

Cancer Control

Knowledge into Action

WHO Guide for Effective Programmes



Policy and
Advocacy



World Health
Organization

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The Cancer Control – Policy and Advocacy module was produced under the direction of Ala Alwan (Assistant Director-General, Noncommunicable Diseases and Mental Health), Serge Resnikoff (Coordinator, Chronic Diseases Prevention and Management) and Cecilia Sepúlveda (Chronic Diseases Prevention and Management, coordinator of the overall series of modules).

Pat Kelly was responsible for the initial draft and has declared no conflict of interest.

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The production of the module was coordinated by María Villanueva and Neeta Kumar.

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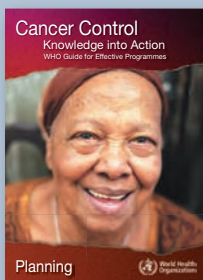
Introduction to the Cancer Control Series

Cancer is to a large extent avoidable. Many cancers can be prevented. Others can be detected early in their development, treated and cured. Even with late stage cancer, the pain can be reduced, the progression of the cancer slowed, and patients and their families helped to cope.

Cancer is a leading cause of death globally. The World Health Organization estimates that 7.6 million people died of cancer in 2005 and 84 million people will die in the next 10 years if action is not taken. More than 70% of all cancer deaths occur in low- and middle-income countries, where resources available for prevention, diagnosis and treatment of cancer are limited or nonexistent.

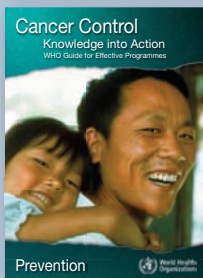
But because of the wealth of available knowledge, all countries can, at some useful level, implement the four basic components of cancer control – ***prevention, early detection, diagnosis and treatment, and palliative care*** – and thus avoid and cure many cancers, as well as palliating the suffering.

Cancer control: knowledge into action, WHO guide for effective programmes is a series of six modules that provides practical advice for programme managers and policy-makers on how to advocate, plan and implement effective cancer control programmes, particularly in low- and middle-income countries.



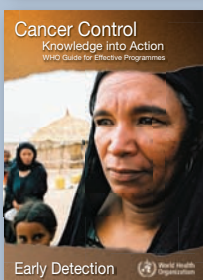
PLANNING

A practical guide for programme managers on how to plan overall cancer control effectively, according to available resources and integrating cancer control with programmes for other chronic diseases and related problems.



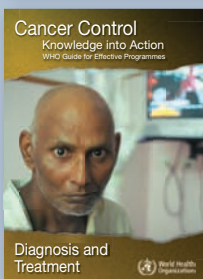
PREVENTION

A practical guide for programme managers on how to implement effective cancer prevention by controlling major avoidable cancer risk factors.



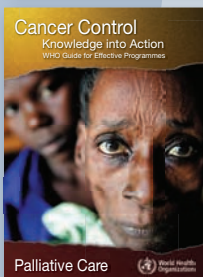
EARLY DETECTION

A practical guide for programme managers on how to implement effective early detection of major types of cancer that are amenable to early diagnosis and screening.



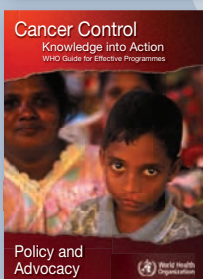
DIAGNOSIS AND TREATMENT

A practical guide for programme managers on how to implement effective cancer diagnosis and treatment, particularly linked to early detection programmes or curable cancers.



PALLIATIVE CARE

A practical guide for programme managers on how to implement effective palliative care for cancer, with a particular focus on community-based care.



POLICY AND ADVOCACY

A practical guide for medium level decision-makers and programme managers on how to advocate for policy development and effective programme implementation for cancer control.

The WHO guide is a response to the World Health Assembly resolution on cancer prevention and control (WHA58.22), adopted in May 2005, which calls on Member States to intensify action against cancer by developing and reinforcing cancer control programmes. It builds on *National cancer control programmes: policies and managerial guidelines* and *Preventing chronic diseases: a vital investment*, as well as on the various WHO policies that have influenced efforts to control cancer.

Cancer control aims to reduce the incidence, morbidity and mortality of cancer and to improve the quality of life of cancer patients in a defined population, through the systematic implementation of evidence-based interventions for prevention, early detection, diagnosis, treatment, and palliative care. Comprehensive cancer control addresses the whole population, while seeking to respond to the needs of the different subgroups at risk.

COMPONENTS OF CANCER CONTROL

Prevention of cancer, especially when integrated with the prevention of chronic diseases and other related problems (such as reproductive health, hepatitis B immunization, HIV/AIDS, occupational and environmental health), offers the greatest public health potential and the most cost-effective long-term method of cancer control. We now have sufficient knowledge to prevent around 40% of all cancers. Most cancers are linked to tobacco use, unhealthy diet, or infectious agents (see Prevention module).

Early detection detects (or diagnoses) the disease at an early stage, when it has a high potential for cure (e.g. cervical or breast cancer). Interventions are available which permit the early detection and effective treatment of around one third of cases (see Early Detection module).

There are two strategies for early detection:

- *early diagnosis*, often involving the patient's awareness of early signs and symptoms, leading to a consultation with a health provider – who then promptly refers the patient for confirmation of diagnosis and treatment;
- *national or regional screening* of asymptomatic and apparently healthy individuals to detect pre-cancerous lesions or an early stage of cancer, and to arrange referral for diagnosis and treatment.

Treatment aims to cure disease, prolong life, and improve the quality of remaining life after the diagnosis of cancer is confirmed by the appropriate available procedures. The most effective and efficient treatment is linked to early detection programmes and follows evidence-based standards of care. Patients can benefit either by cure or by prolonged life, in cases of cancers that although disseminated are highly responsive to treatment, including acute leukaemia and lymphoma. This component also addresses rehabilitation aimed at improving the quality of life of patients with impairments due to cancer (see Diagnosis and Treatment module).

Palliative care meets the needs of all patients requiring relief from symptoms, and the needs of patients and their families for psychosocial and supportive care. This is particularly true when patients are in advanced stages and have a very low chance of being cured, or when they are facing the terminal phase of the disease. Because of the emotional, spiritual, social and economic consequences of cancer and its management, palliative care services addressing the needs of patients and their families, from the time of diagnosis, can improve quality of life and the ability to cope effectively (see Palliative Care module).

Despite cancer being a global public health problem, many governments have not yet included cancer control in their health agendas. There are competing health problems, and interventions may be chosen in response to the demands of interest groups, rather than in response to population needs or on the basis of cost-effectiveness and affordability.

Low-income and disadvantaged groups are generally more exposed to avoidable cancer risk factors, such as environmental carcinogens, tobacco use, alcohol abuse and infectious agents. These groups have less political influence, less access to health services, and lack education that can empower them to make decisions to protect and improve their own health.

BASIC PRINCIPLES OF CANCER CONTROL

- **Leadership** to create clarity and unity of purpose, and to encourage team building, broad participation, ownership of the process, continuous learning and mutual recognition of efforts made.
- **Involvement of stakeholders** of all related sectors, and at all levels of the decision-making process, to enable active participation and commitment of key players for the benefit of the programme.
- **Creation of partnerships** to enhance effectiveness through mutually beneficial relationships, and build upon trust and complementary capacities of partners from different disciplines and sectors.
- **Responding to the needs of people** at risk of developing cancer or already presenting with the disease, in order to meet their physical, psychosocial and spiritual needs across the full continuum of care.
- **Decision-making** based on evidence, social values and efficient and cost-effective use of resources that benefit the target population in a sustainable and equitable way.
- **Application of a systemic approach** by implementing a comprehensive programme with interrelated key components sharing the same goals and integrated with other related programmes and to the health system.
- **Seeking continuous improvement**, innovation and creativity to maximize performance and to address social and cultural diversity, as well as the needs and challenges presented by a changing environment.
- **Adoption of a stepwise approach** to planning and implementing interventions, based on local considerations and needs (see next page for WHO stepwise framework for chronic diseases prevention and control, as applied to cancer control).

WHO stepwise framework



The planning phase is followed by the policy implementation phase.

Implementation step 1 CORE

Implement interventions in the policy that are feasible now, with existing resources.

Implementation step 2 EXPANDED

Implement interventions in the policy that are feasible in the medium term, with a realistically projected increase in, or reallocation of, resources.

Implementation step 3 DESIRABLE

Implement interventions in the policy that are beyond the reach of current resources, if and when such resources become available.

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KEY MESSAGES

Advocacy for cancer control is needed in any resource setting in order to influence policy and to urge decision-makers to create an environment conducive to improving the way cancer control knowledge is put into practice. This module addresses some basic aspects of advocacy, and discusses how advocacy strategies for effective comprehensive cancer control planning and implementation might be developed. It is based on, and is complementary to, the *Planning* module, which provides a template for the overall cancer control planning process and its implementation. It will be updated within the next 5 years as it is intended to evolve in response to new knowledge, national needs and experience in advocacy.

There is no single *right* way to advocate. The guidance provided in this module is thus not intended to be prescriptive but rather to be selected as appropriate to the country context, and revisited as the advocacy process progresses through its planning, implementation and evaluation phases.

The key messages for people involved in advocating for comprehensive cancer control planning and implementation are as follows:

- ▣ Advocacy for cancer control is most likely to be successful if it is synchronized with advocacy for noncommunicable diseases and other cancer-related problems. By combining their voices to deliver the powerful message that comprehensive and integrated cancer control is more effective than fragmented or isolated approaches, advocates can make a real difference.
- ▣ Successful cancer control greatly depends on the ability of stakeholders to define the value of a comprehensive cancer control framework to policy-makers and other potential resource providers whose sustained support is crucial.
- ▣ The lifeblood of advocacy is good strategic communication, which educates people about a need and mobilizes them to meet that need in a collaborative way. Participants in the advocacy process need to interact and freely share information regarding cancer control, and other chronic diseases and related issues.
- ▣ Good communication skills in those advocating for cancer control are vital. These include being able to speak clearly and concisely, and an ability to convey complex information in an organized and easy-to-understand manner.

*Change does not roll in on the wheels of inevitability,
but comes through continuous struggle.*

Dr Martin Luther King Jr
1929–1968

key definitions

What is advocacy?

Advocacy is the effort to influence people, primarily decision-makers, to create change, which in the context of cancer control results in comprehensive policies and effective programme implementation, through various forms of persuasive communication.

What is advocacy leadership?

