Managing a National Cancer Control Programme

There is little evidence so far of a balanced use of resources for population-wide control of cancer by governmental and nongovernmental bodies acting in partnership. Yet the evidence exists that would allow us to prevent at least one-third of the 10 million cancer cases that occur annually throughout the world. Current knowledge would also allow the early detection and effective treatment of a further one-third of those cases. Pain relief and palliative care can also improve the quality of life of patients and their families. With competent management that includes careful planning, implementation, monitoring and evaluation, the establishment of national cancer control programmes offers the most rational means of achieving a substantial degree of cancer control, even where resources are severely limited. It is for this reason that the establishment of a national cancer control programme is recommended wherever the burden of the disease is significant, there is a rising trend of cancer risk factors and there is a need to make the most efficient use of limited resources.

Planning a national cancer control programme means assessing strategic options and choosing those that are feasible, effective, and cost-effective, bearing in mind the specific conditions of the country concerned (Chapter 10).

Implementing a programme requires resources and processes, all of which have to be well managed. This issue is discussed in Chapter 11, along with the range of global initiatives that national cancer control programmes can draw on for experience and support. Moreover, in order to ensure that activities contribute to achieving the priorities that have been established, the programme will also need to be monitored and evaluated (Chapter 12).
WHAT IS A NATIONAL CANCER CONTROL PROGRAMME?

A national cancer control programme is a public health programme designed to reduce the incidence and mortality of cancer and improve the quality of life of cancer patients in a particular country or state, through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, treatment, and palliation, making the best use of available resources.

The following list summarizes the principles essential to a national cancer control programme based on quality management (ISO, 1997):

• **goal orientation** that continuously guides the processes towards improving the health and quality of life of the people covered by the programme;

• **focused on the needs of the people**, which implies focusing on the target population while addressing the needs of all stakeholders and ensuring their active involvement;

• **systematic decision-making process**, based on evidence, social values, and efficient use of resources, that benefits the majority of the target population;

• **systemic and comprehensive approach**, meaning that the programme is a comprehensive system with interrelated key components at the different levels of care, sharing the same goal, integrated with other programmes, to the health system and tailored to the social context (Figure 10.1), rather than a vertical programme operating in isolation;

• **leadership** that creates clarity and unity of purpose, and that encourages team building, broad participation, ownership of the process, continuous learning, and mutual recognition of efforts made;

• **partnership**, enhancing effectiveness through mutually beneficial relationships, built on trust and complementary capacities, with partners from different disciplines and sectors,
continuous improvement, innovation and creativity to maximize performance, and to address social and cultural diversity, and the new needs and challenges presented by a changing environment.

WHY ESTABLISH A NATIONAL CANCER CONTROL PROGRAMME?

Previous chapters of this monograph have provided the scientific background to current knowledge of the causes of cancer, and the components of cancer control: prevention, early detection, treatment and palliative care, cancer control research, and cancer surveillance. With careful planning and appropriate priorities, the establishment of a national cancer control programme offers the most rational means of achieving a substantial degree of cancer control, even where resources are severely limited. For this reason, the establishment of a national cancer control programme is recommended wherever the burden of the disease is significant, there is a rising trend of cancer risk factors, and there is a need to make the most efficient use of limited resources.

Without careful planning, there is a risk that the resources available for cancer control will be used inefficiently, and that the benefits to the population that should flow from the use of such resources will not be realized. In the absence of any national coordinating mechanism, it is possible that limited resources will largely be consumed for the treatment of cancer by prestigious hospitals. Such institutions often serve only selected sub-populations and may do little to reduce the national cancer burden. In contrast, an effective cancer control programme comprises an integrated set of activities covering all aspects of cancer prevention and control, and it operates with an appropriate allocation of available resources among the various activities and equitable coverage of the population.

WHICH COUNTRIES HAVE NATIONAL CANCER CONTROL PROGRAMMES?

A WHO survey of 167 countries in 2001 assessed national capacity for prevention and control of cancer, as well as of other noncommunicable diseases (WHO, 2001b). The results of this survey (see Table 10.1) show that nearly half of the 167 countries responding indicated that they had a cancer control policy or plan. About two-thirds of the countries indicated the availability of national guidelines for prevention, and almost half specified that cancer management guidelines had been produced. While objective
data are difficult to obtain (two-thirds of the countries did not provide supporting documents confirming the existence of these plans and guidelines), this survey demonstrates an awareness in many countries of the need for the planning of programmes to prevent and control cancer.

