**Using Data for Advocacy Purposes: A Step by Step Guide for Patient Groups**

# 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 using data sources related to the prevention and treatment of specific diseases at the clinical, local and national level. The materials are designed to be adapted to your unique local needs, situation and specific disease.

**Goals:** The goals of this Toolkit are:

• 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

⭐ **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

# 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.

In **appendix 1** you will 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.

- **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.

In **appendix 2** you will 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.

**In the appendix 3 you will see 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.

In **appendix 4** you will see the **Stakeholder 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.

In **appendix 5** you will see the **Profile of Potential Partners** tool.

**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:**

In **appendix 6** you will 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**

In **appendix 7** you will see the **"Key Information Gathering Questions"** and easy to use guide.

**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
- **Illustrat**e 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.;

- 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 services.[1]

In **appendix 8** you will see how **HEART UK** uses data to describe the medical reality of under-diagnosis of familial hypercholesterolemia (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?

**C. Data Sources**

**DATA NEEDS FOR HEALTH-RELATED ADVOCACY[2]**

| Type of Data | Advantages | Disadvantages |
|---|---|---|
| National level statistics (e.g., registries) | • Comparable, can show trends from year to year | • Not always reliable due to underreporting, etc. <br> • Doesn't address root causes of problems |
| Country and regional statistics from international bodies (i.e., WHO) | • From well-respected, non-partisan source <br> • Easy and inexpensive to obtain | • Provides overall picture, but does not explain root causes <br> • Findings may be presented in lengthy, technical reports |
| Focus groups | • Provides attitudinal and anecdotal information <br> • Records participants' emotions, motivations, feelings | • Small sample size makes it difficult to generalize <br> • Can be time consuming to conduct and analyze |
| Surveys (e.g., KAP -- Knowledge, attitudes, practices) | • Provides statistical baseline <br> • Provides behavioral information <br> • Can be from respected institution (i.e., University) | • Findings can be subject to widely differing interpretations <br> • Depth constrained by close-ended questions |
| Local clinic-level or project-level reports or surveys | • Can highlight trends <br> • Can provide information on patient services | • Need to consider errors in collection and analysis <br> • Can be costly |

In **appendix 9** you will see some links to useful **sources of disease-specific data for selected diseases and risk factors**