Among the many models and best practices in leadership development, there are several common fundamental skills that enable ordinary people to get extraordinary things done. Effective leaders in cancer control advocacy persuade influential people to *create change*. In particular, they are able to:

- ▣ inspire a shared vision that provides societal benefit;
- ▣ enable others to act;
- ▣ encourage a people-centred focus;
- ▣ understand the challenges facing public policy decision-makers, and the evidence and public support they require to build a convincing case for enhanced cancer control.

What is public policy?

Public policy for cancer control includes legislation, laws, statements, policies or prevailing practices enacted by those in authority to guide or control institutional, community and sometimes individual behaviour to prevent or cure cancer and to care for cancer patients and cancer survivors.

What is social marketing?

Social marketing is the use of commercial marketing concepts and tools to influence individuals' behaviour to improve their well-being and also that of society. It is used in advocacy for cancer control, depending on the goal and the target audience.

What is lobbying?

Lobbying is the act of persuading decision-makers, such as elected officials and government agencies, to strengthen national cancer control planning and implementation through direct communications.

What is social mobilization?

Social mobilization is a broad-scale movement that brings together all feasible and practical intersectoral social allies. Its main purpose is to raise people's awareness of, and demand for, cancer prevention and control, to assist in the delivery of resources and services, and to strengthen community participation for sustainability and self-reliance. It involves all relevant segments of society: decision- and policy-makers, opinion leaders, bureaucrats and technocrats, professional groups, religious associations, commerce and industry, communities and individuals (UNICEF, 1993). Social mobilization supports actions and priorities identified by communities, such as by vulnerable people whose rights may have been denied. Social mobilization activities should not be imposed from the top, but should arise from community action; such activities are, however, usually coordinated at a higher level.

INTRODUCTION

Careful planning of sustainable advocacy strategies involving all the key stakeholders, can contribute much to the development of effective and efficient cancer control planning and implementation. Without a proper advocacy plan, however, there is a risk that the desired changes in national cancer control planning and implementation may never happen or may occur in a fragmented manner, and the benefits to the population that should flow from comprehensive cancer control policies and programmes will not be realized. (The basic principles of comprehensive cancer control are described in the Series overview, page v.)

WHAT IS THE BEST WAY TO DRAW UP AN ADVOCACY PLAN?

The advocacy planning framework presented in this module is based on current WHO guidance, which is set out in *Stop the global epidemic of chronic diseases: a practical guide to successful advocacy* (WHO, 2007a) and the *WHO communications toolkit* (WHO, 2007b). It also draws on the social mobilization model (UNICEF, 1993; Wallack, 1989).

The proposed framework can be applied to action at all levels – local, national and international. It can be used to advocate for the planning and implementation of comprehensive cancer control policy and plans in both developing and developed countries. The framework integrates advocacy efforts in four key areas:

- ▣ stakeholder relations
- ▣ government relations
- ▣ communications and public relations
- ▣ leadership development.

This framework can be used to systematically plan advocacy work. It will enable participants to deepen their understanding of advocacy, and to build partnerships and alliances with other organizations. The recommended advocacy process comprises the following steps:

1. Defining the situation
2. Setting goals and objectives
3. Identifying the target audience
4. Mobilizing support
5. Developing key messages
6. Selecting methods of advocacy
7. Developing and implementing the advocacy plan
8. Monitoring and evaluation.

WHO SHOULD DEVELOP THE ADVOCACY PLAN?

There is no simple answer to the question of who should lead the development of an advocacy plan. In different settings, advocating for change in cancer control may be triggered by different kinds of problems or developments in one of several sectors. People emerge as leaders because they decide to take an action to change the status quo. Those most affected by cancer control efforts, including at-risk or vulnerable individuals and the organizations that represent them, are however necessary participants in the advocacy process in order to ensure that the cancer control plan is people-centred. Involving health-care professionals and researchers is also critical as this ensures that advocacy plans are evidence-based and relevant. Finally, involving patients, family members and caregivers brings both the personal face and a compelling urgency to cancer control.

WHO ARE THE STAKEHOLDERS?

Stakeholders are the individuals, groups or organizations who are affected by or affect a cancer control policy, a programme or the delivery of a service. If there is a recognized need for a comprehensive cancer control plan and a genuine intent to implement such a plan, all key stakeholders should be involved from the beginning of the advocacy planning process to engender a sense of ownership and commitment to sustainability. Each partner will bring resources, networks, expert knowledge and social values, contributing an essential and robust diversity to the stakeholder mix (see *Planning* module).

WHO CAN ADVOCATE?

Everyone directly or indirectly involved in cancer control can advocate for it, so long as there is the will to devote time, knowledge and skills to reach the desired outcomes.

Within countries, national cancer institutes, national cancer leagues, associations of medical professionals working in cancer control, cancer patients groups, as well as bodies dealing with health promotion, environmental health, and prevention of chronic diseases, all can play an important role in advocating for cancer control.

Civil society and academia can contribute by supporting advocacy and patients groups or alliances and coalitions, and by disseminating information and educational materials on comprehensive cancer control through the media, the Internet, meetings and public events. Other interest groups can be invited to participate in cancer control advocacy when there is a focus on risk factors that are common to cancer and other diseases (e.g. tobacco).

Ministries of health usually play a key role in advocacy, primarily by convincing other policy-makers and planners to invest in comprehensive cancer control. In addition, they can help accelerate advocacy efforts by recognizing the legitimacy and credibility of advocacy organizations or by encouraging the development of advocacy groups, including patients groups or coalitions and by disseminating information and educational materials. For instance, a parliamentary advocacy group provided much of the impetus for the development of the United Kingdom's latest cancer control plan (see Box, page 9).

In addition to national agencies and bodies, international organizations can also act as triggers for change by influencing decision-makers in countries. International agencies, such as WHO, the International Union Against Cancer (UICC) and the International Atomic Energy Agency (IAEA) have the potential to encourage decision-makers to recognize the need for a comprehensive cancer control plan in their own countries. Other international agencies

play an important role in advocating for specific components of cancer control, such as the Alliance for Cervical Cancer Prevention (ACCP), the Breast Health Global Initiative (BHGI), the International Network for Cancer Treatment and Research (INCTR) and the Worldwide Palliative Care Alliance (WPCA).

Change is more likely to occur with the external stimulus of advocacy. To trigger change in a country or region, leaders with decision-making authority need to be identified, supported and urged to take action. In the case of Chile, WHO's offer to support the development of a demonstration project prompted the Chilean Minister of Health in 1985 to appoint a national cancer control coordinator and council to develop a plan for the stepwise implementation of a national cancer control programme (see *Planning* module).

UNITED KINGDOM

Updating the national strategy for cancer

In the United Kingdom, the All Party Parliamentary Group on Cancer (APPGC) was founded in 1998 to keep cancer at the forefront of the political agenda, and to ensure that policy-making remains patient-centered. It brings together members of parliament and peers from across the political spectrum to debate key issues and campaign together to improve national cancer planning and cancer services. The APPGC organizes an annual event, Britain Against Cancer, that for the past 8 years has successfully brought together patients, health professionals and policy-makers to look at the impact of public policy on cancer services and research.

According to Dr Ian Gibson MP, Chairman of the APPGC in 2007, "The original National Health System Cancer Plan, launched in 2000, led to improvements in front-line cancer services. The cancer landscape has changed dramatically since then but health inequalities still persist. A new, holistic vision that creates patient entitlements to standards of care covering the whole patient pathway is needed."

Early in 2007, the APPGC launched its new vision for the future of cancer services. The vision focuses on bridging the gap between health and social care; educating professionals and the public; improving prevention, diagnosis and treatment; researching genetics, the causes of, and treatments for, cancer; and producing national standards and specifying entitlements that people with cancer can expect from health and social care services. A few months later, at the Britain Against Cancer event held in December 2007, the Government announced its commitment to an updated national strategy which will include, as top priorities, strengthening prevention and early detection, as well as reducing inequalities and improving cancer services for treatment, care and rehabilitation.

Source: APPGC (2007). All Party Parliamentary Group on Cancer. London (<http://www.appg-cancer.org.uk/>, accessed 12 November 2007).

For further information on Britain Against Cancer, 2007, go to <http://www.appg-cancer.org.uk/BAC2007.htm>.

ADVOCACY STEP 1

DEFINING THE SITUATION

Defining the current state of the cancer problem and cancer control efforts is the first step in developing an understanding of the need for advocacy in the context of a comprehensive and integrated approach to cancer control (see also Planning step 1 in the *Planning, Prevention, Early detection, Diagnosis and treatment* and *Palliative care* modules).

ASK KEY QUESTIONS

In order to assess the current situation, it will be necessary to seek answers to the following questions:

- ▣ What is the current cancer burden (nationally or sub nationally)?
- ▣ What cancer control policies and programmes currently exist? Are they comprehensive, integrated and of good quality? Are they being funded and implemented?
- ▣ What is the level of awareness about cancer and cancer 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 cancer control?
- ▣ What advocacy, lobbying or communications 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, comprehensive cancer control and related advocacy work?

IDENTIFY BARRIERS AND OPPORTUNITIES

Table 1 provides examples of barriers to, and opportunities for, comprehensive cancer control and advocacy.

Table 1. Comprehensive cancer control and advocacy: barriers and opportunities

Barriers	Opportunities
<ul style="list-style-type: none"> ○ Lack of political will and leadership for developing cancer control with a public health approach ○ Excessive reliance on treatment approaches, disregarding prevention, early detection and palliative care ○ Limitations in resources, inequalities and competing health problems ○ Cultural taboos and myths (e.g. a woman with breast cancer may feel guilty that she has brought “bad genes” into the family) ○ Religious attitudes to cancer (e.g. some faith groups see cancer as a punishment from God) ○ Stigma (e.g. a woman with cervical or breast cancer may keep her disease secret to avoid social rejection and social isolation) ○ Limited understanding about advocacy, the need for advocacy, and lack of advocacy skills 	<ul style="list-style-type: none"> ○ Recent commitments by WHO Member States to develop an <i>Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Diseases</i> (World Health Assembly resolution WHA61.14, 2008) and to promote and reinforce the comprehensive approach for cancer control (World Health Assembly resolution WHA58.22, 2005) ○ Increasing number of countries developing comprehensive cancer control programmes ○ Increasing interest among international and national leaders and organizations in advocating for comprehensive policies ○ Availability of a conceptual framework (WHO, 2002) and guidelines on developing comprehensive cancer control, from the governmental (see <i>Planning</i> module) and nongovernmental (UICC, 2006) perspectives ○ Increasing access to cancer control knowledge and best practice, which provides a good basis for advocacy

For more information on World Health Assembly resolution WHA61.14, go to
http://www.who.int/gb/ebwha/pdf_files/A61/A61_R14-en.pdf

For more information on the Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Diseases, go to
<http://www.who.int/nmh/en/>

For more information on World Health Assembly resolution WHA58.22 on cancer prevention and control, go to
http://www.who.int/gb/ebwha/pdf_files/WHA58/WHA58_22-en.pdf



DEFINE THE NEEDS FOR ADVOCACY

Advocacy for effective cancer control planning and implementation may be needed to:

- ▣ increase cancer awareness and reduce the barriers to cancer control;
- ▣ promote the comprehensive cancer control framework as the most effective approach for translating cancer control knowledge into action;
- ▣ develop a comprehensive cancer control plan where cancer is recognized as an important or increasing problem;
- ▣ update an existing plan that has become outdated;
- ▣ revise an existing plan that is not achieving desired outcomes, is inefficient, limited in scope, insufficiently funded or unsatisfactory to stakeholders;
- ▣ secure political will and the public and stakeholder support necessary to implement or sustain an existing cancer control plan;
- ▣ reinforce specific components of comprehensive cancer control that are being neglected, such as prevention, early detection and palliative care;
- ▣ mobilize and allocate the necessary resources for priority interventions to reduce the cancer burden.

