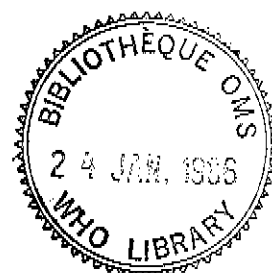


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*Cancer control programming  
in the European Region of the  
World Health Organization*



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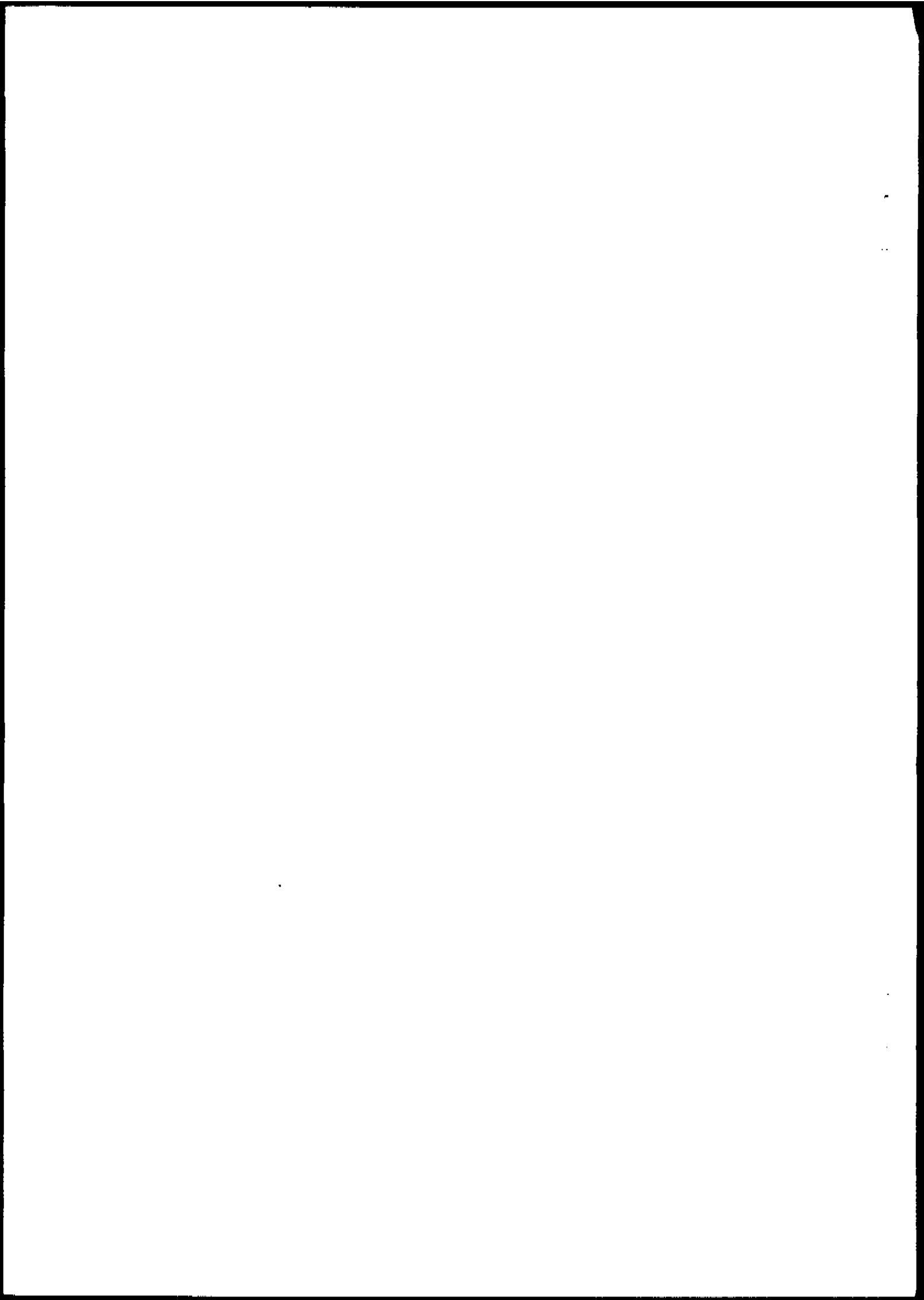
ВСЕМИРНАЯ ОРГАНИЗАЦИЯ ЗДРАВООХРАНЕНИЯ  
ЕВРОПЕЙСКОЕ РЕГИОНАЛЬНОЕ БЮРО

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CANCER CONTROL PROGRAMMING IN THE EUROPEAN REGION OF THE  
WORLD HEALTH ORGANIZATION

Guideline Document



Some 90 people from 25 countries of the European Region of the World Health Organization attended the meetings of working groups on cancer control held from 1981 to 1984. Their work formed the basis for this guideline document.

The participants included public health scientists, health administrators, cancer epidemiologists and bio-statisticians, health economists, directors of cancer centres, clinicians involved in cancer care, specialists in community medicine and people responsible for community cancer programmes. WHO headquarters, the International Agency for Research on Cancer (IARC) and professional organizations such as the International Union against Cancer (UICC), the Organization of European Cancer Institutes (OECI) and the European Organization for Research and Treatment of Cancer (EORTC) were represented in the working groups.

Thanks are due to all the participants, particularly those who have contributed to this guideline document as members of the programme core committee.

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## Introduction

These guidelines are intended to assist people either to develop new comprehensive cancer control programmes or to reorganize and to optimize those already existing in any of the Member States of the European Region of WHO.

In recent years there has been an increasing emphasis on the application of existing knowledge about cancer through community-oriented cancer control programmes<sup>a</sup>. The WHO global cancer programme, endorsed both by the Executive Board (EB 69.R17) and the World Health Assembly (WHA35.30), has been influenced by this conception. The adopted resolution urges Member States "to strengthen development of cancer control measures or, when they are lacking, to consider initiating them as an integral part of national health plans, allocating resources so as to reach the largest possible segments of the population".

Since 1981, a regional cancer programme has been developed in the European Region to assist the Member States in developing national cancer policies and programmes. The objectives of the regional cancer programme have also been shaped by WHO European regional strategies (EUR/RC30/8 Rev.1) that emphasized the reorientation of national health policies in three ways: the promotion of lifestyles conducive to health, the reduction of preventable conditions by controlling risk factors and the provision of adequate, acceptable and accessible health care.

The European regional targets that were recently adopted by the Regional Committee (EUR/RC34/7) reflect the spirit of this regional strategy. Their aim is to reduce mortality from cancer by using primary prevention and early detection measures as well as by providing optimal cancer care to all who require it.

The objective of the regional cancer programme, in collaboration with health authorities, health professions and appropriate intergovernmental<sup>b</sup> and nongovernmental<sup>c</sup> organizations, is to promote the development of comprehensive cancer control programmes<sup>d</sup> in the countries of the Region. The programme should provide cancer control measures of optimal quality for the largest possible segments of the population, with the most effective use of available resources. The measures should:

- reduce mortality and morbidity due to cancer
- increase the rate of cure from cancer;
- improve the quality of life for the people who survive cancer
- reduce the psychological and socioeconomic burden of cancer.

Cancer control services, already exist in most European countries. Today a new cancer control programme is most likely to be an addition to or modification of existing structures. The main task, therefore, is not necessarily to establish new services, but rather to improve cancer programmes by updating and reorganizing existing services.

The WHO regional cancer programme can support cancer control development in Member States by providing guidance:

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<sup>a</sup> Community orientation of a cancer control programme is used to describe a shift of emphasis in care provision from a high technology, hospital-oriented clinical oncology to control measures and services (both curative and preventive) provided outside of specialized institutions. In this context, the responsibility of comprehensive cancer centres for the community aspects of care is stressed (see also Chapter 1, section 1.5)

<sup>b</sup> World Health Organization, International Agency for Research on Cancer (IARC), Council for Mutual Economic Assistance, Commission of the European Communities, Council of Europe.

<sup>c</sup> International Union against Cancer (UICC), Organization of European Cancer Institutes (OECI), European Organization for Research on Treatment of Cancer (EORTC), European Organization for Cooperation in Cancer Prevention Studies and voluntary organizations such as cancer societies.

<sup>d</sup> In this context, comprehensive cancer control is defined as a set of interrelated intervention measures in the prevention, early detection, diagnosis, treatment, after-care, rehabilitation and terminal care, of cancer that are both effective and suitable for wide application.

- in the formulation of national cancer control policies
- in the management of a cancer programme
- in the assessment of services and technologies
- in the provision of control measures
- in the planning, training and use of manpower for cancer control.

