



United Patients

ONLINE TOOLKIT

Engaging the Medical Community as Advocacy Partners,
Communicating Successfully with Decision Makers and Using Data
for Advocacy Purposes: A Step by Step Guide to Advocacy for
Patient Groups

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★ Top United Patients' Tips for Conducting Successful Advocacy

Put patients and people living with disease at the center of advocacy efforts: Involve them in all aspects of advocacy planning and strategies, including media campaigns and meeting with decision makers, etc.

Develop and follow an advocacy plan: Careful planning is critical to success so make sure that all elements of your plan are addressed – research, stakeholder and policy mapping, key messages and communication vehicles, partnership and collaboration, monitoring and evaluation, etc.

Know your policy audience: Study your policy audience systematically, and ask the following questions, among others: Who has the decision-making authority? Who has the power to influence decision makers? What are the main views held by decision makers related to your issue?

Form strategic alliances: Seek out and foster alliances with a variety of actors and stakeholders – other patient groups, medical and health professional societies, domestic, regional or international organizations addressing your issue, other health constituencies, government bodies, public health systems, parliamentarians, international organizations, payers, other business or industry actors, etc.

Cultivate the media: Develop productive relationships with the media, given the instrumental role of media in shaping public opinion. Make sure that the press is educated on your issues and solutions. Involve patients in media exposure when feasible to make a compelling case with personal stories and effective “sound bites.”

Do your research: Know your facts and bring them to the table – do your research to get appropriate data to support your position. Use data strategically to support your messages.

Involve key stakeholders throughout the advocacy process: Make sure to draw upon the opinions and energy of a wide range of stakeholders at all phases of advocacy efforts. Incorporate a wide range of experience and expertise to further your agenda and make a strong, persuasive case.

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About this Toolkit:

This Toolkit provides patient groups (of all diseases) with information and practical tools to conceptualize, develop and implement an advocacy strategy for making policy changes related to the prevention and treatment of specific diseases at the clinical, local and national level. This resource can provide assistance in a variety of ways: from helping your organization develop an overall advocacy strategy; to forming successful advocacy partnerships with the medical community and other stakeholders; to reaching out to the media; to scheduling meetings with key local and national decision makers and effectively communicating your advocacy messages. This Toolkit has a specific focus on strategies to identify and engage members of the medical community as active and committed partners in your advocacy work. The materials are designed to be adapted to your unique local needs, situation and specific disease.

Goals: The goals of this Toolkit are:

- To enable patient groups to enlist the medical community as allies to conceptualize, plan and carry out an advocacy campaign on a selected policy call to action;
- To help patient groups understand the role of data in creating effective advocacy plans and in developing and delivering targeted advocacy messages to different audiences; and
- To prepare patient groups to effectively communicate their advocacy messages with policy makers and other decision makers.

★ **United Patients' Tip:** It is important to remember that no advocacy approach is universally applicable. Please adapt the materials and advice in this Toolkit according to your needs. More resources can be found at the United Patients website <http://www.unitedpatientsacademy.org>

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A 5-step Approach:

This Toolkit focuses on the strategies needed to develop an advocacy campaign related to health promotion and disease prevention and treatment. It consists of 5 sections that guide the reader through the essential steps of conducting health-related advocacy:



Within this structure, the Toolkit features:

- Key concepts related to conducting health and disease-related advocacy;
- Key questions to consider at each stage of advocacy planning;
- Useful tips and tools; and
- Links to relevant resources.

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Step 1: On your mark!

Map and Assess the Environment

 This section of the Toolkit helps you to answer the following “getting ready” questions:

Who should you work with?

What is the scope of your disease and risk factors problem?

What does the relevant policy environment look like?

I. Who Should You Work With? A Multi-Sectorial Approach

★ **United Patients’ Tip:** The challenges posed by diseases and their risk factors require the meaningful engagement of various stakeholders -- a whole-of-society approach.

A. Collaboration

What is multi-sectorial collaboration?

Multi-sectorial collaboration is the partnership that results when business and private sector, government (all the different key sectors), civil society (patient groups, nonprofit community organizations, medical and professional societies), academia, the media and individuals come together to solve problems.

[Click here](#) to see the chart entitled “Stakeholders Framework” that provides a visual framework for how the various stakeholders “surround” a designated advocacy issue. You can create your own and add or subtract categories of stakeholders, as needed.

For various diseases, here are some important stakeholders to include as partners:

- **PATIENTS:** People directly affected by the disease or condition and its risk factors – patients, family members, caregivers, etc.

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- **MEDICAL COMMUNITY:** Doctors, nurses, professional societies and associations, including:
 - **GENERAL PRACTITIONERS:** Internists, family practitioners, pediatricians, nurse practitioners, medical and nursing societies
 - **SPECIALISTS:** Oncologists, gastroenterologists, cardiologists, neurologists, rheumatologists, etc. and their respective societies, etc.
- **CIVIL SOCIETY:** International, regional, national non-governmental organizations (NGOs) that work on related health and disease issues and community groups
- **BUSINESS COMMUNITY:** Business interests and pharmaceutical companies concerned with health issues
- **THINK TANKS:** Technical or health experts
- **POLICY MAKERS:** Decision makers

★ **United Patients' Tip:** Building and maintaining multi-sectorial partnerships can be challenging and may consume substantial time and energy. Understanding these challenges, selecting appropriate partners and setting realistic goals at the outset can enable you to establish manageable expectations for partners' roles, contributions and ways of working together.

[Click here](#) to see “Stakeholder positioning per issue” chart , which demonstrates how you can use a framework to map out the positioning of various stakeholders vis-à-vis the issue (level of alignment on the issue), and by their level of influence. This chart can serve as a “road map” to describe power relationships and the key institutions involved in your issue, as well changes in policies, opinions, and institutions over time, helping you to consider:

- The shifting disease issues policy environment context;
- How health-related policy decisions are made in your country – and who has the most influence over these decisions; and
- The social and political climate in which decision-making occurs.