According to the information collected for a WHO meeting in 2000 on national cancer control programmes, only a few countries have developed nationwide, comprehensive cancer control programmes that include prevention, early detection, treatment and palliative care. Various countries have developed important initiatives at the state or provincial level; others have focused on one or two priority areas, achieving national coverage in some cases.

The major elements of national cancer control programmes in the Americas and in the Western Pacific are described, respectively, in Tables 10.2 and 10.3, by way of example. In the Americas, comprehensive cancer control strategies that address the full spectrum of prevention, early detection, diagnosis, treatment and palliative care for one or more cancer sites exist in five countries: Brazil, Canada, Chile, Colombia and the United States. Most countries are involved in specific cancer efforts, which may not be comprehensive in nature, but that are designed to reduce risks and address some aspects of cancer control. In Latin America, palliative care services for people with advanced cancers are just beginning to be included as part of cancer care.

In the Western Pacific, cervical cancer screening, national tobacco control programmes and routine hepatitis B vaccination are among the activities

<table>
<thead>
<tr>
<th>Region</th>
<th>Number of countries responding (%)</th>
<th>Countries with cancer control policy or plan</th>
<th>Availability of national guidelines</th>
<th>Primary health care (anti-neoplastic drugs)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Prevention</td>
<td>Management</td>
</tr>
<tr>
<td>Africa</td>
<td>39 (85%)</td>
<td>15%</td>
<td>29%</td>
<td>43%</td>
</tr>
<tr>
<td>The Americas</td>
<td>33 (95%)</td>
<td>50%</td>
<td>83%</td>
<td>48%</td>
</tr>
<tr>
<td>Eastern Mediterranean</td>
<td>17 (77%)</td>
<td>56%</td>
<td>60%</td>
<td>33%</td>
</tr>
<tr>
<td>Europe</td>
<td>41 (80%)</td>
<td>62%</td>
<td>84%</td>
<td>59%</td>
</tr>
<tr>
<td>South-East Asia</td>
<td>10 (100%)</td>
<td>78%</td>
<td>43%</td>
<td>43%</td>
</tr>
<tr>
<td>Western Pacific</td>
<td>27 (100%)</td>
<td>64%</td>
<td>65%</td>
<td>47%</td>
</tr>
<tr>
<td>Overall</td>
<td>167 (87%)</td>
<td>48%</td>
<td>67%</td>
<td>48%</td>
</tr>
</tbody>
</table>

implemented. Legislation to make morphine available has been passed in fewer than half of the countries, and the monitoring of progress in cancer control is routinely done in only four countries in this region.

The experience of the cancer control programme in Kerala, India, is described in Box 10.1.

Common hindrances to a national cancer control programme and benefits often seen after development of such a programme are summarized in Table 10.4.

Table 10.3. Cancer Control in the Western Pacific* (Countries with a multi-sectoral policy for cancer control activities)

<table>
<thead>
<tr>
<th>Country</th>
<th>Major elements of the strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mongolia</td>
<td>Cervical cancer screening, tobacco control programme, cancer treatment guidelines, morphine available for cancer pain relief</td>
</tr>
<tr>
<td>Cambodia</td>
<td>Tobacco control programme</td>
</tr>
<tr>
<td>China</td>
<td>Cervical and breast cancer screening, cancer treatment guidelines</td>
</tr>
<tr>
<td>Niue</td>
<td>Cervical and breast cancer screening, tobacco control programme</td>
</tr>
<tr>
<td>Philippines</td>
<td>Cervical and breast cancer screening, tobacco control programme, cancer treatment guidelines, morphine available for cancer pain relief</td>
</tr>
<tr>
<td>Samoa</td>
<td>Cervical cancer screening, tobacco control programme</td>
</tr>
<tr>
<td>Malaysia</td>
<td>Cervical and breast cancer screening, tobacco control programme, cancer treatment guidelines</td>
</tr>
<tr>
<td>Fiji</td>
<td>Cervical cancer screening, cancer treatment guidelines and morphine available for cancer pain relief</td>
</tr>
<tr>
<td>Singapore</td>
<td>Tobacco control programme; cancer treatment guidelines</td>
</tr>
<tr>
<td>Korea, Rep.</td>
<td>Cervical and breast cancer screening, tobacco control programme, cancer treatment guidelines, morphine available for cancer pain relief</td>
</tr>
<tr>
<td>New Zealand</td>
<td>Cervical and breast cancer screening, tobacco control programme, cancer treatment guidelines, morphine available for cancer pain relief</td>
</tr>
<tr>
<td>Australia</td>
<td>Cervical and breast cancer screening, tobacco control programme, cancer treatment guidelines, morphine available for cancer pain relief</td>
</tr>
</tbody>
</table>

* Countries are listed in ascending order of their per capita health expenditure
The national cancer control programme of India was formulated in 1984, focusing on: the primary prevention of tobacco-related cancers, as 50% of all cancer in India was due to tobacco use; early detection of cancers of accessible sites, as the three major forms of cancer were accessible; augmentation of treatment facilities; and establishment of equitable pain control and a palliative care network throughout the country, as more than 80% of cancer patients reported in very late stages.