There are a number of priority or “core” interventions, such as tobacco control legislation, hepatitis B vaccination, and provision of low-cost early detection of cervical cancer and palliative care services that can be advocated for and implemented gradually, even in countries with limited infrastructure and resources. The example of Ethiopia shows how advocating for pain control and palliative care is paving the way for improvements in health services aimed at relieving the suffering of all patients with incurable diseases, including cancer (see Box, page 13). The other modules in this series, in particular the *Prevention, Early detection, Diagnosis and treatment* and *Palliative care* modules, provide more information about selecting and implementing interventions for cancer control according to country resource levels. Additional guidance is available in *National cancer control programmes: policies and managerial guidelines* (WHO, 2002).

For the purposes of cancer control advocacy, an analysis of the cancer situation should:

- ▣ generate accurate information and in-depth understanding of the problem and the current status of any existing cancer control plans and programmes;
- ▣ identify individuals, groups and institutions who can help in achieving advocacy objectives;
- ▣ produce an inventory of potential advocacy resources, for circulation to all stakeholders.

The stronger the foundation of knowledge related to the elements of the cancer problem, the current state of cancer control efforts, and the available resources and potential allies, the more persuasive and effective advocacy will be.

ETHIOPIA

Recognizing a need for advocating for pain control and palliative care

The most common needs among people with incurable illness are for the control of pain and other symptoms, and for love and compassion. In a study of the needs of people with terminal illness in Addis Ababa, all respondents used the term *fakir yefewes kibat* (love – the balm of healing), which they said is denied to most patients facing death. Respondents saw pain relief and counselling as major needs, along with compassionate care by health professionals and family members. Mentioned among other needs were balanced and good nutrition, and financial support. On the issue of how the community can best meet the various needs of patients facing chronic life-threatening conditions (and those of their relatives), respondents said that families and the community – with support from the government – should provide compassionate care, accept and respect patients, and not judge or ostracize them.

Based on the number of deaths from HIV/AIDS and cancer, it is estimated that in Ethiopia around 72 000 patients facing terminal illness are in need of palliative care every year. However, if patients suffering from all chronic life-threatening conditions and not dying that same year were to be included, this figure would be much higher. Despite the urgent humanitarian need for palliative care, there are as yet no government plans to support the development of such services. Opioids for treating moderate and severe pain are not available, in part because of overly restrictive regulations on such drugs. Therefore, pain relief is not an option for the great majority of patients. In the past few years, new opportunities have emerged for providing palliative care through international support. However, the fact that the funds are mainly restricted to HIV/AIDS patients has discouraged local initiatives from caring for patients with other incurable diseases, including cancer.

The Palliative Care Association of Ethiopia is currently in the process of formation. Its founders are determined to play a major role in raising awareness of the need for pain control and palliative care for *all* those in need in Ethiopia. Among its other objectives are reducing the stigma attached to incurable diseases, forming coalitions with other interested partners and advocating for the development of government policies, in particular for making opioids available and for enabling the implementation of pain control and palliative care services that are integrated into a continuum of care for patients suffering from HIV/AIDS, cancer and other incurable diseases.

Sources: WHO (2004). *A community health approach to palliative care for HIV/AIDS and cancer patients in sub-Saharan Africa*. Geneva, World Health Organization (http://www.who.int/hiv/pub/prev_care/en/palliative.pdf, accessed 5 March, 2008). Additional information provided by Dr Nardos Giorgis, founding member of the Palliative Care Association of Ethiopia.

ADVOCACY STEP 2

SETTING GOALS AND OBJECTIVES

Clear goals and **s**pecific, **m**easurable, **a**chievable, **r**ealistic, and **t**ime-bound (SMART) objectives need to be formulated at the beginning of any advocacy work. These should be based on the analysis of the cancer situation and the availability of resources (see Advocacy step 1).

A long-term goal of any comprehensive cancer control programme is *to reduce cancer incidence and mortality and improve quality of life*. A well-planned and well-executed advocacy plan will play a key role in achieving this goal by driving forward the necessary policy and programmatic changes. A good advocacy plan responds to identified needs, builds on opportunities and overcomes barriers to comprehensive cancer control.

The following are examples of short- and medium-term advocacy objectives that can act as incremental steps in the overall development and implementation of a comprehensive cancer control plan:

- ▣ to increase cancer awareness among influential groups and the public;
- ▣ to reduce stigma and fear of cancer in the low socioeconomic groups;
- ▣ to engage and mobilize key stakeholders within the cancer community who will champion the development and implementation of a comprehensive national cancer control plan and its components;
- ▣ to progressively expand advocacy groups, including community volunteers and patients groups, to cover all the regions or provinces of the country;
- ▣ to promote the value of comprehensive cancer control and the need for developing policies and programmes;
- ▣ to launch a simplified version of the comprehensive cancer control plan and disseminate it widely to the media and the lay public using attractive messages;
- ▣ to promote the effective and equitable implementation of key priority (core) interventions;
- ▣ to mobilize resources to support the implementation of key priority (core) interventions;
- ▣ to maintain the involvement of decision-makers and the public profile of cancer control by disseminating information on achievements to date and future challenges.

If levels of cancer awareness are low, and fear and stigma are high, it may well be necessary, at least initially, to focus on the education and empowerment of influential individuals or groups who can then act as societal models, mobilize communities and resources, and influence the demand for change. In certain communities, trained community leaders, including traditional healers, and real-life testimonies from patients, family members and caregivers, can often play a vital role in raising cancer awareness and reducing the stigma and fear of cancer.

Successful advocacy starts with strategy and moves to tactics. Your strategy is the larger mission, the overall map that guides the use of tactical tools towards clear goals. Start by clarifying your bigger goals and then select your tactics.

ADVOCACY STEP 3

IDENTIFYING THE TARGET AUDIENCE

The main target audiences for advocacy work will usually be decision-makers and influencers:

- ▣ **Decision-makers** are the primary audience. These are the individuals or groups who can take decisions in relation to cancer control policies and programmes. The primary audience may include the president, the prime minister, the cabinet, health or deputy health ministers, parliamentarians, funding agencies and community leaders.
- ▣ **Influencers** are the secondary audience. These are the individuals or groups who have access to the decision-makers and who may be able to influence them. Influencers may become partners in the advocacy plan. The secondary audience typically includes cancer associations, cancer patients organizations, medical associations, cancer experts and other health-care professionals, faith-based groups, opinion leaders, the media, international leaders, entertainment and sports personalities, teachers, professors and researchers.

When drawing up a list of potential targets for advocacy, it is helpful to consider the current political climate and ask:

- ▣ How important is cancer control to the general public? Is there adequate understanding of the term “comprehensive cancer control” and of the various components of comprehensive cancer control?
- ▣ Does the government need to be convinced that there is a popular demand to give cancer control a higher priority?
- ▣ Are there other influential municipal or national government departments – parks and recreation, education, environment, industry and innovation – who share the concerns of advocates for cancer control?
- ▣ Do you need to convince other influential groups, such as professional and national medical associations or corporate leaders who have at-risk employees, of the value of cancer control?
- ▣ What influence might the media have through the Internet, radio, television and print?
- ▣ Does the private sector play an influential role in the issue of cancer control?

The process of selecting specific target audiences may be assisted by working through the following steps:

- ▣ Firstly, for each objective in the advocacy plan define your target audience. To do this, you will need an adequate understanding of the decision-making system. Once the decision-making process is clear, it may become evident that a key target decision-maker is not directly accessible. In such cases, it may be necessary to work through others to reach the key decision-maker.
- ▣ Secondly, for each target, identify individuals or groups (i.e. influencers) who can deliver the message to that target. The messenger needs to be a good communicator, eloquent, convincing and genuine. For example, in many settings, a prestigious oncologist is likely to have the greatest influence on a minister of health. On the other hand, a national economist who is able to argue convincingly for the economic benefits of comprehensive cancer control may be more effective in influencing a minister of finance. Pairing the medical or other professional with a cancer patient, survivor or family member who can effectively make the case for an urgent response, will bring the collective leverage of a personal, professional and policy perspective to the political front.
- ▣ Thirdly, understand the target audience(s). Consider their motivation and interests, and the nature and format of information needed to persuade them. Note that targets may be either in favour of the change, undecided, or even opposed to it.

Table 2 provides an overview of the type of information about potential targets that needs to be collected when developing an advocacy plan.

Table 2. Example of advocacy target information

TARGET	HOW TO CONTACT TARGET	TARGET'S POSITION ABOUT THE ISSUE	HOW TO INFLUENCE THE TARGET	TARGET'S WAYS OF DECISION-MAKING	TARGET LISTENS TO
PRESIDENT OR PRIME MINISTER	<ul style="list-style-type: none"> Letter Contact official office Ceremonies Public events 	Unknown	<ul style="list-style-type: none"> Majority rule Media Opposition health critics Cabinet ministers 	Through parliament	<ul style="list-style-type: none"> Ministers Provincial or state-elected officials Bureaucrats
NATIONAL MINISTER OF HEALTH	<ul style="list-style-type: none"> Letter Contact official office Ceremonies Public events 	Supportive	<ul style="list-style-type: none"> Nongovernmental organizations Healthy public policy – effective cancer control reduces burden of all chronic disease 	Consultation	<ul style="list-style-type: none"> Nongovernmental organizations Ministry bureaucrats
PROVINCIAL OR STATE HEALTH MINISTERS	<ul style="list-style-type: none"> Direct approach Visits, e-mails, phone calls, meetings Invite to private functions 	Negative	<ul style="list-style-type: none"> Nongovernmental organizations Patients or family members 	Consultation	<ul style="list-style-type: none"> Health professionals Healers Community leaders
LOCAL HEALTH OFFICIALS	<ul style="list-style-type: none"> Direct approach Visits, e-mails, phone calls, meetings Invite to private functions 	Very supportive	<ul style="list-style-type: none"> Nongovernmental organizations Patients or family members 	Through local governing councils or municipalities or communities	<ul style="list-style-type: none"> Nongovernmental organizations Health professionals Individuals

ADVOCACY STEP 4

MOBILIZING SUPPORT

When people connect with each other and to powerful ideas, creativity and action are released. Barriers are lowered as people connect.

