's mission?** (Your mission statement should define why your organization exists.)

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What is my **organization's vision?** (Your vision statement should be brief, and clearly explain the outcome that will result from your organization's existence.)

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What are the top 5 goals we want to achieve in the next 3 to 5 years?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

**How will we know that we were successful in achieving these goals?** (What are the metrics that we will use to track our progress? Each goal needs a metric to measure success, which will let you know how you are doing and offer a chance to revise your plan if goals are not being met.)

**THINK:** *How often will we report these results — both internally to the board and externally to stakeholders, such as in an annual report?*

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

**What will the key activities of your organization be?** (These should be tied to your organization's goals; these activities will define how you will achieve your top goals.)

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

**What will the name of the organization be?** (Identify a name that is not already taken by another organization—think memorable, descriptive, straightforward.)

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### Operational Questions to Consider

Once you have answered the big-picture questions on why your organization exists, what it will accomplish, and how it will meet these goals, it is time to define the elements that will make up your organization and how it will operate.

**What will the organization structure be?** (Physical office[s] or virtual, budget size, number of paid staff, volunteer roles)

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**How will this structure change over the course of the strategic plan?** (As more resources become available, or as progress is made toward our goals, how will that impact our structure?)

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**What resources are available?** (Monetary: charitable grants, government funding, donations from individuals; non-monetary: volunteers, in-kind donations.)

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# Section 1: The Fundamentals of Patient Advocacy Organizations

## **VOLUNTEER LEADERSHIP: BOARDS AND COMMITTEES**

**Boards:** Typically, your board of directors will be the only governing board with voting powers and significant oversight over the direction and operation of your nonprofit. Establishing nongoverning boards is a great way to not only further your organization's impact but also identify future members for your board of directors.

● **Board of directors:** This is a group of individuals who will be elected and serve terms of service of predetermined length. There are various roles that will need to be filled (chair, vice-chair, treasurer, secretary). The chief executive staff member of your nonprofit will report to the board of directors. A board of directors that meets regularly and documents meeting actions is required to remain a nonprofit in good standing.

● **Medical advisory boards:** These volunteers will help guide your programmatic and policy teams. This board will cover a variety of tasks, from establishing position statements on controversial treatments to translating medical data into patient-friendly language. They can ensure medical accuracy on your organization's website and in printed materials.

**TIP:** *Build a diverse medical advisory board — in addition to oncologists and surgeons, look for thought leaders in areas such as clinical trials, policy, advocacy, patient care, caregivers, etc. Do not limit yourself to doctors. Nurses, patient navigators, social workers, and other medical professionals can be important members of the medical advisory board.*

**TIP:** *The most effective boards are comprised of a diverse group of people with a variety of resources and expertise. Think of the types of skills and expertise that will help further your organization — from those with connections to financial resources, to those who excel at public speaking, fundraising, or recruiting new board members.*



- **Patient and caregiver advisory boards:**

Establishing a separate advisory board to ensure the patient and caregiver voices will be heard will ensure your organization remains current on key patient and caregiver issues.

**TIP:** *While Patient Advisory Boards can be vital in valuing the patient and caregiver voices, be sure to include patients and caregivers on other boards and committees. (For instance, an individual could have a medical background and be a patient, offering two important perspectives, and be a key member of the medical advisory board.)*



- **Committees:** Established committees with experts in specific fields are particularly useful when new or smaller organizations are limited in resources and may not be able to hire expert professionals. A volunteer with an extensive background in a specific discipline can mentor and guide a junior staff member at your organization.

**TIP:** *Volunteers may be eager to join multiple committees. This can often lead to burnout and stalled progress. Limit the number of committees a volunteer may join to ensure each committee remains energized and focused.*