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EXAMPLE: This example highlights how the World Heart Federation (WHF) has engaged in multi-sectoral partnerships to develop a series of cardiovascular disease (CVD)-related “Roadmaps” as advocacy tools to draw global attention to [CVD](#) and its risk factors.

B. Identifying Stakeholders As Partners

Stakeholder mapping is an effective tool to help you identify appropriate partners to engage as allies in your disease and health-related advocacy plan. Below you will find tools that can walk you through this process. Later we will discuss how to engage potential partners, particularly members of the medical community.

[Click here](#) for the Stakeholders Mapping Grid to help you identify other individuals and groups with a “stake” or interest in your disease or health-related issue and to then determine whether or not they could be priority partners; whether they could benefit from education and persuasion to engage in the advocacy issue; and whether or not you could support their development of capabilities related to the issue.

Needs assessment: Partnerships

★ **United Patients’ Tip:** Before you can evaluate which groups are potentially appropriate partners make sure you can answer these core questions:

- Do you have an existing partnership working on your disease or condition?
- Is there a common goal that will bring the organizations together?
- Do your staff and volunteers have connections with medical societies, civil society organizations, academia, or the private sector that you want to involve?

How can you identify potential partners for advocacy actions?

The Profile of Potential Partners tool below can be used to map, analyze and assess stakeholders who might be interested in working with you.

[Click here](#) for the Profile of Potential Partners tool.

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II. Assessing the Scope of the Problem

A. Environmental Assessment

In order to shape your advocacy strategy and to develop your messages, it is important to have a thorough understanding of the policy environment surrounding your health, disease or risk factor issue.

★ **United Patients' Tip:** In order to build a compelling case for your advocacy issue, make sure to answer these overarching questions first:

- What is the medical reality of the problem? What is the burden of disease?
- What is the policy environment?
- What are the main barriers that patients confront in accessing diagnosis, prevention or treatment for the disease, condition or risk factor?
- Why should policy makers care about the problem?

★ **United Patients' Tip:** Become familiar with the main policies directly relevant to your organization's mission.

Understanding root causes and consequences:

[Click here](#) to see a “problem tree” visual representation of root causes and consequences of a sample problem – breast cancer is being diagnosed at advanced rather than early stages.

The next step is to gather specific information on what your government is already doing in the area of your designated disease and on the overall environment for decision-making. Here are some key questions to help guide your advocacy:

KNOW THE ISSUE: ESSENTIAL BACKGROUND INFORMATION

[Click on this link](#) for the “Key Information Gathering Questions” and easy to use guide.

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B. Evidence and Data: Public Sources of Data to Help Create Advocacy Messages

What role does evidence play in making the case for disease and health-related advocacy?

In addition to its central role in public health and clinical decision-making to establish policies and guidelines for clinical care and health services provision, evidence-based research plays a strong role in formulating advocacy strategies.

The Role of Data in Advocacy:

- **Select** issues for action; prioritizing and choosing goals and objectives
- **Ensure** that issues are based on patient needs and grounded in evidence
- **Illustrate** the problem
- **Support** the solution
- **Confirm** existing positions
- **Broaden** the field of possible policy solutions
- **Inform** and persuade decision makers and their allies
- **Provide** counter-arguments
- **Change** perceptions
- **Discredit** myths and incorrect claims
- **Demonstrate** if policies are working or not

★ **United Patients' Tip:** Disease and health-related advocacy messages must be grounded in evidence-based science. Whether you are advocating for increased funding for disease control, policy change to support best practices in treatment, or public education on a particular disease, effective use of sound data is essential to creating and delivering credible messages.

Proper translation of scientific data into easy to understand and compelling advocacy messages can:

- Increase community awareness of and support for programs to help people living with or affected by your disease or health issue;
- Draw public attention to any health and disease-related concerns and needs of special populations, e.g., older people, children, those living in remote or rural settings, people living in poverty, etc.;

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- Enable donors and decision makers to recognize your disease or health issue as a worthy investment and a cost-effective health and development solution; and
- Persuade policy makers of the benefits of developing or revising national health or disease-related policies to support evidence-based, innovative practices to expand prevention, treatment and disease control services¹

EXAMPLE: How HEART UK uses data to describe the medical reality of under-diagnosis of familial hypercholesterolaemia (FH).

- ★ **United Patients' Tip:** In order to provide a strong rationale for policy makers to support your issue, it is essential to distinguish between evidence and opinion.
- ★ **United Patients' Tip:** While advocacy messages should be based on science, they should also be clear, concise, eye-catching and targeted to the interests of your particular audience. For this reason, condense data into engaging briefs, fact sheets, frequently asked questions, short presentations and other forms of targeted communication.
- ★ **United Patients' Tip:** Data produced by your audience, such as a government or health body, will be an especially powerful way of strengthening your messages.

What kinds of questions can data help you answer?

- What are patients' needs? Which populations are most affected by the issue? What do they say about it?
- Who or what has an impact on the issue?
- What are the root causes of the issue?
- How severe is the issue?
- How has the issue changed over the last 1, 5, 10, 20 years?
- Where is the impact of the issue felt most acutely?
- What are the main consequences of the issue?

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C. Data Sources
DATA NEEDS FOR HEALTH-RELATED ADVOCACY²

Type of Data	Advantages	Disadvantages
National level statistics (e.g., registries)	<ul style="list-style-type: none"> Comparable, can show trends from year to year 	<ul style="list-style-type: none"> Not always reliable due to underreporting, etc. Doesn't address root causes of problems
Country and regional statistics from international bodies (i.e., WHO)	<ul style="list-style-type: none"> From well-respected, non-partisan source Easy and inexpensive to obtain 	<ul style="list-style-type: none"> Provides overall picture, but does not explain root causes Findings may be presented in lengthy, technical reports
Focus groups	<ul style="list-style-type: none"> Provides attitudinal and anecdotal information Records participants' emotions, motivations, feelings 	<ul style="list-style-type: none"> Small sample size makes it difficult to generalize Can be time consuming to conduct and analyze
Surveys (e.g., KAP -- Knowledge, attitudes, practices)	<ul style="list-style-type: none"> Provides statistical baseline Provides behavioral information Can be from respected institution (i.e., University) 	<ul style="list-style-type: none"> Findings can be subject to widely differing interpretations Depth constrained by close-ended questions
Local clinic-level or project-level reports or surveys	<ul style="list-style-type: none"> Can highlight trends Can provide information on patient services 	<ul style="list-style-type: none"> Need to consider errors in collection and analysis Can be costly