In 1988, Kerala was the first state in India to formulate a cancer control programme (called a 10 year action plan), with the same goals as the national plan. Kerala is a state in southwest India with a population of 31 million. The well-integrated health service is provided by the government and the private sector. A hospital cancer registry, started in 1982, was a major source of information for planning the programme.

Tobacco habit prevention
Two state-wide programmes targeted teenagers, through the schools. In one programme, 126,000 families were declared “tobacco free”. A second programme, using a similar approach, was implemented in over 6,000 schools.

Training regarding anti-tobacco messages was given to 5,000 doctors and over 9,000 other health workers. More than 130,000 volunteers were trained to support the anti-tobacco messages throughout the villages. Executive orders have banned smoking in educational institutions, government offices, public transport and other public places. A reduction in tobacco consumption of 1% per year has been seen in the Trivandrum Oral Cancer Screening project area.

Early detection programme
Because high technology methods were beyond reach, activities focused on education to improve awareness, followed by diagnosis and treatment. Screening camps were organized periodically, with the support of the government and voluntary organizations. Self-examination of the oral cavity, breast self-examination and physician breast-examination were taught; cytology-based screening for cervical cancer augmented this initiative. At the village level, 12,600 volunteers were trained to create awareness of early signs of cancer, and motivate people to undergo tests and therapy, if needed. The success of Kerala’s programmes can be greatly attributed to the Early Cancer Detection Centres (ECDC), which serve as focal points for coordination of the early detection activities and the provision of clinical examination, cytology and histopathology. Initially established as government programmes, two are now run by the Regional Cancer Centre and five by nongovernmental organizations. The public sees the role of ECDCs to be the screening of normal (asymptomatic) people, whereas hospitals are recognized as places for sickness management. The ECDC at Ernakulam has screened more than 80,000 people since its inception in 1984.

Pain relief and palliative care
A pain control and palliative care division was started by the Regional Cancer Centre in 1986. In 1988 it was the first institution in India to manufacture and supply morphine liquid. Morphine tablets were first made available in 1991 and are now locally manufactured. A cancer pain relief network has been established, consisting of two nodes and 16 peripheral centres. A unit to make home visits to terminally ill patients and to train the relatives of these patients in principles of cancer pain control was initiated in 2000, and will be expanded.

Evaluation
This programme was found to achieve a reduction in tobacco consumption, down-staging of advanced tumours, augmentation of comprehensive therapy programmes, and a network of palliative care centres.
called upon to provide technical assistance and advice in support of the promotion of national cancer control programmes at the country or state level.

With appropriate mobilization of all the stakeholders, it is possible to develop cancer control policies that are acceptable to the people for whom they are intended, affordable, integrated with other national health programmes, and linked effectively with sectors other than health that are relevant to cancer control.

People involved in formulating and implementing the overall strategy for the national cancer control programme should be health professionals with experience in disease control and large-scale health programmes, cancer experts, other health service workers, patients’ groups, and representatives from other sectors involved. Governmental and nongovernmental leaders in the cancer field need to work together closely to develop a successful programme. The national cancer control programme should involve the general public, whose knowledge and awareness of the problem can, and should, become a major force in combating cancer. As a significant and growing aspect of a nation’s health problems, cancer requires the attention of the highest levels of government as well as community involvement.

Political commitment is essential. It should be the responsibility of health leaders to persuade political leaders, health practitioners, and the public as to the magnitude of the national cancer problem and inform them what can be done to overcome it. It is particularly important to emphasize the multifaceted nature of the problem, the essential role of prevention to reduce the future cancer burden, and the current role of early detection, as well as treatment and palliative care.