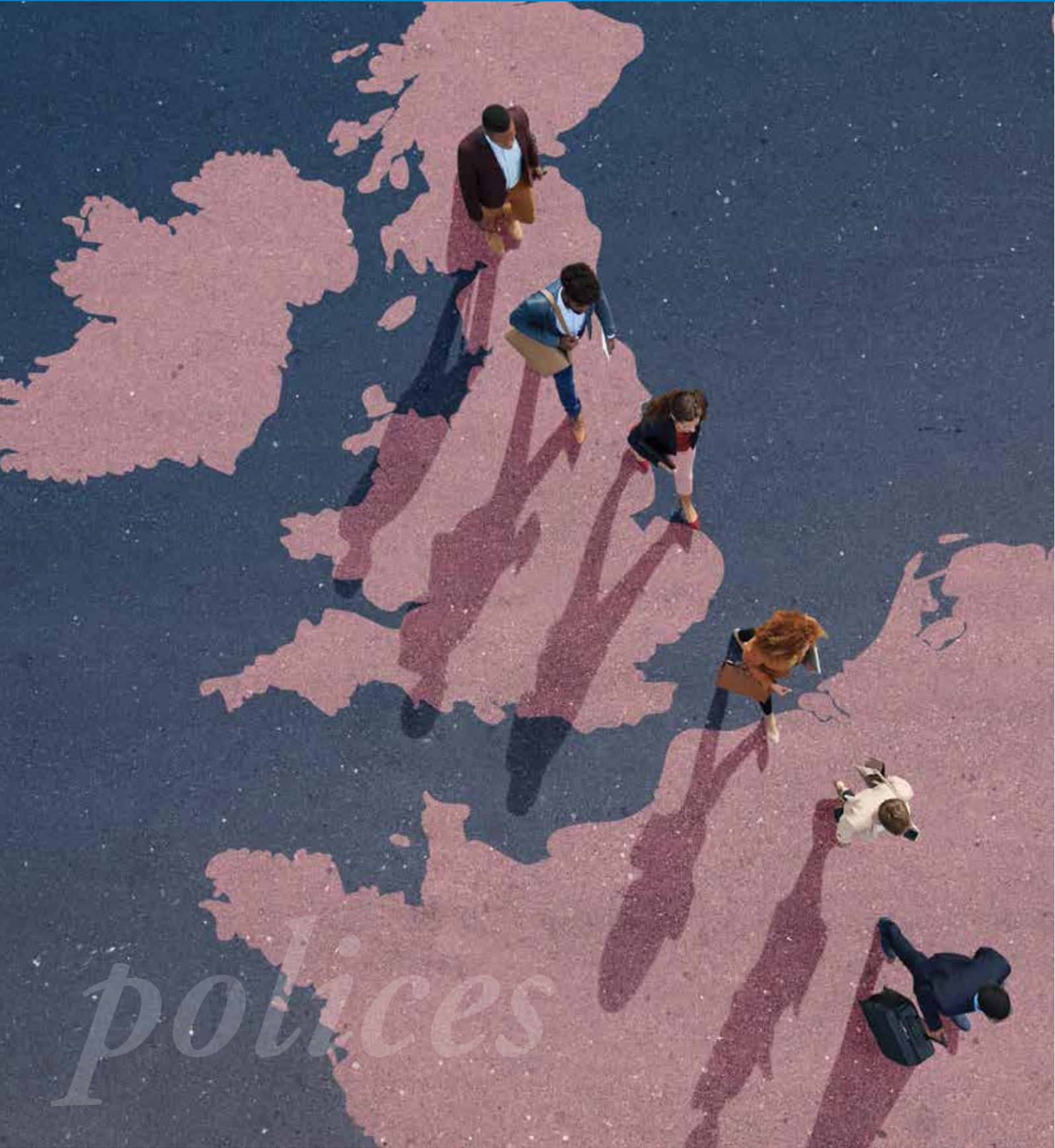
- **Fundraising:** A seasoned development professional on this committee will be key to overseeing revenue opportunities and guiding staff and volunteers. From establishing fundraising activities to creating giving opportunities, this group is key to the future of your nonprofit.

**TIP:** *Successful fundraising committees include people with different strengths, such as those with big ideas, others with an eye for operations and details, and don't forget — those with connections to revenue sources, both monetary and in-kind.*

- **Marketing and communications:** While often combined, marketing and communications are quite different and your committee should include individuals who are experienced and understand the difference. Marketing seeks action from an audience, while communications' goal is for the community to listen. This committee will work with stakeholders to define messaging, branding and marketing, and communication strategies. Members of the media can be particularly effective members of this committee.
- **Programmatic:** This committee may work closely with the medical advisory board, particularly on emerging treatments. Input from the patient community and use of survey and data collection on programmatic effectiveness will help guide the development of new programs or revisions to existing programs.
- **Policy:** Depending on the focus of your nonprofit and the needs in your specific community, this may be one of the most important committees you create. Experts who understand how legislation and policy impact your nonprofit and are able to create plans to meet these goals will enable lifesaving changes in access to prevention services and treatment.

**TIP:** *Consider forming a special sub-committee to address a time-limited issue. For example, if there is an election approaching or a particular bill with a specific issue critical to your mission, the subcommittee could focus on this matter while the overall policy committee keeps a broader focus.*





*polices*

Whether your organization has the resources to hire professionals with marketing and communications experience, or you partner with volunteers with relevant backgrounds, strategic communications and clear marketing messages are critical.

### **POLICIES AND PROCEDURES**

Next, determine what critical documents need to be created to guide your organization. These will be a combination of internal- and external-facing documents that you'll use as a reference. Everything from position statements on legislative matters, to determining how to react when an issue related to colorectal cancer gets media coverage, to how to resolve internal conflict within your organization, establishing these documents now will help your organization be successful in focusing on reaching its goals. These documents can be enhanced as your organization continues to evolve but should be established in the beginning.