The most effective way to mobilize support for cancer control is to inform the parties involved about the cancer problem and ask them to be part of the solution. This creates strong commitment and fosters coalition building and social mobilization based on common goals. Coalition building, patient involvement and social mobilization are critical to the success of advocacy efforts.

COALITION BUILDING

Coalition building strengthens advocacy. Coalitions with organizations that are working on other public health issues that share the same risk factors – heart disease, diabetes, tobacco control, healthy diet and active lifestyles – can be strengthened to the mutual benefit of both parties. This is especially important in low-income countries where there are likely to be many other health problems competing for the same resources. Although cancer may not be high on the list of priorities, by combining common goals that target reducing tobacco and alcohol consumption, promoting a healthy diet and active lifestyles, and reducing infections, coalition members can support cancer control along with other public health efforts.

The elements of effective coalition building include:

- ▣ encouraging all coalition partners to participate actively;
- ▣ planning events incorporating credible speakers from different partner organizations;
- ▣ developing a schedule and sequence of activities for maximum positive impact;
- ▣ delegating responsibilities to coalition members, and monitoring specific events and activities;
- ▣ networking to enlarge coalitions and to keep them together;
- ▣ organizing training and practice in advocacy, using the framework model proposed in this module, to allow participants to deepen their understanding of advocacy while simultaneously creating new partnerships and alliances;
- ▣ presenting information in a brief, dramatic and memorable fashion.

PATIENT INVOLVEMENT

Finding ways of genuinely involving those directly affected by cancer will greatly strengthen advocacy in the long run. This may take time initially, especially if patients are frequently ill, very busy, do not already know and trust you, are hard to reach or identify, or if they have different values, beliefs and ways of working. It may sometimes be necessary to find others, perhaps family members, medical professionals and/or credible community leaders, who can be empowered to speak passionately on behalf of patients and help reduce myths, fears and stigma about this disease.

SOCIAL MOBILIZATION

Today, success in planning and implementing sustainable and comprehensive cancer control depends very much on whether society can be mobilized to increase its expectations of excellence in all aspects of cancer control.

Social mobilization reinforces political coalition building and community action (UNICEF, 1993; Wallack, 1989). Successful social mobilization is based on mutual benefit for partners and a non-hierarchical structure. The more interested and engaged the partners are, the more likely it is that social mobilization for cancer control can be sustained over time. This approach does not require partners to abandon their own interests and perceptions, but it does expect them to be willing to cooperate and collaborate in solving cancer-related problems. The social mobilization model is consistent with, and extends, the basic principles of cancer control (see Series overview, page v).

The benefits of the social mobilization model are that it:

- ▣ accelerates collective momentum and social change;
- ▣ fosters inclusivity (shared goals, aspirations, language and action);
- ▣ heightens credibility and legitimacy;
- ▣ engages highly motivated individuals as credible spokespersons;
- ▣ reduces stigma and isolation;
- ▣ increases effective management and allocation of resources and effort;
- ▣ enhances transparency and accountability;
- ▣ engages decision-makers and key influencers;
- ▣ urges stakeholders and citizens to act.

On its own advocacy will not achieve much. Social mobilization is also absolutely essential to achieving advocacy objectives.

The document *Understanding advocacy, social mobilization and communications* is a good source of further information on the role of social mobilization in advocacy. It is available at <http://www.irc.nl/content/view/full/3420>



Two community-based programmes, one in Indonesia and another in India, demonstrate that social mobilization and coalition building are key elements in successful advocacy efforts. The Neighborhood Network Palliative Care programme in northern Kerala (see Box, page 22) is an excellent example of what can be achieved when the community volunteers representing a variety of sectors share a common goal and participate actively both in identifying health needs and in being part of the solution. The Population-based Cancer Control Program of Indonesia (see Box, page 24) represents another good example of wide community involvement for comprehensive cancer control that includes all sectors and policy-makers. Initiated in Jakarta province in 1996, the programme has since expanded to other provinces in the country.

NORTHERN KERALA, INDIA

Community-based palliative care: a successful primary health care experience

The problems of patients with advanced diseases such as cancer comprise all human dimensions – the physical, the psychosocial and the spiritual. Limited resource settings with poor health infrastructure will not be capable of offering the holistic care that these patients require. This realization led the Pain and Palliative Care Society to initiate a Neighborhood Network Palliative Care (NNPC) scheme through the leadership of the Institute of Palliative Medicine in Calicut, Kerala, India.

The NNPC is an attempt to develop a sustainable, community-led service, capable of offering comprehensive, home-based long-term care and palliative care to the needy. In essence, the NNPC mission is to empower local communities to look after their own chronically ill and dying patients. It is inspired by the concept of primary health care described in the Declaration of Alma-Ata of 1978.

The NNPC was formally launched in 2001 in the district of Malappuramm with the support of the local government. Within 2 years, about 70% coverage of home-based palliative care was achieved. This initial successful experience has become a powerful advocacy tool for gradually expanding the programme to most of the districts in northern Kerala, securing strong support from local governments. The majority of the patients and the community volunteers are from the lower socioeconomic strata of society; however, all segments of society are represented and various professionals and influential people are frequently found among the volunteers.



Sri E Ahmed, India's Minister of State for External Affairs addressing a Second International Workshop on Community Participation in Palliative Care (Manjeri, Kerala, 5th February, 2008)

This community initiative has changed the life of thousands of patients with chronic and incurable illness. Active interaction between patients, family and volunteers from the community has also resulted, over time, in the replacement of the hierarchical doctor-led structure for palliative care in northern Kerala with a collaborative network of community volunteer-led autonomous initiatives. Under the programme, people who can spare at least 2 hours per week to care for the sick in their area are enrolled in a structured training course. On successful completion of this “entry point” training, the volunteers are encouraged to form community groups of 10–15 members and to identify the problems of the chronically ill people in their area and to organize appropriate interventions.

All NNPC volunteer groups are supported by trained doctors and nurses. Typically, volunteers follow up on the patients seen by a palliative care team: during their regular home visits, they also identify and address a variety of non-medical issues, including financial problems, which patients may have. In addition, they organize events to create awareness in the community and raise funds for palliative care activities.

There are now 64 palliative care units supported by more than 4000 volunteers spread over the seven districts in northern Kerala who between them look after more than 7000 patients at any one time. Initially the programme focused on patients with advanced cancers, but it very quickly expanded to all patients facing life-limiting diseases. Many of these volunteer groups, motivated by the needs they identified in the community, have moved on to additional areas of health care, such as caring for patients with geriatric problems, degenerative neurological disorders, chronic psychiatric disorders, and chronic infectious diseases such as tuberculosis, which is endemic in the region.

The strategy of NNPC is to work with the people rather than for the people. It is this philosophy of local ownership that has resulted in the success of the programme. It has been shown that when neighbourhood groups are in charge, both expansion and achievement of financial sustainability happen quickly. Although external funding is used to initiate NNPC activities, the programmes become self-sufficient in 2–3 years through the generation of local funding. Overall, 80% of NNPC funds are generated locally through small donations from the community (e.g. a rupee a day from lower middle class and poor families and shopkeepers, donations from students in various campuses, or regular donations from manual labourers).

The active advocacy role that the groups play has generated government support in all of the areas where programmes are active. It has also allowed for the sustained expansion of the thematic as well as the geographical scope of the programme. NNPC has proved that a combination of community participation and purposeful government support can make good quality care a reality for thousands of people with chronic and incurable illness. There is also great potential for including, in the near future, other health interventions, such as health promotion, primary prevention and early detection of cancer and other chronic diseases.

Source: Kumar S, Numpeli M (2005). Neighborhood network in palliative care. *Indian Journal of Palliative Care*, 11:6–9.

INDONESIA

Community involvement in comprehensive cancer control

During the last two decades, the number of new cancer cases is increasing annually in Indonesia. Most cases come to the health facilities at late stage. Lack of knowledge about cancer and unawareness of its early signs and symptoms result in delayed treatment.

In 1993, Indonesian Minister of Health established the Integrated Comprehensive Cancer Control Program. Since 1996, 8 out of 33 provinces in Indonesia have adopted this programme and have implemented at least one of its basic components i.e. the Population-Based Cancer Control (PBCC) Program.

The PBCC Program aims to improve people's knowledge through education, focusing mainly on prevention, early detection of the most common cancers and home based palliative care. It is implemented by the community for the community and relies heavily on the efforts of a large number of volunteers. These volunteers come from all sectors and disciplines and include health-care providers, government officers, employees of nongovernment organizations (such as Indonesian Cancer Foundation and Community Based Cancer Control), social workers, private employees, self-employed persons and housewives.

All PBCC volunteers and team members receive training in cancer prevention and care. A cascade system of training has been developed, whereby the trainees become the next generation of trainers. Teaching materials (e.g. posters, leaflets) are devised by various specialists, psychologists, and other members of the PBCC team. In reality, more than half of the members of PBCC team are housewives who belong to the Family Welfare Movement (PKK), whose activities are conducted in cooperation with the government. Members of PKK consist of women from all socio economic levels including the grassroot level. The objectives of PKK are to improve the welfare and the health of the community including cancer control, especially in terms of prevention and early detection of cancer.

The PBCC program is now well established in several provinces, including Jakarta, North Sumatra, West Java, Yogyakarta, East Java, Bali, North Sulawesi, South Sulawesi and East Kalimantan. This means that currently just over 74 million people, or 33.6% of the population, are served by PBCC programs. All of these provinces have the network to monitor their PBCC training activities.

This PBCC model which involves whole community from all socioeconomic strata, cooperation between government and community, and the cascade trainings has proved to be effective in a country with vast geographic area like Indonesia, where the population is large and widely scattered.

