Engaging the Medical Community as Advocacy Partners

Introduction & Overview

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 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;

★ **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

Go!

Engage Stakeholders and Partners

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.)
- It always features a clear call to action

In appendix 1 you will see for an example of a call to action on cancer control by the Union for International Cancer Control (UICC).

Also in appendix 2 you will see an example of a template letter[1] 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.

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

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. Go online to **https://ncdalliance.org/** 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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[2] Example adapted from: http://www.who.int/chp/advocacy/chp.manual.EN-webfinal.pdf?ua=1

- 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.

See a **Message Builder** tool to help you organize the process of crafting an advocacy message in **appendix 3** you will .

In **appendix 4** you will find the **Engagement Priorities** tool and in **the appendix 5** you will see for the **Narrative per Priority** tool to help you tailor your messages to reflect the needs and priorities of different audiences.

In **appendix 5** you will see 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.*

Also in **appendix 6** you will find 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*.

FROM: *Stop the Global Epidemic of Chronic Disease, A Practical Guide to Successful Advocacy*, ISBN 92 4 159446 2, ISBN 978 92 4 159446 2, published in 2006.
http://www.who.int/chp/advocacy/chp.manual.EN-webfinal.pdf?ua=1

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.

In appendix 7 you will see a chart on Potential Messengers for Specific Audiences[6] from the World Health Organization's publication, *Stop the Global Epidemic of Chronic Disease, A Practical Guide to Successful Advocacy*.

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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

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:

- 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 BACKROUND 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.

★ **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]

Go online to **http://en.panlar.org/como-y-por-que-incluir-los-pacientes-durante-congresos-medicos** 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."**

In **appendix 8** you will see the International Association of Patient Organizations (IAPO) **top tips for collaborating with other patients**' organizations and healthcare professional associations.[5]

In **appendix 9** you will see an example from **IAPO**[6] of how a patient organization and healthcare professional associations can work together.

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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**

In **the appendix 10** you will see 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 (**http://www.globaleventslist.elsevier.com/calendar/**)

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 (**https://www.iapo.org.uk/events**)

In **the appendix 11** you will find a full list of opportunities for campaigning.

Appendix 1: Example UICC

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In 2012, an estimated 14.1 million people were newly diagnosed with cancer. It is expected that by 2030, this number will rise to 21.6 million. This alarming trend can be reversed with strong action at global and national level.

Investing in cancer control, from prevention to treatment and care, can bring about important changes in disease burden by reducing cancer-related illness and death. It is estimated that increased annual international funding of USD 18 billion globally on prevention, earlier detection and improved care for cancer patients could save three million lives per year by 2030 - and many more in the decades beyond.

What is cancer control advocacy?
Advocacy for cancer control is a strategic process that is designed to influence governments, decision makers and other key stakeholders through the effective use of evidence, to reduce the global cancer burden, to promote greater equity, and to integrate cancer control into the world health and development agenda.

Advocacy at UICC
UICC unites the cancer community through our members and partners to reduce the global cancer burden and drive forward the Non-Communicable Disease (NCD) agenda - building upon key international agreements, such as the Sustainable Development Goals (SDGs), the Global Action Plan on NCDs 2013-2020, the World Cancer Declaration and the 2017 Cancer Resolution - to ensure that these global goals and targets are translated into national action.

In addition to all countries developing and implementing an appropriately resourced and time-bound national cancer plan, we wish to see measurable improvements in the way that cancers are detected, treated and cured around the world.

With global cancer burden trends on the rise, advocacy at UICC is shifting its immediate attention to Treatment for All, a campaign emphasizing improved data, early detection, treatment and care to meet our global commitment of a 25% reduction in cancer and NCD mortality by 2025.

FROM: http://www.rarecancerseurope.org/Patient-Advocacy-Toolkit/Practical-Tools, Speak Up for Rare Cancers, Rare Cancer Patient Toolkit.

Appendix 2: Example of a template letter

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The Honourable .XXXX
House of Commons
SWX London

Ms Julia Smith
Rare Cancers UK
Old Church Road
Cambridge

Date

On behalf of rare cancer patients in the UK

Dear (Minister)

As a constituent and rare cancers patient advocate, I am writing to urge you to ensure that the current legislation reform the government is undertaking provides rare cancer patients proper access to rare cancers Centres of Excellence and European Reference Networks, in accordance with the EU Directive .XXX:X.