**Table 10.4**

<table>
<thead>
<tr>
<th>Hindrances</th>
<th>Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low priority given to cancer by Ministry of Health</td>
<td>Promotes equal coverage of services (social justice)</td>
</tr>
<tr>
<td>Lack of public support</td>
<td>Raises political awareness of the issues</td>
</tr>
<tr>
<td>Shortage of resources</td>
<td>Better use of available funds, avoiding misuse</td>
</tr>
<tr>
<td>Excess reliance on treatment</td>
<td>Puts priorities into perspective, especially the role of prevention</td>
</tr>
<tr>
<td>Uncritical use of Western approach</td>
<td>Local technology can be used</td>
</tr>
<tr>
<td>Shortage of trained staff</td>
<td>Education of health professionals first</td>
</tr>
<tr>
<td>Cultural and religious factors</td>
<td>Programme development leading to process ownership</td>
</tr>
<tr>
<td>Lack of understanding by health professionals</td>
<td>Identifies scientific basis of activities</td>
</tr>
<tr>
<td>Limited access to oral morphine</td>
<td>Ethical obligation to relieve suffering at reasonable cost</td>
</tr>
<tr>
<td>Viewed as vertical programming</td>
<td></td>
</tr>
</tbody>
</table>
HOW TO PLAN A NATIONAL CANCER CONTROL PROGRAMME?

Ideally, the process of establishing a national cancer control programme should be organized, democratic, empowering, and pragmatic, with the boundaries of the programme defined by the social, medical, and political environment of the country concerned. In a national cancer control programme, there is a need to address managerial, technical and financial needs, with evidence-based policy development and involvement of all stakeholders. The aim should be balanced cancer control actions extending to the whole country in an equitable way. Although it is clear that objectives and priorities need to be tailored to the specific country context, the planning processes to be undertaken in all countries – whether a programme is to be introduced for the first time or an existing programme is to be revised to make it more effective – are sufficiently similar to allow for the use of models. Since the first edition of this WHO publication, various countries have developed frameworks for comprehensive cancer control programmes that add new value to the original model elaborated by WHO. An example of such a model is shown in Figure 10.2.

The following model is based on those experiences and comprises phases for planning and implementing a national cancer control programme. As in the model illustrated in Figure 10.2, the phases require the active participation of stakeholders, follow a circular path, and experience a continuous exchange of information for adequate decision making, thus allowing for sustained improvement and adjustment to new needs and knowledge.

The planning process is described below. Chapter 11 proceeds to deal with implementation, and Chapter 12 looks at monitoring and evaluation.

Assessing the magnitude of the cancer problem

As an initial step, a national cancer control programme requires an analysis of the cancer burden and risk factors in the target area, as well as a capacity assessment (analysis of existing facilities, programmes and services in the broader social context).

Four categories of information are needed for the initial analysis:

- demographic data;
- cancer and risk factor data;
- data on other diseases;
- capacity assessment.

Demographic data

Generally speaking, demographic data, with appropriate projections, are
fairly readily available through national censuses. Because cancer rates vary by age, sex and, in some countries, race, data on these population characteristics are essential.

**Cancer data and cancer risk factor data**

Epidemiological data on the occurrence of cancer, and knowledge of causative factors and of how to avoid those factors, provide a basis for determining where the emphasis of cancer control efforts should be placed. Details on the processes required for surveillance of cancer are provided in Chapter 9. A cancer surveillance programme, built around a population-based cancer registry, has a major role in providing the data to justify the establishment of a national cancer control programme, as well as in monitoring the progress of implementation of the cancer control programme.

For a comprehensive assessment of the cancer burden, it is desirable to have incidence, survival and mortality data for all forms of cancer combined, and for each of the most common forms of the disease. Other indicators of “burden”, such as prevalence, (PYLL), (DALY), may also be calculated. Such information is essential for setting priorities for the national cancer control programme, including the planning of cancer-related health care services. If a population-based cancer registry does not exist, incidence will have to be estimated.

When incidence or mortality data are available for several years, an evaluation of time trends in cancer, and how these vary according to age group (or year of birth), sex, or other characteristics of the population, is possible. These data may be used to project the likely evolution of the cancer pattern in future years. The most important variables for forecasting the future burden are overall population trends, changes in the age structure of the population, and the prevalence of important risk factors, especially tobacco use 20–30 years earlier. In assessing the future cancer burden, potential changes in the relative importance of various cancers, the impact of cancer control measures, and forecasting of trends in incidence and mortality are valuable. Projections usually involve the assumption that past trends in rates of incidence or mortality will be maintained, and will apply to projected changes in the population. This assumption is often in error. Experience shows that, for many cancers, past trends will not be maintained because of changes in environmental risk factors, and the development of new techniques for prevention, early detection, and treatment. Projections nevertheless provide a useful benchmark against which the impact of all future changes, including the interventions of the national cancer control programme, can be evaluated.