More recently, the increasing prevalence of cancer and other noncommunicable diseases in Indonesia has prompted the Ministry of Health to establish in December 2005, the Directorate of Noncommunicable Diseases within the Directorate General of Diseases Control and Environmental Health for better coordination and planning of cancer services. A National Comprehensive Cancer Control Plan (NCCCP) was completed in 2006-07 involving professional organizations and nongovernmental organizations. The lessons learned from PBCC experience in 8 provinces were taken into consideration in identifying activities mentioned in the NCCCP. In 2007, cervical cancer screening and services for early detection of breast cancer have been launched in 6 districts as pilot projects. These activities are carried out by the well trained primary health care providers at the sub-district level and fully supported by all team members of the PBCC program.

Thanks to this broad-scale community involvement in several provinces in Indonesia, cancer awareness has increased significantly, advocacy for cancer control has been reinforced, and the commitment from both the governmental and nongovernmental sectors to work collaboratively to fight cancer in Indonesia has been strengthened progressively.

Sources: Ministry of Health (2006). *The National Cancer Control Guidelines*, Jakarta, Ministry of Health of Indonesia. Umar US (2006). *Community involvement in cancer control in Indonesia*, Jakarta, Indonesian Cancer Foundation (<http://2006.confex.com/uicc/uicc/techprogram/P10602.HTM>, accessed 24 November 2007).

ADVOCACY STEP 5

DEVELOPING KEY MESSAGES

Invest time and effort in creating strong, effective messages that will convince decision-makers or influence influencers. Create compelling messages that include a call to action.

CONSIDER YOUR GOALS AND OBJECTIVES

WHAT DO YOU WANT TO ACHIEVE?

The process of designing messages should always take into account the objectives of the planned advocacy campaign (see Advocacy step 2), the target audience(s) and also the availability of resources. If one of your objectives is to obtain support from key policy-makers and influential people to develop or maintain a comprehensive cancer control plan and programme, you need to consider the following requirements for successful advocacy (Selig et al., 2005):

- ▣ Have a clear definition of comprehensive cancer control that can be explained simply and in a way that will resonate with the public as well as policy-makers.
- ▣ Articulate clearly the impact that comprehensive cancer control can have on the cancer burden, particularly in terms of lives affected.
- ▣ Be prepared to answer specific questions such as: What difference will the cancer control programme make? What difference have similar programmes made in other counties? How much will the programme cost? How long will it take?
- ▣ Demonstrate concretely what is being accomplished with optimization of resources and what will be addressed if additional resources are provided in the future.
- ▣ Be specific about outcomes and results when explaining the planning of new priority programmes, and emphasize how these actions will reduce the cancer burden directly.
- ▣ Have a unified message that crosses regional and programmatic boundaries, brings together disparate stakeholders, and tells a nationwide story in addition to the local one.
- ▣ Define, measure and deliver tangible results to show how comprehensive cancer control is making a real difference.

It may be necessary to impress upon politicians the fact that few cancer control interventions can be expected to have a significant impact in the short term. For example:

- ▣ Although tobacco control actions could reduce the prevalence of adult cigarette smoking relatively quickly, it would take several decades to reduce the burden of tobacco-related cancers. A reduction in tobacco smoking among young people now would significantly reduce lung cancer rates in 40 years time.
- ▣ Effective early detection programmes could achieve down-staging of cancers within 5 years, and could reduce mortality within 10 years.
- ▣ Within 5 years, affordable improvements in the treatment of curable cancers or cancers that are treatable but not curable could increase survival for some patients.
- ▣ A large number of advanced cancer patients can be relieved from moderate to severe pain within a relatively short time frame, within a few months, by making opioid analgesics readily accessible at all levels of care, including at the community level.

CONSIDER YOUR AUDIENCES

WHAT WILL MOTIVATE THEM TO ACT?

WHAT BENEFITS WILL ACTION ON CANCER-RELATED PROBLEMS BRING THEM?

WHAT ATTITUDES WILL PREVENT THEM FROM ACTING?

Messages should always be tailored to the target audience's level of understanding and awareness. Consider also cultural and political feelings and sensitivities: it is important to connect to your audience's values and political views. There may be a need to dispel common myths or misunderstandings about cancer control, for instance, that it is too expensive or that the disease affects only old people. However, rather than telling people they are wrong, try to reframe the issue with information that will gain their interest. For example, stress the cost-effectiveness of primary prevention, highlight the increasing incidence of cancer, or explain the benefits of integration of cancer control with chronic disease efforts.

For examples of advocacy messages for chronic diseases, including cancer, see *Stop the global epidemic of chronic disease: a practical guide to successful advocacy*, published by WHO, and available at <http://www.who.int/chp/advocacy/en/index.html>



DEVELOP YOUR MESSAGES

Once you have defined your objectives and your target audience, you can go on to develop your specific messages. These messages will determine how your target audience perceives you and your arguments for developing or reinforcing a cancer control plan. These messages need to demonstrate both the problem and an evidence-based solution. Above all, messages need to be:

- ▣ credible, clear, compelling, concise, consistent and convincing;
- ▣ simple and persuasive, incorporating a direct call to action;
- ▣ rational, moral and appealing to hearts and minds;
- ▣ repetitive and reinforced;
- ▣ consistent in visual style.

The generally recommended approach is to have one *primary message* supported by two or three *secondary messages*. The *primary message* is the main message. It is broad, appealing to all audiences, simple and direct. It is the theme that holds the whole advocacy campaign together. For example:

Every year, thousands of people die or suffer from an advanced cancer that we know could be prevented, cured or cared for. Now is the time to act and stop this needless suffering!

The purpose of the *secondary messages* is to support the core message and to explain how it can be achieved. Secondary messages should be targeted to the needs, perceptions and preferences of the target audiences. The following are examples of secondary messages for audiences involved in cancer control planning and implementation:

- ▣ We can prevent around 30% of all cancers in this country. All we need to do is control tobacco use, promote a healthy diet and physical activity, and vaccinate against hepatitis B.
- ▣ 80% of cancer patients are diagnosed late when treatment can no longer be effective. We must therefore focus on two urgent actions:
 - palliate the suffering of all advanced cancer patients;
 - promote early detection and treatment of frequent cancers and cancers that are amenable to early detection, in particular, breast and cervical cancers.
- ▣ The majority of low-income and disadvantaged people are at higher risk and have less power to protect and improve their health. They are solely dependent on their government. For their sakes, the time to act is now.
- ▣ An integrated, comprehensive cancer control strategy allows for a more balanced, efficient and equitable use of limited resources.
- ▣ A cancer control plan that is goal-oriented, people-centred, realistic and carefully prepared through a participatory process is more likely to translate into effective implementation.
- ▣ In lower-resource settings, a plan that considers the gradual implementation of a few, affordable, cost-effective and priority interventions will have a better chance of succeeding.

Remember to:

- ▣ choose effective spokespeople who are credible, eloquent and convincing communicators;
- ▣ articulate the problem and the desired actions clearly;
- ▣ emphasize the urgency and high priority of the recommended actions;
- ▣ incorporate human interest and anecdotes into the messages.

Real-life stories can have great impact, particularly if they are brought to life with photographs or videos. Several real-life stories are recounted in the *Planning, Prevention, Diagnosis and treatment* and *Palliative care* modules.

For more real-life stories, go to

<http://www.who.int/cancer/en/>

http://www.who.int/chp/chronic_disease_report/cancer_case_studies/en/index.html



ADVOCACY STEP 6

SELECTING METHODS OF ADVOCACY

Generally speaking, there are two main methods of advocacy:

- ▣ **Lobbying or direct communication:** involves influencing through direct, private communications with decision-makers. Lobbying, particularly through personal meetings with decision-makers, can be a powerful and cost-effective advocacy tool.
- ▣ **Campaigning:** involves speaking publicly on an issue with a view to generating a response from the wider public and using a variety of techniques such as:
 - chain e-mail or letter
 - opinion pieces and letters to the editor in newspapers
 - newsletters
 - celebrity endorsements
 - media partnerships with newspapers, journalists and film-makers
 - web-based bulletins and online discussions
 - public events
 - large-scale advertising campaigns.

The choice of method will very much depend on the target audience, the message to be conveyed, the resources available, and the cultural and socioeconomic context. Table 3 provides a template that can be used to help decide which advocacy methods would be most appropriate in a given setting.

Table 3. Template for deciding on possible methods of advocacy

Method	Strengths	Weaknesses	Efficacy in ideal conditions	Effectiveness in real conditions	Risks (safety)	Cost or cost-effectiveness
Position paper or briefing notes						
Working from inside organizations or government						
Lobbying or face-to-face meetings						
Presentations at professional conferences, public gatherings, health-care events						
Dramatic emotional appeals						
Press releases						
Media interviews						
Press conferences						

APPROACHING DECISION-MAKERS

When approaching decision-makers with a view to influencing cancer control policy and planning, it pays to bear in mind the following pointers:

BE PREPARED

- ▣ Read over the key messages and background documents relating to your national cancer plan. Know your facts and be prepared to tell your personal story – why you feel cancer is important, and why the government needs to take action.
- ▣ Provide simple print and audiovisual material with attractive illustrations to reinforce the main points and actions to be taken by decision-makers. For example, when raising awareness of the cancer burden and possible interventions, have simple graphs showing the magnitude and trends of the cancer problem and cancer risk factors, and specify the number of cancers that could be prevented, detected early, cured or for which suffering could be palliated if comprehensive policies and actions were in place. Provide real-life stories and examples of best practice from countries with similar socioeconomic situations.
- ▣ Do a risk assessment. What are the counter-arguments? What do opponents and non-supporters believe or say about cancer control? Who is influencing the decision-makers?

Suggested text for this purpose is as follows:

Comprehensive cancer control provides a framework for all levels of government to work together to:

- *reduce the risks of developing cancer and dying from cancer;*
- *improve cancer care and quality of life through better screening, treatment, and access to services.*

Implementing comprehensive cancer control means that:

- *fewer citizens will get cancer and fewer citizens will die from cancer;*
- *people with cancer will have access to high-quality, timely treatment and care;*
- *when cancer cannot be cured, patients will receive high-quality, compassionate end-of-life care, close to family and friends, without enduring unnecessary pain;*
- *money will be saved by eliminating duplication in the current systems;*
- *cancer trends will be reliably tracked to help monitor how our country is doing compared with the rest of the world.*

Implementing the comprehensive cancer control plan will involve costs:

- *it is estimated that the cost of implementing the plan will be X;*
- *however, the cost of not implementing a national plan to control cancer is unimaginable.*

ARRANGE A MEETING

- ▣ Call the decision-maker's office and make an appointment.
- ▣ Confirm the time and place of your meeting in a follow-up letter which also clearly states your purpose in arranging the meeting. Also state who will be attending the meeting.
- ▣ Consider inviting representatives from other local supporting organizations – the more you are able to demonstrate a strong, unified community with a clear message about cancer control to your elected officials, the more compelling your presentation will be and the more likely you are to gain their support.