**TIP:** *Create a timeline that includes time for revisions and involvement from key stakeholders in reviewing and approving the documents.*



Consider the following types of key organizational documents:

- **Healthcare policy and position statements:** These documents ensure that your nonprofit has established and agreed upon opinions on issues that are important to patients. These often are related to emerging or controversial treatments, or a governmental decision regarding access to treatments.
- **Employee handbook:** This document will establish your expectation of employees, and how you will engage with your employees. It provides information that outlines the rights of your employees and your obligations to your employees.
- **Volunteer handbook:** Clearly outline what activities a volunteer can engage in. It is just as important to establish what a volunteer may not do on behalf of the organization.

**TIP:** *Create a separate handbook for the board of directors due to their legal and financial responsibility to the organization.*



# Section 1: The Fundamentals of Patient Advocacy Organizations

## MARKETING AND COMMUNICATIONS

Marketing and communications are often led by one team or department, but have two distinct purposes. Marketing seeks action from an audience, while the goal of communications is for the community to listen.

Whether your organization has the resources to hire professionals with marketing and communications experience, or you partner with volunteers with relevant backgrounds, strategic communications and clear marketing messages are critical.

### Planning Your Communication Efforts

Revisit your strategic plan as you develop your communication efforts. Think about what you want to say, and who you want to say it to.

### Standard Terminology

It is important to establish and be consistent in the language your organization uses. Research what language is used in your specific community. Example: colorectal cancer vs. bowel cancer.

**TIP:** *Engage your stakeholders, particularly the medical community and industry, to ensure accurate and regionally appropriate terms.*



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### Specific Communication Plans

As you create specific communication plans for your various audiences, remember your internal audiences of staff, volunteers, and board members. They will communicate your established messaging to your external audience, which could be existing and potential partners, the general public, and political entities.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

4. \_\_\_\_\_
5. \_\_\_\_\_

### Communication Channels

What channels will you use to communicate your messages? (Think: face-to-face, social media, print materials, traditional media, grassroots, and support groups, and through key stakeholders)

Channel #1: \_\_\_\_\_

Channel #2: \_\_\_\_\_

Channel #3: \_\_\_\_\_

Channel #4: \_\_\_\_\_

Channel #5: \_\_\_\_\_

How will you measure the effectiveness of your communication efforts for the various channels?

**TIP:** *Create a Google alert to be notified when your organization or a specific search term is mentioned online.*

Channel #1: \_\_\_\_\_

Channel #2: \_\_\_\_\_

Channel #3: \_\_\_\_\_

Channel #4: \_\_\_\_\_

Channel #5: \_\_\_\_\_

## Communication Objectives and Key Messaging

Define your communication objectives and key messages by working with your stakeholders. Your communication objectives and key messages should be tied to your strategic plan and should be used in all communication activities.

### Communication Objectives:

Communication objectives are specific outcomes achieved through communication activities.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

### Key Messages:

Key messages are the core messages you want your audience to hear and remember.

#### Hints:

- Short and concise key messages are most effective.
- Avoid acronyms and confusing language.
- Check your key messages to ensure they align with your established mission and strategic plan.

Key Message #1: \_\_\_\_\_

Key Message #2: \_\_\_\_\_

Key Message #3: \_\_\_\_\_

Key Message #4: \_\_\_\_\_

Key Message #5: \_\_\_\_\_

### Get Social

Social media can be powerful! But before sharing information, be sure it comes from a credible source, and check their facts.

- Create a hashtag to track engagement, but first ensure the hashtag is not already in use, and is appropriate.
- Partner with existing organizations and campaigns, such as the Colorectal Cancer Alliance's #Never2Young campaign or the Global Colon Cancer Association's #KnowYourBiomarker.
- Engage with your constituents when they comment or post on your social media channels. Be sure to like, comment and when appropriate, send direct messages. Social media never sleeps, especially on a global scale.

# Section 1: The Fundamentals of Patient Advocacy Organizations

## Marketing

How will your organization promote its mission and goals to prospective donors and patients?

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**Outbound marketing** refers to an organization initiating a conversation and sending a message out to an audience, typically a broad message to the general public. The audience in outbound marketing often has no connection to the cause.

What outbound marketing strategies will your organization invest in? (Think: television advertisements, brochures, online pop-up advertisements, billboards)

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**Inbound marketing** seeks to pull constituents in with relevant and interesting content. Social media and using a search engine optimization service can improve your inbound marketing.

**TIP:** *Be authentic; do not use a sales pitch tone for inbound marketing.*



What inbound marketing strategies will your organization invest in? (Think: podcasts, blogs, thought-provoking opinion pieces)

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## Media

Attention from the media has the power to change the future of the disease by creating awareness and inspiring individuals to take action and be screened for colorectal cancer.

Human interest stories are articles or news segments that are specifically designed to engage the audience in a sympathetic way. By sharing your story, and the individual stories of your community, you can gain attention from the media and in turn build your audience. Be sure to mention your website, hotline, social media handles, or other key ways for the community to connect with your organization.

