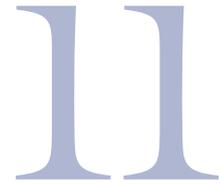


IMPLEMENTING A NATIONAL CANCER CONTROL PROGRAMME



MOVING FROM POLICY TO IMPLEMENTATION

The process of implementing a national cancer control programme needs competent management to identify priorities and resources (planning), and to organize and coordinate those resources to guarantee sustained progress to meet the planned objectives (implementation monitoring and evaluation). Good management is therefore essential to maintain momentum and introduce any necessary modifications. A quality management approach is essential to improving the performance of the programme. Such an approach encourages all participants in the programme, including staff volunteers, community groups, and patients to practice positive, initiative-taking behaviour and adopt a systematic approach to managing the various processes in order to prevent problems.

Schematically, the programme can be seen as a system, with inputs, processes, outputs, and outcomes (Figure 11.1). The inputs are the various resources needed to run the programme. The term resources is used here in a broad sense, implying people, staff, finance, facilities, techniques, methods, and so on. The processes are the means by which programme services are delivered, or how the programme organizes resources to carry out its mission. The outputs are the units of services provided or the direct products of programme activities. The outcomes are the impacts on the people receiving the services or participating in the programme.

What resources are needed for a national cancer control programme?

Leadership and team building

The various activities of a national cancer control programme share common objectives. Competent management is needed to integrate these activities into a coherent programme. Key to competent management is the leadership of the programme, who should be facilitative, participatory and empowering in how vision and goals are established and carried out. A coordinator and a board constitute the core of the programme management. Whenever possi-

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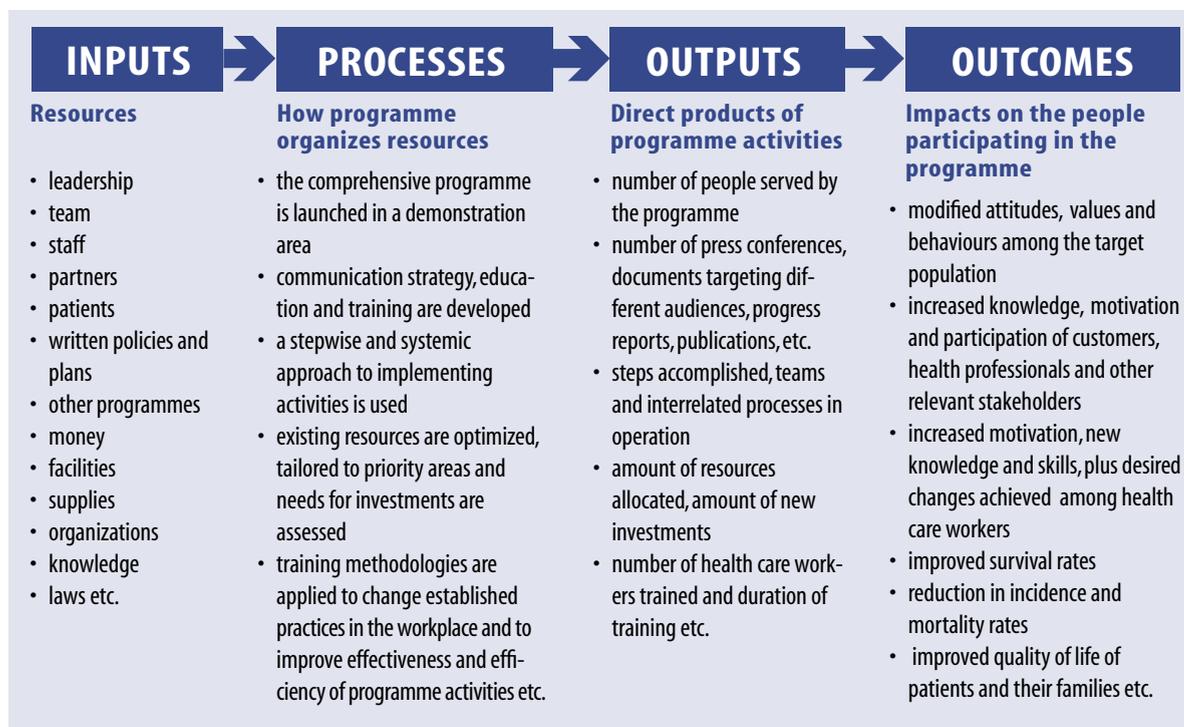
ble, both should be appointed early in the establishment of a national cancer control programme and given appropriate responsibility and support.

Ideally, the individual selected as the programme coordinator should have technical competence and political influence, charisma, good management and communication skills, and relevant knowledge and experience in public health. It is also desirable for this individual to have expertise in public relations, fundraising, lobbying, consensus building, information systems and evaluation techniques. It may not be possible to find all these characteristics in one person, and a leadership team may therefore be a preferable solution. The coordinator needs to keep a balance among the prevention, treatment and palliative care components. This person also needs to be persevering, flexible and creative, in order to overcome the numerous barriers the programme will face.

In addition to organizing the work of the board, the coordinator is responsible for the following tasks:

- creating the culture of the programme;
- representing the programme to the public and to the various collaborating agencies;

Figure 11.1
System model of
a national cancer
control programme



- providing assistance to the individuals responsible for the various programme activities;
- ensuring that activities and events are coordinated to gain maximum effect;
- ensuring that the programme is reviewed at regular intervals;
- setting targets for quality assurance and improvement.

The board of the national cancer control programme should amply represent all key sectors of the community. It should consist of the people responsible for various programme activities, whether governmental or nongovernmental, including oncology specialists and the general public. This multidisciplinary group should work as a team, led by the programme coordinator. The board should have a constitution that sets out its mandate, specifies its accountability, defines its membership, and specifies the frequency of its meetings.

The coordinator of the national cancer control programme should facilitate or reinforce the building of a network of local coordinators, backed by their own teams, who will take a leadership role in their areas or regions. Ideally, these local leaders should coordinate with the central organization, but keep their autonomy to administer their own resources and adjust national cancer control plans to their local situation.

The functions of the board of the national cancer control programme are given in Box 11.1.

Box 11.1 Functions of the board of a national cancer control programme

The board of a national cancer control programme should:

- oversee the development and revision of the written programme plan;
- assume responsibility for implementation of the plan;
- obtain political commitment from the government;
- coordinate the work of all agencies that can contribute to cancer control;
- oversee the systematic development and coordination of specific cancer control activities, such as prevention, early detec-

tion, treatment, and palliative care, so as to ensure the best use of available resources for the whole population;

- oversee financial aspects of the programme, including budgeting and fundraising;
- recommend legislative action to change cancer control policies;
- oversee public education and participation;
- oversee development of national diagnosis and treatment guidelines
- oversee professional education and development;
- identify and recommend research priorities;

- forecast future trends and coordinate the strategic development of health services, the health system, and the training and supply of health professionals;
- develop and support cancer control programmes for sub-populations within the country;
- recommend priorities for the investment of additional resources;
- develop a communication strategy;
- oversee the information systems;
- oversee the programme evaluation process, and implement corrective changes as needed.

Team building, or the ability to gather the right people and get them working together for the benefit of a project, is essential in a cancer control programme. Most of the managerial, clinical or community activities require teamwork. Effective teams are results-oriented and are committed to project objectives, milestones, goals and strategies. The team's behaviour is subject to socially acceptable standards that are shared by all members. In the work environment the most important standards relate to the group performance.

Characteristics of good team building include the following:

- team is clear about goals and established targets;
- each team member is willing to contribute;
- team leader has good interpersonal skills and is committed to team approach;
- high level of interdependence exists among team members;
- team develops a relaxed climate for communication;
- team members develop mutual trust;
- team and individuals are prepared to take risks;
- roles of team members are defined;
- team norms are defined;
- team members know how to examine team and individual errors without personal animosity;
- team has capacity to create new ideas;
- team members know that they can each influence the team agenda.

It is important to keep in mind the various barriers to team development. A high proportion of health professionals, who work mainly at the clinical level, may resist public health approaches. In addition, health managers and their team generally work in unfavourable conditions, have low salaries and have to perform competing tasks for other programmes. Motivating them and keeping them involved may constitute a major challenge. Meetings and training workshops should create an appropriate environment, so that the team—and especially new team members—understand the team's overall goal, their specific role within the team in contributing to the attainment of that goal, and the rationale for the public health strategies the team will be implementing. When resources are limited, there is a need to provide actively for psychosocial and cultural incentives, such as public and private acknowledgement of their efforts, enhancement of the contribution each team member plays in the achievement of the common goal, and continuous training.

The written plan for the national cancer control programme

Steps in development of the national cancer control programme were dis-

cussed in the previous chapter. Oversight of this process and the preparation of a written plan are the responsibility of the programme board, working by itself or through coordination of the work of various committees. The written plan should be formulated and tailored to the needs of the country. The following outline has served as a valuable model for national cancer control programme plans:

- assessment of the cancer situation;
- clear definition of goals and objectives
- identification of the priority needs of the country;
- outlining the strategies for cancer control;
- assessment of resources available and how they are organized in the health system;
- setting of achievable targets, and indicating by whom, when and where they are to be carried out.

Acceptance of the plan may be facilitated by drafting a discussion paper on cancer control, and circulating it for comment by the government and by nongovernmental organizations. Review and approval of a plan can be a lengthy process, but a draft plan that the board can use for lobbying may assist in speeding up the process. Copies of national cancer control programme plans and related materials for a number of developed and developing countries are available in the literature and on the Internet.

Written guidelines

For each priority area, evidence-based guidelines should be elaborated. These guidelines should be accepted by consensus, and must address clinical and management aspects, in order to standardize the procedures and contribute to quality assurance of the different activities.