PREPARE FOR THE MEETING

- ▣ Know your elected officials – you can usually find background information about government officials on government web sites and from media reports.
- ▣ Prepare an agenda – remember the purpose of the meeting is to get decision-makers to support cancer control – preferably sooner rather than later.
- ▣ Be prepared to talk about the benefits of working together and providing support to the cancer plan. Focus on possible solutions.
- ▣ Identify what decision-makers can do to help – support sustainable funding for cancer control, gain commitment from other elected officials in the party, raise the issue in caucus or with the health or finance committees, ask their party colleagues to support the cancer control plan, speak to or write a letter of support to the relevant ministers, ask questions in legislative meetings.

AT THE MEETING

- ▣ Introduce yourself and your organization, and also any representatives of other organizations who may be attending with you.
- ▣ Outline your goals and objectives – what it is you want to achieve as a result of the meeting.
- ▣ Take a petition (if you have one) to the elected official and ask if he or she will help collect signatures – including from other constituents and caucus colleagues.

INTERACTING WITH THE MEDIA

To talk to the mass media is to talk to the public or at least part of it. The *WHO communications toolkit* (WHO, 2007b) provides practical guidance on how to interact successfully with the media and develop effective media products. When dealing with the media, it is important to recognize that media forms are not all the same. Television, radio and print often have different and sometimes competing demands. Some want a 30-second video clip, while others require in-depth factual analysis. Larger or national media agencies tend to have dedicated staff who specialize in health matters. These are the people that ideally you would want to reach. They have the contacts, they know the players, and they are (or pretend to be) knowledgeable. At the regional or local level, however, and depending on their interest or otherwise, your story is more likely to be assigned to a general reporter who covered an environmental spill yesterday, and a human interest or car accident story the day before.

General tips for interacting with the media are as follows:

- ▣ It is inevitable that, whomever you speak to, you will know more about the subject than they will. Thus the easier you make a reporter's job, the more likely you are to get fair or even favourable treatment. One way to do this is to provide written summary statements or a press release.
- ▣ Expect your messages to be filtered and altered by the media. Certainly, most reporters will attempt to do so, especially if they are any good. All the more reason therefore to keep your message simple and repeat it as often as possible, especially in a broadcast interview.
- ▣ Do not speak on behalf of others. If you are asked for an opinion about why the minister is doing this or that, do not answer on his or her behalf, especially if there is an adversarial relationship between you.
- ▣ 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:
 - Decide in advance what your key messages are going to be. Choose a few messages that you are familiar or comfortable with and stick to them.
 - Do a sales job. To do that, use the active, not the passive tense. Do not say "Cancer must come under control", but rather "We must control cancer". Say "We are . . ." instead of "Citizens are . . .".
 - Once you have developed your messages, practice what you are going to say, word for word, until it is second nature.
 - Use concrete but short examples and do not hesitate to repeat your unique selling point (USP), which must be clear, simple and easy to remember (for both you and the interviewer). Follow this tried and trusted advice: KEEP IT SHORT and SIMPLE.

For examples of cancer advocacy campaigns and tools, see

Canadian Campaign to Control Cancer: <http://www.controlcancer.ca/>

Useful cancer advocacy tools: <http://www.cancerforum.ca/>

World Cancer Day: <http://www.worldcancercampaign.org/>

World No Tobacco Day: <http://www.who.int/tobacco/communications/events/wntd/en/index.html>



For information on the use of the Internet to gain direct access to an audience, and further advice on how to plan effective public events, refer to WHO's *Stop the global epidemic of chronic disease: a practical guide to successful advocacy*, which is available at <http://www.who.int/chp/advocacy/en/index.html>



The advocacy efforts of the Breast Cancer Foundation of Egypt (see Box, page 34) has led to increased awareness among the general public and health professionals of the importance of screening, and laid the foundation for a government-run pilot national screening programme for breast cancer.

EGYPT

Advocacy efforts to raise awareness about breast cancer

The Breast Cancer Foundation of Egypt (BCFE) was established in 2003 by a small group of health-care professionals, breast-cancer survivors and public-spirited citizens as a nongovernmental, non-profit organization under the Ministry of Social Solidarity. At that time, there was no government-led breast cancer awareness programme and no other nongovernmental organization working in this area. The public in general was not receptive to information about cancer, a topic considered taboo in this culture.



The BCFE advocated for breast cancer awareness and services on the basis that serving the public in an appropriate manner generates happy clients and positive recognition: this was achieved primarily through a series of educational presentations and by offering screening programmes and direct services. More specifically, the initial strategy of BCFE involved:

- offering the public non-threatening information that would demystify the subject and correct the widely believed misinformation;
- providing this information in oral presentations to groups with minimal amounts of written material (recognizing that this is a culture that prefers oral to written communication);
- introducing the idea of screening following the oral information sessions;
- providing assistance to the public and private sectors upon request;
- announcing a philosophy of cooperation with government to fill the gap between what citizens need and what any developing country government with a large indigent population can realistically provide;
- maintaining a non-critical position on the lack of government progress towards breast cancer awareness and services;
- developing ongoing relationships with government agencies and facilities;
- keeping the Minister of Health and Population informed of its activities.

Fundraising is an important activity of BCFE. Operational funds are generated through sponsorship of the annual event Run for Cure, Ramadan donations from the public and active fund raising by board chairman and members.

Currently, as a result of BCFE work, breast cancer early detection services are being provided by 41 clinics in Cairo, Alexandria, the Delta and Aswan. In all its projects, BCFE has taken a low-key role and allowed credit for the project to be enjoyed by government officials.

Recently, the Ministry of Health and Population announced the launch of a year-long pilot national screening programme for breast cancer. BCFE has already laid the foundation upon which the national programme can be successfully built and will continue to promote a realistic, economical, efficient and culturally-sensitive national screening programme.

BCFE has never formally lobbied government to influence policy, opting instead to adopt a non-threatening posture that allows for a cooperative rather than a competitive or judgemental relationship. It has succeeded in offering much-needed education and services in a professional manner. By offering services only upon request, BCFE has meticulously avoided militant advocacy and successfully tailored its advocacy strategies to the local culture. A low-key profile, efficient services and the discreet use of *wasta* (personal connections in high places) seem to work best in this setting.

Sources: Information provided by Lois Crooks, Volunteer Executive Director, General Secretary and Founding Member, Breast Cancer Foundation of Egypt, and Dr Mohamed Shaalan, Associate Professor of Surgery, Co-Director of the Prevention and Early Detection Unit, National Cancer Institute, and Founding Chairman, Breast Cancer Foundation of Egypt.

For more information on the various activities of the Breast Cancer Foundation of Egypt, go to: <http://www.bcfе.org/>.

ADVOCACY STEP 7

DEVELOPING AND IMPLEMENTING THE ADVOCACY PLAN

An advocacy plan should factor in all the elements described in the previous sections – goals and objectives, target groups and the specific activities to be undertaken, as well as set out stakeholder roles and responsibilities, time frames, expected short-term and long-term outcomes, and available and needed resources.

The advocacy implementation plan should be dynamic and capable of addressing changing needs as the national cancer control programme planning and implementation process evolves over time. A good advocacy plan will be able to respond to newly identified needs for political support and awareness-raising in the community, for instance, for reactivating the development of a comprehensive cancer control plan that has been put on hold; for implementing and scaling up priority interventions; or for influencing improvement strategies that include reorganizing or mobilizing additional resources for a specific component of the cancer control programme.

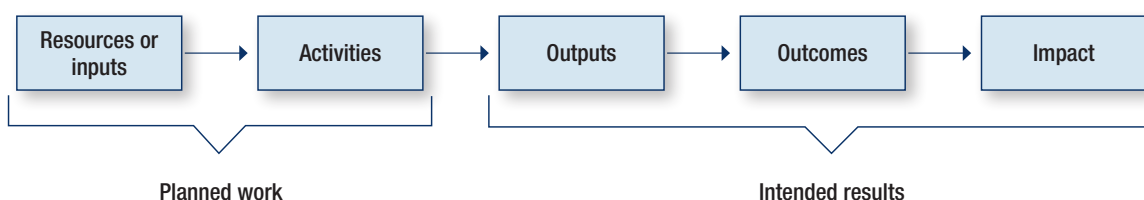
Further details on the planning and implementation of a comprehensive cancer control programme and its various components, are provided in the *Planning, Prevention, Early detection, Diagnosis and treatment* and *Palliative care* modules.

USE A LOGIC MODEL TO MAP OUT YOUR PLAN

A logic model is a visual presentation of how your group will do its advocacy work, and of the theory and assumptions underlying the action plan you are seeking to implement. It shows the relationships between the many resources you have (or need) to implement your plan, the activities you plan to do, and the results you hope to achieve (Figure 1).

Each component in a logic model is linked to the next in a conditional logic “if-then” relationship, in much the same way as in computer programming. If you have access to resources, then you can carry out planned activities. If you carry out activities (inputs), then you can deliver advocacy actions (outputs). If you have a positive effect on cancer control policies, then the public will benefit (outcomes). If your citizens benefit, then hoped for changes will happen in your community and your country (impact).

Figure 1. Components of a logic model



In taking action, remember:

- ❑ Do not fear controversy. Rather, try to turn it to your own advantage.
- ❑ Avoid any illegal or unethical activities.
- ❑ Hold policy-makers accountable to their commitments.
- ❑ Keep a record of successes and failures.
- ❑ Post your advocacy plan on your web site (or the web site of one of your member groups), and use it to measure your progress every month.
- ❑ Schedule a monthly meeting or conference phone call to keep your advocacy group members on track, informed and motivated.
- ❑ Monitor public opinion and publicize positive developments.
- ❑ Acknowledge and credit the role of policy-makers and coalition partners.

The Campaign to Control Cancer in Canada provides a good example of what an effective advocacy plan can achieve in terms of advancing the adoption of a comprehensive national cancer control strategy (see Box, page 38).

CANADA

A successful nationwide advocacy campaign to control cancer

The Canadian Strategy for Cancer Control was unveiled, in 2002, by an intersectoral coalition of governmental and nongovernmental stakeholders as a coordinated national health initiative intended to enable Canada's health systems meet the growing cancer challenge.