2  Adapted from "Social Mobilization for Reproductive Health, A Trainer's Manual," CEDPA, 2000, session four, p. 39.

**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)
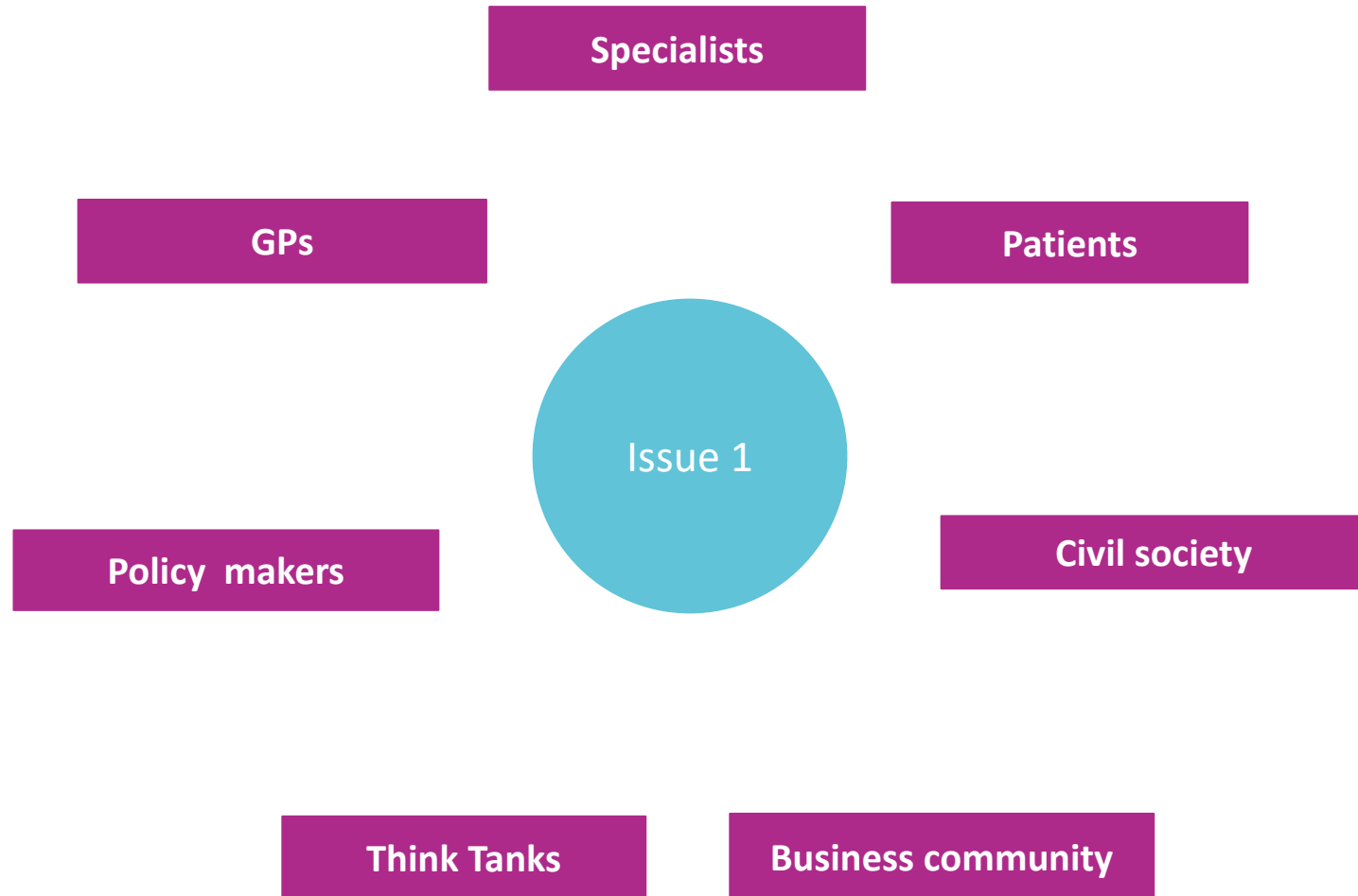
In **appendix 10** you will see an example of how **American Cancer Society (ACS)** adapts research to demonstrate the economic impact of cancer.

Go online to **http://www.bcsc-research.org/data/ptshort6.pdf** 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.