[Click here](#) for some links to useful sources of disease-specific data for selected diseases and risk factors

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D. Data Collection for Advocacy: How to collect your own data for advocacy messages

Although it is generally easier to use data that is already compiled by credible global or local institutions, in some instances it may be beneficial to collect your own data for advocacy purposes. For example, depending on the capacity of your organization, you may consider collecting your own or adapting existing data for the following uses, among others:

- Identify any challenges or barriers to access of care from individual doctors, clinics, hospitals, or through the healthcare system overall and use data to transform solutions into advocacy “asks”;
- Assist with public health and clinical decision-making to establish policies and guidelines in clinical care and health services;
- Apply data derived from high-quality research studies to solving clinical and access to care issues;
- Collect qualitative (e.g., bring together a small focus group of patients for a guided discussion on your advocacy issue) or quantitative (e.g., develop and administer a simple quantitative survey of patients in a clinic) data as tools to enhance your advocacy capacity;
- Adapt global or national issues to your local context; and
- Support operational decision-making within your organization.

★ **United Patients’ Tip:** Ask yourself these questions in order to assess your advocacy-related research needs:

- What data or information is needed to help you make the case for your advocacy issue?
- Can you use existing data or do you need to collect or adapt your own data?
- How will you obtain information about the needs and priorities of patients and the general public?
- What information do decision makers need to support your issue?
- How much time and resources will be needed to collect data?

★ **United Patients’ Tip:** You can increase your organization’s research capacity and stretch limited resources by:

- Collaborating with universities and graduate students
- Collaborating with professional societies
- Seeking collaborations through your organization’s scientific or medical board (if applicable)

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[Click here](#) to see an example of how American Cancer Society ([ACS](#)) adapts research to demonstrate the economic impact of cancer.

[Click here](#) for an example from the Breast Cancer Surveillance Consortium of an easy to use and adapt “patient information intake form” that you can use to improve and standardize data collection for consistency over time.

- ★ **United Patients’ Tip:** You can collect important data through small interventions. Data collection does not necessarily require a large investment of time or money.
 - ★ **United Patients’ Tip:** Actively seek to enhance your research capabilities as part of your strategy to increase your advocacy capacity.
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Step 2: Get Set! Set Your Strategy

Set Your Strategy: Define your advocacy issue

Now that you have identified your partners and assessed the policy environment in which decision-making related to your disease occurs, your organization can select your main advocacy issue.

I. Selecting Your Advocacy Issue

- What needs to be changed?
- How do you select and define your advocacy issues?

Health and human rights – the role of civil society

As there are a myriad of health-related problems and potential solutions, it is important to select an issue that is both meaningful to your organization and allies and feasible as a policy win. It is also important to acknowledge that health is a basic human right, and as such, is a political commodity. Health care merits the attention and resources of societies to ensure that all people have access to and awareness of preventive and diagnostic care and treatment for all diseases and conditions and their associated risk factors.

- ★ **United Patients' Tip:** Civil society has an important role in calling upon governments and policy makers to enact and enforce policies that promote peoples' rights to health and wellbeing, and holding them accountable for safeguarding these rights. Your organization can make a difference.

Health-related advocacy is a mechanism for civil society actors to engage as change agents for systemic transformations in policies and procedures to promote health and patient rights. As a tool for influencing decision makers to bring about more favorable policies and programs, the main aim of advocacy is to identify a problem, propose a solution and reach a measurable goal.

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Understanding advocacy issues

Health advocates mobilize around a proposed change – an issue -- that is a policy solution to an identified problem that can be solved through the intervention of an institution or organization. Selecting an advocacy issue requires researching and analyzing the problem and determining possible solutions. Organizations formulate policy solutions, choosing one that is feasible -- politically, economically, and socially.

[Click here](#) to see Key Issues to Address, a tool to brainstorm and organize a list of possible health-related issues.

A. Criteria

Criteria for evaluating and selecting your health advocacy issue

- What is the scope of the issue? Is it important to those most affected by the problem? Can you demonstrate the impact on patients? Can you demonstrate how the solution will impact those most affected?
- Is the solution based on sound evidence and data? Can it be verified by data?
- Is the proposed solution feasible, winnable?
- Is the issue easy to understand and explain?
- Will it attract support?
- Do established networks based on the issue exist?
- How would it impact your reputation?

Example of a health-related advocacy issue and ways to evaluate policy solutions: improving rates of early detection of breast cancer

Policy problem: More than 50 percent of breast cancer cases in region X in country Y are diagnosed in later stages, leading to high rates of breast cancer related mortality.

Question: Which policies could help to better identify and treat breast cancer among women in region X in earlier stages?

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- Educate the public on the importance of seeking screening and treatment
- Educate clinicians on how to talk to patients about risks, screening, treatment options
- Implement population-based screening programs
- Increase access to mammography machines in private and public health sectors to increase screening coverage
- Increase access to screening in both the private and public health sectors

Consider for each possible solution:

- Can you demonstrate how the solution will impact those most affected?
- Is the solution based on sound evidence and data? Can it be verified by data?
- Is the proposed solution feasible, winnable?
- Is it easy to understand and explain?
- Will it attract support?
- Do established networks exist?

You can use the checklist below to assess the feasibility of a potential advocacy issue and to help you choose among different policy solutions.

[Click here](#) for an East-To-Follow Checklist for Selecting an Advocacy Issue.¹

- ★ **United Patients' Tip:** When formulating solutions to your disease or health problem, keep in mind that:
- The patient is always central – make the solution relevant to patients' needs, and keep patients involved in the process; this empowers patients and lends legitimacy to your organization and allies.
 - Evidence – solutions should be grounded in scientific and clinical evidence and supported by reliable data (i.e., data driven).