## Develop a Media Plan and Media Kit

Prior to engaging with any members of the media, make sure your organization is prepared. Establish a media plan, using elements from your strategic plan and communications and marketing plan.

**What is your media objective?** These should be goals that can be measured and tied back to your strategic plan. Your media objective should not detail how you will reach your goal, but rather what the target is.

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**What is your media strategy?** This includes setting a budget and establishing your target audience, including what age, demographics, race, and economic background you are seeking to reach.

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**What channels will you use?** Identify existing channels, such as your website or social media, and include future channels that you may not have access to when your organization is in its early stages (such as resources for television advertisements or a podcast).

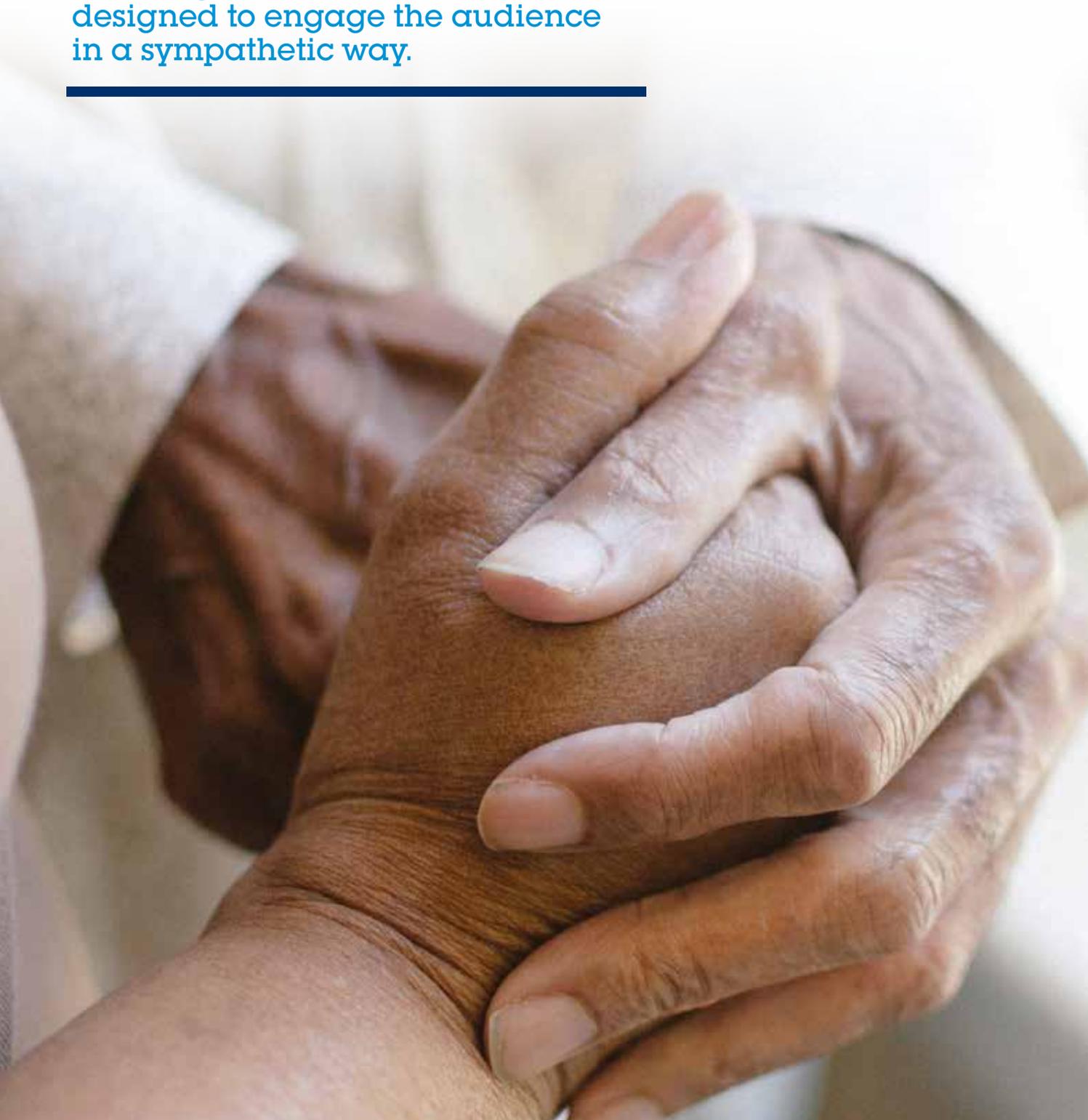
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Human interest stories are articles or news segments that are specifically designed to engage the audience in a sympathetic way.

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# Section 1: The Fundamentals of Patient Advocacy Organizations

What **natural fit** media outlets are prospects? (Think: wellness, prevention, patient-focused outlets)

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What are the **key talking points** about your organization that you want to use when speaking to the media?