United Patients

**Specialists**

**GPs**

**Patients**

Issue 1

**Policy  makers**

**Civil society**

**Think Tanks**

**Business community**

<< BACK

Issue 1

Stakeholder Influence

+

−

Specialists

Patients

GPs

Media

**Stakeholder Alignment on the Issue**
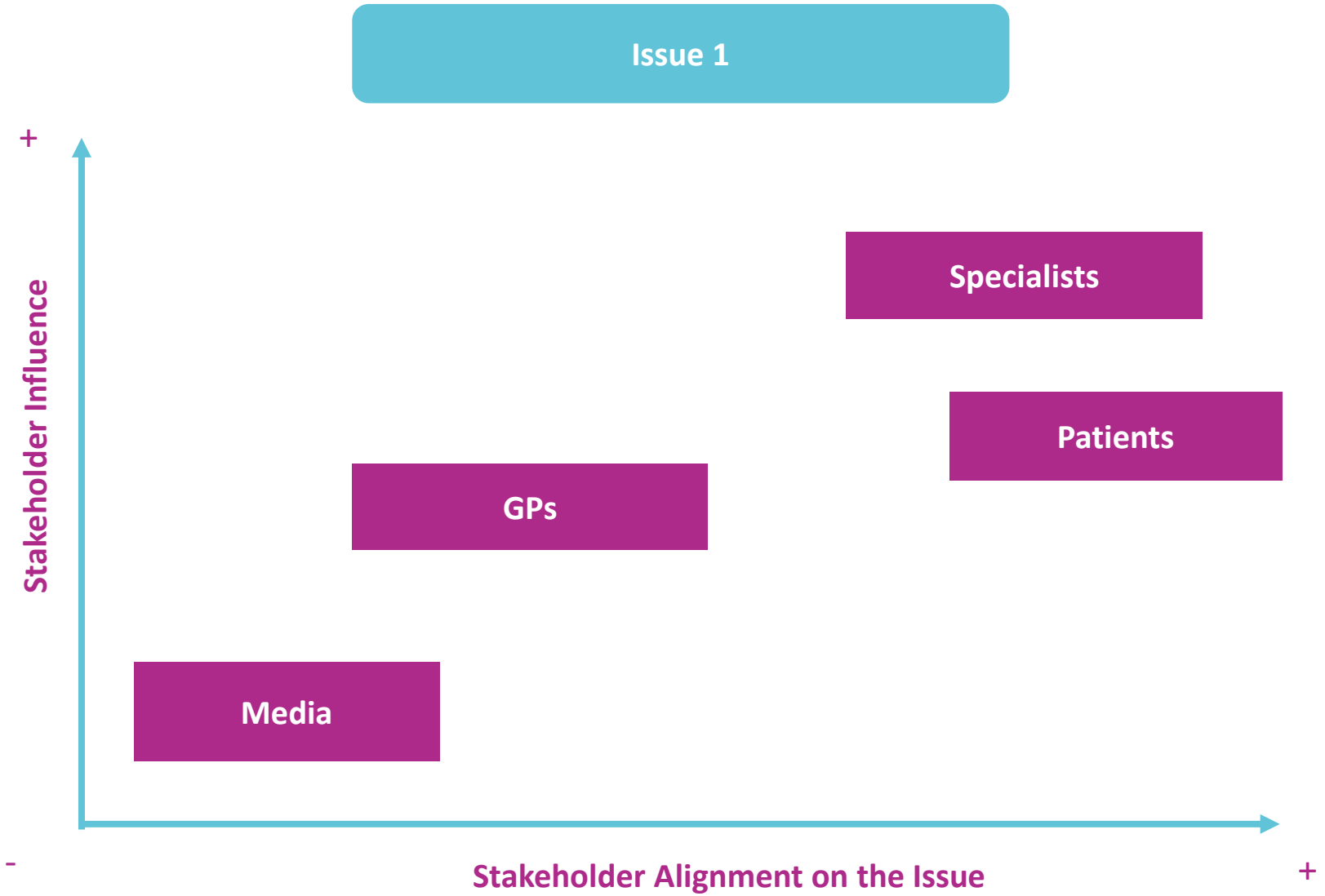
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The World Heart Federation (WHF) is designing a series of cardiovascular disease (CVD)-related Roadmaps to translate existing knowledge of best practices, barriers, and solutions into practical strategies for improved cardiovascular health.