¹ Adapted from CEDPA Advocacy Training Manuals – “Advocacy: Building Skills for NGO Leaders,” and “Social Mobilization for Reproductive Health, A Trainer’s Manual” and from ACS and Midwest Academy, ACS Direct Action Trainers Manual, 4th Edition, February 2008, “Choosing Problems and Issues,” pp. 6-11.

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B. Who should organizations consult to select advocacy issues?

There are a variety of actors that organizations can consult in order to select appropriate advocacy issues, including:

- People directly affected by the problem – patients, caregivers, etc.
- Organizational leadership and board members
- Patient groups working on similar issues locally (campaigns, advocacy networks, etc.)
- Technical experts (scientists, doctors, developers of clinical guidelines, social science researchers, etc.)
- Decision makers, legal experts

★ **United Patients' Tip:** If your organization is involved in advocacy, establish an organizational process for issue prioritization.



Step 3: Go!

Engage Stakeholders and Partners

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 This section addresses these main questions:

How can we engage a wide range of collaborators?

How can we communicate effectively?

How can we work together?

At this phase in the advocacy process, your organization will identify and approach stakeholders, including members of the medical community, to understand common points of interest or similar priorities in your agendas. Then you can use engagement strategies to start building relationships based on trust.

I. Communicating Your Health Advocacy Issue

Now that you have identified your health advocacy issue, it is time to engage partners to activate their voice in your joint efforts. The first step is communicating.

A. Making the Case

How do you create your “policy ask”?

Given your assessments of the policy environment and the chief barriers to addressing your designated advocacy issue, how do you formulate your “policy ask”? Developing and delivering effective advocacy messages is an intrinsic part of building support for your issue.

What is strategic communications for health advocacy?

- A planned communications activity that seeks to inform, persuade, motivate, and move to action a designated policy audience
- It involves expertise to formulate compelling arguments to achieve advocacy objectives
- It considers policy audience characteristics (demographics, social/political standing, etc.)

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- It always features a clear call to action

[Click here](#) for an example of a call to action on cancer control by the Union for International Cancer Control (UICC).

[Click here](#) for an example of a template letter¹ by Rare Cancers Europe for organizations to send to decision makers.

B. Effective Messages

What makes an effective advocacy message?

In general, a successful advocacy message is a concise, persuasive statement about your advocacy objective that describes what you want to accomplish, why and how. It specifies precisely how your policy audience can take action on the issue.

As you formulate your advocacy messages, consider the following:

- Language: Select words and phrases appropriate for and tailored to the audience
- Messenger: Whom will the audience best respond to?
- Format: How will you deliver the message for greatest impact?
- Time and setting: Selecting appropriate timing and location for message delivery may lead to greater political impact

★ **United Patients' Tip:** Tailor communication materials to your target audience. Anticipate opponents' arguments and understand how to communicate in a way that will identify common ground.

★ **United Patients' Tip:** Design your messages to appeal to your target audiences. Remember that it is easier to motivate someone to act on the basis of their already existing beliefs than trying to convince them of something new.

¹ FROM: <http://www.rarecancerseurope.org/Patient-Advocacy-Toolkit/Practical-Tools> Speak Up for Rare Cancers Rare Cancer Patient Tool kit

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Framing messages for greatest support:

Effective advocacy is based on the message you are delivering, how you deliver the message, and the audience you are intending to reach. How you frame the issue will depend on who you are talking to, and their personal and professional experience.

★ **United Patients' Tip:** Take care when positioning your issue. Advocates can reframe issues to attract broader support, thereby changing the discussion around the issue by providing a new reference point, e.g., specific disease-focused organizations such as cancer, diabetes and heart disease advocacy groups have come together in recent years under the non-communicable disease (NCD) umbrella. These groups have brought attention to their shared risk factors, and have collectively raised awareness about NCDs as a group. [Click here](#) for information about the NCD Alliance and its mission.

Tailoring messages to different audiences:

Investing in tailoring messages to your audience will allow you to leverage their interests to increase their engagement. It is important to translate scientific data into messages that motivate government officials, the media, and potential advocacy partners to take action.

Create “sound-bites” or “quotable quotes:”

Tobacco control advocacy organizations, for example, have used sound-bites such as “cigarettes kill many more people in the US every year than would be killed by the crash of two fully-loaded Boeing 747s each day of the entire year.”²

★ **United Patients' Tip:** Facts and figures are essential to making your case, but use numbers carefully – if you use too many it can overwhelm your audience. Balance statistics with stories that convey the human cost of disease.

★ **United Patients' Tips for developing effective advocacy messages:**

- Use credible data to support the message

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- Who cares? Offer a human element by using real life examples and featuring the patient voice and experience
- The messenger can be as important as the message
- Invite the audience to join their peers in supporting your issue
- Be familiar with opposing arguments and prepare counter-arguments
- Why now? Create urgency
- Involve an expert for credibility
- Involve a big name, someone they care about

★ **United Patients' Tip:** Effective health and disease related advocacy is contingent upon your organization's ability to move decision makers to take action. This requires a high degree of expertise in strategic communication – formulating and articulating arguments in a compelling way – to achieve your advocacy objectives.

★ **United Patients' Tip:** A successful message targets the needs and interests of your audience. Demonstrate how the solution to the problem requires change that they have the power to implement. Explain why it is important that they take action and how they and those they serve will benefit. Think about what factors you will emphasize – e.g., the link between education and disease reduction, the cost savings of prevention and early detection, or quality of life, among other factors.

[Click here](#) for Message Builder tool to help you organize the process of crafting an advocacy message.

[Click here](#) for the Engagement Priorities tool and [click here](#) for the Narrative per Priority tool to help you tailor your messages to reflect the needs and priorities of different audiences.

[Click here](#) for a chart on Audiences and Considerations from the World Health Organization's publication, *Stop the Global Epidemic of Chronic Disease, A Practical Guide to Successful Advocacy*.