Programmes that already exist

When the national cancer control plan and the priorities for initial cancer control activities have been agreed, the resources to implement the plan must be mobilized, either by bidding for new resources or by using existing resources. It may often be possible to mobilize existing resources that can be incorporated into the national cancer control programme or with which the programme can collaborate in order to maximize their usefulness. Linkages between existing cancer control activities and other programmes, such as those for the control of other non-communicable diseases, tobacco, sexually transmitted diseases/AIDS, nutrition, and environmental contamination, will be conducive to the primary prevention of cancer. Close coordination

with hepatitis B virus vaccination programmes and schistosomiasis control projects should be planned in areas where these diseases present significant problems.

The national cancer control programme should be integrated into, and collaborate with, existing healthcare systems, both public and private, at the different levels of care, including hospitals, and primary health care clinics. The programme cannot, however, be run exclusively within any one of these levels, since activities will be concerned with different levels, or sometimes a combination of levels. Thus many primary prevention activities may be run largely within the primary healthcare level (for example, HBV immunization), whereas others, such as early detection and screening strategies, may involve all three levels. Diagnosis and treatment require a multidisciplinary approach, and coordination among the different disciplines should be enhanced to improve quality of care. Primary healthcare centres have a major role to play in public health education and early detection; medical, paramedical, and community care workers should be the resource persons for these activities, and an effective link in the referral chain. Active participation of primary health care workers is an important component of an effective cancer control programme.

Partnership

Partners who are engaged in the fight against cancer may come from governmental, nongovernmental, and private sectors, as well as professional organizations. All have the common objective of reducing cancer morbidity and mortality. Partners from each sector must play a role in the development of a national cancer control programme, though the relative extent of that role will vary from country to country. In close collaboration with WHO, the International Union Against Cancer (UICC) promotes the participation of nongovernmental organizations in the development and implementation of national (regional) cancer control plans, and helps to build capacity in the areas of cancer prevention and early detection, particularly through education and training programmes.

NGOs can often perform roles in cancer control that cannot be undertaken by government because of fiscal or political constraints. It is important to consult NGOs early in the development of a national cancer control programme in order to secure their collaboration. Particular areas of activity should be identified as the responsibility of government (for example, government is usually responsible for providing most health personnel and services), and others as the responsibility of NGOs. NGOs need to work within the national cancer control programme, and should avoid promoting measures that are appropriate in other countries but impractical in their own.

NGOs are involved in a variety of cancer control activities, ranging from research, registration, and prevention to treatment and patient care and facilities, either through direct provision of the services or as funding bodies. In some countries, funding for treatment comes from the central government, while funding for disease prevention and screening is provided by local government sources. In other countries, funding comes mostly from private sources, with NGOs playing a major role in initiating prevention and early detection activities. It is very important that all players are aware of the complexity of the national situation and of the role each can or should play to achieve the goals of a national cancer control programme. A comprehensive and systematic approach to the cancer problem, as presented in a national cancer control programme, gives all partners the opportunity of contributing their best to a unified endeavour.

The nongovernmental sector is an important source of technical know-how, expertise, and resources, and provides outreach to the professional and public communities. The need for community participation in cancer control and patient care is evident. This need is particularly acute in developing countries, given the resource constraints and operational limitations of their governmental health care systems. In many countries, major portions of their healthcare budgets are dedicated to the control of communicable diseases, leaving little for allocation to noncommunicable diseases. Nongovernmental and voluntary organizations should, therefore, play a significant role in reducing disparities in the level of cancer prevention, early detection and patient care that governmental health systems are able to provide.

A budget for cancer control

In drawing up the budget of the national cancer control programme, it is useful to start by identifying all the budgets currently used for every aspect of cancer control. Bodies already active in related activities may be defensive about their budgets, but should understand that there may be opportunities for the reallocation or sharing of resources in the future, when the national programme has developed a sense of common purpose. Even if precise budgetary information is not available, it is useful to estimate current expenditure on each of the four major strategy components: primary prevention, early diagnosis and screening, treatment (surgery, radiotherapy and chemotherapy), and palliative care. Based upon agreement within the national cancer control programme board on priorities, and with the relevant agencies, resources should be reallocated from unproductive areas to areas with greater potential for success.

In general, resources for the national cancer control programme should be provided by the government and supplemented by NGOs and, if necessary,

by special fundraising. Since the establishment of a national cancer control programme is intended to increase the priority given to cancer control in the country's health care programme; to raise the profile of those working in cancer control; and to increase the resources devoted to cancer control; it is probable that the availability of funds within the country concerned will increase. The very process of developing a national cancer control programme will facilitate the mobilization of funds and may increase the accessibility of funds within the country. In addition, international donors are likely to be attracted by a well-conceived programme that promises to increase the efficiency and effectiveness of cancer control. Fund-raising from these and other sources is a major part of the responsibilities of the programme coordinator and board.

Information systems

Information systems should be developed in order to monitor the programme processes and indicate ad hoc changes to improve them. For example, effective patient care requires timely diagnosis, treatment and adequate follow-up. A good information system should be able to identify delays or bottlenecks in the system, and impediments to follow-up and adherence so that such problems can be readily solved. Ideal, comprehensive, information systems can be very costly and difficult to maintain. In limited resource settings, information systems should be tailored to the basic needs of the selected priorities, and carefully developed to ensure the monitoring and evaluation of key process components and outcome measures in the priority areas. Information systems should be linked to population-based cancer registries in the areas where they exist so outcome measures such as incidence, stage distribution and survival can be provided by the surveillance system. Sample survey methods can be used to supplement this approach.

Legislation

In some countries, legislation may be needed to provide the necessary authority for those who are to run the national cancer control programme. In others, legislation may have to be introduced or amended to allow the costs of some activities (for example, screening tests) to be covered by the government or by health insurance schemes.

Which are key processes for a national cancer control programme to fulfil its goals?

Processes should be managed to meet the requirements and needs of cus-

tomers, providers and other stakeholders. Clear roles and responsibilities must be established for managing the process and the interrelations with functions of other processes or programmes must be identified as well. The processes must align with the national cancer control programme objectives and should include continual improvement of performance. Decisions and actions should be based on the analysis of data and information to improve results, and not rely merely on opinions as usually occurs.

The following paragraphs describe some key processes that are useful to consider when implementing or reorienting a national cancer control programme. These processes are based on principles of quality management as well as on practical experiences at the country level.

Launching the programme

A successful launch can facilitate public acceptance of a national cancer control programme, increase the understanding of the principles underlying the programme, and rally support for its strategies. Once the programme plan has been developed, consideration can be given to the approaches to be used for launching the programme. If only minimal resistance is anticipated and if there is confidence that the planned strategies can be successfully implemented nationally, the programme board can move directly to a launch with a national conference. This implies careful planning and involvement of media experts. From the beginning, the board needs to work closely with the media experts and others preparing all aspects of the conference, including press releases, brochures, and other background material, and ensuring that such material is acceptable to the government and the NGOs involved. If any resistance is anticipated, careful analysis of the situation is needed to identify the barriers and the possible mechanisms for overcoming them. In some cases it is preferable to focus the programme initially in a demonstration area.

Demonstration areas

Experience gained by various countries show that it is often advisable to start small and consider that success breeds success. Efforts can concentrate on a demonstration area, which has a good likelihood of successfully implementing one or two priority initiatives that can serve as entry points. Thus political and financial support can be enhanced and the expansion of the programme both geographically and thematic can be considered in a second stage, once concrete achievements can be demonstrated.

Sustained communication strategy

The board of the national cancer control programme should oversee the development of a sustained communication strategy to support the implementation and progress of the programme, bearing in mind the following questions:

- whom do we wish to inform or influence;
- how often to communicate;
- by what means to communicate most cost-effectively;
- whether to publish a newsletter;
- whether to publish reports on cancer control;
- how to use an annual report to best effect.

Step-by-step implementation

A step-by-step process is recommended when starting or reorienting a cancer control programme, especially in a developing country setting. Implementation of a cancer control programme may proceed in a series of stages, each stage having clear measurable objectives and representing the basis for the development of the next stage, thereby permitting visible and controlled progress. Every stage should involve decision-makers and operational staff from the different levels of care that need to participate actively.

Optimizing existing resources from the start

Quite often, priority setting is neglected or does not follow the proper methodology. Scarce resources may not be well allocated or distributed. They may not be targeted to the right population group and they may be misused. There may be a lack of training and quality control. Thus, it is essential that at the first stage the programme considers reallocation of existing resources according to the new strategies, and foresees the development and incorporation of new technologies that are cost-effective, sustainable and of benefit to the majority of the targeted population.

Organizing activities of the priority areas with a systemic approach

Activities carried out according to the selected priorities should be tailored to the populations at risk. The activities should be adequately organized so as to make the best use of the available resources. Furthermore, it is important to take a systemic approach to ensure that the various interrelated components of the intervention strategy that share common objectives, are coordinated, directed to achieving the objectives, and integrated with other related pro-

grammes or initiatives. An example of such an organization approach for a cervical cancer screening programme was given in Figure 10.3. Different components at various levels of care are essential and complementary parts of the system. All these components need to be managed efficiently in order to guarantee quality and their permanent coordination. They also need to be continuously monitored to achieve reduction in incidence and mortality from invasive cancer. Furthermore, each component is a subsystem with its own particular management process. At the primary level of care, where the majority of the women at risk are screened, the activities are integrated with programmes of reproductive health, other preventive clinical services and community-outreach initiatives. At the secondary and tertiary levels the components are integrated with the hospital services that provide diagnosis, treatment, and eventually, palliative care to the cases that were not detected early by the system.

Education and training

Ideally, health professionals, including nurses, doctors and health managers, should have some public health training during their undergraduate and post-graduate courses. Such training should give healthcare providers knowledge and skills in epidemiology, screening, and health services organization and management. Programmes to educate and train health care professionals, consumers, and other stakeholders should be tailored to the type of audience, the local situation and the momentum in the national cancer control programme development so as to ensure that they contribute to improving the programme. The teaching of behavioural modification skills should be encouraged, as many aspects of cancer prevention, treatment and palliative care require behavioural changes from the public, the patient and the health worker.