In order to create these Roadmaps, WHF convenes a global advisory group of experts including patient groups, medical societies, researchers, academia, policy makers and the private sector in CVD prevention, including specialists in health policy, health systems and health economics.
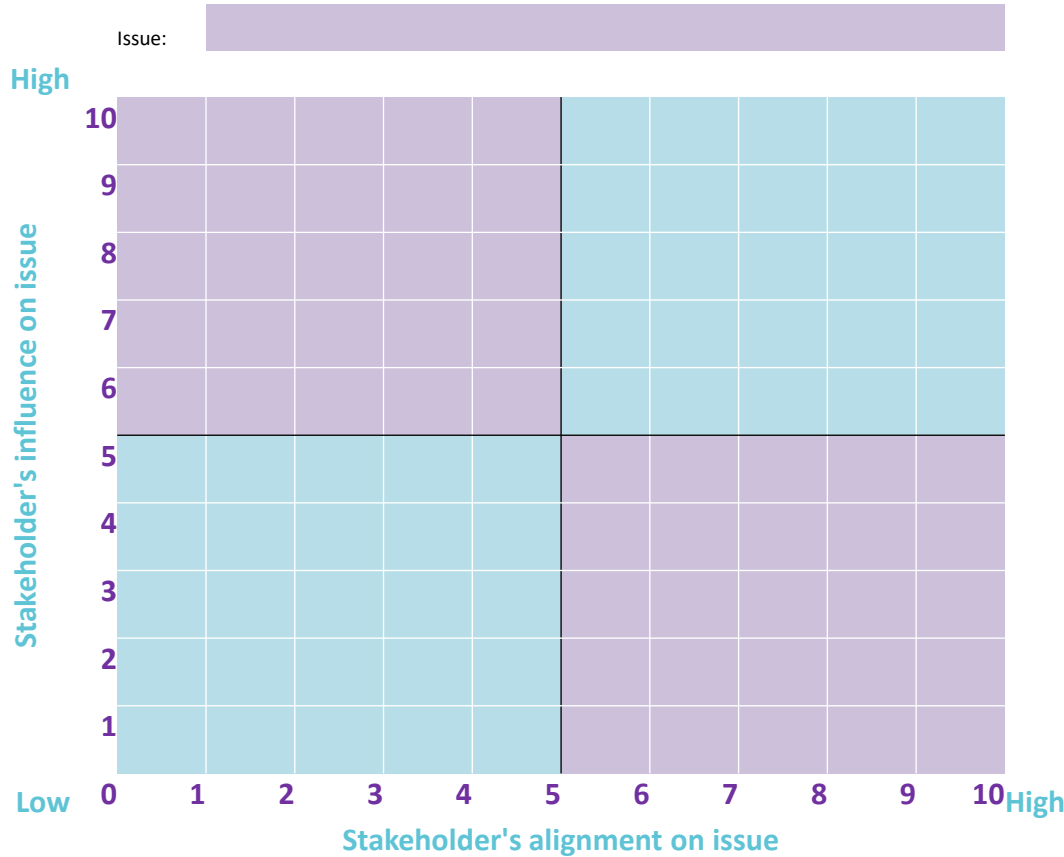
The Roadmaps serve as models so countries can meet their commitments to develop or update national non-communicable disease plans using the framework provided by the World Health Organization's Global Action Plan (GAP).

These Roadmaps focus on providing healthcare professionals and policy makers across the world with tools and solutions to manage the secondary prevention of CVD and reduce premature death globally. The Roadmaps will help drive the WHO target of reducing heart attack and stroke by 25% by 2025 by providing practical tools to improve healthcare and prevent CVD in low, middle and high-income countries. Roadmaps dedicated to secondary prevention of CVD, tobacco control and raised blood pressure have already been published, and Roadmaps for blood cholesterol, rheumatic heart disease, and atrial fibrillation are forthcoming.

- Reducing Cardiovascular Mortality Through Prevention and Management of [Raised Blood Pressure](): A World Heart Federation Roadmap
- Reducing Cardiovascular Mortality Through [Tobacco Control]() : A World Heart Federation Roadmap

**<< BACK**

Issue:

**High**

**Stakeholder's influence on issue**

10
9
8
7
6
5
4
3
2
1

**Low**    0    1    2    3    4    5    6    7    8    9    10    **High**

**Stakeholder's alignment on issue**

### Instructions

Use this tool to map key stakeholders in relation to important policy issues

Identify each stakeholder and their alignment on the issue.