With all these considerations in mind, along with WHO headquarters' effort to set guiding principles for developed countries, the Regional Office for Europe has selected a step-by-step approach to assist the developed European countries in modifying their cancer control programmes. In addition to fact-finding visits and consultations with health authorities and relevant experts, a series of working group meetings were held from 1981 to 1984. These meetings:

- reviewed the current status of cancer control in Europe and identified the aims that a national cancer control programme should achieve (EURO Reports and Studies, No. 70, October 1981, Luxembourg);
- identified the epidemiological approaches and information necessary to planning a cancer control programme (ICP/CAN 015, November 1982, Lyon);
- defined the term national policy for cancer control, and gave recommendations on planning national cancer control programmes (ICP/CAN 014, May 1983, Stockholm);
- specified methods of evaluating the components of a cancer control programme as well as the programme as a whole (ICP/CAN 016, November 1983, San Marino); and
- worked out the rationale of cancer patient care programmes (ICP/CAN 019(3), December 1983, Berlin, DDR).<sup>a</sup>

These activities were an attempt to apply current managerial knowledge to the national health planning process advocated by WHO (see "Health for All" Series, No. 5) to cancer control in order to develop a framework for the interrelated activities comprising a national cancer control programme. The immediate aim is to provide guidance to the Member States in planning, implementing and evaluating cancer control programmes.

The recommendations and conclusions of the working groups formed the basis for this comprehensive guideline document. The draft of the document was discussed and fully endorsed by the Advisory Committee on Cancer Control in Europe at its session in London in June 1984.

This document includes all the items that are now considered relevant to the process of developing cancer control programmes in the countries of the European Region:

- the essential characteristics of a cancer control programme;
- the information requirements for cancer control;
- the formulation of national policy for cancer control within general policies of health care;
- the organization and management of a cancer control programme;
- the translation of policy through various stages of planning into cancer control activities;
- the implementation of a cancer control programme and provision of cancer control measures; and
- the evaluation of a cancer control programme.

Special attention was paid to the manpower requirements and economic appraisal of cancer control programmes.

The document is primarily intended for health administrators responsible for planning cancer control programmes, but will also be useful to health authorities making decisions at the national level and health professionals providing care at all levels.

The intention of the Regional Office for Europe in presenting this model guideline is to stimulate the countries of the Region, with their different health problems, health services, and planning systems, to evolve their own guidelines for their own process of cancer control development by adapting those recommended in this document to their needs and opportunities.

<sup>a</sup> Reports of the meetings are available from the Cancer unit at the WHO Regional Office for Europe on request and are listed in the bibliography.

In coming years, the WHO regional cancer programme in Europe, by providing advisory and consultant services and channelling expertise, experiences and resources from one country to another, will assist the countries whose governments request its aid in developing national cancer control programmes.

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## CHAPTER 1

### Essential characteristics of a cancer control programme

In developing a cancer control programme it is necessary first to define the aims of cancer control and the objectives of the programme that can achieve them.

#### 1.1 The aims of cancer control are:

- the reduction of morbidity/incidence of cancer through improvement of the effectiveness of prevention;
- the reduction of mortality from the disease; and
- the improvement of the quality of life for people who survive cancer.

#### 1.2 Objectives of a cancer control programme are:

- to implement measures for primary prevention, where feasible;
- to promote public education in all aspects of cancer, particularly to increase understanding of the advantages of healthy lifestyle and early diagnosis and treatment;
- to improve early detection of cancer and to implement screening programmes which are of demonstrated effectiveness;
- to assess the state of cancer services and the demands made upon them in order to identify areas that need strengthening;
- to secure for all people with cancer an equal and high standard of care in all settings of care provision, encouraging the use of agreed medical protocols or care programmes for patient management and determining the most appropriate disposition of treatment facilities for the patients;
- to foster cooperation with local authorities and other agencies in order to provide the best possible after-care for cancer patients;
- to promote the development of rehabilitation services for cancer patients;
- to assist in the development of humane terminal care;
- to promote the further education of physicians and other health professionals in all aspects of cancer control and in the organization and management of cancer control programmes;
- to promote the compilation, distribution and understanding of cancer information and to encourage its use in the improvement of cancer services; and
- to promote research into all aspects of cancer and to evaluate the effectiveness of the cancer control programme.

1.3 As national needs differ, the precise wording of the objectives can be adapted to particular national circumstances. The relative priorities accorded to them will also vary from country to country depending on which are the most pressing problems and where action is most likely to be fruitful.

1.4 The objectives will provide the basis for a cancer control policy and a framework for the development of a programme. The detailed structure of the programme can be defined in terms of the components which need to be covered. Components 1-6 refer to the essence of cancer control, and components 7-11 to support measures.

The components of a cancer control programme include:

1. primary prevention
2. health education
3. early diagnosis and screening

4. cancer care
5. rehabilitation
6. continuing and terminal care
7. information
8. evaluation
9. research
10. professional training and education
11. organization and management.

1.5 The activities within the cancer control programme will be undertaken inside and outside the specialized cancer services. The cancer centre and community-oriented programme are equally important elements in cancer control and are mutually supportive. Where both exist they must be properly linked to each other and to the general health care services. However, the cancer centre as a centre of excellence in cancer care, is expected to make a major contribution to national policies for cancer control and to provide leadership in the development of community cancer control programmes.

1.6 The specific activities within the components that the programme will need to consider are indicated below. The relative importance of each activity will vary according to national and regional needs and opportunities.

#### Activities within a cancer control programme

1.6.1 Primary prevention (see also Chapter 6, section 6.4) includes the following activities:

- 1.6.1.1 control of exposure of the public to known and suspected carcinogens such as chemicals, industrial processes and ionizing radiation in the workplace; building materials in the home; and biological and chemical carcinogens and radiation in the general environment; and
- 1.6.1.2 control of exposure of individuals to known and suspected carcinogens such as tobacco, alcohol, ultraviolet light, ionizing radiation, sexually transmitted infections, dietary factors and iatrogenic use of X-rays and certain drugs.

1.6.2 Health education includes the following activities:

- 1.6.2.1 promotion of healthy behaviour and increasing awareness of the general public of:
  - (a) beliefs, feelings and ideas about the nature of cancer;
  - (b) contributing causative factors such as smoking, alcohol abuse, reproductive and sexual behaviour, excessive exposure to sunlight, dietary and some culinary practices and occupational exposure; and
  - (c) the importance of early detection, the possibilities of successful treatment and the services available;
- 1.6.2.2 provision of cancer education in schools and for groups at greater than average risk; and
- 1.6.2.3 education of the patient and the patient's family to assist them in coping with the disease.

1.6.3 Early diagnosis and screening (see also Chapter 6, section 6.2.2) includes the following activities:

- 1.6.3.1 provision of facilities for proven population screening procedures for the general public, such as cytology-based screening for cervical cancer;
- 1.6.3.2 provision of facilities for proven screening procedures for high risk groups such as human chorionic gonadotrophin (HCG) assays (choriocarcinoma), exfoliative cytology (bladder), and
- 1.6.3.3 provision of early diagnosis facilities for particular cancers (e.g. breast) through education in self-examination techniques, education of primary care professionals, provision of self-referral (e.g. well-women) clinics, easy access to general practitioners, referral clinics, as well as through such procedures as occult blood for colon and rectum cancers, cytology for prostate and oral cancer and inspection for skin and oral cancer.

1.6.4 Cancer care (see also Chapter 7) includes the following activities:

1.6.4.1 provision of sufficient high quality diagnostic facilities of the following kinds:

(a) clinical facilities at the primary care, general hospital, special hospital and cancer centre levels;

(b) instrumental imaging, including computed tomography, nuclear magnetic resonance and radionuclide procedures and endoscopy;

(c) biochemical pathology; and

(d) histopathology (vital for verification of diagnosis) and cytology, including aspiration biopsy cytology;

1.6.4.2 provision of sufficient out-patient and in-patient facilities for interdisciplinary management of cancer patients without undue delay in surgery, chemotherapy or radiotherapy;

1.6.4.3 provision of special treatment facilities in proportion to need;

1.6.4.4 provision of special facilities for the management of particular types of cancer such as: leukaemia and lymphomas, gynaecological, central nervous system, head and neck, genitourinary, breast and dermatological, or groups of cancer patients, such as children;

1.6.4.5 maintenance of adequate levels of clinical maintenance, nursing, support services, administrative and auxiliary staff;

1.6.4.6 coordination of services at different levels, through referral channels, communication of information, multidisciplinary teams, grouping patients by the location of their cancers, management or care programmes and consultant services from cancer centres and specialized departments; and

1.6.4.7 provision of adequate arrangements for the follow-up of cancer patients such as links between public and private hospital and community services.