The Campaign to Control Cancer emerged as a unique collaboration of more than 70 leading cancer organizations of Canada, to raise public awareness of cancer control nationwide through prominent media advertisements, galvanize grassroots advocacy and media support. The primary aim of the campaign was to educate political leaders about cancer statistics and the need for sustainable commitment of pan-Canadian cancer control efforts. Leadership training workshops were set up to train groups across the country in advocacy skills, to enable them to speak about the need for cancer control and to raise funds to support the efforts. Workshop participants then met with members of parliament, members of provincial parliaments and members of legislative assemblies, wrote letters to the newspapers, circulated petitions and engaged their organizations in the effort to fund and implement the Canadian Strategy for Cancer Control. By spreading the word, the cancer community began to align to support the strategy.

At the same time, a national newspaper advertisement media campaign raised the profile of the cancer situation among the general public and engaged the public in the debate about the need for a national strategy. The advertisements called for fundamental improvements in Canada's response to cancer control by "putting what we know to work to cut cancer down to size". This phrase subsequently became a unifying mantra for the cancer community. Once the media seized upon the topic, multiple stories began to unfold on national radio, in newspapers and on television, gathering public responses through letters and calling political attention to the need for a national strategy.

These advocacy actions culminated in government commitment to fund Canada's cancer control strategy, through the Canadian Partnership against Cancer. Two measures that indicate success of the advocacy are the formal funding commitment in the federal budget, and the establishment of an independent structure to administer the funding and implementation of the strategy.

Evaluation of the plan indicated that several overarching approaches fostered pan-Canadian leadership to advance cancer control policy. Valuable lessons from the Canadian experience in cancer control advocacy are thus:

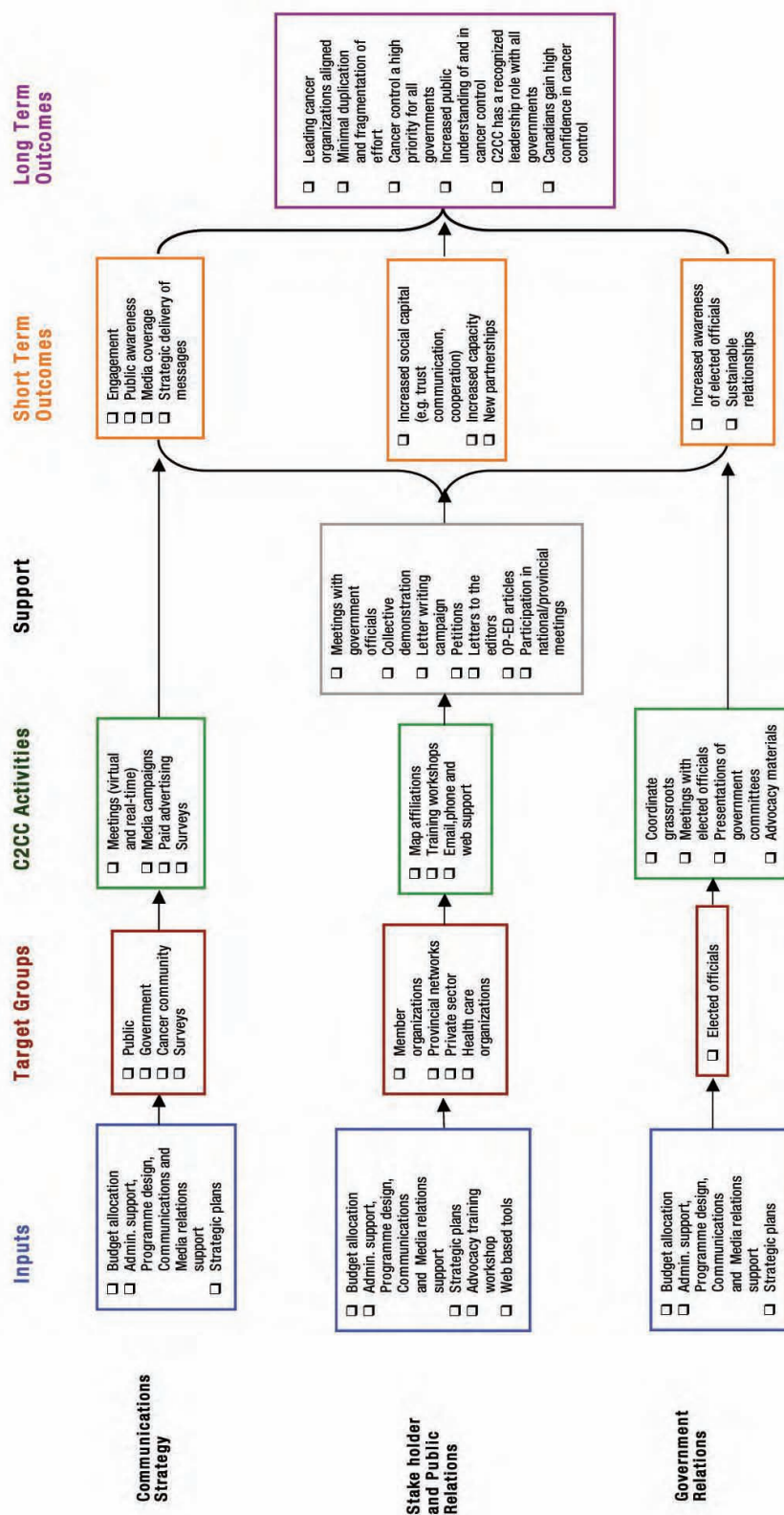
- maintain pressure and momentum over the long term;
- pay attention to timing;
- be highly organized and informed;
- be forceful yet flexible;
- share success with others;
- be visible to politicians and within communities;
- build win-win situations;
- learn from the business community how models of efficiency can work.

Source: The Campaign to Control Cancer in Canada, (<http://www.controlcancer.ca> accessed 24 November, 2007)

For more information on Canadian partnership against cancer, go to <http://www.partnershipagainstcancer.ca/>

Figure 2 shows the logic model used by the Canadian Campaign to Control Cancer for their advocacy plan for 2008–2009.

Figure 2. The Campaign to Control Cancer (C2CC) Canada – Advocacy Plan Logic Model 2008–2009



Our Goal: A better Canadian response to cancer control
 Our Mission: A Canada where what we know and learn is fully deployed so Canadians are not suffering or dying unnecessarily from cancer
 Source: Supplied by Pat Kelly, (2008), National Program Director, The Campaign to Control Cancer, Canada, available at <http://www.controlcancer.ca/en/about-campaign>

MOBILIZE RESOURCES

The voices and priorities of stakeholders in health care, especially those representing vulnerable populations, are often left out of public debates and policy decisions. Advocacy thus often involves changing public opinion and community, institutional or government policies to include these voices. Moreover, corporate and public health-care funders with an eye on broader, systemic change are increasingly considering advocacy strategies as a means to expand health-care access, mobilize and make more efficient use of resources, eliminate disparities, tackle rising incidence rates, and take on other tough problems.

Using advocacy to create change is, however, not without its challenges. You can encourage funders to think about how advocacy might fit into their work and how it can be used as a strategy for advancing shared goals, but as with most strategies, one size does not fit all. Every funder's approach to advocacy is different and is rooted in different ideologies and motivations.

Advocacy for comprehensive cancer control can be seen as an investment because good advocacy strategies will help to mobilize resources for the development of policies and for scaling up programmes, as in the case of United States of America (see Box, page 42). Many of the advocacy strategies used in the United States can be adapted to any country setting; in this regard, the following actions are likely to be of particular interest to users of this guidance:

- ▣ pilot testing of the comprehensive actions in a relatively small geographical area and measuring the results (see also *Planning* module);
- ▣ using the successful results to advocate for comprehensive action and for further support to expand the programme;
- ▣ keeping all partners together and persisting in making the case with one voice.

Keep in mind that much can be achieved by using relatively inexpensive techniques, such as e-mail or letter chains, Internet chats, letters to newspaper editors, and participation in radio and television programmes. “Piggy-backing” onto related and already funded events can also be a cost-effective way to achieve exposure. For example, it is often possible to invite key decision-makers to the opening or closing sessions of a training workshop or conference, where they can be directly informed on progress made in a given programme and can also be exposed to relevant messages for action.

Electronic databases, web sites and e-mail lists allow for rapid and inexpensive dissemination of information and calls for action. All participants in your advocacy actions should be using the same messages, and be citing the same current evidence or facts. They should also all have the appropriate information (name, position, contact information) for the decision-makers you are targeting.

TAKE STRATEGIC ADVOCACY ACTIONS

The following list of actions suggests a possible sequence of steps to take when implementing the advocacy plan:

- ▣ Gather the community to define the current national or regional cancer advocacy needs.
- ▣ Identify, categorize and map the affiliations and influence of the cancer care stakeholder community.
- ▣ Decide on and document the current goals and objectives (e.g. engage the cancer professional and patient community in order to raise awareness of the cancer issue and the need for a comprehensive cancer control plan among key political decision-makers within one year).
- ▣ Assess and document the advocacy methods used (e.g. the media used, the network of contacts, communications vehicles, government relations).
- ▣ Assess the quantity and quality of services (e.g. education, information dissemination and new legislation).
- ▣ Assess and document the available collective resources (e.g. financial resources, human resources (staff, professional, volunteer), social capital (trust, understanding, communications)).
- ▣ Consult and cultivate a network of champions who lead by example and demonstrate the values and goals of comprehensive cancer control.
- ▣ Engage members and stakeholders by building common ground through shared visioning, planning, actions and learning.
- ▣ Enable and mobilize the stakeholder network to act collectively with a unified voice and vision.
- ▣ Measure the impact of action to date, modify the advocacy methods as necessary, and expand the network through community outreach and public engagement, leveraging the collaborative momentum created.

One voice calling for change is more powerful when combined with many others.

UNITED STATES OF AMERICA

The impact of advocacy in scaling up comprehensive cancer control

In 1994 the United States Centres for Disease Control and Prevention (CDC) began to develop a comprehensive approach to cancer control which included a framework for cancer strategic planning applicable at state level. After the model had been successfully tested in a few states, advocates began to inform policy-makers about its value.

One Voice Against Cancer (OVAC) was established to communicate a unified message about national cancer priorities to the executive and legislative branches of the United States Government, and to encourage federal funding for cancer research at the National Institutes of Health and the National Cancer Institute, as well as for the public outreach and screening programmes of the CDC. Since its inception in 2000, OVAC has grown into a well integrated coalition of more than 40 national organizations. Because of its unified purpose to support sustained funding for cancer programmes in the above-mentioned institutions, OVAC has been effective in meeting its goals.