[Click here](#) for the chart WHO Messages That Can Be Tailored To Specific Audiences from the World Health Organization's publication, *Stop the Global Epidemic of Chronic Disease, A Practical Guide to Successful Advocacy*.

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C. Messengers

Your message can have a very different impact, depending on who is delivering it.

★ **United Patients' Tip:** Choose your messengers strategically. You may wish to have different messengers for different audiences, e.g., a celebrity could be very effective at delivering your message to the general public, whereas a scientific expert could lend credibility in a political forum.

Who speaks for the issue? Designating and preparing spokespeople

After you formulate your advocacy messages, it is important to train spokespeople to confidently and competently address different subjects.

★ **United Patients' Tip:** Create a database of trained patients you can call on to share their disease or risk factor story.

★ **United Patients' Tip:** Whenever feasible, patients can be particularly effective messengers.

[Click here](#) for a chart on Potential Messengers for Specific Audiences⁶ from the World Health Organization's publication, *Stop the Global Epidemic of Chronic Disease, A Practical Guide to Successful Advocacy*.

II. Engagement Strategies

A. The Importance of Patient Engagement – putting a face to a cause

Giving a voice to patients and people affected by your designated disease and risk factors

Giving a voice to patients and people affected by disease is critical to the development of your successful

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advocacy strategies. When people affected by diseases bring personal experiences to the attention of decision makers, they put a “human face” on complex societal problems. Patients can be especially effective as advocates because they have their personal experience to draw upon, allowing them to:

- Speak to the media and decision makers to help change public opinion and advocate for systems-level changes;
- Serve as role models for others touched by different diseases;
- Put a face and story to a cause;
- Add credibility to your advocacy efforts; and
- Become an advocate for healthy lifestyles and wellbeing.

B. Engaging the Medical Community as Advocacy Partners

★ **United Patients’ Tip:** Create opportunities to interact and engage with partners to build relationships based on trust. In many ways, members of the medical community are natural allies for patient advocates.

Commonalities between patient groups and medical community:

- Have patients’ best interests at heart
- Interested in state-of-the-art therapies, medications and screening processes to prevent, slow the progression of, or cure disease
- Committed to providing (in the case of the medical community) or obtaining (in the case of patient groups) high-quality, comprehensive medical care
- Desire a strong patient-doctor relationship based on trust and communication
- Want patients to be active participants in clinical trials and drug development, to reflect their needs and concerns
- Confront similar struggles navigating health systems to obtain access for patients

Furthermore, doctors and other medical personnel commonly face barriers in their work that may be areas of joint interest to your health or disease organization. These shared concerns may provide you with an approach to the medical community to explore potential advocacy collaboration:

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- Pressure to see too many patients in not enough time allotted
- Inability to prescribe the most effective medications for particular diseases or conditions due to cost control policies
- Lack of time to communicate effectively with patients about disease prevention or treatment options due to time pressures
- Lack of specialized of state-of-the-art equipment, devices, etc. for high-quality prevention, treatment and care due to inadequate resources

Strategies to engage the medical community as partners:

The next steps include:

- **IDENTIFY:** Make a list of medical societies and leaders to reach out to about joining the campaign.
- **CREATE BACKGROUND MATERIALS:** Develop outreach materials that include background information, the goals of the campaign, and how the organizations can be involved – make sure these highlight the common interests and concerns of patient groups and the medical community.
- **MEET:** Hold face-to-face outreach meetings to discuss the campaign and your common issues and goals.
- **FORMALIZE:** Create a specific role for a medical professional in your campaign and write up a description of responsibilities so potential partners can decide if they want to participate and commit to a role in the campaign.

Different models of medical community engagement – selecting what works best for you

Once you achieve a critical mass of partnerships, consider forming a coalition or network to come together specifically on a campaign. The network can be as formal or informal as your needs warrant. A strong coalition allows advocates to pool resources, extend their outreach, and increases the power of their voice. This is especially critical in low-resource countries where there are likely to be many other health problems competing for the same limited resources.

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- ★ **United Patients' Tip:** Consider building a coalition with organizations that are working on other public health issues that share risk factors (e.g., cancer, heart disease, diabetes, tobacco control, healthy diet and active lifestyles). These can be beneficial to all parties.
- ★ **United Patients' Tip:** Advocacy is most successful when it involves collaboration among diverse groups to magnify the power of the participants through carrying out campaigns and community organizing together (e.g., patient groups and medical practitioners can collaborate to enhance the scope and reach of their campaign).

Engagement at medical conferences:

The quote below illustrates how patient and medical community engagement at medical conferences can lead to mutually beneficial outcomes:

“Perhaps the most important reason why patients should be included in medical congresses is the need to help patients understand (and reinforce) their role in the research. Every poster presented at every congress is possible ONLY because of the patients’ willingness to participate in the study effort. Helping patients understand the net output of their participation – what’s learned, understood or needs be figured out – can be a huge driver for future participation and engagement by the patient. This, in turn, will unlock more clues about these conditions and hopefully lead to even more breakthroughs and discoveries.” Seth Ginsberg, CreakyJoints Co-Founder (an Arthritis Advocacy Online Patient Community, part of the nonprofit Global Healthy Living Foundation)⁴

[Click here](#) to see the full article from the Pan American League of Associations for Rheumatology (PANLAR): “Why and how to include patients during a medical conference.”

[Click here](#) to see International Association of Patient Organizations (IAPO) top tips for collaborating with other patients’ organizations and healthcare professional associations.⁵

[Click here](#) for an example from IAPO⁶ of how a patient organization and healthcare professional associations can work together.

4 FROM <http://en.panlar.org/como-y-por-que-incluir-los-pacientes-durante-congresos-medicos>

5 FROM <https://www.iapo.org.uk/sites/default/files/files/IAPO%20toolkit%20-%20Working%20with%20partners%20and%20stakeholders.pdf>

6 FROM: <https://www.iapo.org.uk/sites/default/files/files/IAPO%20toolkit%20-%20Working%20with%20partners%20and%20stakeholders.pdf>

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[Click here](#) for the Engagement Tactics tool to help you plan how you will engage medical groups and societies as committed collaborators and partners in advocacy.