One way of establishing a broad base of support and improving programme performance, is to hold a national problem-solving workshop with the participation of professionals from all related disciplines and from all levels of the health system, covering all the targeted administrative areas. The goal of the workshop could be to strengthen national capacity to manage cancer control programmes. The initiative includes follow-up meetings to reinforce the processes generated by the initial workshop.

Continuous training of health care workers needs to be developed along the lines of quality management. That is, it should focus on active involvement, continual improvement and innovation and creativity. Such training is key to achieving the desired changes in behaviour in line with new policies, and thus to improve the performance of the programme.

Spiral of problem solving and team learning methodology

This is an example of a learning methodology that can be used to improve the effectiveness and efficiency of a public health programme by changing established practices in the workplace. A common problem encountered in the implementation of a national cancer control programme is how to produce a change in the established practices of professional workers. The spiral of problem solving and team learning is an effective methodology to deal with this situation (Salas 2001). This methodology is a combination of problem-based learning methodology (Barrows and Tamblyn 1980) and the study of work for better decision-making (Sketchley et al. 1986). The approach is designed to give ownership of the process to the local manager and team by promoting their active participation in planning, implementation, monitoring and evaluation. The basic assumptions underlying this approach are that:

- health workers can learn from their workplace experiences;
- human and material resources already in use can be redirected through low cost intervention to produce a more efficient programme;
- formal lines of authority in the public health sector must be respected to minimize resistance and improve potential support;
- existing levels of authority are interested in improving the programme when they are involved, respected, motivated, trained and supported.

The methodological principles governing this intervention concern both personal and collective components. The first personal principle is that programme leaders must begin by changing themselves before asking others around them to change. Individuals perceive obstacles as limiting their possible choices, so an important principle is to stop that restrictive attitude and think of obstacles as an opportunity for creativity. Another important personal principle is to learn not only from personal experience, but from everyone, thus people should always be open to new ideas. Further, each person deserves respect and appreciation, so rejection and criticism should be avoided.

As a collective, the group always needs to keep the big picture in mind, continuously aware of what part is taking place at any given time. The objective should always be clarified first, and then the plan of action should be designed to achieve that objective. Another important principle is that the use of available resources should be optimized first, before consideration of adding any new resources. Similarly, the focus of the group should be teamwork, using the skills and talents of existing staff. When an outline of any plan is developed, part of the plan should always be left open to allow the local team to make adjustments and to innovate. Lastly, the process needs to

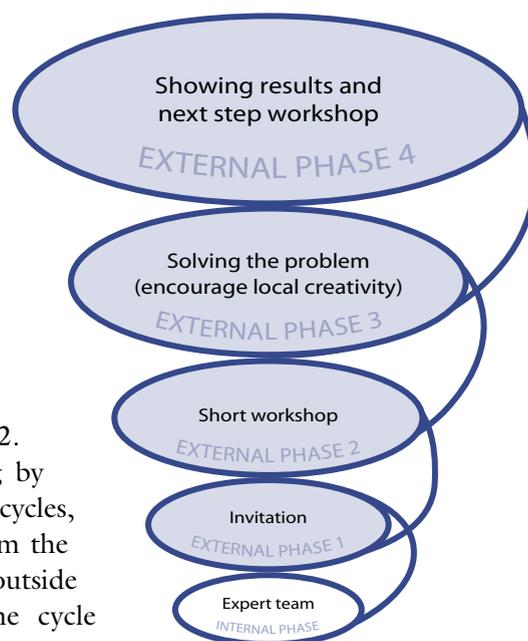
be sustained with high quality information, with the teams taking an active part in collecting, interpreting and disseminating the information.

A cycle of the spiral of problem solving and team learning methodology has an internal phase and a public or external phase. During the internal phase an expert team plans a project. During the public phase, the participants work at the managerial and operation levels to implement and evaluate the project. Initially, the expert team identifies the problems and drafts a general sequence for solving them. Then it selects one specific problem and develops a plan. The plan should have a fixed framework, providing opportunities for input from the health managers and teams. Subsequently, a public phase is initiated, consisting of the following steps:

- invitation of the established responsible managers to a short workshop, usually one day; this respects the existing hierarchy and develops a critical mass that will positively influence others.
- the initial short workshop should be carefully designed and implemented so as to create the momentum to initiate the programme and obtain the commitment of the participants. The workshop includes a presentation from an expert clearly identifying the problem; the managers and their teams work to analyse the shortcomings and suggest solutions, following written guidelines; the teams are taught the essential skills for solving the problem, generally through demonstrations; the teams are given guidance on how to present the results of the field work; and the teams are invited to develop solutions to the problem in their own workplace and present the results at the next workshop.
- the teams return to their place of work, pursue their plan of action in their health establishment using local creativity to solve the problem, and collect information on the results;
- at the next short workshop, teams make oral presentations of their results; successes and innovation are recognized; and as soon as the presentations are finished, the same workshop starts the next cycle of problem-solving, building on the successful solution of the previous problem.

The strategy is described schematically in Figure 11.2.

Consequently, the staff is involved in “learning by doing”. This is done in a gradual way or successive cycles, going from the simplest to the most complex, from the inner environment (healthcare services) to the outside environment (community outreach). Initially, the cycle



*Figure 11.2
Spiral of problem-
solving and
team learning
at the workplace*

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typically focuses on the health service officials themselves. For example, if the problem were related to reducing smoking rates, the initial cycle would involve reducing the smoking rate of health care professionals and promoting non-smoking in indoor premises. Likewise, if the problem were related to cervical cancer screening, the initial cycle would be the screening of female personnel of the health care centres. Then the cycles are expanded step-wise to eventually reach the general public. In the example of cervical cancer screening (see Figure 11.3), the expanding set of cycles include the quality control of the Pap smear samples, which is addressed using the same approach.

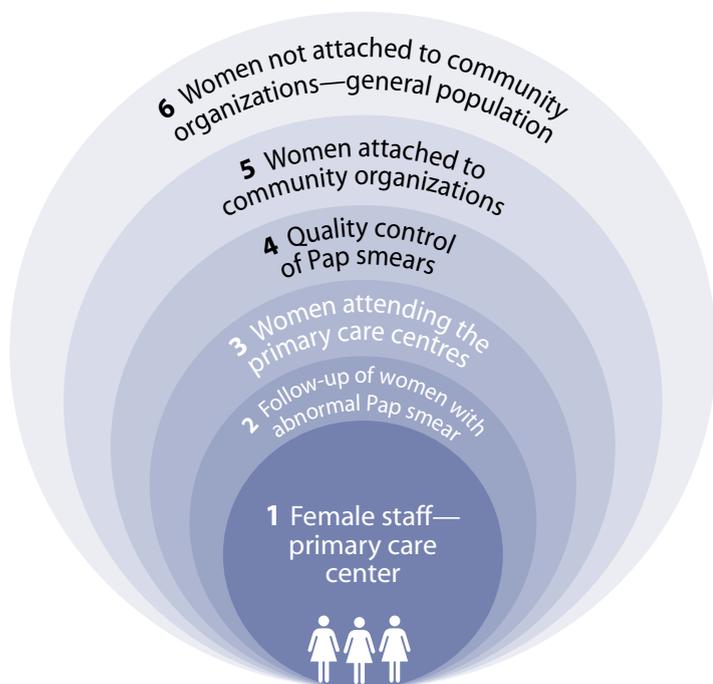
The reorganization of the cervical cytology screening programme in Chile, a middle-income country, is given as an example of this methodology (Box 11.2). In this example, each cycle was accomplished in 3 to 8 months. In the first cycle, from July to October 1988, the Pap smear coverage of women, aged 25–64, working at the primary health centres of the Metropolitan Region of Santiago, increased from 41% to 79%.

Constraints in moving from policy to implementation

The challenge for the national cancer control programme is to provide guidance compatible with the scientific evidence, in order to justify cancer control endeavours within the context of fiscal and other constraints. Implementation of a national cancer control programme means facing up to issues such as health sector reform, health care financing, globalization, and the impact of various financial policies that are forcing cuts in social service spending. Further, given the scarcity of resources, the focus on high priority public health problems, in particular HIV/AIDS, must be taken into account.

In some countries, especially in the least developed ones, implementation will be slow. Sometimes cancer

Figure 11.3
Expanding cycles—
cervical cancer



control activities will take place outside the concept of a national cancer control programme. In other countries comprehensive tobacco control interventions may move ahead independently because of political will, and because their justification is wider than cancer, involving cardiovascular and respiratory diseases and maternal and child health as well. In some countries, the implementation of a national cervical screening programme may be linked to maternal, child and women's health, although in such a case, it may be difficult to ensure that priorities reside with the screening of women over the age of 35 years.

Frequently, health initiatives do not address the thorny question of collaboration. It is left to front line primary care providers to work out how to collaborate when they are confronted with multiple guidelines and protocols on how to deal with the management of childhood illnesses, safe

Box 11.2 Reorganization of the cervical cancer screening programme in Chile

In 1985, with the assistance of WHO, a national cancer control programme was founded at the Ministry of Health, with cervical cancer as one of the main priorities.

Over the two previous decades, opportunistic annual screening for cervical cancer had not achieved the expected reduction in mortality. Therefore, in 1987, a public health oriented cervical screening programme was launched, based on screening women aged 25 to 64 with a Pap smear every three years. Unfortunately many health professionals were reluctant to apply the ministry's approach. Consequently, efforts and resources were initially focused on the Santiago Metropolitan Region, which constitutes one third of the population, as a demonstration area. Seven years later, the programme was expanded to the remainder of the country.

The programme emphasized network organization; timeliness of diagnosis and treatment (more than 80% of women with abnormal Pap smears get prompt medical attention); reliability of Pap smear (100% of public laboratories are included in an external quality control system), and low cost screening promotion strategies at the community level. An information system covering the women

entering the programme was implemented and included case registries in every level of the health system.