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Who from your organization will be authorized to speak to the media on behalf of your nonprofit? (Think: Will they need media training? What resources are needed to ensure your organization is best represented?)

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A media kit, also known as a press kit, will provide reporters quick access to understanding who your organization is, what you are setting out to accomplish, and the specifics of the media-worthy pitch. A media kit can be a tangible kit with printed materials or it can be entirely digital. While a physical media kit can be useful for in-person meetings, consider the value of an online media kit, which can be shared widely and updated often.

Elements of a media kit:

- **The story of your organization.** Tell how and why your patient advocacy organization was established.
- **Facts about colorectal cancer incidence and prevention.** Include local statistics when possible. Be sure to use credible facts and cite your sources.
- **Images, including photos, graphs, and logos.** Always provide high-resolution images and credit

the photographer. Only use images that you own the rights to, or when necessary, use a stock photo and purchase the right to use the image. When using pictures of an individual, always obtain written permission to use their image.

- **Press releases** provide key information about your organization and the specific initiative or event that you are pitching.
- **Contact information** should include a cellphone number and email address for the media contact at your organization. Also remember to provide your nonprofit's website address, social media handles, and when appropriate, physical locations.

## FUNDRAISING

Fundraising, or development, is critical to your organization's ability to fulfill its mission. At its core, fundraising is asking for financial support for your nonprofit. In order to raise funds effectively, it is important to establish what your financial needs are and how the funds will be used. Fundraising regulations and reporting requirements will vary depending on your location.

There are several categories for raising funds, and you may identify that your organization will be more successful in one particular area over another.

**TIP:** *In order to maintain financial stability, it is important to have multiple revenue streams. While having great success in one area or with one major donor, it is risky to rely on one donor or type of fundraising.*



Types of funding sources:

- Government
- Foundations
- Corporations
- Individuals

Types of fundraising:

- **Grants:** Typically, a grant will be gifted by a foundation, a corporation, a government entity, or even another nonprofit. Grants are often restricted for a specific project or purpose and must be applied for its intended use. A well-written grant proposal will describe the issue, how your nonprofit will address the problem, how the funds will be used, and what the donor's involvement or recognition will be. A budget and project timeline will need to be submitted with the grant request.
- **Annual fund:** These are typically smaller, unrestricted gifts from individuals that can be used wherever your nonprofit has the greatest need. Annual fund gifts are often solicited through direct mail appeals, email campaigns, or the telephone.
- **Major gifts:** You will need to define what your nonprofit considers to be a major gift. This can change over time as your organization grows. While major gifts are an important part of your annual revenue, most nonprofits have fewer donors at the higher level and more donors who make small gifts. Major donors will require the most amount of staff and volunteer time to provide appropriate stewardship of the funder.
- **Planned giving/estate gifts:** Also known as legacy gifts, a donor may choose to leave a specific dollar amount or a percentage of their estate to your nonprofit in their will. These gifts will range in size but are well worth the investment to promote this giving opportunity to your constituency. Tax benefits for estate gifts will vary based on your local laws and government regulations. Always advise donors to consult legal counsel with regard to estate planning.
- **Special events/fundraisers:** These events are often 5K run/walks, gala dinners, golf events, or other activities where attendees typically pay an entrance fee and have additional opportunities to make donations at the event. Fundraisers where participants ask their contacts to make donations on their behalf are a great way to build your

database and grow your constituency. Special events are the least cost-effective way to raise funds because of the expenses required to put on an event. Proper planning, ticket presales, and securing in-kind donations can ensure a successful fundraising event.

- **Sponsorships:** These are gifts that provide marketing benefits to the donor, such as recognition at the special event or promotion of the corporate donor. A portion of the sponsorship may not be eligible for a tax deduction if there is a monetary value attached to the benefits the donor receives.
- **Membership:** This revenue stream provides donors an opportunity to belong to your nonprofit in exchange for recognition and other benefits.

**TIP:** *Thanking your donors is a key part of building relationships and securing future gifts. Always get permission from a donor before recognizing their gift publicly as they may prefer to remain anonymous.*



## Section 2: Collaborating with Stakeholders

Partnering with stakeholders can increase your organization's impact and amplify the community's voice. Successful partnerships require advance planning, involving key stakeholders in planning and execution, and evaluating the effectiveness of the program.

### **KEY STEPS TO ESTABLISHING SUCCESSFUL PARTNERSHIPS:**

#### **Research**

What is the need? How will your nonprofit address the issue?

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What support (financial and other) do you need from the partner?

 **TIP:** *Establish a preliminary budget that can be finalized during the planning phase.*

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Who are potential partners for this project?

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Are other organizations currently involved with this issue? Are there opportunities for collaboration with an existing nonprofit?

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#### **Planning**

What are the main objectives for this project?

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How much time is needed to plan the project? What is the timeline for the overall project?