★ **United Patients' Tip:** Plan your stakeholder engagement tactics around existing events (e.g., a national medical conference on your disease) for greatest impact.

Maximize Your Opportunities:

Make the most of opportunities to work with health professionals, your government, business leaders and other civil society partners. Consider opportunities such as medical conferences, the launch of United Nations and governmental programs, international meetings, national and international days, celebrations and holidays.

Sample events through which to engage partners:

When forming strong partnerships, face-to-face conversations are key. Look for opportunities to engage potential advocacy partners around already scheduled conferences and events. The links below are to calendars of global events for different diseases to facilitate engaging partners:

- [Elsevier Global Events List](#)

The International Alliance of Patient Organizations (IAPO) has a comprehensive list of upcoming events and days for a range of diseases, for example, World Oral Health Day, Global Patients Congress, etc.:

- [IAPO list of events](#)

[Click here](#) for a full list of opportunities for campaigning.

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Step 4: Run! Advocate

 Now that you have done the preliminary work of selecting your advocacy issue and forming partnerships, this section will walk you through the basics of:

Creating an advocacy campaign

Selecting your advocacy tactics

Making an advocacy plan

Conducting media advocacy

Communicating with decision makers

I. Campaigns and Tactics

A. Campaign

An advocacy campaign is a series of actions and activities that are carried out to achieve the specific objectives and overall goal related to your advocacy issue. The purpose is to win your advocacy issue.

B. Tactics

While advocacy activities can be more general in scope, advocacy tactics are a more specific subset of activities. Tactics always require some measure of power (e.g., your constituents have the power to vote against legislators who do not support your policy issue). Above all, tactics must confront decision makers with a face-to-face ask for support.

Tactics are:

- Influencing activities
- Steps in carrying out your advocacy plan

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- Actions done to decision makers to make them give you what you want
- Requires someone to do it, someone to whom it is done, some reason why the person to whom it is done does not want it done and will make a concession to get you to stop doing it
- Involve showing or demonstrating real power (numbers of supporters, support of influential people in the community, etc.)

Almost anything can be a tactic as long as it actually puts pressure on a decision maker either directly or through the media. Here are some examples:

- Face-to-face meetings
- Consultation responses
- Public meetings or conferences
- Citizen/Patient jury
- Turnout events
- Petition drives
- Letter writing
- Media advocacy
- E-advocacy
- Public hearings
- Demonstrations

EXAMPLE: Here are some suggestions by WHO¹ for campaign ideas that involve different tactics:

- Ask supporters to write to your target decision makers; provide guidance on content but suggest that letters and e-mails be written in their own words
- Send a chain e-mail communicating about your campaign and ask people to forward it to help you reach large audiences
- Create a template letter for submission to newspapers that can be tailored and used by supporters in different settings

¹ Adapted from: <http://www.who.int/chp/advocacy/chp.manual.EN-webfinal.pdf?ua=1>

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- Record an audio file with celebrities reading a short appeal to send to radio stations or to use at public events
- Develop case studies of people living with your disease to feature on your website or to print out and distribute in information packets for decision makers

[Click Here](#) to see an example that highlights some of the tactics used by the Cimab Foundation, a Mexican breast cancer organization, in their advocacy campaigns.

- ★ **United Patients' Tip:** Advocacy tactics should demonstrate how broad your base of support is for your issue. You might consider bringing together the largest number of supporters in one place (e.g., marches) to rally supporters and to secure media coverage.
- ★ **United Patients' Tip:** The point of advocacy is to be respected for your power, not to be liked by decision makers.

Criteria for selecting advocacy tactics

- Is it appropriate for your policy audience?
- Will it compel the decision maker to act?
- Does it highlight the patient voice and perspective?
- Does it put power behind a specific demand made towards a specific audience?
- Is it flexible? Is it likely to work?

[Click Here](#) for Template for Deciding on Possible Advocacy Tactics ([from WHO](#)).

- ★ **United Patients' Tip:** Plan tactics to build on each other, and schedule a series of tactics in advance.

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II. Advocacy Planning

A. Goals and Objectives

 **Goals:** Primary outcomes you would like to achieve
Strategies: Approaches you will take to achieve the goals
Objectives: Measureable steps to achieve your strategy
Tactics: Tools to achieve your objective

Advocacy goals:

The first step in creating your advocacy plan is to develop your goals, which are your long-term (5-10 years) vision for change. This vision should be far-reaching, in that no one organization working alone could achieve it. Goals address the question of how the long-term policy environment will be changed as a result of your advocacy efforts.

EXAMPLE: Advocacy goal

Provide widespread access to breast cancer treatment for women with late stage breast care within the public and private health sectors.

Advocacy objectives:

Advocacy objectives are specific, short-term (1-2 years), measurable, action-oriented targets that help you take incremental steps towards achieving your vision of change. They describe what you want to change, who will make the change, by how much, and by when.

EXAMPLE: Advocacy objective

By the end of the year, redirect XX percent of the Ministry of Health's cancer control budget to include a line item for treatment options for women with late stage breast cancer.

B. Plan

An advocacy plan lists your goals, objectives, actions, targets, timeline, partners, and resources as a critical part of ensuring success in achieving your long-term goals and short-term objectives. You need to make sure that

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your strategy is sound, that you have chosen the right targets, and that the right methods are adopted to reach those targets.

Basic steps of creating an advocacy plan:

- **ISSUE:** Select disease-related advocacy issues, goals, objectives
- **DATA:** Identify appropriate data to support issues
- **AUDIENCES:** Identify appropriate policy audiences (those capable of making the needed change and those who influence the decision makers)
- **MESSAGES:** Develop and deliver persuasive advocacy messages
- **PARTNERS:** Build support among constituencies, coalitions
- **TIME LINE:** Create work plan with timeline for advocacy activities
- **ACTION:** Carry out work plan
- **ASSESS:** Monitor and evaluate results, learning from successes and failures

- ★ **United Patients' Tip:** The difference between successful and unsuccessful advocacy campaigns is rarely the merit of the cause, and more likely to be the strength of the plan.
- ★ **United Patients' Tip:** Successful advocacy begins with strategy and shifts to tactics. Your strategy is the larger mission, the map that guides the use of tactical tools towards well-defined goals. Begin by clarifying your overall goals and then select your tactics.²

Planning tools:

[Click Here](#) for the Advocacy Plan tool to help you organize and plan your advocacy strategy.