During the initial years, the financial support for the programme was minimal. Additional funding from the government was provided after 6 years to upgrade equipment at the secondary level, and to support community-based, low cost promotion activities.

The strategy adopted in the Metropolitan Area, which was later applied to the rest of the country, included involvement of health authorities and a series of training workshops for health professionals concerned with the programme at each level of care. The workshops were conducted with the help of a physician who was an expert in education and health communication. In each workshop, the participants received motivational input and updated information on the programme. They were trained how to assess the current situation, how to compare it to the desired one, and how to develop specific strategies to bridge the existing gaps. After a few months, in the next workshop, the progress and constraints encountered were evaluated and subsequent tasks were planned accordingly.

The first strategy implemented was motivation of female health care providers within the health care system to be screened.

The second strategy was monitoring the follow-up of women with abnormal Pap smears in the different levels of care. Different process indicators were evaluated, such as compliance and timeliness of diagnosis and treatment, quality control of cytology, information system, and coordination among different programme components. Serious weaknesses were encountered, and for several months all efforts focused on reorganization before invitations to women to be screened were issued widely.

The third and fourth strategies offered screening to women in the target group. Promotion to invite women attending primary health care centres for screening was followed by community strategies to reach older women. These activities were carefully synchronized with health centres to ensure adequate provision of care.

Coverage of the target group by Pap smear rose from 40% in 1990 to 66% in 1997. The age-adjusted mortality rate for cancer of the cervix decreased from 13.3 per 100 000 women in 1970 to 7.7 per 100 000 women in 1999.

motherhood, HIV/AIDS, tuberculosis, cancer, reproductive health, and so on. If specialists with years of training cannot integrate their work, it will be difficult for a primary health care provider; often under-trained and usually under-supported, to do so.

Countries with unstable economies and politics often face competing priorities for social and health actions, thus affecting their ability to plan and implement national programmes. In addition, their often-insufficient financial, technical, and human resources deleteriously affect national interventions. In many countries, there is limited organizational and management capacity for cancer control within Ministries of Health. Furthermore, evidence on cost-effective preventive, early detection and treatment methods may not be accessible to national health authorities. Without basic tools for assessment, such as surveillance systems and cancer registries, many countries will not have the capacity for accurate monitoring and evaluation of interventions.

Many of these constraints to planning and implementing a national cancer control programme can be counteracted by good management that ensures the selection of adequate priorities. Effective management will also ensure that the right methodologies are applied in the right place at the right time with the right people and within the framework of a national cancer control programme. Good management will focus on: goal orientation; the needs of customers; effective leadership and partnership; active involvement of all stakeholders; the promotion of political will; rational planning, innovative and creative approaches; effective and efficient stepwise implementation; continuous training; problem solving and behavioural change; monitoring progress and outcomes; and a systemic, comprehensive approach. International cooperation and global initiatives, also play a major role in supporting initiatives at country level.

GLOBAL ACTION TO SUPPORT NATIONAL EFFORTS

WHO and other United Nations technical and development agencies can assist countries with national cancer control programme infrastructure development, strategy development, management issues, manpower training and research capacity building. A number of programmes and activities have been developed for broader health purposes, and these provide a context in which cancer control activities can, and should, be developed. Resources can be used most efficiently if activities are well coordinated to avoid duplication of effort. This is especially important in developing countries, where funds are particularly limited. Global actions, focusing on the reduction of risk, the improvement of treatment, and the training of health professionals are described below and can provide support for the development of effective

national cancer control programmes.

Alliances for healthy lifestyles, healthy environments and cancer control

WHO is promoting an integrated approach for the prevention and control of noncommunicable diseases. In Europe, the WHO CINDI programme (Countrywide Integrated Noncommunicable Diseases Intervention programme) advocates coordinated, comprehensive action to target common risk factors and unhealthy lifestyles, such as tobacco and alcohol use, physical inactivity, and obesity. In Latin America, the CARMEN programme (Conjunte de Acciones para Reduccion Multifactorial de Enfermedades No Transmisibles) promotes the adaptation of the same strategies and aims. Through a WHO Global Forum on Noncommunicable Diseases, WHO and its partners are working to establish similar networks for integrated noncommunicable diseases prevention in the other WHO regions: Africa, Eastern Mediterranean, South East Asia and the Western Pacific.

In the area of food safety WHO provides assessments of carcinogenic chemicals present in food through joint expert committees with the Food and Agriculture Organization of the United Nations (FAO). The results are used by the Codex Alimentarius Commission to establish international food standards. In the field of environmental health risks, a comprehensive risk assessment of carcinogenic chemicals is undertaken by the International Programme on Chemical Safety (IPCS) and the joint programme of WHO, the International Labour Organization (ILO) and the United Nations Environment Programme (UNEP).

In order to promote a healthy diet on the basis of the most up-to-date scientific evidence, joint WHO/FAO expert consultations elaborate guidelines on diet, nutrition and the prevention of chronic diseases including cancer.

Intersun, WHO's global UV project, in cooperation with the United Nations Environment Programme, the World Meteorological Organization, the International Agency on Cancer Research and the International Commission on Non-Ionizing Radiation, aims to reduce the global burden of disease, including skin cancer, resulting from exposure to ultraviolet radiation. The programme encourages and evaluates research to fill gaps in scientific knowledge, assesses and quantifies health risks, and facilitates public and occupational programmes to reduce UV radiation-related health risks.

Framework convention for tobacco control

In 1999, based on a resolution adopted unanimously by the World Health Assembly, WHO took a leadership role in strengthening global tobacco con-

trol. It did this by initiating a process of multilateral negotiations between WHO Member States on a set of rules and regulations aimed towards governing the global rise and spread of tobacco. The Framework Convention on Tobacco Control (FCTC) will be an international legal instrument to improve transnational tobacco control. Once the Convention is adopted and enters into force, State Parties will take appropriate measures to fulfil the objectives and guiding principles of the convention through provisions which could address advertising and promotion, product regulation, elimination of illicit trade, and protection from exposure to environmental tobacco smoke, among others. Since the pre-negotiation phase concluded in 2000, four sessions of the Intergovernmental Negotiating Body have been held and significant progress has been achieved. The target date for adoption of the FCTC by the World Health Assembly is May 2003. The process is on schedule and Member States have reiterated the need to meet the deadline for the adoption of the Convention.

Immunization

For many years, infant vaccination has been recognized as a cost-effective approach to preventing life-threatening infections. Extension of these vaccination programmes to include the major oncogenic types of infectious agents associated with cancer could have a large impact on the global cancer burden, particularly if made available to populations where other prevention strategies are unavailable or not affordable. Liver cancer, the fifth most common cancer worldwide in males, has been shown to be associated with chronic infection with hepatitis B virus. The efficacy of hepatitis B vaccines against chronic infection exceeds 85% in regions where child and adult infection predominate. Hepatitis B vaccine is included in routine infant vaccination programmes in 135 of the 241 countries that report to WHO. International support and extension of WHO efforts to promote infant vaccination would not only be beneficial regarding the life-threatening infections to which they are directly targeted, but would also reduce the incidence of one of the most common cancers.

International efforts are being undertaken to support the development of new vaccines to help control other infections and their associated cancers. Of particular interest are the human papillomavirus (HPV) vaccines to control cervical cancer and *Helicobacter pylori* vaccines to reduce stomach cancer, both among the most common cancers worldwide.

Drug availability

WHO has identified essential drugs for cancer treatment and palliative

care. The 17 essential drugs for treatment are those that alone, or in conjunction with other therapeutic measures, will result in cure for some patients or a prolongation of survival for others. A WHO survey of 167 countries indicated that anti-neoplastic drugs were only available in 60% and affordable in less than half of those countries. In order to make these essential drugs available and affordable, national authorities need to develop national plans of action. WHO and other organizations can assist by identifying mechanisms to improve access, reduce costs and, where feasible, promote the local production of the essential agents.

Most of the strong painkillers are opioid analgesics that are subject to international control as narcotic drugs. Previous studies indicate that overly stringent regulations can reduce the availability of controlled drugs for medical use, such as oral morphine, a key to providing relief from cancer pain. To improve access to opioid analgesics, WHO is promoting balanced regulatory approaches so that control measures do not unduly restrict access to opioids. WHO has developed guidelines to assist national authorities to conduct self-diagnoses of their regulatory systems and identify any deficiencies that might exist. WHO also promotes a balanced opioids control policy through national and international workshops. In this regard, WHO is working with the International Narcotics Control Board, which has endorsed the above mentioned guidelines.

Strengthening cancer treatment facilities in least developed countries

Only about 50% of the population of Africa has access to radiation oncology services (Levin, 1999). The African Regional Agreement (AFRA) supported by the International Atomic Energy Agency (IAEA) is promoting the improvement of clinical radiotherapy in Africa by identifying areas with greatest need, facilitating equipment provision and sponsoring training. External assistance in this and other regions is needed to speed the pace of provision of these basic services. Of particular importance is the donation of diagnostic imaging and teletherapy equipment. Success in this area, however, depends on the informed commitment of the recipient countries and a commitment to long-term support, both for equipment and infrastructure, on the part of the donor.

Human resources for cancer control

Most developing countries lack an adequate number of professionals to staff their cancer control services according to the results of the WHO assessment of the national capacity for non communicable disease prevention and

control (WHO, 2001b). Often, both an increase in the number of specialists and improved training are needed. Areas of professional specialization in cancer control include not only diagnosis and treatment, but also disease prevention, early detection, palliative care, and research. For many years WHO, IARC and other international organizations have been actively involved in the development of human resources for cancer control. The number of individuals trained in these initiatives is, however, still woefully short of what is needed. Additional organizations need to join this effort in order to ensure that basic training needs are met, while avoiding excessive specialization and sophistication.

Even in industrialized countries, human resources for cancer control need to be improved. Although tobacco is the most preventable cause of ill-health in the world today, few schools of public health offer specialization or even courses in tobacco control.