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What is the budget for the project?

**TIP:** *Itemize all expenses and costs per person/item.*



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Which key stakeholders will serve on the planning committee?

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Who will be the lead on this project at your organization? What will their role be? Who will be the lead at the partner company?

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What type of agreement needs to be created with the partner? What key elements need to be covered in the contract?

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How will the program be disseminated to the community? How can you ensure maximum reach to the intended audience?

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# Section 2: Collaborating with Stakeholders



## Execution

During regular check-ins with internal and external stakeholders involved with this project, how will you know that the collaboration is on target?

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If necessary, how will the team address issues and change the existing plan for better outcomes prior to the completion of the project?

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Are both parties adhering to the partnership agreement?

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Has the partner been recognized appropriately as per the agreement? Are there any additional opportunities to thank the partner?

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## Evaluation

What was the impact of the program on the intended audience? Were the goals of the partnership achieved?

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**TIP:** Use surveys and focus groups to determine if key objectives were met.

What feedback has the partner provided to you with regard to the project?

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In what ways could the project have been more successful? How will you take what you've learned from this project and implement it for future partnerships?

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Is there an opportunity to renew the project with the sponsor, and/or bring in additional partners?

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## PARTNERSHIPS:

Your partnership needs will vary depending on your strategic plan and what potential partners exist in your region. These four types of organization are common partners for patient advocate nonprofits:

- **Patient organizations:** Colorectal cancer-specific nonprofits as well as organizations that focus on similar patient care or access issues can boost the impact of your collaborations.
- **Healthcare professional associations:** These groups can be particularly useful in providing credible medical information and often have experts on complex specific issues.
- **Government bodies and elected officials:** You can boost your advocacy efforts by partnering with the government and bringing attention to issues and rallying legislative support.
- **Industry:** Pharmaceutical companies, hospital systems, and companies with products related to the prevention and treatment of colorectal cancer can be valuable partners. The industry can offer expertise and access to key opinion leaders, as well as financial support to your nonprofit via grants or sponsorships.

## Section 2: Collaborating with Stakeholders

### Patient Organizations

By working with other patient organizations, you can amplify your voice, increase your impact, and cut down on expenses. Partner with organizations that are particularly successful in areas where you have fewer resources or expertise.

Research existing patient organizations to determine where potential partnerships may be beneficial. Potential organization partners may be local, regional, national, or international.

In addition to colorectal cancer nonprofits, seek out nonprofits that are not specific to colorectal cancer, including general cancer groups, or organizations that focus on patient and caregiver issues overall. Partnering with existing nonprofits can be particularly important for newly established organizations with limited resources. There may be opportunities to sign on to another organization's legislative efforts and make more progress, rather than creating an initiative from scratch. World Patients Alliance ([www.worldpatientsalliance.org](http://www.worldpatientsalliance.org)) is an example of a global organization that represents patient groups and advocates for patients' rights and access to care.

### Professional Healthcare Associations

A professional healthcare association is an organization that brings together individuals who work in a similar healthcare field. Medical professionals may belong to several associations, and they may be specific to colorectal cancer or broader associations that cover general issues.

Partnering with a professional healthcare association can:

- **Provide up-to-date statistics and studies** that relate to a particular medical issue. Associations often publish papers and articles, which you may wish to cite or link to.
- **Offer networking opportunities** for you to grow your constituency. By joining an association, you may meet prospects for your medical advisory board, board of directors, volunteers, and more.
- **Build credibility** with your new nonprofit within the community. When a professional healthcare association signs on to your petition, joins your organization as a member, or participates in your programmatic or fundraising efforts, get

permission to use their logo and promote their partnership with your organization.

### GOVERNMENT ENTITIES

By partnering with your government, your organization has the opportunity to improve access to lifesaving screenings and treatment. Your nonprofit may achieve this through educating your government on the issues colorectal cancer patients face and mobilizing a representative's constituents to action.

Prior to partnering with government entities, make sure your organization is well versed in how to collaborate with your government on both local and national levels. If resources are limited and your nonprofit is not able to hire a staff member with government relations experience, consider hiring a consultant. Seek out individuals with experience in partnering with the government on behalf of a patient group to volunteer with your organization and serve on a policy committee or on the board of directors.

**TIP:** *Seek out elected officials that may have a personal connection to colorectal cancer. This can attract media attention and inspire others to take action.*

Depending on where your nonprofit is located, what a partnership with the government looks like will vary. You may work directly with individual representatives, health policy teams, regulatory bodies, or health technology assessment teams.

The process for how drugs and devices become approved for patient use varies depending on the regulatory bodies in your country. These are government agencies that determine if a drug or medical device can be licensed and marketed.