Write the name of the stakeholder in the good cell according to the scale of 1 to 10 of its influence the stakeholder has with this issue and its alignment on this issue.
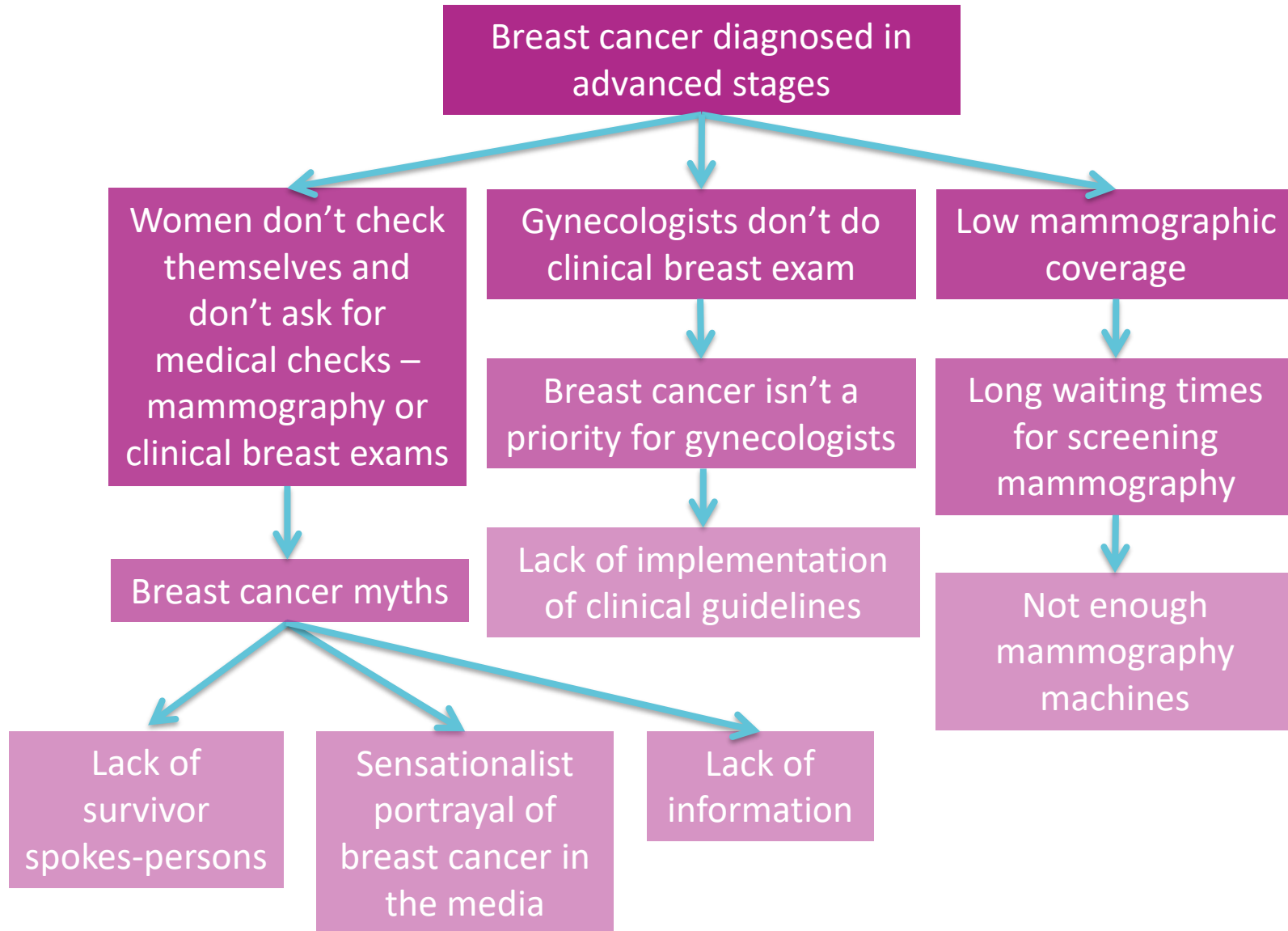
**Determine then if:**
- This is a Priority partner (top/right)
- You can support development of stakeholder capabilities around the issue (bottom/right)
- This is an opportunity to educate and convince the stakeholder (top/left)
- This not a priority for you (bottom/left)

<< BACK

## Instructions

Use this tool to capture in-depth information on each of the stakeholders. Complete this information with as much detail as possible.