Promotion of reliable information

The quality of medical care depends on the quality and availability of information. A number of sources, including prestigious institutions and the major medical journals, provide reliable, peer-reviewed information. A great deal of information is available regarding basic, epidemiological and clinical research, but far less is available in the applied public health field, especially from a developing country perspective. International efforts are being undertaken to promote quality standards for reliable information on the World Wide Web. There are also initiatives aimed at providing greater access to reliable information, especially for professionals in developing countries, by making peer-reviewed journals available free or at reduced cost. WHO has brokered an agreement among the world's leading publishers of medical journals to provide online access to their journals free or almost free to developing countries. In order to promote the technical preconditions needed to access information online, WHO is spearheading the United Nation Health InterNetwork project.

MONITORING AND EVALUATING THE PROGRAMME



WHAT IS PROGRAMME EVALUATION?

Programme evaluation is “the systematic assessment of the operation and/or outcomes of a programme or policy compared to a set of explicit or implicit standards, as a means of contributing to the improvement of the programme or policy” (Weiss, 1998). Continuous evaluation of processes and outcomes of a national cancer control programme is an essential tool for assessing its organizational progress and enhancing its effectiveness. Evaluation is also necessary for fulfilling its operational principles as described in Chapter 10.

HOW TO CARRY OUT EFFECTIVE EVALUATION OF A NATIONAL CANCER CONTROL PROGRAMME?

Any programme evaluation requires careful design and planning that should start early in the process of programming. There is abundant literature on evaluation regarding design, combination of methods and techniques of analysis. A comprehensive framework for programme evaluation (Centers for Disease Control, 1999) is adapted here to guide the process of evaluating a national cancer control programme. The following key questions should be formulated when planning an evaluation and later on when reviewing its implementation:

- Who will evaluate?
- What will be evaluated?
- How should the evaluation be designed and implemented?
- By what means can the credibility of the evidence gathered be enhanced?
- What standards (type or level of performance) must be reached for the national cancer control programme to be considered successful?
- What conclusions regarding the national cancer control programme performance are justified by comparing available evidence to the standards?
- How will lessons learnt from the results of the evaluation be used to improve the national cancer control programme performance?

Who will evaluate?

The national cancer control programme coordinator and the board should take the lead in planning and implementing the evaluation and should ensure that the relevant stakeholders are involved throughout the whole process. These include those involved in the programmes's operations, those served by the national cancer control programme, and primary users of the evaluation. If stakeholders are not involved, the evaluation might overlook key elements of the programme and thus its findings might be ignored or resisted. Involving stakeholders should consider their perspectives, skills and concerns. Different expertise or complementary competencies can enrich the process and make the evaluation more effective. For example, social and behavioural scientists can be instrumental in helping to analyse how the programme operates in the organizational and community contexts. Creative thinking can help ensure the results of the evaluation influence the decision-making process in the right direction.

What will be evaluated?

The programme coordinator, the board and relevant stakeholders should decide what will be systematically evaluated in the national cancer control programme. It should include the national cancer control programme and its context. A thorough description of the programme will ensure that there is an understanding of programme goals, strategies, resources, stages of development, sociopolitical context and the programme's capacity to produce change. It is useful to construct a logic model that synthesizes the main programme elements and gives a picture of how the programme is supposed to work. Such a model improves and focuses programme direction. Examples of such models were given in Figures 10.3 and 11.2 in the previous chapters.

How should the evaluation be designed and implemented?

The evaluation design depends on the purposes of the evaluation, the users, and the resources available to carry out the evaluation. The more an evaluation is focused on the concerns of stakeholders the more efficient it will be in ensuring that the findings of the evaluation will be used as intended. Consideration of the questions to be answered and the units of analysis are essential in selecting methods and gathering evidence.

Evaluation activities are part of a continuum of actions that support the decision-making process in all stages of programming: planning, implementation and outcome evaluation. Evaluation is thus useful to all programme

activities and provides a wide scope for evidence-based decisions within a national cancer control programme (Brazil, 1999).

Programme monitoring

Monitoring is intended to assess whether the implementation of a national cancer control programme is performing as was devised, and whether or not the programme is reaching the target population and meeting the needs of customers.

Suitable criteria for overall evaluation of a national cancer control programme in its early stages are:

- the endorsement by the Ministry of Health and key NGOs of the concept of a national cancer control programme, with a commitment to provide the necessary political and financial support;
- the existence of a defined budget to enable the programme to support initiatives;
- the existence of a clear plan and measures that can be used to judge progress in implementation of the plan;
- the appointment of a programme coordinator and board and the allocation of sufficient resources to support the work;
- a written programme of work that assigns clear roles and responsibilities, and covers the following issues:
 - prevention;
 - early diagnosis and treatment;
 - palliative care;
 - monitoring and evaluation systems.

Once a national cancer control programme is more advanced in its implementation or is well established, programme performance can be assessed by different methods, depending on how comprehensive an evaluation is required (organization, prevention, early detection, treatment and palliative care) and on which quality dimensions are included for controlling the processes. Performance measurements are useful tools for continual quality improvement initiatives. They are used to establish the baseline level of performance and to re-measure the performance level after quality improvement has been done.

The classical approach to the assessment of quality is through structure, process and outcome measures (Donabedian 1980). *Structure measures* evaluate resources available in the programme; *Process measures* evaluate the workings of, and interactions between, the various components of a programme; *Outcome measures* evaluate the effects of a programme on the population that are expected to have short, medium or long-term conse-

quences, depending on the nature of the processes involved. Examples of structure, process and outcome measures are summarized in Table 12.1.

These measures can be evaluated in the system model of inputs, processes, outputs and outcomes—elements that were analysed in Chapter 11. It is important that evaluation of a national cancer control programme encompasses leadership, stakeholder’s involvement, and partnerships; as well as how policies, plans, products and services are managed, updated and delivered. The above methodology facilitates scrutiny of all those issues. Monitoring and setting appropriate information systems, such as that discussed for cervical screening (Miller 1992), is very important in ensuring that implementation will produce efficient and timely outputs. Tracking systems will be required for prevention and for service delivery in relation to screening, treatment and palliative care. Continuous monitoring and analysis of operational and financial data – which can be facilitated by the use of appropriate computer programs – not only highlight the areas of the national cancer control programme that should be modified, but

Table 12.1
Evaluation
of a national
cancer control
programme

Evaluation category	Programme	Primary prevention	Early detection and screening	Treatment	Palliative care
Structure measures	Published plan endorsed by ministry of health	Agency or consortium identified responsible for health promotion	Policy agreed upon for education for early detection	Guidelines on treatment agreed	Pain relief policy adopted
	Programme coordinator and board appointed	Sampling surveys of risk factor prevalence performed	Organized screening programmes planned for priority cancers	Essential drug list for chemotherapy adopted	Education of health professionals Legislation passed to ensure availability of oral morphine
Process measures	Collaboration obtained for programmes with relevant government ministries and NGOs	Anti-tobacco education in >80% of schools	>80% of people aware of warning signs for cancer	>70% of patients treated according to guidelines	Trends in morphine and other opioids consumption
		>70% of infants HBV vaccinated	>80% of people in target groups examined once	>20% of cancer patients receive curative treatment	>50% of general hospitals adopt WHO guidelines
Short-term outcomes (within 5 years)	Substantially increased knowledge of cancer obtained in all relevant sectors	Significant reduction in exposure to risk factors in the general population	>30% of cancers detected on examination or by tests	>50% of cancer patients survive one year	>40% of cancer patients in pain are relieved from pain
Medium-term outcomes (within 10 years)	Effect of programme shown on cancer incidence	Reduction in incidence of other diseases (e.g. cardiovascular, respiratory)	>30% reduction in targeted advanced cancers	>30% of cancer patients survive 5 years	Quality of life is improved in >60% of patients
Long-term outcomes (15–20 years)	>15% of reduction in peak cancer mortality	Reduction in incidence of relevant cancers (e.g. lung) has begun	>15% reduction in mortality for targeted cancers	>10% reduction in cancer mortality attributable to treatment	Quality of life is improved in >80% of patients

also provide the information feedback required by government ministries and other funding agencies. For instance, data on the costs per patient of an intervention at a particular stage of a particular cancer can be linked to future projections of patient loads, or to data on the number and type of inpatient and outpatient visits and treatments. This would provide a wealth of information for programme budgeting and for estimation of the equipment, personnel, and accommodation needed by treatment facilities.

In the context of continuous quality improvement (CQI), which focuses mainly on the needs of customers, team work and continual improvement of performance, quality is described and measured according to a number of dimensions including accessibility, appropriateness, efficiency and effectiveness (Canadian Council On Health Services Accreditation, 1996). This type of evaluation impacts everyone, from senior management to operational staff. Examples of quality dimension and their possible performance indicators for prevention, early detection, treatment and palliation are illustrated in Table 12.2.

Outcome evaluation

Once a national cancer control programme becomes established and has a regular budget, it is important to assess its overall effectiveness. Outcome indicators comprise the impacts on the people receiving the services of the programme. For a national cancer control programme, these indicators are concerned with the quality of life of cancer patients, disease recurrence rates, disease-free survival rates, overall survival rates among treated patients, incidence, and mortality rates. Reliable baseline data on the common types of cancer, their stage at diagnosis, and the outcome of disease are essential if valid programme outcome measures are to be set. It is therefore important that data collection systems are developed as early in the programme as possible. Where they exist, population-based cancer registries will yield valuable material for this purpose and can provide a continuous input of epidemiological data.

The best way of assessing programme outcomes is by means of a randomized experimental design, which compares the results of the programme to a control group. However, most outcome evaluations cannot use this model, and have to rely on quasi-experimental designs to ensure that the outcomes can be attributed to the programme. Assessment of programme efficiency, on the other hand, relies on analysis of cost-benefit, cost-effectiveness, and cost-utility. An efficient programme is one that achieves the best possible results using the available resources. A programme that seems likely to have a significant impact on a country's cancer problems is of little value if the resources required to sustain it exceed those that can be made available.