Rare Cancers Europe recently released its 2014 Rare Cancers Priority Agenda. This document highlights the changes we must make to improve diagnosis and treatment of Rare Cancers in (your country), based on current evidence and on our longstanding advocacy efforts.

Specifically, Rare Cancers (your country) is recommending that new health legislation works towards removing the red tape which makes access to new treatments difficult for rare cancer patients. We urge you to include the following provisions:

- Standardise second opinions, scans & mutational analysis
- Reimburse second opinions and diagnostic tools
- Improve access to existing treatments including drug approval for small groups
- Reimbursement for "off label" use of existing and licensed drugs in Europe
- Educate doctors and pathologists to recognise rare cancers earlier (primary care/GPs)
- An Infrastructure supporting translational research/cross-border cooperation
    - Tumour banks & easy tissue transfer for research
    - Clinical trials on an international scale to maximise patient numbers
    - Harmonised European patient data registries
    - Access to patient data
    - Data protection regulation should facilitate access for health research

We urge you to work to ensure that these key provisions are considered as Parliament moves forward with efforts to reform our nation's health system.

Thank you for your attention to my request and I look forward to hearing your position on this critical issue.

Yours sincerely,

(Name)
(Postal and email address) (Telephone number)

Appendix 3: MESSAGE BUILDER

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Priority:

Narrative:

Proof point 1

Proof point 2

Proof point 3

Raw materials

Patients

Healthcare professionals

…

Instructions

Use this tool to define the messages for the stakeholder.
Define for each engagement priority a narrative.

The narrative is the statement to tell to all stakeholders.

Divide the the narrative in several proof points and identify the scientifically proven materials supporting them.

Adapt this narrative in order to reach each defined stakeholder.

Appendix 4: Engagement priorities

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Internal alignment

1 E.g., Raise disease awareness

2

3

4

1 Raise disease awareness

Narrative	*e.g. « X is an established disease with X number of people diagnosed per year; its risk factors inlcude XYZ… »*		
Supporting materials	*e.g. published studies…*		
Adapted messages to stakeholders	*E.g., Patients:*	*Medical community*	

Appendix 6: Audiences and Considerations

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AUDIENCE	CONSIDERATIONS
Ministers of Health and their Deputies	Ministers of health can become powerful advocates for action on chronic disease, informing other policy makers about the issue. They will need to know the scale and cost of tackling chronic disease and the cost–effectiveness of interventions.
Presidents and Prime Ministers	Enormously influential. Along with their own views and personal experience, they may draw on the advice of ministers or other leaders, and on the views of experts, including their personal physicians.
Budgetary decision makers (e.g. cabinet, ministers of finance and planning). Ministers of related sectors and their deputies (e.g. ministers of education, transport, and agriculture)	Require sophisticated information and detailed arguments. Depending on their area of responsibility, they will want to know how making changes in health policy will affect other areas, such as the economy, education, transport or tourism.
Donors/funding agencies for low- and middle-income countries	Will want to assess the return on their investment. May need information on chronic disease and the impact they could achieve with relatively little investment. Will want to see that their investment will help the poorest members of society.
Private sector employers, such as national and local businesses and business associations, and multinationals	Motivation may be a healthy workforce or desire to be good employers. Can implement cost-effective actions on workplace health, such as smoking bans and physical activity opportunities.
Community leaders	Include local government bodies, city councils, mayors and prominent members of civil society, such as religious leaders. They often want what is best for their community but need information and suggestions for specific actions that they can take.
Opinion leaders within the health- care profession	Often scientists and academics. Extremely influential with strong understanding of the issues. Powerful advocates once convinced of the need for action.
Potential allies such as UN agencies and NGOs, including disease-specific charities	Require compelling arguments about why they should get involved, along with facts, figures and messages. Some NGOs will be emotionally motivated, and focused on the need to generate funds. Consumer/patient groups working at the community level are often very motivated, but will probably require information on the issues.