For a more comprehensive planning tool, [click here](#) for The Advocacy Progress Planner, an online tool for advocacy planning and evaluation, by the Aspen Institute.

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III. Media Advocacy

Engaging the media is a key component of most advocacy campaigns. Mass media is the quickest and most cost-effective way to reach a large number of people. The media plays a large role in shaping current debate around key issues, beyond raising awareness and information sharing. The media can also put pressure on policy makers to take action, educate and motivate the public, help dispel myths and clarify key points around your issue, and add credibility to your message.

★ **United Patients' Tip:** Monitor media coverage by answering the following questions:

- How is your disease and issue being covered in your country? How is it portrayed in the media? What are the main arguments and concerns?
- How much news coverage has the issue received?
- Which newspapers, blogs and TV stations have had stories about your issue? Do you have relationships with the journalists covering the issue?

Strategies for media engagement:

Build Relationships with Journalists: Seek out major media actors and establish yourself as an expert on your disease and issue. Try to find out what information they need and provide it in a timely manner.

Seek Opportunities: As you monitor the media, look for opportunities to promote your message (e.g., breaking research on your disease).

Utilize Your Social Media Network: The effective use of Social Media (Twitter, Facebook, Instagram, blogs etc.) can help spread your campaign message, engage the traditional media, and bring new people to your cause.

Ways of using the media to address health issues³:

- **Advertising:** Expensive but can reach large numbers of people and your messages can be controlled. Generally less influential than editorial coverage, which represents an impartial point of view.

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- **Media relations and publicity:** Involves the creation of news stories to raise awareness, or to frame issues and actions. Harder to control the messages.
- **Comment and opinion pieces:** Includes editorials and letters to editors.
- **Education via entertainment:** The placement of education messages in the entertainment media in order to promote changes in health knowledge, attitudes, practices (e.g., in soap operas, music, comic books and novels).

★ **TOP SEVEN UNITED PATIENTS' TIPS for successful media advocacy tactics**

1. **Make it newsworthy:** Make it compelling by bringing together a large number of people; highlight a celebrity or well-known spokesperson; tie it in to the launch of a new program or campaign or a breaking story.
2. **Make it visual:** Envision how it will look and make it interesting for television/video.
3. **Use a catch phrase/hash-tag:** Make sure that a consistent theme anchors the event and that speakers use the same quote as an effective "sound bite."
4. **Help journalists write their stories:** Write press releases as if they were news articles in the style of stories in your local newspaper.
5. **Cultivate relationships with the media:** Find out which journalists cover topics related to your disease or other health issues and cultivate relationships with them.
6. **Make it about real people:** Showcase patients and others touched by your disease telling their stories to make it relevant.
7. **Keep it short and simple:** Make sure that your messages are interesting, complete, clear and concise. The clearer and more concise they are, the greater the chance they will be transmitted with accuracy.

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★ **United Patients' Tip:** A press release should be newsworthy and include the following:

- A memorable, informative headline;
- Information on “who, what, why, where, when” in the first paragraph;
- A quote by your most senior spokesperson;
- Your contact details.

IV. Engaging Decision Makers

Understanding your advocacy audiences:

It is important to identify the key decision makers related to your advocacy issue in your country or setting. These are the people with the power to bring about change and they usually work in places of influence, such as government departments, leading hospitals, or businesses. They can be divided into “primary” and “secondary targets.”

Primary Targets: The person who has the most power to give you what you want to advance your campaign or fulfill your requests. It is always a person and not an institution (e.g. Minister of Foreign Affairs rather than Government of X Country).

Secondary Targets: Individuals with strong influence over your primary target (e.g. the editor of the leading national newspaper, your primary target's personal physician, etc.).

★ **United Patients' Tip:** Research and identify the actors that have the greatest impact on your primary targets.

★ **United Patients' Tip:** Be creative and turn to your own professional and social networks to see if you have existing connections to both primary and secondary targets.

★ **United Patients' Tip:** Effective advocacy depends on the relationships that your organization develops with decision makers. The stronger the ties of trust and credibility between advocates and audiences, the more effective the advocacy messages will be.

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[Click Here](#) for a table, Advocacy Target Information (by WHO), that provides examples of the types of information about primary and secondary targets to collect when developing an advocacy plan.

How to develop relationships with decision makers:

- Offer support and help with other issues that they care about
- Find out how you can help them accomplish tasks
- Be a trustworthy, reliable source of information on your disease and risk factors
- Develop contacts with influential people in a variety of fields
- Keep in touch regularly

★ **United Patients' Tips for face-to-face meetings with decision makers:**

- **Plan carefully:** Before the meeting, review your key points, your request, and each person's role, including who will be the primary spokesperson. Anticipate questions that may arise.
- **Get consensus:** Make sure that everyone agrees on the message and how it will be presented – unity will increase your impact.
- **Demonstrate your power as a constituent:** Remind elected officials that you are constituents.
- **Bring someone the decision maker might know or respect:** Sometimes bringing a familiar or respected person to the meeting gives the meeting more weight for the decision maker. The person could be a member of your board, a doctor you work with or a recognized patient/spokesperson.
- **Stay on message:** Stay focused on your issue throughout the meeting; make sure to make your most important points first in case you get interrupted or run out of time.
- **Get to the point:** Present your message clearly and consistently. Make sure you tell them why they should care by connecting your issue to their interests. Tell them what you want them to do. Be prepared to explain your advocacy issue in five minutes.