Table 12.2: Examples of quality dimensions that can be used to evaluate the performance of a national cancer control programme

Quality Dimensions in the performance of a national cancer control programme	Example of indicators for smoking cessation programme	Example of indicators for cervical cancer screening (including treatment)	Example of indicators for treatment of curable cancers	Example of indicators for palliative care
Acceptability <i>How well the health system is meeting expectations of the providers and the public</i>	<ul style="list-style-type: none"> Level of satisfaction of providers and patients with tobacco cessation counselling in the workplace 	<ul style="list-style-type: none"> Level of satisfaction of providers and patients with the screening programme 	<ul style="list-style-type: none"> Level of satisfaction of providers and patients with the treatment 	<ul style="list-style-type: none"> Level of satisfaction of providers and patients with the palliative care programme
Accessibility <i>Whether or not the public and patients can obtain the preventive and control services they need at the right place and time</i>	<ul style="list-style-type: none"> Percentage of providers and patients who are smokers that have access to tobacco cessation counselling 	<ul style="list-style-type: none"> Percentage of at risk women with a Pap smear taken in the last 5 years Timeliness of diagnosis and treatment for patients referred for having an abnormal cytology 	<ul style="list-style-type: none"> Percentage of patients with curable cancers that receive adequate treatment Timeliness of diagnosis and treatment of cases referred for having warning signs 	<ul style="list-style-type: none"> Level of morphine and other opioids consumption Percentage of cancer patients with advanced cancer who have access to palliative care services
Appropriateness <i>Whether care is relevant to the needs and is based on established standards</i>	<ul style="list-style-type: none"> Percentage of patients with a non-communicable disease that are assessed about their tobacco smoking status 	<ul style="list-style-type: none"> Quality of Pap smears taken by primary health care workers and gynaecologists Percentage of patients with pre-cancerous cervical lesions that are treated with non-invasive procedures 	<ul style="list-style-type: none"> Percentage of patients that are treated according to guidelines 	<ul style="list-style-type: none"> Percentage of patients who receive palliative care according to guidelines
Competence <i>Whether the knowledge and skills of providers are appropriate to the services that they are providing</i>	<ul style="list-style-type: none"> Percentage of primary health care workers with the necessary skills to give counselling on smoking cessation 	<ul style="list-style-type: none"> Continuing training of primary health care workers and laboratory staff regarding Pap smears collection, processing and analysis 	<ul style="list-style-type: none"> Quality assurance activities for diagnosis and treatment of the most common cancers 	<ul style="list-style-type: none"> Percentage of primary healthcare workers with the skills to provide basic palliative care
Continuity <i>How services fit together—coordination, integration, and ease of navigation</i>	<ul style="list-style-type: none"> Plans implemented for avoiding relapse in ex-tobacco smokers 	<ul style="list-style-type: none"> Plans for follow-up of target population to repeat screening every 5 years Follow-up mechanisms for patients treated for non-invasive cancer 	<ul style="list-style-type: none"> Mechanisms for long-term follow-up of treated patients 	<ul style="list-style-type: none"> Percentage of patients that have access to a trained health care worker in palliative care in their community
Effectiveness <i>How well services work and how they affect health status of the population at risk of cancer or affected by cancer</i>	<ul style="list-style-type: none"> Tobacco cessation rates among smokers with low to severe addiction 	<ul style="list-style-type: none"> Changes in stage distribution of cervical cancer Incidence of invasive cancer Mortality from cervical cancer 	<ul style="list-style-type: none"> Overall and stage-specific survival rates 	<ul style="list-style-type: none"> Improved control of symptoms in patients with advanced cancer Improved quality of life
Efficiency <i>Achieving best results at lowest cost</i>	<ul style="list-style-type: none"> Costs of counselling 	<ul style="list-style-type: none"> Percentage of Pap smears taken from at risk women 	<ul style="list-style-type: none"> Comparative data on cost of treatments Reduction in hospital stays 	<ul style="list-style-type: none"> Reduction of invasive procedures Reduction in hospital stays
Safety <i>Minimizing potential risks of a health environment or service</i>	<ul style="list-style-type: none"> Regulations to avoid passive smoking in healthcare settings 	<ul style="list-style-type: none"> Regulations to protect laboratory staff 	<ul style="list-style-type: none"> Radiation protection for patients and providers in radiotherapy services 	<ul style="list-style-type: none"> Measures to avoid abuse of opioids

By what means can the credibility of the evidence gathered be enhanced?

The following are aspects of evidence gathering that affect perception of credibility of evaluation results:

- Stakeholders are more likely to accept the conclusions and recommendations of the evaluation when they have been actively involved in defining and gathering data that they find credible. Health care managers and providers will increase their sense of responsibility in the services they provide and will be able to assess their own accomplishments.
- The number of measurements used should be limited. If not, the whole data collection process gets too burdensome. However, multiple indicators are usually needed for tracking the implementation and effectiveness of a programme. Using the logic model to define a spectrum of indicators can be very useful. For cervical cancer screening, for example, the model presented in Figure 10.3 can be used to define indicators such as the compliance to screening (of the target age group), compliance to diagnosis and treatment (of women with abnormal Pap smears), as well as the time it takes women to go through each step of the process.
- Performance indicators should be well defined and analysed within the context of the programme. For example, a reduction in the mortality of cervical cancer may be also influenced by improved standards of living among at risk women or by improved access to treatment of early invasive cancers, and not only to the screening programme.
- Multiple sources of information, which include different perspectives, enhance the credibility of the evaluation. The criteria used for selecting sources should be stated clearly so users are aware of the limitations and the interpretation of the information can be done correctly.
- Quality, quantity, and logistics for gathering the evidence will also affect the credibility of the evaluation. Quality refers to the appropriateness and integrity of the information used. Well-defined indicators enable easier collection of quality data. Quantity of the information should be established in advance. It affects the potential confidence level and partly determines whether the evaluation will have sufficient power to detect effects. The procedures for gathering the evidence must be easy and the timeframe short enough so that the data collection can be repeated frequently to allow for trend changes over time without being too much of a burden on the system.

What standards (type or level of performance) must be reached for the national cancer control programme to be considered successful?

The standards are values set by stakeholders, and these reflect the principles

of a national cancer control programme as well as the expected results in both the processes and the outcomes. Regarding the principles of a national cancer control programme described in Chapter 10, standards should be developed to assess how the implementation of the national cancer control programme is corresponding with those principles. In the case of process and outcome measures, they should be feasible and adjusted to the context of the programme as well as to its stage of development.

Regarding outcome measures, the reduction in the incidence of tobacco-related cancers will take over 20 years, and a screening programme may take at least 10 years to show reduction in mortality rates. Thus, in the first years of development of a national cancer control programme the emphasis should be on process measures and short-term outcome measures. It should be taken into consideration that within political circles, there may be unrealistic expectations concerning the time needed to achieve the programme's long-term objectives. Stakeholders may have different ideas about programme goals and objectives. It should be pointed out that, despite general recognition in the 1960s that cigarette smoking was a cause of lung cancer, it was the end of the 1980s before the resulting control measures began to have an appreciable impact on lung cancer mortality in North America and the United Kingdom. Similarly, even if a population shows adequate compliance with screening, it may be more than 10 years before mortality from a particular form of cancer begins to decline. Hence the short-term emphasis (that is, within the first 5 years) should be on process measures that confirm initially that the relevant component of the programme is in place. These should be followed with measures that will indicate whether there has been sufficient uptake of the activity for there to be an impact on outcome measures in the medium term (within 10 years) and the long term (15–20 years).

What conclusions regarding a national cancer control programme performance are justified by comparing available evidence to the standards?

Conclusions of the evaluation can be justified by judging the evidence gathered against values or standards set by stakeholders. This allows the identification of gaps between present programme performance and desired performance and determination of which kinds of actions must be implemented to bridge those gaps. Usually the gaps are due to lack of resources; but even more importantly, they are often due to improper management, inefficient use of limited resources, improper translation of the evidence into practice, lack of motivation, weaknesses in skills and knowledge of healthcare providers; and limited participation of consumers in the decision-making process.

How will lessons learnt from the results of the evaluation be used to improving national cancer control programme performance?

Effort is needed to ensure that the evaluation results are disseminated and appropriately used in the decision-making process.

The following are critical elements for ensuring appropriate use of an evaluation.

- evaluation recommendations must be ready when needed; thus timeliness is essential;
- reporting techniques must suit the users and be adapted to different audiences;
- a detailed plan of action for improving performance must be elaborated with the participation of primary users of the evaluation and other relevant stakeholders;
- follow up is needed to ensure consistency between findings and subsequent actions.

Chapter 11 describes a model for changing established practices of health care providers in the workplace that can be useful to apply if substantial reorganization is needed to improve the programme's performance.

Specific considerations regarding outcome evaluation of the different programme components of prevention, early detection, treatment and palliative care are discussed below.

Evaluation of prevention

The major determinants of the risk of cancer are clearly related to individual lifestyle (for example, tobacco usage and diet) and environment factors (for example, solar radiation). At the population level, therefore, cancer patterns depend on the prevalence of such exposures, and the risk each one poses to the individual. The WHO stepwise approach to surveillance (STEPS), described in Chapter 9, provides a methodology for measuring the key risk factors for noncommunicable diseases, including cancer. The risk factors for cancer monitored in the STEPS surveillance mechanism include:

- tobacco use;
- alcohol;
- nutrition;
- physical inactivity; and
- obesity.

The first step of this methodology involves the use of standardized questionnaires. The second step comprises physical measurements. The third step

includes biochemical measurements. At each step the core information can be expanded, to the extent resources permit.

In addition to the above mentioned risk factors, several infections are important causes of cancer. These include:

- hepatitis B and C viruses, important causes of liver cancer;
- human papillomavirus (HPV), a major cause of cancer of the cervix;
- HIV infection, a major cause of sarcoma and non-Hodgkin lymphoma.