1.6.5 Rehabilitation includes the following activities:

1.6.5.1 provision of services and advice such as reconstructive surgery, aids and appliances, stoma care, post-mastectomy care, dietary advice and psychological advice and support;

1.6.5.2 coordination with social, educational and employment agencies in the identification of special social, educational and employment factors, social security support, provision of aids and housing adaptations, and

1.6.5.3 coordination with patient-support groups, including general cancer care groups or site-oriented groups such as laryngectomy, mastectomy and ostomy groups.

1.6.6 Continuing and terminal care includes the following activities:

1.6.6.1 provision of facilities for palliative surgery and radiotherapy, symptom relief (particularly pain control), nutrition advice and psychological counselling.

1.6.7 Information (see also Chapter 2) includes demographic data, cancer statistics, morbidity and mortality data for other diseases and statistics on the use of resources.

1.6.8 Evaluation (see also Chapter 8) includes the following activities:

1.6.8.1 development and application of evaluation techniques for clinical management, patterns of service provision, the dynamics of patient care and educational and early diagnosis programmes;

1.6.8.2 control of the quality of procedures by the use of performance indicators, diagnostic procedures and information; and

1.6.8.3 economic appraisal (see Annex 1).

1.6.9 Research includes the following activities:

- 1.6.9.1 identification of research aims;
- 1.6.9.2 development of research programmes in cancer epidemiology, basic cancer research, clinical research, cancer control research<sup>a</sup> and health services research;
- 1.6.9.3 coordination of research programmes with each other and with clinical management.

1.6.10 Professional education and training in cancer control includes the following activities:

- 1.6.10.1 promotion of oncology in general medical training in the undergraduate curriculum, in postgraduate training of primary health care personnel, physicians and specialists other than oncologists;
- 1.6.10.2 provision of regular training for those specializing in oncology, physicians, specialists other than oncologists, paramedical personnel, such as cytotechnologists, nurses and people in other disciplines;
- 1.6.10.3 organization of update and refresher courses for professionals concerned with cancer control; and
- 1.6.10.4 provision of undergraduate and postgraduate training in cancer epidemiology.

1.6.11 Organization and management include the following activities:

- 1.6.11.1 establishment of appropriate organizational structures for planning of cancer control, management of cancer control programmes and evaluation of programmes;
- 1.6.11.2 maintenance of adequate numbers of staff expert in health services management, finance, health economics, epidemiology and information and statistics.

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<sup>a</sup> The term cancer control research is defined to mean applied research to test a specific action or intervention for effectiveness, feasibility, acceptance in controlled trials, and in defined population studies before it is used in a community.

## CHAPTER 2

### Information requirements for cancer control programmes

The information requirements of a cancer control programme cannot be developed separately from information systems for health care in general, or from the general availability of statistical data in the community.

2.1 Baseline data. Several kinds of data must be collected to provide the information necessary to a cancer control programme.

2.1.1 Population. Necessary demographic data include the age, sex, marital status, occupation, social-economic status, place of birth and place of residence of the people of the community, along with population projections.

The backbone of a comprehensive information system for cancer control is data on the population to be served by control measures. Estimation of cancer risk to the community, as well as the significance of the cancer problem for society, requires knowledge of the number of people in the community with cancer.

2.1.2 Environment. Information is needed on the prevalence of known causal risk factors in the environment<sup>a</sup>.

2.1.3 Cancer epidemiology<sup>b</sup>. Three different types of cancer data are needed to describe the cancer experience of the community:

2.1.3.1 incidence<sup>c</sup>

2.1.3.2 mortality<sup>d</sup>

2.1.3.3 prevalence<sup>e</sup> including quality of life indicators.

The cancer data may also include information on the primary site, histopathology, stage of disease and treatment of the cancer.

Incidence and mortality rates of cancers at different sites are particularly important in planning preventive, diagnostic and curative services. Prevalence rates, which show the rate of successful curative interventions, are most important in the planning and administration of patient follow-up, rehabilitation and continuing care services. Further, changes in incidence and mortality rates over time are regarded as valid measures of the effectiveness of a cancer control programme.

Differences in incidence and mortality from particular cancers associated with sex differences, differences in socioeconomic conditions, geographical distribution, migration patterns, or occupational, behavioural and lifestyle patterns can contribute to the understanding of the causes of cancer by generating etiological hypotheses.

2.1.4 Other diseases. When setting priorities for a cancer control programme in the framework of national health care policies and programmes, general information on the health of the people,

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<sup>a</sup> Meaning exposure coming from air, water, food, at place of work, in the home, personal habits such as smoking, alcohol misuse, diet, and culturally influenced factors such as age at first full-term pregnancy. It is now estimated that 80-90% of all cancer cases are due to these external, and therefore avoidable, factors.

<sup>b</sup> The use of information on occurrence and patterns of disease by its determinants for the purposes of causal research and providing measures for cancer control.

<sup>c</sup> The number of new cancer cases in a defined area/population in a defined time period.

<sup>d</sup> The number of deaths due to various types of cancer in a population in a defined time period.

<sup>e</sup> The number of persons alive in a given period of time who have ever been diagnosed as having a cancer.

particularly data on the main causes of death, morbidity pattern from other noncommunicable diseases such as heart disease, stroke and diabetes, must be considered by policy makers and planners.

2.1.5 Information on resources. Information should be gathered on various aspects of the resources of a cancer control programme, including:

- 2.1.5.1 services devoted to or available for provision of cancer control measures such as specialized institutions, including comprehensive cancer centres, university clinics, general hospitals with or without oncology departments, dispensaries, outpatient clinics, screening centres, care units, hospital beds and diagnostic and treatment equipment;
- 2.1.5.2 manpower such as specialists in clinical oncology and radiotherapy, other specialists, cytotechnologists, nurses and managerial and epidemiological experts;
- 2.1.5.3 use of resources, broken down by level of care, preventive and diagnostic treatment and follow-up and after-care services; and
- 2.1.5.4 expenditure, depending on the organization and structure of the health care system, the degree of specialization in the provision of cancer control measures in primary health centres, general hospitals or comprehensive cancer centres and the allocation of funding responsibility.

The integration of cancer control services into general health care systems makes the collection of reliable data difficult. There is a need for new information systems and an internationally agreed standardization of data on cancer control resources.

## 2.2 Data sources

2.2.1 Vital statistics and national health statistics are sources of demographic data (see section 2.1.1) and data on other diseases (see section 2.1.4). Cancer mortality data can be obtained from both national vital statistics and cancer registries. For a number of countries, national mortality statistics provide the only source of reliable data on patterns and trends. As the quality of data has a major influence on the confidence with which conclusions can be drawn, the quality of death certification should be periodically reviewed and instruction should be provided in the correct completion of death certificates.

2.2.2 Cancer registries are the most valuable sources of information for cancer control. There are two types of registry, population-based and hospital-based, with different aims, functions and kinds of information.

2.2.2.1 Population-based registries provide basic data for planning and evaluation of cancer control programmes, as they collect information on all cancer cases diagnosed in a defined population. Items collected include:

- identification of patient by name<sup>a</sup> or by personal identification number with basic personal characteristics;
- verification of diagnosis, time of diagnosis, primary site, extent of disease, histology and basic data on treatment; and
- cause of death, although the proper staging of tumour and detailed treatment data are usually not recorded.

2.2.2.2 The hospital-based registry, an essential part of a comprehensive cancer centre, focuses on clinical issues. It is used to plan and evaluate clinical care, follow-up and rehabilitation services as well as resource use. Information collected includes:

- primary site, histology, recurrence and size and extent (TNM) of the cancer, and treatment in detail, adverse effects of the treatment, short- and long-term response and quality of life of the patient.

2.2.2.3 It is recommended that cancer registries be established in those areas where only mortality data now exist.

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<sup>a</sup> Anonymous data for registration are of no value.

2.2.3 Sample surveys and other special studies. As an alternative and supplement to cancer registration, when some data of interest are not known to the entire population, a sample survey can be carried out, similar to specifically designed epidemiological studies, to obtain data on the prevalence of exposure to some risk factors or on the effectiveness of some intervention measure such as screening. The two types of sample studies are the retrospective case-referrent study and the prospective cohort-study; results derived from these studies may then be applicable to the total population. It is the general view, however, that some of the disadvantages of the sample approach, particularly in terms of optimum size and representativeness of the sample, outweigh the advantages. Therefore, for the purposes of cancer control programmes, the establishment of new registries with specific tasks should be encouraged.