Estimates of the numbers of cancer cases and deaths due to cancer may be higher than the numbers known to the health services. In countries where
awareness of cancer is low and access to health care is limited, only a small proportion of actual cases are known to the health services. With greater awareness of cancer, a higher proportion of people with the disease will present to the health services for care. Thus, demands for care will rise more rapidly than the increase in need resulting from increased incidence.

**Data on other diseases**

It is essential to establish the importance of cancer relative to that of other diseases. Good vital-statistics systems will provide the necessary data on mortality but, in their absence, proxy data, such as hospital admissions by cause, may have to be used.

**Figure 10.2**

Framework for comprehensive cancer prevention and control

The relative burden of cancer in the future is a function not only of the absolute amount of cancer, but also of trends in other causes of death. In most countries, a decrease in deaths from infectious diseases or cardiovascular disease is followed by an increase in the number of cancer deaths. The net result is that deaths from cancer will constitute an increasing proportion of all deaths.

Capacity assessment

According to the United Nations Development Programme, “capacity can be defined as the ability of individuals and organizations or organizational units to perform functions effectively, efficiently and sustainably in a given socio-political context”. This definition implies that capacity is not a passive state but part of a continuing process and that individuals, both providers and beneficiaries, are central to capacity development. The overall context in which organizations function is also a key element. (United Nations Development Programme, 1998).

Capacity assessment in the area of cancer involves collecting and analysing data on:

- the overall context, implying an examination of the broad economic, social, cultural and political conditions that are directly or indirectly related to the development of a national cancer control programme;
- the policy, and institutional environment of the existing health system\(^1\) that directly or indirectly relate to cancer:
  - overall health system performance (WHO, 2001c), health policies, laws, regulations, financing, organization and management of services according to levels of care, definitions of responsibilities of the public and private sectors;
  - existing programmes and services for cancer prevention, early detection, treatment and palliation, including their organization, facilities, personnel, drugs and technologies, budgeting, and information and evaluation systems;
  - quality performance indicators, such as effectiveness, efficiency, appropriateness, accessibility, and sustainability, which measure the interaction between the system and beneficiaries of cancer prevention and control activities;
  - existing education and continuous training programmes in the technical and management field;

\(^{1}\) According to The World Health Report 2000, a health system is defined as: all organizations, institutions, and resources devoted to the production of health actions. Health actions are defined as any efforts whether in personal health care, public health services, or through intersectoral initiatives, whose primary purpose is to improve health.
linkages of cancer prevention and control activities with other programmes, both in the health sector and other sectors, and partnerships between governmental and nongovernmental organizations.

The capacity assessment can be done quite simply, or at a greater level of complexity, depending on practical constraints such as budget, time, and availability of information. Whatever the degree of complexity, it is important to maintain a systemic approach that focuses on how the problem being studied interacts with the other constituents of the system. Instead of isolating small components, the systemic approach expands its view to take into account a large number of interactions. For example, a cytology cervical screening programme cannot be viewed as an isolated project. It should be considered as a subsystem of a cancer early detection programme, with various interacting components (primary health care clinics, pathology, colposcopy, and so on). At the same time, interaction with other programmes or initiatives, such as reproductive health, breast cancer screening, and clinical preventive services at the primary level of health care is essential (see Figure 10.3).

After the above-mentioned data have been collected and reviewed, they must be analysed to identify needs and gaps in services, as well as gaps in data. This analysis should provide a solid basis for setting objectives for the national cancer control programme.
Setting measurable cancer control objectives

A clear statement of aims, goals, and objectives is essential to any disease control strategy.

The overall aims of a national cancer control programme are to reduce the incidence and mortality of cancer, as well as to improve overall survival and the quality of life of cancer patients and their families.

The goals of a national cancer control programme may be summarized as follows:
- to prevent future cancers;
- to diagnose cancers early;
- to provide curative therapy;
- to ensure freedom from suffering;
- to reach all members of the population.

Objectives are more specific than general aims, and are formulated to achieve the goals. They cannot be fully specified in the absence of a detailed situation analysis or performance evaluation. Decisions on objectives for any particular country must “ensure that the limited resources are directed to areas of greatest need and support efforts with the highest probability of success” (Mertens, 1999). Cancer control objectives should be compatible with general health objectives and can be formulated along the lines of quality dimensions such as effectiveness, efficiency, and accessibility. Examples of possible objectives are listed below:

*Reducing the risk of cancer:*
- to reduce tobacco smoking rates among health care professionals and patients attending primary care clinics;
- to avoid passive smoking in the workplace, public transportation and public places;
- to increase physical activity and reduce overweight rates among young adults.