| Organization | | | Stakeholder Details | | | | | | Sphere of Influence | | | | | | | ROLE IN CAMPAIGN |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Country | Name of Entity | Type | Stakeholder Name | Contact details | Position within the Entity | Other Affiliations | Topics of Expertise | Current Projects | Position on Issue | Kind of Impact | Influenced by whom? | Influencing who? | Geographic area of Impact | Frequency of Contact | Existing Collaborations | |
| | | | | | | | | | | | | | | | | |
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Breast cancer diagnosed in advanced stages

Women don't check themselves and don't ask for medical checks – mammography or clinical breast exams

Gynecologists don't do clinical breast exam

Low mammographic coverage

Breast cancer isn't a priority for gynecologists

Long waiting times for screening mammography

Breast cancer myths

Lack of implementation of clinical guidelines

Not enough mammography machines

Lack of survivor spokes-persons

Sensationalist portrayal of breast cancer in the media

Lack of information

<< BACK

| KEY INFORMATION GATHERING QUESTIONS | ANSWERS |
|---|---|
| Who is responsible for the monitoring and surveillance of the disease at the Ministry of Health? | |
| What disease policies and programs currently exist? Are they comprehensive, integrated and of good quality? Are they being funded and implemented? | |
| What disease or condition-related goals, targets, and indicators is the government currently tracking? | |
| Is there a national surveillance system that tracks risk factors related to the disease or condition? | |
| How engaged is your Ministry of Health in control of the disease or condition? | |
| Who funds control of the disease or condition in your setting? | |
| What are funds for control of the disease or condition primarily spent on? | |
| What is the level of awareness about the disease and risk factors in the population? Among government officials, influential people, organizations and the public in general, what is the level of understanding of, and commitment to, comprehensive control of the disease? | |
| What specific disease or condition-related information would be helpful to share with the ministries? | |
| What advocacy activities are currently being undertaken, and which organizations and individuals are involved? What are their goals, objectives and target audiences? What resources do they have and what has been the impact of their advocacy efforts to date? | |
| What are the barriers to, and opportunities for advocacy work? | |

FROM: The HEART UK FH Guideline Implementation Team Toolkit

The under-diagnosis of familial hypercholesterolaemia

FH is a genetic condition that leads to a high concentration of cholesterol in the blood. It is caused by genetic mutations in the pathway that clears LDL-C (low density lipoprotein) from the bloodstream, usually in the LDL-C receptor.

FH can lead to the early onset of atherosclerosis and particularly coronary heart disease. It is passed to offspring in a dominant pattern, meaning that siblings and children of FH patients have a 50% risk of inheriting the condition.

It is estimated that around 1 in 500 people in the UK are affected by FH, which equates to around 120,000 people. This is on a level with Type 1 diabetes.

FH is significantly under-diagnosed in the population, particularly in the under-35 age group. Currently less than 15,000 patients have been identified, meaning that up to 85 per cent of patients with the condition have not been identified or treated. The implementation of cascade testing of family members of FH patients is a vital part of addressing this gap in diagnosis. https://heartuk.org.uk/FHToolkit/

**CANCER:**

**American Cancer Society (ACS):**
https://www.cancer.org/research/cancer-facts-statistics/global.html

**Infographics:**
https://www.cancer.org/research/infographics-gallery/rising-global-cancer-epidemic.html

**Union for International Cancer Control (UICC):**
**Cancer Atlas:**
https://www.uicc.org/resources/access-all-resources/cancer-atlas

**CARDIOVASCULAR DISEASE (CVD):**

**World Heart Federation (WHF):**

**FACT SHEETS: Cardiovascular diseases by country**
http://www.world-heart-federation.org/heart-facts/fact-sheets/cardiovascular-disease-by-country/

**Infographics:**
http://www.world-heart-federation.org/heart-facts/resources/infographics/

**European Society of Cardiology (ESC):**
**ESC Atlas of Cardiology:**
http://www.escardio.org/Research/ESC-Atlas-of-cardiology