FROM: *Stop the Global Epidemic of Chronic Disease, A Practical Guide to Successful Advocacy*, ISBN 92 4 159446 2, ISBN 978 92 4 159446 2, published in 2006.
http://www.who.int/chp/advocacy/chp.manual.EN-webfinal.pdf?ua=1

Appendix 7: WHO Messages That Can Be Tailored To Specific Audiences

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TOPIC	MESSAGES
Core Message	Stop the global epidemic of chronic disease. Variations: » The global epidemic of chronic disease is largely invisible and the global response is largely inadequate. » The epidemic is rapidly evolving, the threat is growing, but the response is not keeping pace. » More and more people are dying too early and suffering too long from chronic disease. We know what to do to prevent most of it and so we must act now.
The Problem	More and more people are dying too early and suffering too long from chronic disease. Statistics: » 6 out of 10 deaths worldwide are due to chronic diseases. » 4 out of 5 chronic disease deaths are in low and middle-income countries. » Half of all chronic disease deaths are premature (people aged under 70 years). » One quarter are in people under 60 years of age. » Half of all cases of chronic disease are in women. » 35 million people died of chronic disease in 2005, 17 million prematurely. » Predicted in report: 388 million will die from chronic disease in the next 10 years without urgent action. Talking points: » In all but the least developed countries the poor are the worst affected: they have highest exposure to risk factors, lowest access to preventive measures or health care, highest rates of premature death, and experience the greatest personal impact. » People with chronic diseases and at high risk are often not getting the necessary treatment, although many cost-effective interventions exist.
Risk Factors	The three major risk factors are: an unhealthy diet, physical inactivity and tobacco use. Talking points: » We are seeing rapid increases in these risk factors worldwide. » Increasingly unhealthy diet. Processed foods high in salt, fat and sugars are more widely available than ever. » Decreasing physical activity as urbanization increases and life becomes more sedentary. » More tobacco use due to aggressive marketing and lack of regulation of tobacco products.
Solutions	The solution is prevention. We can have an impact immediately. Talking points: » It is not necessary to wait years to see the benefits of prevention and control. » We know the solutions. Many are simple, cheap and cost-effective. » The major causes of chronic diseases are known. If these risk factors were eliminated, at least 80% of premature heart disease, stroke and type 2 diabetes would be prevented. Over 40% of cancer would be prevented. » Examples: reduce salt in processed food, increase tobacco taxes, improve school meals, improve and increase access to walking and biking paths. » Many of these solutions have been proven to have immediate impact and rapid health gains. » People at high risk of and those living with chronic diseases also need to obtain treatment; much can be done cost-effectively. » No one sector of society has the resources or necessary reach to implement all the solutions alone. » Everyone has a role to play in the solution: governments at all levels must take a leadership role, but there are also important measures to be taken by private industry, communities and schools, international organizations, NGOs, charities and advocacy groups.
Macro Economic Impact	The costs to national economies will run into economic billions of dollars. Governments should invest in prevention now, or pay the rising costs later. Talking points: The cost of chronic disease can be measured in lives lost; lost productivity and earning power (people are often afflicted in the prime of life); health care costs to individuals, families, countries; burden on the health-care system, often on top of infectious diseases; lost national income. » For example, lost national income in the coming decade due to heart disease, stroke and diabetes for China: $ 558 billion; India: $ 237 billion; Russian Federation: $ 303 billion (figures in international dollars). » Chronic disease and poverty are locked together in a vicious cycle, which can become a downward spiral into deeper poverty and worsening illness for individuals and their families.
The 2% Goal	If we can reduce global chronic disease death rates by an additional 2% over the next 10 years, we can prevent 36 million people dying from heart disease, stroke, cancer and other chronic diseases. Talking points: The effects of the 2% goal: » Averting 36 million deaths from chronic disease in the next 10 years. » Huge economic gains. For example, over 10 years, China will gain $ 36 billion, Russian Federation $ 20 billion, India $ 15 billion (figures in international dollars).

FROM: *Stop the Global Epidemic of Chronic Disease, A Practical Guide to Successful Advocacy*, ISBN 92 4 159446 2, ISBN 978 92 4 159446 2, published in 2006.
http://www.who.int/chp/advocacy/chp.manual.EN-webfinal.pdf?ua=1