*Detecting cancer earlier:*
- to improve early diagnosis rates of cervical, breast, oral, colorectal, and skin cancers through raising awareness of early signs and symptoms;
- to develop an effective and efficient cytology screening programme for cervical cancer.

*Provide curative therapy:*
- to improve access to good quality, standardized treatments for all patients having early detectable cancers or cancers having high potential of curability;
• to ensure the use of non-invasive procedures for all patients with pre-cancerous cervical lesions.

**End of life care:**
• to improve control of symptoms and prolong physical autonomy in all patients with advanced cancer;
• to provide psychosocial assistance and facilitate spiritual support to the majority of incurable patients and their families.

**Reduce inequalities:**
• to ensure that prioritized cancer preventive and control services are provided to all sectors of the population.

---

**Evaluating possible strategies for cancer control**

The activities, standards and guidelines of a cancer strategy need to be based on sound and current scientific evidence. This requires expertise to critically review scientific information and evaluate the costs of various interventions. In particular, those designing the strategy need to understand how to analyse the evidence or undertake systematic reviews. If this expertise is not available within a country, outside experts should be called upon to assess the evidence. This assessment should highlight points for discussion and identify points of contention. For example, if there are conflicting research results, the original papers should be presented and the differences between them, including methodological differences, should be discussed.

Cost-effectiveness studies should be considered in the critical review. These usually consider only direct medical costs, an approach that works well in a public system with set pricing. It is, however, also important to assess cost-effectiveness based on societal perspectives, and to include non-medical as well as direct medical costs when evaluating strategies.

Further, the effectiveness of interventions needs to be defined as a function of tangible outcomes, based on epidemiological or clinical knowledge. The assumptions inherent in the stated outcomes need to be considered, especially as to whether or not they are applicable in a developing country.

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**Choosing priorities for initial cancer control activities**

Once possible strategies are identified there is a need to choose those that are feasible to implement and that are acceptable and relevant to the society. In developed and developing countries alike, resources for cancer control (funds, trained people, equipment, and facilities) are insufficient to allow all possible activities to be undertaken. It is, therefore, essential that resources
Planning a National Cancer Control Programme

are used as effectively and efficiently as possible. Health authorities should, therefore, establish appropriate priorities.

When a range of possible activities has been identified, the measures of effectiveness and cost should be defined and the following steps carried out for each activity:

– identifying the immediate target;
– estimating the impact in terms of reduction in incidence or mortality;
– estimating the resources needed;
– estimating the cost of the activity.

A number of models have been developed by WHO and others to facilitate this process (Eddy, 1986; WHO, 1986a). It must be recognized, however, that the validity of a model is entirely dependent on the validity of the assumptions made and of the data entered into the model. The models incorporate epidemiological data, knowledge gained in research, and expert judgements for applying the principles of cost-effectiveness analysis in setting priorities. The use of such quantitative methods allows estimation of the impact of various cancer control activities in a population over a given period of time and thus permits priorities to be set.

The application of such methods in Chile in 1986, for example, indicated that, by 1995, the average cost of screening for cervical cancer beginning at age 35 years would be nearly a third less than the cost of screening starting at age 20 (Eddy, 1986). Either of these options, however, would be far more cost-effective than screening for stomach cancer, also a common cancer in Chile.

ASSESSMENT OF STRATEGIES FOR EIGHT COMMON CANCERS

Table 10.5 assesses the strategies for eight common cancers worldwide. In order to make the best use of resources, it is important to identify both effective strategies and strategies that are largely ineffective. Although it is difficult to place a cost on the various strategies for cancer control because of variations between countries, including different levels of existing infrastructure and differences in local strategy implementation, an approximate relative indicator of expense is also included in Table 10.5. In general, prevention and palliative care require less national resources commitment than early detection (screening) and treatment. However, the benefits of a cancer prevention programme will only be realized 20–30 years after effective implementation of the programme.

Since cancer control depends on the application of existing knowledge, no activity should be introduced unless its effectiveness is strongly supported by
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Data from research programmes or from cancer control programmes elsewhere. Such programmes usually provide data that enable the costs of the activity to be estimated, although the information may have to be modified, for example, to reflect different salary scales, if it is to be relevant to another country. Once cost estimates have been made, it is possible to compare the effectiveness and cost of all activities, and make a rational decision about priorities for both current and proposed new activities. It is useful to classify priority areas in two groups: activities that can be introduced (or improved) without the need for additional resources, and activities that will require extra resources (staff, technology, drugs, and so on).

### FORMULATING THE NATIONAL CANCER CONTROL PROGRAMME POLICY

Ideally, the national cancer control programme policy should be formulated once the planning process has been completed. It will provide a solid platform for implementing and maintaining the national cancer control programme.