In Europe, the European Medicines Agency (EMA) is a decentralized agency of the European Union. This group began operating in 1995 and is responsible for ensuring that medicines that are available on the EU market are safe, effective, and high quality ([ema.europa.eu](http://ema.europa.eu)). The EMA has established a Working Party with Patients committee, which has representatives from numerous patient groups. In addition to advocating on critical patient matters, they conduct workshops, survey the

## Prior to partnering with government entities, make sure your organization is well versed in how to collaborate with your government on both local and national levels.

community, and publish their findings. The EMA has increased its involvement with the patient stakeholder in the past decade by including patients on committees, developing a public engagement department, and establishing public hearings.

In the U.S., the Food and Drug Administration (FDA) is the agency that is responsible for protecting public health by assuring the safety, efficacy, and security of human drugs, biological products, and medical devices. Established in 1906, the FDA has increased its involvement and partnership with patient advocacy organizations over the years. Partnerships include patient advocacy organizations and patients serving on advisory panels that review drugs and devices under review for FDA approval and participating in the FDA's Patient Representative Program.

The EMA and the FDA partnered to form a Patient Engagement Cluster. This collaboration includes sharing best practices, working on high-profile issues, and identifying opportunities for future partnership.

In Japan, the Pharmaceuticals and Medical Devices Agency (PMDA) is the independent agency that works with the Ministry of Health, Labour, and Welfare (MHLW) to regulate pharmaceuticals and medical devices. The PMDA was established in 2004 and operates patient centricity workgroups in order to incorporate the patient's voice. The MHLW, established in 2001, involves patients in surveys and summits to address patient needs.

In India, the Central Drugs Standard Control Organization (CDSCO) operates under the Ministry of Health & Welfare. Established in 1940, the CDSCO is responsible for the approval of new treatments.

**TIP:** *Research a successful non-colorectal cancer patient advocacy group in your region to see how they have effectively partnered with your local government.*

### **HEALTH TECHNOLOGY ASSESSMENT (HTA) PROCESSES**

Innovations in technology are responsible for driving significant improvements in healthcare. From the development of drugs that treat diseases, to vaccines that prevent diseases, to lifesaving medical devices, technology has been a key factor in these developments. **A health technology** is the use of a particular intervention to solve a health issue. Health technologies can include medicines or procedures and can be therapeutic (treatment) or preventive (stopping a problem before it starts).

**Health technology assessment (HTA)** evaluates the impact and the direct and indirect consequences of the use of a health technology. Health technology assessments look at both the short-term and the long-term consequences of using a particular health technology. HTA guides and informs healthcare policy makers with critical data about particular health technologies.

Depending on your location, health technology assessments may currently be used by your government and guide policy as it relates to a variety of healthcare areas, including new treatment drugs. Often, the information that is gathered as a result of health technology assessments is used to create quality of care and national treatment guidelines for a particular country.

There are a variety of complex factors for a health technology assessment team to consider prior to making a recommendation. These include evaluating the new technology, looking at the health problem, and the research surrounding the issue. Looking at the efficacy (effectiveness) and safety of the technology, as well as the economic value, are key parts of the evaluation. In addition, ethical considerations as well as policy and social context are thoroughly vetted.

## Section 2: Collaborating with Stakeholders

### Patient Involvement in Health Technology Assessments

Patient advocacy groups can provide HTAs valuable insights into the patient perspective and experience. Depending on where your patient advocacy organization is located, the opportunities for partnership with HTA will vary. Patient advocacy organizations often serve on special committees or HTA boards, provide recommendations on a variety of topics, and evaluate draft recommendations from HTAs.

**TIP:** *When determining which staff member or volunteer will serve as the liaison and spokesperson for your organization in an HTA partnership, look at the skillset and experience that are needed for the most effective partnership. The most senior staff member may not be the best choice, depending on the specific partnership needs. A staff member or volunteer with prior HTA experience may be the most suitable representative.*

For more information on collaborating with government and health technology assessments, visit [www.globalcca.org/toolkit](http://www.globalcca.org/toolkit).

#### Industry:

Industry is a term that is commonly used within our community to refer to pharmaceutical and medical device companies, as well as companies that manufacture products related to the prevention or treatment of colorectal cancer.

Patient advocacy organizations typically partner with industry in the following ways:

#### Financial Contributions:

- **Grants** are typically designated for a specific project, such as a conference or a support group. The nonprofit is responsible for tracking the use of the grant and providing the donor a report following the conclusion of the program or event. Industry often provides a template for you to provide the report that details use of funds and the effectiveness of the program.
- **Unrestricted grants** are donations where it is up to the discretion of the nonprofit to use the funds where they are needed most.
- **Sponsorships** are donations where the company will receive recognition and marketing benefits in exchange for their gift. The value of the benefit that the corporation receives is not tax-deductible (for example: a company sponsors your organization's annual gala dinner, and receives five complimentary tickets as a part of their sponsorship. You would calculate the cost per attendee and multiply it by five to determine what portion of their sponsorship is not tax-deductible.)