Appendix 8: POTENTIAL MESSENGERS FOR SPECIFIC AUDIENCES

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TARGET AUDIENCE	MESSENGER
General public – when you want to illustrate the human cost of chronic disease.	An individual who suffers from a chronic disease, or a family member who has lost a relative to a preventable condition.
A minister of finance – when you are arguing that investment in chronic disease prevention and control is not only cost-effective but could also provide economic benefits.	A leading international or national economist, or a finance minister from another country, who is able to argue convincingly for the economic benefits of action.
A prime minister considering supporting legislation.	Ministers; current and former aides; political leaders in his or her political party; respected religious and community leaders; leading businesspeople; financial supporters.
General public – when you are seeking to educate and motivate.	Physicians, scientists, academics. Sports figures and celebrities may also be effective messengers for education and motivation.
Physicians – when you are educating about the need for an integrated approach to chronic disease.	Internationally or nationally respected physicians, or physicians who have institutional or economic influence within the medical community. As well as professional contact with their colleagues, such people are often used as expert commentators within the popular or professional media.
Trainee physicians	Medical school professors and lecturers.
Journalists – when you are seeking media coverage of an issue.	Individuals who have personally suffered from chronic disease. If someone from your organization is to be interviewed, it is usually best to have someone who can speak from their own experience – someone who works directly on the issue – as long as (s)he is a good communicator.

FROM: *Stop the Global Epidemic of Chronic Disease, A Practical Guide to Successful Advocacy*, ISBN 92 4 159446 2, ISBN 978 92 4 159446 2, published in 2006.
http://www.who.int/chp/advocacy/chp.manual.EN-webfinal.pdf?ua=1

Appendix 9: Top tips for collaborating with other patients' organisations and healthcare professional associations

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1. Collaborate with other patients' organisations/healthcare professional associations that share similar goals and ambitions to that of your own organisation, e.g. to raise disease awareness in a given disease.
2. Agree the scope, objectives and timeframe of any collaboration in advance of starting any project or alliance.
3. Review the scope and objectives of the project or alliance at regular intervals to ensure that things are running as planned, and to identify ways that the collaboration could be improved if required.
4. Where possible explore how best to share resources, e.g. educational materials, access to information.
5. Assign clear roles, responsibilities and tasks for any project or alliance and ensure that they are clearly communicated to the relevant individuals.
6. Ensure that each party is appropriately acknowledged for their input or contribution.
7. Work together to maximise each party's strengths and be sensitive to any limitations or constraints they may have.
8. Be prepared to invest time, effort and resources in establishing, building and maintaining any relationships.
9. Ensure that you keep in regular communication using emails, telephone and face-to-face meetings. Any written communications should be as clear and concise as possible.
10. Appoint one individual to take responsibility and manage the collaboration on behalf of your patient organisation.
11. Be flexible and willing to discuss how to resolve any potential areas of conflict.
12. Always be open, transparent and ethical.
13. Develop an agreement specifying:
    - The objectives and scope of the project/interaction
    - The roles, responsibilities and tasks of each party
    - Timelines
    - The amount and source of any relevant funding
    - How each party will be acknowledged for its contribution and involvement.

[NOTE: This document is part of the IAPO toolkit 'Working with partners and stakeholders', which can be accessed from the IAPO website.]

Appendix 10: Example IAPO

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The UK Haemophilia Alliance

The UK Haemophilia Alliance is a union between the patients' organisation, the Haemophilia Society, and several healthcare professional associations including the Haemophilia Centre Doctors Organisation and the Haemophilia Nurses Association.
The mission of this alliance is to "work together with the aim of continually improving standards of care and support for all patients with haemophilia and other inherited bleeding disorders and their families throughout the UK". Through this formal partnership the alliance developed the 'National Service Specification for Haemophilia', which promotes best practice and tries to standardise care throughout the country. The alliance also works with an unofficial parliamentary group (All Party Parliamentary Pressure Group on Haemophilia), which promotes and keeps the Government informed of haemophilia issues, and ensures that haemophilia is kept on the political agenda.

Appendix 11: FULL LIST OF OPPORTUNITIES FOR CAMPAIGNING

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- World Cancer Day: 4 February. http://www.worldcancerday.org
- Rare Disease Day: 28 February. https://www.rarediseaseday.org
- World Health Day: 4 April. http://www.who.int/campaigns/world-health-day/2018/en/
- World No Tobacco Day: 31 May. http://www.who.int/tobacco/wntd/en/
- World Heart Day: Last Sunday of September. https://www.worldheartday.org
- International Brain Tumour Awareness Week: Last week of October. https://theibta.org/awareness-raising/
- Neuroendocrine tumors (NET) cancer day: 10 November http://netcancerday.org
- World Diabetes Day: 14 November. http://worlddiabetesday.org
  Breast Cáncer Awareness Month—— http://www.nationalbreastcancer.org/breast-cancer-awareness-month
- Lung Cancer Awareness Month—- https://www.iaslc.org/lcam
- WHO World Antibiotic Awareness Week—— http://www.who.int/campaigns/world-antibiotic-awareness-week/en/