Prevalence surveys are available for hepatitis B and C, HIV and HPV infections.

Lastly, the exposure of inadequately protected workers to carcinogenic chemicals should be evaluated. Special government departments dealing with occupational hazards usually monitor this.

Cancer control by prevention has a long timescale, often 15-20 years. Usually, evaluation is based upon time trends in incidence of cancer, to see whether the desired effect is being achieved. For cancers with a poor, or unchanging survival, mortality rates may be used for the same purpose. Examples are the monitoring of the incidence of tobacco-related cancer in response to tobacco control programmes or, in the longer term, of liver cancer following hepatitis vaccination. Occasionally, when implementation has been confined to one area, comparisons of the changes in the intervention area with the situation in ‘control’ areas may be possible.

Evaluation of early detection

Outcome evaluation of early detection programmes depends upon measuring whether their ultimate objective has been achieved. Thus, screening for cervical cancer aims to reduce incidence of invasive cancer. This is also the aim of oral cancer detection programmes. Other screening programmes, which aim to detect invasive cancers early (for example, breast), do not reduce incidence. Incidence may increase initially, as such programmes bring forward the diagnosis date of pre-existing but undiagnosed cancers. The objective in this case is to decrease mortality.

Time trend studies may examine trends in incidence in relation to screening activity. For instance, the population-based registries in the Nordic countries provided data on time trends in incidence of cervical cancer in relation to screening (Hakama, 1982). The fall in incidence was closely related to the coverage offered by the organized mass screening programmes. The introduction of screening was followed by an apparent increase in incidence as prevalent sub-clinical cases were detected, before a fall was observed. Other similar studies have compared the change in incidence of cervical cancer with the registration (detection) rate of carcinoma *in situ* in different geographical areas.

When the records of the screening programme can be linked with those of a population-based cancer registry, it is possible to compare the risk of cancer in those screened and those not screened. It is also possible to estimate the incidence of cancer at different intervals (within 1 year, 1–2 years, and so on.) after a negative screening test, as a fraction of the “expected” incidence without screening. This rate of “interval cancers” is a very useful indicator of the sensitivity of the programme (Day, Williams, Khaw, 1989)

Case-control studies have also been widely used to evaluate early detection programmes. The principle is to study the past history of screening in cases of cancer, and compare this with an appropriate control group (Prorok, 1984). This approach has been used, for example, in auditing cervical cancer screening programmes (Sasieni, Cuzick, Lynch, 1996). Cohort studies and case-control studies of screening must, however be interpreted with care, as they cannot exclude selection bias, and they measure the effect of choosing to be screened. For cancer of the cervix, people who chose to be screened are often at lower risk of the disease, even without the test (selection bias).

Although earlier detection, as shown by ‘intermediate endpoints’, such as the size or stage of cancers detected, as recorded by the registry, is essential if a screening programme is to be successful in reducing mortality, it is no guarantee that it will do so. Intermediate endpoints may appear to improve, even though mortality does not.

Thus, only when a screening programme is known to be effective should intermediate endpoints be used to monitor it. Suitable monitoring statistics from cancer registries are:

- the incidence of interval cancers;
- the size and stage distribution of cancers detected by screening (compared to the expected distribution);
- the incidence rate of advanced cancers, compared with the period pre-screening (or an unscreened comparison group).

These important indicators, provided by population-based registries, are now widely used to monitor the effectiveness of breast cancer screening programmes.

Changes in the stage at which cancer of the cervix, breast, and mouth is diagnosed should be evaluated at cancer treatment centres. Evaluation of population coverage in screening programmes should concentrate particularly on coverage of target age groups, rural areas, and low socioeconomic groups. The proportion of people with abnormalities revealed in screening tests who subsequently obtain appropriate diagnosis and treatment should be determined, as should the proportion of all cases of particular cancers that were diagnosed by screening. The technical quality of screening tests and of the facilities that undertake them should also be carefully monitored.

With a view to future expansion of the screening programme by coverage of a wider age range or increase in the frequency of screening, the monitoring of staff development and training processes is essential.

Evaluation of treatment

Many cancer registries aim to follow up their cases, in order to produce survival statistics. Follow up is active (contacting the patient or their relatives), or by matching death certificates against cancer notifications and assuming that unmatched cases are still alive.

Survival following a diagnosis of cancer is used to evaluate the impact of the extent to which new or improved cancer treatments are incorporated in clinical practice. Such measures at the population level are quite different from the survival rates reported by studies of selected case series or clinical trials. For instance, the advances made in clinical trial settings in the treatment of childhood cancers, Hodgkin disease and testicular tumours, have already been widely implemented in the community in many industrialized countries, and the population-based survival from these cancers has shown a significant increase over the last three decades.

Comparisons of cancer survival rates are increasingly used to compare the effectiveness of cancer treatment in different populations (including within the same country, for example by region, or by social class). This requires careful standardization of the registry methods (definition of incident cases, date of diagnosis, method of follow up). Comparisons also mean that other parameters, such as stage distribution, are known, since these greatly influence the success of treatment.

Cancer registries are increasingly being used to look at patterns of care received by cancer patients, and whether these meet pre-set criteria, with a view to improving the services provided. Thus, for example, it may be possible to see what proportion of patients appear to wait a long time between diagnosis and treatment, or receive treatment in hospitals not adapted to their needs.

Evaluation of palliative care

Evaluating the outcome of palliative care will usually require setting up special mechanisms to assess quality of life. Special studies may be conducted among patients, their families and healthcare providers considering the various dimensions of quality of life: pain relief and other symptom control, functionality, psychosocial and spiritual well-being, family and medical interaction, financial issues, and so on. There are several quality-of-life instruments available in the literature but very few have been validated

within palliative care populations. Further development of these tools is needed, especially for palliative care populations from different cultural and socioeconomic settings.

*Monitoring and
Evaluating the
Programme*

Focusing on Priorities

ALL COUNTRIES should endeavour to implement national cancer control programmes, with a view to reducing cancer incidence and mortality, improving quality of life, and reducing cancer risk factors.

What can actually be implemented and achieved depends on a variety of factors, including the resources available. Chapter 13 outlines the priority actions that countries should undertake, according to their level of resources.

PRIORITIES FOR VARIOUS RESOURCE LEVELS

13

All countries should aim to implement a national cancer control programme within a comprehensive, systemic framework. The recommendations for minimum essential actions by national cancer control programmes, in countries with different levels of resources, are summarized in Table 13.1. This is the best way to effectively reduce cancer incidence and mortality, improve survival and quality of life, and reduce cancer risk factors by making the most efficient use of resources. Special attention should be given to the training of health care workers at the different levels of care. The level of complexity of the training will depend on the role each worker plays. Health care workers should be trained in basic skills that allow them to integrate palliative care, prevention and early detection activities into their daily work.

Moreover, all countries should establish core surveillance and information systems that allow them to monitor and evaluate epidemiological and programmatic data, and to use this data as a basis for appropriate decision-making.

Countries with low to medium levels of resources should consider addressing key priorities in a demonstration area. Each priority can be approached in a stepwise manner allowing for a systematic progression and expansion, both in terms of programme content and in geographical scope. It is also important to ensure the use of appropriate technology that is cost-effective and sustainable in situations where resources are constrained.

For countries with low levels of resources, where the majority of patients are currently diagnosed in advanced stages, low-cost and effective palliative care may constitute a powerful entry point, progressively leading to a more comprehensive approach that includes early diagnosis and primary prevention.

Countries with high levels of resources can afford full implementation of evidence-based strategies within the framework of a national cancer control programme. A review of current resource allocation, followed by an adjustment of strategies to allow more efficient and effective use of resources, releases funds that can then be directed to improving weak areas in the cancer field or provide support for less affluent countries.

Table 13.1 Priority actions for national cancer control programmes, according to level of resources