2.3 Comprehensive information system. Considering the complexity of information requirements for a cancer control programme developed as a part of the national health services and the need for interdisciplinary and intersectoral cooperation in implementing the programme, it is obvious that a comprehensive cancer information system must be coordinated with other relevant data sources.

2.3.1 Linkage of information. It is a great advantage to link cancer data to population censuses, mortality-registries, screening registries, hospital and other disease registries, employment and other occupational records, drug registers, environmental information such as risk factor exposure and biological sample banks<sup>a</sup>.

The use of computers is necessary for an effective linkage.

2.3.2 Confidentiality. Such linkage of data is becoming increasingly difficult due to considerations of confidentiality and data protection laws and regulations. Confidentiality legislation should not be allowed to prevent the effective use of data in planning, management and evaluation of a cancer control programme. Therefore, a resolution (Resolution GC/20/R9) made by the Governing Council of the International Agency for Research on Cancer recommends that, "legal and administrative measures be taken by relevant national authorities which, while preserving confidentiality of medical and employment records, make them accessible for an effective approach to the solution of public health problems". Furthermore, written codes of practice for the protection of data in cancer registries from destruction, loss and disclosure must be worked out and observed.

2.3.3 Standardization of data and data classification schemes improve the quality of data collection and the comparability of data at both national and international levels.

2.3.3.1 Internationally agreed nomenclatures and classifications include:

- coding by topography, histology and behaviour, as in the International Classification of Diseases for Oncology (ICD-O) published by WHO;
- classification by histology as in the International Histological Classification of Tumors (No. 1-25) published by WHO; and
- classification by clinical stage as in TNM Classification of Malignant Tumors published by the International Union against Cancer (UICC).

2.3.3.2 Proposed international standardized data systems include:

- the population-based cancer registry described in Cancer registration and its techniques, published by IARC;
- the hospital-based cancer registry described in WHO Handbook for standardized cancer registries (hospital based), published by WHO; and
- the results of cancer treatment described in WHO Handbook for Reporting Results of Cancer Treatment, published by WHO.

2.3.3.3 It is recommended that the use of such schemes be further encouraged, they should be flexible enough to be adapted to further developments and local conditions.

<sup>a</sup> A biological sample bank is where human biological materials, such as blood or urine, are stored for later analysis in connection with specific epidemiological surveys, which will permit precise comparison of biochemical measures in individuals and groups and test new hypotheses.

2.3.4 Prediction of cancer risk. Long-term planning of cancer control services and resources is based on the prediction of future trends in the incidence and prevalence of different cancer types, as well as on population forecasts. Direct extrapolation of past trends may lead to gross errors. Many factors, including estimated exposure to known risks and the long period between exposure to risks and the onset or diagnosis of cancer must be taken into account.

#### 2.4 Strategies for development of a cancer information system

2.4.1 An information system is an essential component of a comprehensive cancer control programme. The planning of a cancer control programme should include careful thought about the design, management and evaluation of an appropriate information system.

2.4.2 A cancer information system must be appropriately coordinated with the information systems of other areas of health care services when cooperative activities are undertaken, as when a cancer unit and a cardiovascular unit combine to create an integrated programme for the prevention of noncommunicable disease.

2.4.3 Because trained epidemiologists are needed in cancer control programmes, it is recommended that attention be given to the training of such scientists.

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## CHAPTER 3

### Organization and management of cancer control programmes

3.1 A cancer control programme must be planned at the national level and an advisory group should be established to do this. Detailed planning and implementation will be carried out at national, regional and local levels through executive agencies. Both kinds of groups are discussed below.

3.2 National advisory bodies should be set up by governments to advise them on the planning of national cancer control measures and to develop planning guidelines for use at regional and local levels.

This body may also be very helpful in the development of policy (see also Chapter 4, section 4.2.1).

It should work primarily with the central health authorities.

3.2.1 Structure. The national body may be:

- a ministerial or departmental group with direct accountability to a government minister;
- a departmental advisory committee with access to ministers through the executive system;
- a quasi-independent board or commission set up by ministers and accountable to parliament, but not an integral part of government machinery,
- an independent body without formal government links but with access to ministers; or
- a public health commission or national board concerned with overall health care needs.

The most appropriate structure for any country will depend on its system of government.

3.2.2 Membership. The group's members should be experts in each of the major components of a cancer control programme and the standing membership should not exceed 20. The group should have its own secretarial staff. In addition, representatives of ministries or other interested groups should attend meetings as members or observers.

3.2.3 Working methods. The national body must have ready access to information and expert advice on all aspects of cancer control. It should be able to undertake special studies through its staff and to commission research from independent agencies. Though concerned with health, it must be fully informed of relevant issues in non-health areas and must establish the appropriate links to ensure this. Within the health field it must be aware of the needs of other areas of health care and their relative priorities.

The advisory group should present its advice to the executive in a readily comprehensible form and should monitor its use. Finally, it should develop criteria for the evaluation of cancer control plans, obtain the results of evaluation studies and interpret the results to the executive agencies.

Specialist sub-committees or working groups should be set up to consider particular topics in detail. These groups will function as planning teams and should also include experts in health services management, epidemiology, health economics and systems analysis.

The national advisory body will consider the planning proposals put forward by the working groups and advise the executive on their relative priorities.

3.2.4 Interrelationships. Suitable lines of communication should be established between the national advisory body and other relevant agencies, such as those responsible for employment, industry, health and safety, agriculture and food processing, the environment, finance and taxation, customs, advertising, public broadcasting, education and customer protection.

The relevant organizations within each sector include: government ministries, public service bodies, employers' organizations, trade unions, voluntary organizations, local authorities and the general public. Links may be forged through representation on the national advisory body, joint sub-committees and working groups.

These interrelationships are particularly important to cancer prevention and a multisectoral body must be established to promote collaboration in this field and identify areas for executive action. Such a group would be linked to the national advisory body.

### 3.3 Executive system

3.3.1 At the national level. In some areas of cancer control, plans must be implemented at the national level. In these instances the executive authority will either be the appropriate government ministry, acting alone or in conjunction with other relevant ministries, or an appropriate nongovernmental national agency.

3.3.2 At the regional or local level, the appropriate executive agency will vary according to the structure of the health care system. In many countries regional and/or local authorities are responsible for providing health care and these groups should plan cancer control activities within the health service.

3.3.3 Planning teams established by the executive authorities should make the detailed plans required to achieve the objectives of the national plan, using planning guidelines developed by the national advisory body. A team may be set up for each of the major components of the programme or for a combination of components. The planning teams should include experts on health services management, epidemiology, health economics and systems analysis and the cancer programme's components. The teams should have close links with relevant voluntary and private agencies to ensure that planning is as comprehensive as possible. The planning of some cancer control activities may be undertaken by planning teams responsible for health activities other than cancer services.

If specialist teams are set up for planning cancer control activities they should work within the planning system for general health care.

The executive authority, advised by the planning teams, must decide between different sets of proposals and ensure that the necessary resources are made available for implementation.

3.3.4 Implementation and management. The planning teams should identify the people or groups to be responsible for implementing their advice. However, implementation of the programme is the responsibility of the executive agencies, who may set up management teams for this purpose.

Management teams will need people expert in health services management and finance. These groups should have close links to the relevant planning team; perhaps some people should be members of both groups. Together, both groups should work out a timed programme of implementation.

The planning team should receive regular information on the progress of implementation and should update plans as necessary.

The executive authority should coordinate the work of planning teams and management teams.

3.3.5 Evaluation (see also Chapter 8) of the implementation process should be made by the executive authority.

Ideally, people outside both the planning and management teams should evaluate their work. The executive authority may wish to establish its own evaluation team or commission evaluation studies by outside agencies. Evaluation teams should include experts in health services research, health economics and epidemiology.

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## CHAPTER 4

### National policy on cancer control

4.1 What is policy? National policy on cancer control was defined by the WHO Working Group on the Development of Guidelines for the Design of National Cancer Control Plans in Stockholm, May 1983, as "an explicit statement of intent by government which:

- defines the objectives of cancer control and the relative priority of each objective;
- indicates the measures required to attain the objectives; and
- provides a basis for planning".

4.1.1 Justification of the need for a national cancer policy. A national cancer control programme must result from a planned process. After considering the problem, the decision-making health authority should issue general directives on planning programmes in cancer control. An integrated health policy, as part of an overall socioeconomic policy, will provide the best basis for planning. However, considering the magnitude and trends of the cancer problem in the industrialized nations, the complexity of the disease and of the multidisciplinary and multisectoral approaches to dealing with it, as well as cancer's overall emotional and economic burden on society and on the health services system, cancer control policy should have a high priority in the planning of national health services and in the allocation of resources.