**DIABETES:**

**International Diabetes Federation (IDF):**
**Diabetes Atlas:**
http://www.diabetesatlas.org

**World Health Organization (WHO):**
**Global Report on Diabetes:**
http://apps.who.int/iris/bitstream/10665/204871/1/9789241565257_eng.pdf

**MULTIPLE DISEASES AND CONDITIONS:**

Global Health Observatory (GHO) Repository
The GHO data repository contains an extensive list of indicators, which can be selected by theme or through a multi-dimension query functionality. It is the World Health Organization's main health statistics repository. Click here to: Browse the GHO data repository

**US Centers for Disease Control (CDC):**
https://www.cdc.gov/datastatistics/index.html

**RARE DISEASES:**

**EURORDIS/Rare Diseases International**
**Rare Disease Info Hub**
https://www.eurordis.org/rare-disease-information

**Additional examples of Fact Sheets, Infographics and Tools to Help Develop Them:**

• *Visualising Information for Advocacy* is a book about how advocates and activists use visual elements in their campaigns. This 170-page guide features more than 60 case studies from around the world to provide an introduction to understanding visual information and a framework for using images for influence. The book's website contains reviews of, and links to, a number of data visualization tools.
**https://visualisingadvocacy.org**

• The MEASURE DHS STATcompiler allows users to make custom tables based on hundreds of demographic and health indicators across more than 70 countries. Users can customize tables to view indicators by background characteristics, over time, and across countries.
https://www.statcompiler.com/en/

**NON-COMMUNICABLE DISEASES (NCDs):**

**NCD Alliance:**

**NCD Atlas:**
**https://ncdalliance.org/resources/ncd-atlas**

**Infographics:**
https://ncdalliance.org/resources/infographic-2018-un-hlmncds-campaign-priorities

**World Health Organization (WHO):**

To understand the NCD burden in your setting:
http://www.who.int/nmh/publications/ncd-status-report-2014/en/

See WHO's multimedia fact file for useful facts and figures that can be used as talking points -- "10 facts about chronic disease":
www.who.int/features/factfiles/chp/01_en.html

See WHO's region-specific and country-specific information sheets for facts and figures on chronic disease:
www.who.int/chp/chronic_disease_report/media/impact/en/index.html

See WHO's Global InfoBase Online, a data warehouse with a search engine that allows access to country-level NCD risk factor data including overweight, obesity, tobacco use, blood pressure, cholesterol and mortality. Also, nationally representative country surveys are available, and internationally comparable country estimates have been produced to allow comparisons of NCD risk factors and mortality between countries.
http://www.who.int/gho/en/

NCDs and the Sustainable Development Goals:
To communicate about the need to take action on NCDs, and the feasibility to do so, WHO provides a range of materials related to support national advocacy efforts:
http://www.who.int/beat-ncds/take-action/download-campaign-essentials/en/

**Economic Impact of Cancer**
"The financial costs of cancer are high for both the person with cancer and for society as a whole. The Agency for Healthcare research and Quality (AHRQ) estimates that the direct medical costs (total of all health care costs) for cancer in the US in 2015 were **$80.2 billion**.
52% of this cost is for hospital outpatient or doctor office visits
38% of this cost is for inpatient hospital stays

One of the major costs of cancer is cancer treatment. But lack of health insurance and other barriers to health care prevent many Americans from getting optimal health care.
According to the US Census Bureau, about 28 million people (9%) in the US were uninsured in 2016.
The percentage of uninsured ranged from 3% in Massachusetts to 17% in Texas.

And according to *Cancer Facts & Figures 2018*, 'Uninsured patients and those from many ethnic minority groups are substantially more likely to be diagnosed with cancer at a later stage, when treatment can be more extensive, costlier, and less successful.'

This year, about 609,640 Americans are expected to die of cancer – that's more than 1,670 people a day. Cancer is the second most common cause of death in the US, exceeded only by heart disease.

Cancer costs us billions of dollars. It also costs us the people we love. Reducing barriers to cancer care is critical in the fight to eliminate suffering and death due to cancer." FROM: **https://www.cancer.org/cancer-basics/economic-impact-of-cancer.html**