**TIP:** *In addition to partnering with industry, seek out companies that are not directly related to the disease. Large corporations will typically list their charitable giving areas of interest on their website. Companies, regardless of their charitable giving focus, often reserve funds for employee-recommended nonprofits. A volunteer who is willing to advocate to their employer for support of your nonprofit is a valuable resource. Remember to thank them for their efforts!*

**Patient Involvement:**

Patient advocacy organizations have a lot to offer industry. As a trusted voice of the patient, your organization can provide an unbiased perspective that can make a positive impact on the lives of patients. Many pharmaceutical companies have established committees and other formal opportunities for patient advocacy groups to partner. These may be specific to an issue that is important to both industry and patient advocacy organizations (for instance, access to treatment) or it could be a committee that meets regularly covering general topics related to colorectal cancer.

**Planning for Successful Partnerships with Industry:**

Establishing guidelines that define how your organization will partner with industry will ensure successful collaborations. These documents should clearly state what activities are appropriate, how the partnership will operate, as well as how the partnership will be communicated and be referred to publicly.

Establishing parameters for partnership will help guide your decisions when faced with potentially controversial opportunities. When creating these documents, be sure to include key stakeholders, including boards of directors, medical and scientific advisory board members, industry, patients, caregivers, and staff. After you establish these guidelines with industry, post them on your website and share them with your community. By being transparent with your stakeholders you will build trust.

As you create guidelines for partnering with industry, consider the following:

Why is industry partnership important to your organization and how does it help fulfill your mission?

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Define why your nonprofit is establishing these guidelines and why it is important to your organization:

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In which ways will your organization seek to partner with industry?

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_
- 3. \_\_\_\_\_
- 4. \_\_\_\_\_
- 5. \_\_\_\_\_

Which policies will you need to develop that outline guidelines for partnering with industry?

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How will you evaluate potential partnerships? Which of your stakeholders will be involved and what will their roles be in the vetting process?

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*collaborating*

Who at the organization will evaluate potential partnerships? Who will ultimately be responsible for approving or denying partnerships?

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How will you determine if there is a potential conflict of interest?

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What types of promotion or endorsement will you not engage with? Example: Industry will be recognized with their corporate logo but not a brand-specific logo.

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What will the approval process be at your organization and with your industry partner? Create a checklist, for instance, listing approval of press release, logo, programmatic content, and media talking points.

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Who will create the partnership agreement? Who at your organization has the authority to sign off on agreements with industry?

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What type of agreements will need to be established and signed prior to the launch of a partnership?

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## Section 2: Collaborating with Stakeholders

### Partnership Tips:

- Research all potential partners, including their key supporters and stakeholders, to ensure that you are collaborating with an organization that you align with on all key areas. Be particularly mindful to investigate and understand potential partners' stance on controversial issues; for example, the use of marijuana for treating cancer.
- Create a memorandum of understanding that clearly outlines roles, responsibilities, specific project plans, and any financial obligations, as well as how the partnership will operate and how long it will last.
- Establish regular check-ins with your partners to review progress and change or create new initiatives as needed.
- Remember your audience and be sure to use patient-friendly language when appropriate, particularly if the association is providing materials written for medical professionals or legislative groups.
- Keep an open line of communication with your partners and work to resolve potential areas of conflict early on. This will ensure your ability to keep your organization focused on your mission and goals.
- Use your predetermined key messages and standard terminology when working with partners. If a message or terminology does not fit with the partnership, determine if the collaboration is appropriate, and if so, revisit your key messages and terminology.
- Remember to thank your partners, particularly those who are volunteering their time and expertise. A thank-you email or public recognition thanking your partners can go a long way in building a lasting and successful relationship.

Are there any types of support that your organization will not accept? Establishing a gift acceptance policy can prevent conflicts that can distract your organization from fulfilling its mission.

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Will your organization establish exclusive partnerships limited to only one company? If so, what particular guidelines will need to be established to show transparency?

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What will the process be to withdraw from a contract if the guidelines are not met?

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What role will your industry partner have in project planning and execution?

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How will you evaluate the effectiveness of the program? If necessary, how will you implement changes to the partnership during the project period?

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How will you communicate the success of the partnership with your community?

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An aerial photograph of a massive crowd of people, seen from above. The crowd is densely packed and fills most of the frame. In the center of the crowd, there is a bright, circular area of light, possibly a stage or a focal point of attention. The word "partnerships" is written in a large, white, cursive font across the upper portion of the image. The top-left corner of the image has an orange triangular overlay.

# *partnerships*

For more information on colorectal cancer and the Global Colon Cancer Association, visit [www.globalcca.org](http://www.globalcca.org).

## Join Us On:



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For more information on creating a patient advocacy organization and planning successful partnerships, visit [www.globalcca.org/toolkit](http://www.globalcca.org/toolkit).

The Global Colon Cancer Association thanks Pfizer for its support of this educational resource.