4.1.2 Benefit of a national policy. When no such a policy exists, random events, locally available resources and pressure from special interest groups decide what actions are taken; this can result in low-quality activities and haphazard development. On the other hand, a successful comprehensive cancer control programme, based on a national cancer policy, benefits the general public and aids the authorities in planning the economic, manpower, equipment and other resources to fulfil its stated objectives.

#### 4.2 Who is to develop policy?

4.2.1 A national cancer policy will be formulated by a national advisory body set up by the ministry of health or a corresponding department (see also Chapter 3, section 3.2) and then approved by the executive authority at the highest level. Only with the approval of the appropriate minister(s) can a policy gain acceptance. The political commitment of the national leadership is essential both for the development and implementation of the policy.

4.2.2 To provide an appropriate basis for planners and administrators in their task of translating policy into action, the national cancer policy should identify the objectives of each component of the cancer control programme (see Chapter 1, section 1.4). Therefore, the membership of the advisory group must include experts from each area concerned. The policy must be based on up-to-date, scientifically sound knowledge and must be supported by the health and other relevant professions.

4.2.3 The degree of centralization of planning in a country will determine the extent to which a centrally formulated national cancer policy can be adapted to regional needs and opportunities when it is implemented.

4.3 Intersectoral collaboration. Several reviews of the causes of cancer have conclusively demonstrated the importance of environmental factors such as lifestyle. Government can influence many of these factors, including food, tobacco, alcohol, agriculture, industry, trade and environment. Furthermore, the allocation of resources devoted to cancer control services requires consideration of the needs of other health services and other sectors of government. Therefore, the need for intersectoral collaboration in formulation of national cancer policy should be recognized, and cancer control policies should be combined with the policies of other sectors when appropriate.

#### 4.4 Items to be included

4.4.1 The national cancer policy should contain statements on the objectives of the cancer control programme, the time necessary for its development, provision for the facilities needed, the necessary personnel resources and funding.

4.4.2 It could also include detailed guidance on:

- the organization of cancer control in the country, including the responsibilities of institutions or departments for cancer care, community-based programmes such as early detection and follow-up and the delegation of authority;
- cancer reporting and registration systems, evaluation of cancer control;
- the training of personnel for cancer control;
- the provision of preventive measures and intersectoral cooperation;
- the provision of medical establishments and equipment;
- the provision of staff patterns and posts; and
- the funding of the activities.

4.5 Time scale. A policy document should include a time scale; either it could be valid until otherwise stated, or it could have definite time limits. This would help planners in their short-term, medium-term and long-term planning (see also Chapter 5, section 5.1.4). A detailed policy, with funding principles and planning norms, is more likely to be short lived. It must be clear, however, that making policy is a dynamic process; policies must be revised at certain intervals and updated in the light of the changing knowledge and technology in cancer control.

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## CHAPTER 5

### Planning a cancer control programme

#### 5.1 Overview of planning

5.1.1 Definition. Planning is the foundation of effective management. Planning is the process through which a policy is implemented; the process includes the practical steps needed to achieve the aims of the policy.

Planning may be described as a systematic process of defining a problem, assessing its extent, formulating realistic goals and objectives whose achievement would solve or improve the problem; discovering, examining and selecting intervention strategies; monitoring the implementation and operation of intervention; and assessing their impact on the problem.

5.1.2 Continuous planning. Planning should be a continuous process; plans must be responsive to changing needs and new information such as technical improvements. The planning system must be flexible enough to accommodate changes and sensitive to political, cultural, social, economic and demographic conditions.

5.1.3 Purposes of planning. Cancer control planning will be concerned not only with the adequacy, efficacy and efficiency of control services, but also with the general goals of health, equity and the integrity of the individual.

Improving health involves an emphasis on environmental determinants of cancer and the promotion of healthy lifestyle, in addition to the reduction of the incidence and mortality of cancer and improved quality of survival for cancer patients. The goal of equity requires the planner to try to provide good health and equal access to health services to everyone. The issue of personal integrity involves the protection of the patients' privacy against the improper use of information on them, as well as the need to safeguard their rights and dignity.

#### 5.1.4 Time scales in planning

5.1.4.1 Time is a very important element in planning. There are three kinds of time scales.

Long-term or perspective planning looks 10-15 years or more ahead, now to the year 2000, and is concerned with the broad measures required to reach the desired future. Policies set down at this level determine the activities projected by shorter term plans.

Medium-term planning deals with periods three to five years ahead and allows scope for recognizing new needs, obtaining new resources and re-allocating resources between competing objectives.

Short-term planning usually covers periods of one to three years ahead and is concerned with needs as defined by current trends and resources whose availability is already decided. Short-term plans contain the practical measures that will carry out the aims of the other planning levels.

5.1.4.2 The use of standard time scales and levels of planning allows the health sector and non-health sectors to create coordinated or integrated preventive programmes.

#### 5.1.5 Levels of planning

5.1.5.1 The division of planning into hierarchical levels is subject to the constitution and administrative structure of each country and the extent to which the planning system is centralized or decentralized. In general, these levels can be described as national, intermediate (for the region or county) and local. The higher the level of planning, the more decisions are concerned with general policy; at lower levels, the planning is shifted from philosophical to practical measures.

5.1.5.2 At the national level the criteria for setting priorities and allocating resources to cancer control programmes are established in conformity with the government's socioeconomic goals, and in line with the needs of other health programmes, such as cardiovascular disease control, in a national health policy. The objectives are broadly formulated (for example, reduction of cancer incidence and mortality by a certain

percentage by a specific target date). Strategies may include legislative action such as regulations on environmental control, on taxation practices or on the establishment of training institutions. Research priorities in cancer control could also be identified.

5.1.5.3 A national body (see also Chapter 3, section 3.2) should develop planning guidelines for use at the intermediate and local levels.

5.2 The steps in the planning process. The planning process can be broken down into a number of stages, each with particular tasks and special requirements. The problems and priority considerations, as well as approaches, indicated in the policy statements must be kept in mind when the planning is carried out.

5.2.1 Identifying the problem. The description of current conditions and possible future conditions, along with the precise identification of current problems and the obstacles to their solution, depend heavily on the availability of information about the present conditions and trends, and projections for the future. The basic information requirements in planning cancer control programmes are described elsewhere in this document (see Chapter 2).

5.2.2 Setting priorities and objectives

5.2.2.1 The defined problems should be arranged according to:

- their relative importance in terms of incidence, prevalence and mortality of various types of cancer;
- the feasibility of solution, and the availability of manpower, equipment and scientifically sound, effective intervention measures suitable for wide use; and
- political, social and economic considerations such as public concern about the problem, the social acceptance of intervention measures, effects on economic productivity and the speed of expected results.

5.2.2.2 Overall and immediate objectives. When the overall objectives of the cancer control programme have been defined, meaningful, clearly stated, measurable objectives must be established. These objectives are immediate goals that must be achieved by the programme's activities in order to improve or to solve the problem. A series of goals might be set to handle some problems. The immediate objectives can be formulated in practical terms and each activity should have a measurable outcome.

5.2.3 Designing strategies

5.2.3.1 A strategy is a set of activities to be undertaken to achieve a specific goal or objective. The components of cancer control and the activities that the planners will need to consider are listed in Chapter 1, sections 1.4 and 1.6. There will be more than one way of achieving most objectives, so various approaches can be designed. Sometimes, interrelated strategies will require coordinated planning.

5.2.3.2 The process of designing strategies will involve the search for alternatives, analysis of alternative strategies and selection of the most appropriate.

5.2.3.3 Considerations in making decisions include appraising the social and economic implications of the programme:

- in terms of cost-benefit (whether the advantage gained justifies the cost of the measure) and cost-effectiveness (how best to use available resources to achieve an objective) (see Annex 1);
- by systematic assessment of technologies, including both equipment and procedures used in cancer control, for efficacy, safety and social acceptance; and
- by pilot tests of alternative strategies.

5.2.3.4 The feasibility of certain strategies in terms of the availability of resources should also be analysed.

5.2.4 Resource allocation. When the planners have chosen a set of activities, they must then allocate the resources needed to implement the strategies. These include personnel, equipment and materials and may be assigned to specific tasks with a work schedule indicating what must be done,

who must do it, when it must be done and with what resources. It is possible that resources will have to be reassigned from one activity to another during the implementation of the programme.

5.2.5 Designing an evaluation mechanism. A means of monitoring the implementation of the plan and evaluating its effects must be designed before implementation begins. The information requirements for monitoring and evaluation, as well as the process of evaluation are described elsewhere in this document (see Chapters 2 and 8).

5.2.6 Formulation of programme document. Before it is put into action, the plan should be fully documented and published. The amount of detail in the programme document will depend on the level and time scale of the plan.