A policy may be defined as an explicit commitment by government and its partners that provides objectives for a balanced cancer control programme, specifies the relative priority of each objective and indicates the resources and measures required to obtain the objectives. It should cover the following elements:

<table>
<thead>
<tr>
<th>Site of cancer</th>
<th>Prevention</th>
<th>Early detection</th>
<th>Curative therapy</th>
<th>Palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mouth/pharynx</td>
<td>++</td>
<td>$</td>
<td>–</td>
<td>$</td>
</tr>
<tr>
<td>Oesophagus</td>
<td>+</td>
<td>$</td>
<td>–</td>
<td>++</td>
</tr>
<tr>
<td>Stomach</td>
<td>++</td>
<td>$</td>
<td>+</td>
<td>$</td>
</tr>
<tr>
<td>Colon/rectum</td>
<td>++</td>
<td>$</td>
<td>+</td>
<td>++</td>
</tr>
<tr>
<td>Liver</td>
<td>++</td>
<td>$</td>
<td>–</td>
<td>++</td>
</tr>
<tr>
<td>Lung</td>
<td>++</td>
<td>$</td>
<td>–</td>
<td>++</td>
</tr>
<tr>
<td>Breast</td>
<td>+</td>
<td>$</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Cervix</td>
<td>+</td>
<td>$</td>
<td>++</td>
<td>++</td>
</tr>
</tbody>
</table>

++ effective; + partly effective; – largely ineffective
$ less expensive; $$ more expensive


Table 10.5 Assessment of strategies for eight common cancers
Planning a National Cancer Control Programme

- the challenges posed by cancer, both now and in the future: current challenges are identified by the cancer data described above, together with information (if available) on the stage at diagnosis of the important cancers in the country;

**Box 10.2 Cancer Policy as part of the National Health Plan**

Fundamental, long-term social interests—including employment, productivity, and the economy, as well as health—can be served by making cancer control an integral part of a nation's health programme.

The WHO Seventh, Eighth, and Ninth General Programmes of Work for the periods 1984–1989, 1990–1995, and 1996–2001, respectively, all endorsed by the World Health Assembly, urge Member States to strengthen, or to consider initiating, the development of cancer control measures as an integral part of national health plans. Control of cancer can be achieved most efficiently in the context of a comprehensive national plan. A cancer control policy will enrich the total health effort, and cancer control efforts will themselves be enhanced by becoming an integral part of a total national health plan. Equity, within both oncology and other health services should be promoted.

**Intersectoral aspects of a cancer control policy**

Because the control of cancer involves so many social vectors—economic, educational, and political—a broad, society-based approach is required; expertise in the disease alone will not suffice. The intersectoral approach requires analysis of all the social elements that can affect the control of cancer. Those concerned with cancer control must work with authorities in agriculture, commerce, communications, education, industry, and law in order to achieve success.

The spirit and philosophy of full participation must be part of the planning process. It is critical that the ministry of health understand, accept and adopt a stakeholder-driven approach. The importance of involving a range of multiple stakeholders in the process must not be overlooked, since successful implementation depends on recommendations for the strategy originating from the groups that will eventually be expected to execute the strategy. Particularly important is ensuring the involvement of community representatives, notably cancer survivors who can offer insights into programme design based on their needs and experiences with the health care system. This is exemplified by the need to control tobacco use as a means of preventing cancer. Social and economic pressures are the key factors in the initiation and maintenance of tobacco addiction. Controlling tobacco use, therefore, requires a multisectoral and comprehensive approach. This may entail dealing with international agencies, governments, nongovernmental organizations, the media, the health professions, childhood education, as well as with civil society, to curb the tobacco epidemic. Another example is the need to increase the availability of oral morphine for palliative care, which requires the cooperation of drug regulators and legislators, in addition to the expertise of cancer specialists.