As a result, in part, of these advocacy efforts, the United States Congress formally recognized the concept of comprehensive cancer control and launched a separate programme to undertake this work. During the following 6 years, funding for the Comprehensive Cancer Control Programme has increased more than 10-fold. With the additional funds, the total number of comprehensive cancer control programmes in states and territories has grown from 6 to 61. This success demonstrates the power of working together to advocate for a comprehensive approach to fight cancer.

Source: Selig W et al. (2005). Advocacy and comprehensive cancer control. *Cancer Causes and Control*,16(Suppl.1):S61–S68.

For further information on OVAC activities, see <http://www.ovaconline.org/>

ADVOCACY STEP 8

MONITORING AND EVALUATION

Continuity does not end – advocacy is an ongoing learning process of planning, reflecting and acting.

Advocacy efforts must be evaluated in the same way as any other communication campaign. Since advocacy often only provides partial results, an advocacy team needs to monitor and measure regularly and objectively what has been accomplished and what more remains to be done.

Monitoring is the measurement of progress towards the achievement of set objectives, noting which activities are going well and which are not. Evaluation is about judging the quality and impact of activities. Evaluation asks 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 considered (see *Planning* module).

There are numerous ways of monitoring and evaluating advocacy work. Methods can be:

- ▣ qualitative (e.g. case studies, stories, opinions, survey questionnaires);
- ▣ quantitative (e.g. statistics or trends that indicate a change over time).

Monitoring methods should be chosen according to the indicators that you have selected to evaluate the impact of your work. Monitoring methods may include:

- ▣ keeping records of meetings, correspondence or conversations with target audiences and the responses elicited;
- ▣ tracking when your key messages or briefing notes are used by elected officials, other key influencers or the media;
- ▣ carrying out surveys and interviews to determine the impact your actions have had and the recognition they have received;
- ▣ monitoring the media and keeping track of coverage of your topic in the media.

Evaluation should be based on the goals and objectives that were set at the outset of the advocacy planning process. Questions that you might ask in order to evaluate the impact of your work are as follows:

- ▣ 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 were taken by these target decision-makers?
- ▣ Is the situation better than before? By how much?
- ▣ If there is no change, how might you change your advocacy methods?
- ▣ What would you do differently next time?
- ▣ Are the people involved with the advocacy effort happy with the results and the way the work was implemented? Are they still involved?

Cancer control outcome indicators will be useful for determining what difference advocacy efforts have made. *National cancer control programmes: policies and management guidelines* (WHO, 2002) or the *Early detection, Diagnosis and treatment* and *Palliative care* modules provide further information and guidance on appropriate monitoring and evaluation frameworks that are relevant to comprehensive cancer control and its components. Go to <http://www.who.int/cancer/modules/en/index.html>



Advocacy is often an ongoing process. Thus rather than simply aiming for a single policy or piece of legislation, advocacy plans may have multiple or even changing goals and objectives. Ideally then, advocacy plans should be designed to be sustainable over time. Planning for continuity means articulating long-term goals, keeping functional coalitions together and adjusting advocacy methods as situations change.

Over the long term, you will need to evaluate the situations that result from advocacy activities. Possible scenarios, and recommended courses of action, are:

- ▣ If desired policy changes occur, monitor their implementation.
- ▣ If desired policy changes do not occur, review previous advocacy strategy and action, revise the strategy, enact a new advocacy process or identify other actions to be taken.
- ▣ Develop plans to sustain or reinforce the desired change.

CONCLUSION

Advocacy is needed in all settings and throughout the entire life-cycle of comprehensive cancer control planning, implementation, monitoring and evaluation in order to influence decision-makers to make the desired policy changes and raise resources for the programme in a timely, sustainable and equitable way. Advocacy strategies can be relatively inexpensive and effective provided they form part of a well-conceived advocacy plan.

Advocacy for comprehensive cancer control is usually aimed at decision-makers, but it also needs to target influential leaders and groups, and also the public in general, in order to eventually mobilize whole societies in a sustained fight against cancer. Both coalition building and social mobilization are critical factors for successful advocacy efforts.

Ministries of health are usually the main targets of both national and international leaders and organizations advocating for comprehensive cancer control policies and programmes. Developing a comprehensive programme (or one of its components) as an entry point, in a relatively small area, to demonstrate success in the short- or medium-term is a very powerful tool that advocates can use to engage the support of health ministries and other local authorities, and for arguing the case for further support and the expansion of the programme.

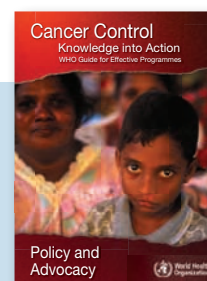
As the situation evolves, health ministries can play a crucial role in advocating for other policy-makers and planners to focus on, and invest in, cancer prevention and control. Ministries of health may implement advocacy actions directly, or indirectly by supporting advocacy organizations.

Anyone directly or indirectly involved in cancer control can be an advocate, so long as they are prepared to devote time, knowledge and skills, work collaboratively and speak with one voice in order to reach the desired outcomes. However, regardless of who acts as an advocate for cancer control, the advocacy effort requires careful planning and sustained advocacy strategies tailored to the political, cultural, social and economic environment.

Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it's the only thing that ever has.

Margaret Mead, anthropologist
1901–1978

This module on policy and advocacy is intended to evolve in response to national needs and experience. WHO welcomes input from countries wishing to share their successes in policy and advocacy. WHO also welcomes requests from countries for information relevant to their specific needs. Evidence on the barriers to policy and advocacy in country contexts – and the lessons learned in overcoming them – would be especially welcome (contact at <http://www.who.int/cancer>).



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Neil Berman, British Columbia Cancer Agency, Canada
 Yasmin Bhurgri, Karachi Cancer Registry and Aga Khan University Karachi, Pakistan
 Heather Bryant, Alberta Cancer Board, Division of Population Health and Information, Canada
 Eduardo L. Cazap, Latin-American and Caribbean Society of Medical Oncology, Argentina
 Frances Prescilla L. Cuevas, Department of Health, Philippines
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 Sania Nishtar, Heartfile, Pakistan
 Rimma Potemkina, State Research Centre for Preventive Medicine, Russian Federation
 You-Lin Qiao, Chinese Academy of Medical Sciences and Peking Union Medical College, China

THE FOLLOWING WHO STAFF ALSO REVIEWED DRAFT VERSIONS OF THE MODULE

WHO regional and country offices

Cherian Varghese, WHO India Country Office

WHO headquarters

Rebecca Harding
 Christine MacNab
 Iqbal Nandra
 Armando Peruga
 Luminita Sanda
 Cecilia Sepúlveda
 Kristine Thompson
 Maria Villanueva

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Baffour Awuah, Komfo Anokye Teaching Hospital, Ghana
 Volker Beck, Deutsche Krebsgesellschaft e.V, Germany
 Yasmin Bhurgri, Karachi Cancer Registry and Aga Khan University Karachi, Pakistan
 Vladimir N. Bogatyrev, Russian Oncological

Research Centre, Russian Federation
 Heather Bryant, Alberta Cancer Board, Division of Population Health and Information, Canada
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 Eduardo L. Cazap, Latin-American and Caribbean Society of Medical Oncology, Argentina
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 Anton G.J.M. Hanselaar, Dutch Cancer Society, the Netherlands
 Christoffer Johansen, Danish Institute of Cancer Epidemiology, Danish Cancer Society, Denmark
 Ian Magrath, International Network for Cancer Treatment and Research, Belgium
 Anthony Miller, University of Toronto, Canada
 M. Krishnan Nair, Regional Cancer Centre, India
 Twalib A. Ngoma, Ocean Road Cancer Institute, United Republic of Tanzania
 D. M. Parkin, Clinical Trials Service Unit and Epidemiological Studies Unit, England
 Julietta Patnick, NHS Cancer Screening Programmes, England

Paola Pisani, International Agency for
Research on Cancer, France
You-Lin Qiao, Cancer Institute, Chinese
Academy of Medical Sciences and
Peking Union Medical College, China
Eduardo Rosenblatt, International Atomic
Energy Agency, Austria
Michael Rosenthal, International Atomic
Energy Agency, Austria
Anne Lise Ryel, Norwegian Cancer Society,
Norway
Inés Salas, University of Santiago, Chile
Hélène Sancho-Garnier, Centre Val
d'Aurelle-Paul Lamarque, France
Hai-Rim Shin, National Cancer Center,
Republic of Korea
José Gomes Temporão, Ministry of Health,
Brazil

Other participants

Barry D. Bultz, Tom Baker Cancer Centre
and University of Calgary, Canada
Jon F. Kerner, National Cancer Institute,
USA
Luiz Antônio Santini Rodrigues da Silva,
National Cancer Institute, Brazil

Observers

Benjamin Anderson, Breast Health Center,
University of Washington School of
Medicine, USA
Maria Stella de Sabata, International Union
Against Cancer, Switzerland
Joe Harford, National Cancer Institute, USA
Jo Kennelly, National Cancer Institute of
Canada, Canada

Luiz Figueiredo Mathias, National Cancer
Institute, Brazil
Les Mery, Public Health Agency of Canada,
Canada
Kavita Sarwal, Canadian Strategy for
Cancer Control, Canada
Nina Solberg, Norwegian Cancer Society,
Norway
Cynthia Vinson, National Cancer Institute,
USA

The World Health Organization estimates that 7.6 million people died of cancer in 2005 and 84 million people will die in the next 10 years if action is not taken.

More than 70% of all cancer deaths occur in low and middle income countries, where resources available for prevention, diagnosis and treatment of cancer are limited or nonexistent.

Yet cancer is to a large extent avoidable. Over 40% of all cancers can be prevented. Some of the most common cancers are curable if detected early and treated. Even with late cancer, the suffering of patients can be relieved with good palliative care.

Cancer control: knowledge into action: WHO guide for effective programmes is a series of six modules offering guidance on all important aspects of effective cancer control planning and implementation.

This *Policy and advocacy* module provides tools and advice on how to plan and advocate for sustainable cancer control policy and effective programme implementation. It outlines the capacity required for collaboration and communication, and sets out the optimal roles of various groups in advocacy. It recommends practical action steps, indicating how diverse groups can support effective cancer control efforts.

This module is intended to provide encouragement and ideas to people, having various levels of experience, who:

- are concerned about the status of comprehensive cancer control in their province, state or country;
- want to know more about how advocacy works;
- are thinking about applying an advocacy strategy;
- are engaged in advocacy and want to learn more about a stepwise approach.

This module is intended to help build knowledge, confidence, skills and passion for action in people concerned about cancer. Its target audience ranges from policy-makers to implementers of cancer control plans at national, regional or local level.

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