The programme document summarizes the problems, priorities, objectives and the strategies selected to solve the problem. It should provide practical guidance and a timetable for implementation and evaluation by assigning resources, delegating executive authority, and delegating responsibility for the activities of and adjustments to the programme.

5.2.7 Implementation means the provision of preventive and early detection measures, where feasible and scientifically justified (see Chapter 6), and the provision of optimal care for cancer patients, based on current knowledge and technologies (see Chapter 7).

5.2.8 Evaluation is the regular process of making judgements on the success of the programme (see Chapter 8).

### 5.3 Manpower for planning

5.3.1 Planning is a multidisciplinary activity and various experts must work together at various stages (see Chapter 3, section 3.3.3). A planning team should be led by experts in health services management, but they will need help from cancer epidemiologists, health economists and statisticians, in addition to experts in cancer control. Where these skills are in short supply, efforts should be made to establish suitable training programmes (see Chapter 9, section 9.3.4).

5.3.2 The planning of a cancer control programme must be based on up-to-date knowledge on cancer. Therefore, it is essential that cancer centres, as centres of excellence in the field of cancer control, be consulted when appropriate.

### 5.4 Coordination

5.4.1 Intersectoral. The people who plan cancer control programmes must cooperate with other sectors of the economy whenever cancer control activities affect those sectors (see also Chapter 3, section 3.2.4 and Chapter 4, section 4.3).

5.4.2 In the health sector, coordination with other health programmes, such as a cardiovascular disease control programme is essential when an opportunity for integrated action emerges.

5.4.3 Voluntary or nongovernmental organizations involved in cancer control should also be involved in the government's planning activities because of their experience in influencing public opinion and mobilizing manpower and funds.

5.4.4 International organizations such as WHO and the International Union against Cancer have run cancer control programmes and can provide expert advice, consultant services and other kinds of support to national efforts. They can also help coordinate cancer control programmes in different countries.

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## CHAPTER 6

### Cancer control measures: primary prevention and early detection

In addition to the patient management<sup>a</sup> provided at any level of health care services, the cancer prevention<sup>b</sup> that is now feasible for some cancers is an essential part of cancer control.

Experience has shown a gap in most developed countries, between curative and preventive medicine. Even in recent years, a number of facts reflects the almost completely therapeutic orientation of both health policies and health professionals. However, health professionals and authorities have also begun to recognize the necessity of preventive measures. Therefore, it is essential that plans for cancer prevention be included in cancer control programmes, along with strategies for patient management (see Chapter 7).

#### 6.1. Levels of prevention

Cancer prevention means both primary prevention and the early detection of disease.

6.1.1 Primary prevention aims at preventing the disease from occurring, through avoiding or reducing the exposure of individuals and populations to known carcinogens.

6.1.2 Early detection aims at detecting the cancer in its earliest stages or even its precursor stage, when it is generally more responsive to effective treatment. This means an attempt to keep the symptomatic or invasive cancer from developing. For this reason, early detection is a term widely considered to be synonymous with secondary prevention (see also section 6.2.2).<sup>c</sup>

#### 6.2 Intervention strategies

6.2.1 Prevention measures include the following activities.

6.2.1.1 Administrative and legislative measures necessary to protect individuals and the community can include laws or regulations on product control, advertising, food safety, workers' protection, taxation and price policies, non-smoking areas and chemical testing programmes. In this area, research and practice may overlap. For example, primary detection of carcinogens can be regarded as both a research and intervention measure.

6.2.1.2 Health education should influence individuals and populations to create safer lifestyles,<sup>d</sup> and teach the public to understand and accept public health measures.

6.2.1.3 Cancer communication is the exchange of information between the scientific community, health professionals, government and the general public. These exchanges should quickly spread new knowledge in cancer control and should increase public awareness of the availability and benefits of prevention and early detection.

<sup>a</sup> Patient management is the diagnosis, treatment, patterns of referral, follow-up, rehabilitation and continuing and terminal care of people with cancer (see also Chapter 1, sections 1.6.4-1.6.6).

<sup>b</sup> Prevention means primary prevention and early detection (see also Chapter 1, sections 1.6.1-1.6.3).

<sup>c</sup> We deliberately avoid using the term tertiary prevention because it involves quite different concepts, denoting measures designated to reduce and to minimize the pain, discomfort, worry and other psychological problems associated with cancer. These functions are covered by the terms treatment, after care, rehabilitation and terminal care.

<sup>d</sup> Lifestyle is here defined as a characteristic cluster of customs and habits, determined by social conventions and traditions, that become so automatic that they are difficult to change. This is now the best description of the factors determined by human activities and personal behaviour that Doll and Peto call avoidable causes of cancer.

6.2.2 Early detection measures include the following activities.

6.2.2.1 An organized screening programme should be set up for the early detection of presymptomatic cancer cases, based on screening tests that are scientifically justified and can be recommended as public health measures.

The organized screening programme is to meet the following criteria:

1. The target, or high risk, population should be defined and invited to participate in the programme on individual basis, for example by personal letter; thus the population coverage of the screening is fairly complete and well-recorded, and non-responders can be identified.
2. There should be an agreed policy on screening strategies, such as the age of the person at commencement of screening, the age at which screening may be considered no longer necessary, and the optimal interval of screening.
3. The screening test should be performed in a centralized way, such as at a central cytology laboratory; this ensures the quality of both the test and its analysis.
4. There should be an organized referral system, including the invitation of everyone with positive test results to treatment and follow-up.
5. The target population should be covered by a comprehensive cancer registry, and death certificates; where such a registry does not exist, some type of screening registration system should be used.
6. The screening tests should be evaluated in terms of incidence and mortality, as valid indicators of outcome.

6.2.2.2 Some people should have regular medical checkups, including available tests and procedures that seem to be suitable for detecting asymptomatic cancer cases, even though their value in population screening has not yet been established. These procedures include physical examination, mammography, digital-rectal examination, sigmoidoscopy, stool-blood test, chest X-rays and exfoliative cytology.

6.2.2.3 People should learn self-examination techniques that they can use, if practised regularly, to detect the so-called interval cancers that become manifest between routine examinations, and all those cancers for which no specific presymptomatic test exists.

6.3 The criteria for the wide use of preventive public health measures are feasibility and proved effectiveness. The effectiveness of a screening technique is scientifically proved through specifically designed epidemiological studies (see also Chapter 2, section 2.2.3).

6.4 Control of carcinogenic risks

6.4.1 Primary prevention and smoking. Since the link between tobacco use and cancer has been so conclusively demonstrated, the major cause of cancer is also its most avoidable risk. An important task is to devise efficient strategies for:

6.4.1.1 prevention programmes, to keep people, particularly the young, from starting to smoke, possibly through programmes in schools;

6.4.1.2 cessation programmes, to help people, especially such groups as pregnant women, heavy smokers and workers at high risk due to occupational exposure to risk factors, stop smoking; and

6.4.1.3 administrative and legislative regulations, to decrease the availability of tobacco products and ban advertisement.

6.4.2 Primary prevention and diet. Recently, attention has been focused on the links between diet, nutrition and cancer. On the basis of current evidence it is now possible:

- 6.4.2.1 to formulate interim dietary guidelines which are both consistent with good nutritional practices<sup>a</sup> and likely to reduce the risk of cancer;
- 6.4.2.2 to advise the public through education and public information on healthy dietary habits; and
- 6.4.2.3 to introduce national dietary policies and measures, possibly through governmental regulations, cooperation with food industry in production and processing, coordination with agricultural policies, selective food price control and food quality regulations.
- 6.4.3 Primary prevention and occupational risk. Even though the total amount of occupational exposure to carcinogens is not very high for the whole population, those groups who are exposed to carcinogens at work may be at high risk. Therefore consideration should be given in any prevention programme to the detection and control of occupational hazards by legislation and regulations for protection against both defined occupational chemicals and defined industrial processes with undefined agents. These occupational risks, as defined by the International Agency for Research on Cancer (IARC), should be considered when setting priorities for intervention programmes.
- 6.4.4 Integrated prevention programmes should be developed to control the risk factors that are common to cancer and to some other noncommunicable chronic diseases, especially cardiovascular diseases.
- 6.5 State-of-the-art in early detection by screening. Some screening tests, according to recent reviews, have been proved effective while others remain experimental.
- 6.5.1 Cytology-based screening for cervical cancer is the only test whose effectiveness is well-established. Health authorities should introduce organized screening programmes (see section 6.2.2.1), similar to the ones in Finland, Iceland and Sweden.
- 6.5.2 The value and feasibility of screening for breast cancer by mammography and physical examination (with or without self-examination) has not yet been proved. WHO is eagerly awaiting the results of collaborative evaluative studies carried out by international agencies such as IARC and the International Union against Cancer (UICC) before recommending such tests for whole populations.
- 6.5.3 Screening for colo-rectal cancer with occult blood tests is an experimental procedure.
- 6.5.4 Screening for lung cancer with X-rays and sputum cytology has not proved its applicability as a routine public health measure.
- 6.6 Organization of cancer prevention. Cancer prevention is a multisectoral activity involving several ministries and effective collaboration among these different sectors is essential (see also Chapter 3, section 3.2.4, and Chapter 4, section 4.3).