Intersectoral collaboration is also essential if programmes are to be cost-effective. The public cannot cope with conflicting educational messages coming from different sectors, such as one set of dietary recommendations for the avoidance of cancer and another for the avoidance of cardiovascular disease. Similar coordination is required for counselling on sexual lifestyles, designed to prevent sexually transmitted diseases, cervical cancer, and AIDS.
• the broad aims of the cancer control policy, which are:
  – prevention of cancer;
  – early detection, coupled with effective and efficient treatment of potentially curable disease;
  – relief of pain and palliative care to improve the quality of life of patients;
• the principles on which the policy is to be based;
• an explicit statement of goals, objectives and priorities within the policy;
• the programmes, both new and revised, that will be required to carry out the policy;
• the resources currently available and those that will be required to carry out the policy in full;
• the roles and responsibilities of those involved in carrying out the various activities at the different levels of the health system;
• any legislative measures that will be required, such as those to control tobacco use, allocate funds for recommended activities, or ensure the availability of oral morphine;
• indicators for monitoring and evaluating the national cancer control programme.
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-
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 detection, 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.
Implementing a National Cancer Control 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
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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...
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 Reducccion Multifactorial de Enfermedades No Transmissibles) 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 Alimenatrius 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-
Implementing a National Cancer Control Programme

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
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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.
**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-
Monitoring and Evaluating the Programme

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

<table>
<thead>
<tr>
<th>Quality Dimensions in the performance of a national cancer control programme</th>
<th>Example of indicators for smoking cessation programme</th>
<th>Example of indicators for cervical cancer screening (including treatment)</th>
<th>Example of indicators for treatment of curable cancers</th>
<th>Example of indicators for palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Acceptability</strong>&lt;br&gt;How well the health system is meeting expectations of the providers and the public</td>
<td>• Level of satisfaction of providers and patients with tobacco cessation counselling in the workplace</td>
<td>• Level of satisfaction of providers and patients with the screening programme</td>
<td>• Level of satisfaction of providers and patients with the treatment</td>
<td>• Level of satisfaction of providers and patients with the palliative care programme</td>
</tr>
<tr>
<td><strong>Accessibility</strong>&lt;br&gt;Whether or not the public and patients can obtain the preventive and control services they need at the right place and time</td>
<td>• Percentage of providers and patients who are smokers who have access to tobacco cessation counselling</td>
<td>• Percentage of at risk women with a Pap smear taken in the last 5 years</td>
<td>• Percentage of patients with curable cancers that receive adequate treatment</td>
<td>• Level of morphine and other opioids consumption</td>
</tr>
<tr>
<td><strong>Appropriateness</strong>&lt;br&gt;Whether care is relevant to the needs and is based on established standards</td>
<td>• Percentage of patients with a non-communicable disease that are assessed about their tobacco smoking status</td>
<td>• Quality of Pap smears taken by primary health care workers and gynaecologists</td>
<td>• Percentage of patients that are treated according to guidelines</td>
<td>• Percentage of patients who receive palliative care according to guidelines</td>
</tr>
<tr>
<td><strong>Competence</strong>&lt;br&gt;Whether the knowledge and skills of providers are appropriate to the services that they are providing</td>
<td>• Percentage of primary health care workers with the necessary skills to give counselling on smoking cessation</td>
<td>• Continuing training of primary health care workers and laboratory staff regarding Pap smears collection, processing and analysis</td>
<td>• Quality assurance activities for diagnosis and treatment of the most common cancers</td>
<td>• Percentage of primary healthcare workers with the skills to provide basic palliative care</td>
</tr>
<tr>
<td><strong>Continuity</strong>&lt;br&gt;How services fit together—coordination, integration, and ease of navigation</td>
<td>• Plans implemented for avoiding relapse in ex-tobacco smokers</td>
<td>• Plans for follow-up of target population to repeat screening every 5 years</td>
<td>• Mechanisms for long-term follow-up of treated patients</td>
<td>• Percentage of patients that have access to a trained health care worker in palliative care in their community</td>
</tr>
<tr>
<td><strong>Effectiveness</strong>&lt;br&gt;How well services work and how they affect health status of the population at risk of cancer or affected by cancer</td>
<td>• Tobacco cessation rates among smokers with low to severe addiction</td>
<td>• Changes in stage distribution of cervical cancer</td>
<td>• Overall and stage-specific survival rates</td>
<td>• Improved control of symptoms in patients with advanced cancer</td>
</tr>
<tr>
<td><strong>Efficiency</strong>&lt;br&gt;Achieving best results at lowest cost</td>
<td>• Costs of counselling</td>
<td>• Percentage of Pap smears taken from at risk women</td>
<td>• Comparative data on cost of treatments</td>
<td>• Reduction of invasive procedures</td>
</tr>
<tr>
<td><strong>Safety</strong>&lt;br&gt;Minimizing potential risks of a health environment or service</td>
<td>• Regulations to avoid passive smoking in healthcare settings</td>
<td>• Regulations to protect laboratory staff</td>
<td>• Radiation protection for patients and providers in radiotherapy services</td>
<td>• Measures to avoid abuse of opioids</td>
</tr>
</tbody>
</table>
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
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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
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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.
Monitoring and Evaluating the Programme

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.