Component	All countries	Scenario A: Low level of resources	Scenario B: Medium level of resources	Scenario C: High level of resources
National cancer control programme	<ul style="list-style-type: none"> Develop a national cancer control programme to ensure effective, efficient and equitable use of existing resources Establish a core surveillance mechanism to monitor and evaluate outcomes as well as processes Develop education and continuous training for health care workers 	<ul style="list-style-type: none"> Consider the implementation of one or two key priorities in a demonstration area with a stepwise approach Consider palliative care as an entry point to a more comprehensive approach Use appropriate technologies that are effective and sustainable in this type of setting 	<ul style="list-style-type: none"> When initiating or formulating a cancer control programme, consider implementation of a comprehensive approach in a demonstration area using a stepwise methodology Use appropriate technologies that are effective and sustainable in this type of setting 	<ul style="list-style-type: none"> Full, nationwide implementation of evidence-based strategies guaranteeing effectiveness, efficiency, and accessibility Implement a comprehensive surveillance system, tracking all programme components and results Provide support for less affluent countries
Prevention	<ul style="list-style-type: none"> Implement integrated health promotion and prevention strategies for noncommunicable diseases that include legislative/regulatory and environmental measures as well as education for the general public, targeted communities and individuals Control tobacco use, and address alcohol use, unhealthy diet, physical activity and sexual and reproductive factors Promote policy to minimize occupational-related cancers and known environmental carcinogens Promote avoidance of unnecessary exposure to sunlight in high risk populations 	<ul style="list-style-type: none"> Focus on areas where there are great needs and potential for success Ensure that priority prevention strategies are targeted to those groups that are influential and can spearhead the process (e.g., policy-makers, and teachers) In areas endemic for liver cancer, integrate HBV with other vaccination programmes 	<ul style="list-style-type: none"> Develop integrated clinical preventive services for counselling on risk factors in primary health care settings, schools and workplaces Develop model community programmes for an integrated approach to prevention of noncommunicable diseases 	<ul style="list-style-type: none"> Strengthen comprehensive evidence-based health promotion and prevention programmes and ensure nationwide implementation in collaboration with other sectors Establish routine monitoring of ultraviolet radiation levels if the risk of skin cancer is high
Early diagnosis	<ul style="list-style-type: none"> Promote early diagnosis through awareness of early signs and symptoms of detectable and curable tumours that have high prevalence in the community, such as breast and cervical cancer Ensure proper diagnostic and treatment services are available for the detected cases Provide education and continuous training to target populations and health care providers 	<ul style="list-style-type: none"> Use low cost and effective community approaches to promote, in a first phase, early diagnosis of one or two priority detectable tumours in a pilot area with relatively good access to diagnosis and treatment 	<ul style="list-style-type: none"> Use low cost and effective community approaches to promote early diagnosis of all priority detectable tumours 	<ul style="list-style-type: none"> Use comprehensive nationwide promotion strategies for early diagnosis of all highly prevalent detectable tumours
Screening	<ul style="list-style-type: none"> Implement screening for cancers of the breast and cervix where incidence justifies such action and the necessary resources are available 	<ul style="list-style-type: none"> If there is already infrastructure for cervical cytology screening, provide high coverage of effective and efficient cytology screening for women aged 35 to 40 years once in their lifetime or, if more resources are available, every 10 years for women aged 30 to 60 years 	<ul style="list-style-type: none"> Provide national coverage cytology screening for cervical cancer at 5 year intervals to women aged 30 to 60 years 	<ul style="list-style-type: none"> Effective and efficient national screening for cervical cancer (cytology) of women over 30 years old and breast cancer screening (mammography) of women over 50 years of age
Curative therapy	<ul style="list-style-type: none"> Ensure accessibility of effective diagnostic and treatment services Promote national minimum essential standards for disease staging and treatment Establish management guidelines for treatment services, essential drugs list, and continuous training Avoid performing curative therapy when cancer is incurable and patients should be offered palliative care instead 	<ul style="list-style-type: none"> Organize diagnosis and treatment services giving priority to early detectable tumours 	<ul style="list-style-type: none"> Organize diagnosis and treatment services, giving priority to early detectable tumours or to those with high potential of curability 	<ul style="list-style-type: none"> Reinforce the network of comprehensive cancer treatment centres that are active for clinical training and research and give special support to the ones acting as national and international reference centres
Pain relief and palliative care	<ul style="list-style-type: none"> Implement comprehensive palliative care that provides pain relief, other symptom control, and psychosocial and spiritual support Promote national minimum standards for management of pain and palliative care Ensure availability and accessibility of opioids, especially oral morphine Provide education and training for carers and public 	<ul style="list-style-type: none"> Ensure that minimum standards for pain relief and palliative care are progressively adopted by all levels of care in targeted areas and that there is high coverage of patients through services provided mainly by home-based care 	<ul style="list-style-type: none"> Ensure that minimum standards for pain relief and palliative care are progressively adopted by all levels of care and nationwide there is rising coverage of patients through services provided by primary health care clinics and home-based care 	<ul style="list-style-type: none"> Ensure that national pain relief and palliative care guidelines are adopted by all levels of care and nationwide there is high coverage of patients through a variety of options, including home-based care

PRIORITY PREVENTION ACTIONS FOR VARIOUS RESOURCE LEVELS

*Priorities for
Various Resource
Levels*

All countries should give priority to implementing integrated health promotion and prevention strategies for noncommunicable diseases that are consistent with the present and projected epidemiological situation. As a minimum, these interventions should include tobacco prevention and control, reduction of alcohol use, promotion of a healthy diet and physical activity, and education about sexual and reproductive factors.

Furthermore, all countries should establish policies aimed at minimizing occupationally-related cancers, and legislate to control known environmental carcinogenic agents. Strategies should include legislation and regulation, environmental measures, and education at community, school and individual levels.

Avoidance of unnecessary exposure to sunlight should be recommended, particularly in high-risk populations.

Low-resource countries should focus on areas where there are not only great needs, but also the potential for success. They should ensure that priority prevention strategies are targeted to those groups that are influential and can spearhead the whole process, such as policy-makers, health workers, and teachers. In areas with a high prevalence of cancers induced by biological agents, special measures should be developed to combat the infections concerned, for example, schistosomiasis and hepatitis B. In areas endemic for liver cancer, HBV vaccination should be integrated with other vaccination programmes.

Countries with medium levels of resources should consider developing clinical services for brief, effective counselling on tobacco cessation and other cancer risk factors and strengthening education for healthy lifestyles. These activities should take place in primary health care settings, schools and workplaces. Medium-resource countries should also consider developing model community programmes for an integrated approach to the prevention of noncommunicable diseases.

Countries with high levels of resources should implement comprehensive, evidence-based health promotion and prevention programmes, and ensure nationwide implementation of these programmes in collaboration with other sectors. Routine monitoring of ultraviolet radiation levels should be established if the risk of skin cancer is high.

RECOMMENDED EARLY DETECTION POLICIES FOR VARIOUS RESOURCE LEVELS

Early Diagnosis (already symptomatic populations)

As part of a national cancer control programme, all countries should promote awareness of the warning signs for those cancers that display signs and symptoms early in the evolution of the disease. The public should be educated about the changes to watch for, and what to do if they notice these signs. Health workers should be trained to recognize early cancer cases, and refer them rapidly to places where the disease can be diagnosed and treated. Cancer sites amenable to early diagnosis include: oral cavity, larynx, colorectum, skin, breast, cervix, urinary bladder, and prostate.

In low-resource settings, low cost and effective community approaches should be used in the first phase to promote early diagnosis of one or two priority detectable tumours. This approach should be adopted initially in a pilot area with relatively good access to diagnosis and treatment.

Countries with medium levels of resources should use low-cost and effective community approaches to promote early diagnosis of all priority detectable tumours.

Countries with high levels of resources should use comprehensive nationwide promotion strategies for early diagnosis of all highly prevalent, detectable tumours.

Screening (asymptomatic populations)

Where level of incidence of the cancer justify it, and the necessary resources can be made available, screening for cancers of the breast and cervix is recommended. This is feasible mainly in medium- and high-resource level countries. Screening for other cancer sites must be regarded as experimental and cannot be recommended at present as public health policy. All countries implementing screening policies should consider the programmatic factors that determine whether or not the programmes achieve effectiveness and efficiency.

In low-resource countries, if there is already infrastructure for cervical cytology screening, the recommendation is to provide high coverage of effective and efficient cytology screening for women 35–40 years old once in their lifetime or, if more resources are available, every 10 years for women 30–60 years old.

Low-income countries that do not have screening facilities should be discouraged from initiating cytology screening. They should wait until the

cost-effectiveness of a low cost approach (VIA) is demonstrated.

Countries with medium levels of resources should aim to provide national coverage by cytology screening for cervical cancer at 5-year intervals to women 30–60 years old.

Countries with high levels of resources should reinforce and improve the performance of national screening for cervical cancer and breast cancer if those cancers are common.

PRIORITY ACTIONS FOR CANCER TREATMENT ACCORDING TO RESOURCE LEVELS

All countries should ensure the accessibility and effectiveness of diagnosis and treatment services by establishing evidence-based clinical and management guidelines, an essential drugs list, good referral, follow-up and evaluation systems, and continuous training of the different health professionals involved. Furthermore, guidelines should emphasize the avoidance of offering curative therapy when cancer is incurable, and patients should be offered palliative care instead.

Countries with low or medium levels of resources should organize diagnosis and treatment services to give priority to common, early detectable tumours, or to those with high potential for cure.

Countries with a high level of resources should reinforce the development of comprehensive cancer treatment and palliative care centres that are especially active for clinical training and research, and that can act as reference centres within the country as well as at the international level.

PRIORITY ACTIONS FOR PALLIATIVE CARE ACCORDING TO RESOURCE LEVELS

All countries should implement comprehensive palliative care programmes with the purpose of improving the quality of life of the majority of patients with cancer, or other life-threatening conditions, and their families. These programmes should provide pain relief, other symptom control, and psychosocial and spiritual support. All countries should promote awareness among the public and health professionals that cancer pain can be avoided, and should ensure the availability of oral morphine in all healthcare settings.

In low-resource settings it is important to ensure that minimum standards for pain relief and palliative care are progressively adopted at all levels of care in targeted areas, and that there is high coverage of patients through services provided mainly by home-based care. Home-based care is generally the best

*Priorities for
Various Resource
Levels*

way of achieving good quality care and coverage in countries with strong family support and poor health infrastructure.

Countries with medium levels of resources should ensure that minimum standards for cancer pain relief and palliative care are progressively adopted at all levels of care, and that, nationwide, there is increasing coverage of patients through services provided by health care workers and home-based care.

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Each year, cancer affects more than 10 million people worldwide, and kills 6 million. Without effective control of the disease, these figures will increase significantly, with the most marked rise occurring in the developing countries. Although much remains to be learned about the etiology of cancer, enough is now known about the causes of cancer and means of control for suitable interventions to have a significant impact. At least one-third of cases are preventable by such means as controlling tobacco and alcohol use, moderating diet, and immunizing against viral hepatitis B. Early detection, and therefore prompt treatment, of a further one-third of cases is possible where resources allow. Effective techniques for pain relief are sufficiently well established to permit comprehensive palliative care for the remaining, more advanced, cases. The establishment of a national cancer control programme, tailored to the socio-economic and cultural context, should allow countries to effectively and efficiently translate the present knowledge into action.

Implementation of the necessary measures requires the formulation of evidence-based policies, the mobilization and appropriate allocation of resources, the active participation of all stakeholders and – above all – government commitment to legislation, education, and national and international collaboration in support of cancer control.

This monograph provides guidance for policy-makers and others on the establishment of national cancer control programmes. It outlines the scientific basis of feasible approaches to the control of cancer, and considers possibilities for prevention, early detection, cure, and care. It discusses the appropriateness of particular technologies, and describes how to manage national programmes tailored to different resource settings.

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