A national group on cancer prevention should be established to promote such collaboration. The group should be linked to the national advisory body on cancer control (see also Chapter 3, section 3.2) and the precise relationship between the two bodies will vary from country to country. Its main function would be to identify those areas where different sectors of the health services could combine to prevent cancer and other diseases by attacking common risk factors together.

Information on prospects for cancer prevention and related activities should also be exchanged among nations. The work of international agencies is particularly important.

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<sup>a</sup> Partly based on what we know about the link between diet and cancer and partly because they do not contradict with the dietary recommendations in relation to other diseases, prudent dietary recommendations advise people to: reduce fat, eat less, drink moderately and add fibre, fresh fruit and vegetables to their diets.

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## CHAPTER 7

### Cancer control measures: cancer patient care programmes

The main strategy of the WHO health for all programme is equal access to appropriate health care for everybody. Any programme for cancer care, therefore, should take into account how best to use the national health care system for this aim. Even in countries where cancer centres are available, such centres usually only provide a small part of all care of cancer patients. Thus, all levels of care must be actively involved in cancer care in the community.

7.1 Levels of cancer care include: primary or district care level, general hospitals and specialized cancer hospitals and comprehensive cancer centres.

7.1.1 Primary or district health care is the level most patients use first. Thus the primary level physician is responsible for diagnosing the condition or for referring people to the appropriate level for diagnostic procedures. After being treated for cancer, the patient may contact the primary level physician or general practitioner again about other problems that may or may not be related to the disease. People from this level of care help in caring for patients with incurable cancer at their homes, although support from specialized oncology services may be necessary.

7.1.2 General hospitals are usually the first referral level and an intermediate level between the district health care and the highest level. Most patients have their initial work-up and treatment at this level.

7.1.3 Oncology facilities within comprehensive cancer centres, various specialties in university hospitals and specialized cancer hospitals constitute the highest level of cancer care. Such units are also involved in graduate and postgraduate education, and so extend their influence to the other levels of care.

7.2 Interdisciplinary interaction in cancer care. In the management of malignant diseases, a multidisciplinary approach is usually recommended to coordinate the resources for cancer care. The optimal level for diagnostic and therapeutic procedures and for follow-up varies according to the nature of cancer in question. Medical, economic, geographical and human factors must be considered.

Primary level physicians and general hospitals must be involved in cancer control programmes if they are to provide optimal care, since in most cases patients will be examined and may be treated first at these levels. On the other hand, only a specialized and dedicated body, such as the oncology section of a university hospital or a comprehensive cancer centre, will have the necessary knowledge and resources to initiate and evaluate management programmes.

7.3 The principles of the management programme include optimal care for all, the optimal allocation of resources, the evaluation of medical practices and education. A management programme should have written and agreed guidelines for the care of a person with a certain medical problem. The objective of the management programme should be to extend the equal right for the best possible standard of care to everyone in all settings, given the available resources. This is achieved through defining the responsibilities of the people at each level of care, and the responsibilities for coordinating the activities of different levels and different disciplines.

The programme may cover all aspects of the disease and the treatment of the patient, including:

- the magnitude of the problem;
- the availability and feasibility of primary prevention and early diagnosis and treatment;
- referral routes;
- diagnostic work-up;
- treatment options in different stages of disease;
- rehabilitation and psychological and social support of the patient;
- follow-up procedures after treatment;
- evaluation of techniques; and
- updating the programme.

Further, management programmes support the education of physicians and of paramedical workers. The increasing cost of medical care and the economic recession necessitate the most effective allocation of financial resources. A management programme, therefore, should also critically evaluate the cost-effectiveness of present and proposed medical procedures. Such a

programme must also be flexible and should include means for the evaluation of procedures and updating of the programme itself. The mechanisms for evaluating technologies may include controlled clinical trials (see also Chapter 2, section 2.2.3).

7.4 Site or problem specificity. The general framework of a management programme for cancer care can probably be the same for cancers located at different sites. Likewise, the palliative and supportive management of patients with malignant diseases is generally similar, irrespective of tumour site. A management programme that deals with detection, diagnosis and treatment should probably be organized according to the site of the cancer, since different combinations of medical disciplines may be involved in the management of different diseases.

7.5 Mechanisms for evaluating and updating management programmes are essential. Both basic and applied research should be encouraged within the programme; research issues tend to increase the enthusiasm and interest of the participants. A management group must be responsible for the evaluation of the programme. At regular intervals, the group should report on the progress of the programme and suggest changes.

7.6 Mechanisms for development of management programmes. Since medical knowledge, traditions and systems vary between different countries and within countries, detailed management programmes should be developed in the regions where they will be implemented. A management programme has to be accepted by all care providers concerned. People at all levels should have an opportunity to influence the programme.

The management programmes should be included in the existing health service system. The health authority must appoint people to a board to set the priorities for development of treatment for different types of cancer or managerial programmes. The board should create a multidisciplinary group to define the actual problem, to identify the present role of each level in care and to suggest guidelines. An expert panel of representatives from all the specialties and all levels concerned should then define optimal care and work out the detailed programme.

7.7 Resources. Management programmes should use their resources as efficiently as possible. However, health authorities should recognize that adequate resources are required for the formulation, implementation and evaluation of management programmes. A coordinating office, preferably connected with an epidemiological and statistical unit and/or a cancer registry may give clerical and technical support to the management groups.

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## CHAPTER 8

### Evaluating cancer control programmes

#### 8.1 Overview

8.1.1 Definition. Programme evaluation is the process of assembling information and using it to judge the degree to which a programme is accomplishing its aims and objectives. While sophisticated techniques and methods can be used to evaluate a programme, evaluation is also an everyday process of considering the results of an action in light of its original intent, and drawing conclusions about its effectiveness. Formal programme evaluation makes this natural process a conscious effort, using objectives and scientific techniques for collecting and analysing data and making conclusions.

8.1.2 Purposes of evaluation. The primary purpose of evaluation is to assist health authorities and administrators, as well as programme managers, in making informed decisions about the relevance of the programme to the problem and the best utilization of resources for current and future programmes. Evaluation examines the past, but its objective is improving the efficiency of resource use in the future.

Evaluation is not a substitute for creativity and sound judgement. Once evaluation results are available, people must still interpret them and decide how they will be used to guide the programme.

A cancer control programme is the application of scientifically sound knowledge gained from basic, epidemiological and clinical research. Hypotheses about the links between risks and cancer, and about control measures, must be tested for effectiveness, feasibility, acceptance in controlled intervention trials and then in defined population studies before being used in the community. In this process evaluation is the bridge between research and the application of its results.

8.1.3 Outcomes. What are the best indicators of a programme's results? Ideally, the ultimate objectives and therefore the basic measures of the benefits of a cancer control programme are the improved health of the population, including changes in incidence, and a reduction in mortality.

However, the direct measurement of such cancer rates is often impossible in an evaluation, due to the time lag between implementation and its effects. Such outcomes as reduction in exposure to risk factors, increased survival and a shift to a more favourable stage distribution of diagnosed cases should also be included as indicators of immediate effects. However, in measuring the effect of screening programmes, indicators such as survival and stage distribution have limited value. Increased survival is unreliable because of lead-time bias,<sup>a</sup> and length bias<sup>b</sup> limits a favourable shift in stage distribution.

It will often be impossible to quantify results in terms of these measures, and other results, such as the number of smears taken, the number of cases treated, and the proportion of the target population informed may be used instead.

8.1.4 Four types of evaluation can be done.

8.1.4.1 Pretesting is the limited testing of the programme's methods and procedures before they are used in the national programme.

8.1.4.2 Process evaluation examines the concrete actions of the programme and how they were taken.

8.1.4.3 Outcome evaluation describes the immediate results of those actions.

<sup>a</sup> Lead-time bias. Because screening advances the date of diagnosis, the time interval between diagnosis and death is extended even if the time when death occurs is not altered. Therefore, people seem to survive longer because their disease was detected earlier.