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- **Provide details in writing:** Leave a fact sheet with your policy ask.
 - **Be a good listener:** Listen carefully to the responses you receive. Give the decision maker time to talk.
 - **Provide additional information:** Answer questions as they arise. Offer to provide further information.
 - **Counter arguments respectfully:** Respond to opposing arguments in a direct but principled way. If you know that the decision maker opposes your position, make sure to point out areas of commonality.
 - **Cultivate an ongoing relationship:** Meetings are part of developing an ongoing relationship with decision makers so treat them respectfully, convey flexibility, and thank them before you leave.
 - **Follow-up after the meeting:** Send a thank-you letter, and any further information that was requested. This reminds policy makers about your issue and is an important step in relationship-building.
 - **Evaluate and track process:** Review what happened in the meeting. Track the progress of your request.
 - **Send a follow up note thanking for their time:** A thank you note reinforcing the points discussed in a short format is a way to stay top of mind.
- ★ **United Patients' Tip:** When going into a meeting with a decision maker, make sure to be ready to respond to the question, "What do you want me to do?"
- ★ **United Patients' Tip:** Real life stories about the shocking reality of what it is like to live with disease can influence decision makers by capturing their hearts and then their minds. You can support these stories with photos to bring them to life.
- ★ **United Patients' Tip:** Be prepared to tell your personal story – why you feel your disease is important, and why the government needs to take action. Include simple printed materials with illustrations to reinforce the main points and actions to be taken by decision makers.

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This Campaign Checklist below will assist you in measuring the progress of your advocacy campaign, and can be adapted to suit your local conditions. Please add more activities as you see fit.

[Click Here](#) for the United Patients' Campaign Checklist.

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Step 5: Post-Race Analysis!

Evaluate and Identify Lessons Learned

I. Monitoring and Evaluation

A. The importance of monitoring and evaluation of advocacy strategies

Monitoring and evaluation are essential to successful advocacy strategies in equally important but different ways. Since advocacy often only provides partial results, advocates need to monitor regularly and objectively what has been accomplished and what more remains to be done.

Monitoring refers to ongoing, systematic data collection, such as media tracking, meeting tracking, etc. This type of information is helpful for generating trend data to gauge progress over time. It will enable you to assess your progress in meeting your objectives, to note which activities are going well and which are not, and to make adjustments if needed.

Evaluation will help you to assess your overall results and your lessons learned, and to apply these lessons to future advocacy work. It judges the quality and impact of activities, asking why some actions went well and others did not, and why some activities had the desired impact while others did not. Both process evaluation (how you worked) and impact evaluation (what changed) need to be taken into account.

B. Monitoring and evaluation targets

Given that changes in policies and institutions occur over the long-term, it is important that you create targets that can help you assess your progress in carrying out your advocacy plans.

EXAMPLE: Meeting the objective of “building relationships with Minister of Health and key staff” may be quantified through the number of meetings and types of interactions sustained during the advocacy campaign.

Monitoring and evaluation methods can be qualitative (e.g., case studies, stories, opinions, survey questionnaires) or quantitative (e.g., statistics that indicate a change over time).

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Examples of Monitoring Methods:¹

- Keep records of meetings, correspondence or conversations with target audiences and the responses;
- Track when your key messages or briefing notes are used by elected officials, other key influencers or the media;
- Conducting surveys and interviews to determine the impact your actions have had;
- Monitor the media and keep track of coverage of your issue.

★ **United Patients' Tip:** Evaluation should be based on the goals and objectives that were set at the beginning of the advocacy planning process. Answer the following questions to evaluate the impact of your work:²

- Have you achieved your objectives?
- How many meetings have you had with key target decision makers and what were the outcomes of those meetings?
- What actions did the decision makers take? Is the situation better now? By how much?
- If there is no change, how might you adjust your advocacy methods?
- What would you do differently?
- Are the people involved with the advocacy effort pleased with the results and the process?

[Click Here](#) to see a comprehensive list of Suggested Indicators for Evaluating Advocacy Efforts.

[Click Here](#) to see the Activity Monitoring and Updates Tool. This tool can help you monitor your progress, and to assess how individual tactics are contributing to your overall advocacy strategy.

[Click Here](#) to see the Advocacy Tracking Tool to serve as your evaluation template.

¹ Adapted from: <http://www.who.int/cancer/FINAL-Advocacy-Module%206.pdf>, pages 43-44.

² Adapted from: <http://www.who.int/cancer/FINAL-Advocacy-Module%206.pdf>, pages 43-44.

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C. Sharing your lessons learned

★ **United Patients' Tip:** Tell your story so others can understand the complexities of your environment and work, and the choices you made along the way. Make sure to describe the engagement strategies you used to work with the medical community and your relationship as advocacy partners.

1. What worked?
2. What would you do differently next time?
3. What are some new avenues for the partnership?
4. What would you recommend for other organizations seeking to form advocacy partnerships with the medical community?

[Click here](#) to see a chart from UNICEF called, "Sample advocacy activities, interim outcomes, goals, and impacts, and their measurement indicators."¹

¹ https://www.unicef.org/evaluation/files/Advocacy_Toolkit_Companion.pdf, pages 17-19.

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ASC: [American Cancer Society](#)



AHA: [American Heart Association](#)



BCSC: [Breast Cancer Surveillance Consortium](#)



CDC: [US Centers for Disease Control](#)

CVD: Cardiovascular disease



ESC: [European Society of Cardiology](#)



EURORDIS/RDI: [Rare Diseases Europe /Rare Diseases International](#)

FH: Familial hypercholesterolemia

GPs: General practitioners



IARC: [International Agency for Research on Cancer](#)



IAPO: [International Alliance of Patient Organizations](#)



IDF: [International Diabetes Foundation](#)

KAP: Knowledge, attitudes, practices survey

NCDs: Non-communicable diseases

 NCD Alliance [NCD Alliance](#)

NETs: Neuroendocrine tumors

NGOs: Non-governmental organizations



PANLAR: [Pan American League of Associations for Rheumatology](#)



PRB: [Population Reference Bureau](#)



UN: [United Nations](#)



UP: [United Patients](#)



UICC: [Union for International Cancer Control](#)



WHO: [World Health Organization](#)



WHF: [World Heart Federation](#)