<sup>b</sup> Length bias. Screening tests detect cases in the preclinical or asymptomatic stage and the length of time spent in that stage by different tumours depends upon their growth rates. Fast growing tumours will progress rapidly through that stage and are less likely to be detected by infrequent screening. Therefore, screening seems more effective than it is, since a disproportionate number of slow-growing tumours with good prognosis will be detected.

8.1.4.4 Impact evaluation is the most comprehensive, difficult and expensive type of evaluation because it is an examination of the long-range results of the programme, including its effects on rates of the incidence and mortality of cancer.

The availability of technical experts and resources will influence the choice of the types of evaluation to be done. However, impact evaluation is particularly important for avoiding the waste of scarce resources on ineffective strategies.

8.1.5 Scope of evaluation. National cancer control programmes generally consist of many components (see also Chapter 1, section 1.4) carried out to different extents in different geographic areas. What parts of the programme will be evaluated?

8.1.5.1 The evaluation of a national programme should monitor national cancer rates. A national programme is effective only if the desired changes in cancer rates occur (see also Chapter 2, section 2.1.3). In addition, evaluation should focus on process measures and give national programme managers complete information on the extent to which various components of the national programme are being implemented uniformly, effectively and efficiently.

8.1.5.2 An evaluation of the components of a national programme should be done regularly, particularly when the components are new or have been substantially changed. Process, outcome and, if possible, impact evaluation should be conducted in these cases. If a programme component is to be implemented throughout the country, evaluating it in only one or two geographic areas may be most efficient. Ideally, this would be done before full-scale, national implementation. Once the outcome and impact indicators of a programme component are chosen, programme managers can do process evaluation themselves.

8.1.6 Timing. A successful evaluation must be planned and carried out at the same time as the programme. The evaluators must be involved in the planning process (see also Chapter 5, section 5.2.5). One of the biggest and most common mistakes in evaluation is to implement a programme and attempt to evaluate it afterwards. The first step in evaluation is collecting unbiased data.

8.2 Evaluation prerequisites. The commitment or will to evaluate is the first prerequisite for evaluation.

8.2.1 Objectives. Clearly stated, measurable objectives and carefully selected end points of investigation must be established before an evaluation or a programme can be effective (see also Chapters 1 and 5).

8.2.2 Information requirements for programme evaluation, as well as the sources of information, are described elsewhere in this document (see Chapter 2).

8.2.3 Appropriate methods should be used to evaluate each item of the cancer control programme. Methods of appraising the economic aspects of a cancer control programme are described in Annex 1.

8.2.4 Technical expertise. Knowledgeable and independent people, with sound scientific judgement, creativity and sensitivity to programme requirements, are essential for a successful evaluation. Programme managers could also use the knowledge gained by other countries in evaluating their programmes.

8.2.5 Resource commitment. Complete evaluations can be expensive; on the other hand, some process and even outcome data may be available at very little cost. Considering that it prevents the use of inefficient methods, all evaluation is cheap in the long run. Anyhow, programme managers should commit some resources to evaluation, particularly for obtaining competent evaluators. Nevertheless, any programme should undertake some evaluation.

8.3 Steps in programme evaluation. An evaluation should follow the steps discussed below.

8.3.1 Choosing programme objectives. Evaluation staff should be included in the earliest discussions on the objectives of the programme because they will help planners choose measurable objectives for the programme.

8.3.2 Allocating resources. Evaluators should know about the resources allocated to the programme if they are to interpret its results accurately, particularly when they must decide if a failure was due to the programme itself or the resources allocated for its implementation. The evaluator must also know exactly which resources are available for the evaluation, since these will limit the choice of specific methods and end points.

8.3.3 Choosing evaluation objectives. The information that the evaluation is expected to provide for decision-makers and programme managers must be clearly defined in advance. The items to be evaluated and the measures used to evaluate them must also be indicated.

Both the total cancer control programme and its separate components should be evaluated. Information services, the managerial process, training, research and technologies may also be examined, but the main subject of evaluation, however, remains the programme's objectives.<sup>a</sup>

Specific and meaningful questions must be formulated for evaluating each programme element and activity.

8.3.4 Selecting measurement criteria. What will evaluators measure to determine if the programme objectives have been met?

The people who select measurement criteria must consider the resources available for the evaluation, the needs of decision-makers and programme managers, and how much is already known from the scientific state-of-the-art. Evaluators may use measures of both process and outcome evaluation including the proportion of target population screened, informed and properly treated, the stage distribution of the cases of cancer and changes in cancer rates. When feasible, incidence and mortality rates should be used to measure the programme's impact, and the use of other indicators must be adequately justified.

As well as the usefulness and effectiveness of the programme, the provision of services and use of resources should also be evaluated (see also Chapter 10).

8.3.5 Determining an appropriate evaluation plan. The evaluation design used for a given programme should suit the objectives of the evaluation and must allow the evaluators to answer the questions posed by the decision-makers and programme managers. The method chosen depends, furthermore, on the availability of information, technical expertise and resources. Once the plan of evaluation is made, it must be followed to the end.

8.3.6 Choosing instruments and methods of measurement. This step is absolutely essential if valid and reliable evaluation results are to be obtained. Evaluators should attempt to apply evaluation methods that have already been tested and standardized to reduce costs and increase the validity and reliability of results.

8.3.7 Collecting, processing and analysing data. The quality of the data to be examined should be high and the evaluation plan should include steps to ensure this. Careful attention should be given to ensuring that the data is analysed correctly. Experts in bio-statistics can help evaluators use the appropriate statistical tests correctly.

8.3.8 Analysing and reporting results. The extent to which programme objectives are being met will be assessed. The results and findings of the evaluation must be expressed so that decision-makers and programme managers can use them to make policy and management decisions. Also, recommendations based on the interpretation of results should indicate how to improve the effectiveness of the programme's components and the programme as a whole.

Every effort should be made to share evaluation results with cancer control experts in other regions and countries.

Evaluation should be used to show non-health sectors and agencies how they can contribute to cancer control programmes.

8.3.9 Continuous process evaluation. Evaluating the success of the programme, along with ways to improve the programme, should be a continuous process. Such monitoring reveals shortcomings in planning and deviations of the implemented programme from the plan. Thus managers can use evaluation to identify problems in the programme and justify the changes that will solve them.

Evaluation is necessary not only to monitor trends in cancer incidence and to assess the impact of control programmes as they are introduced, but it is also to re-assess periodically the national cancer control policy and strategy in the light of the changing burden of cancer on the society and knowledge about cancer (see also Chapter 4, section 4.5).

<sup>a</sup> Most of the methods used in the cancer control programme of one country may already have been evaluated in others or in evaluation projects run by international agencies.

8.4 External and internal evaluation. An evaluator must have knowledge, independence and good judgement. Programme managers will normally be responsible for requesting an evaluation. A team, led and controlled by an independent external evaluator, but including experts with knowledge of the field and programme managers, can evaluate a programme most effectively.

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## CHAPTER 9

### Resource allocation: planning manpower for a cancer control programme

#### 9.1 Manpower development

9.1.1 Manpower development should be an inherent part of the national health policy and an integral part of the development of cancer control services and programmes.

9.1.2 Manpower is one of the essential resources of a cancer control programme. The resource allocation for the programme should include the provision of manpower.

9.1.3 The process of manpower development includes

- planning or specifying the quantity and quality of manpower needed;
- producing manpower by arranging for the training of adequate numbers of people; and
- managing manpower, to use it most efficiently.

#### 9.2 Planning manpower

9.2.1 Planning manpower for a cancer control programme is an essential element of the planning process.

9.2.2 The manpower plan should provide the quantity and quality of people needed for cancer control services, in both the present and the future.

9.2.3 Quantitative requirements

9.2.3.1 The planning should be based on information on:

- current and projected rates of cancer incidence in the period covered by the plan; and
- current and projected data on the population served by cancer control services.

9.2.3.2 An inventory of existing manpower should be made, indicating the number of people currently available in each component of cancer control, in each category of personnel and at all levels of cancer control services, broken down by age, sex, specialty, institution and geographical distribution.

9.2.3.3 The need for each kind of personnel in the period of time covered by the plan should then be estimated. Both expected increases, and depletion in manpower, as well as temporary fluctuations, must be considered.

9.2.3.4 The most efficient use of manpower must be kept in mind in planning the division of responsibilities between professional groups and specialties and the functions that can be performed by properly trained paramedical personnel.

9.2.3.5 Planners should consider the numbers and kinds of personnel necessary to the programme when planning training facilities.

9.2.4 The requirements for developing manpower for cancer control are essentially identical to those in other areas of health care. The planning should reflect the shift from the high-technology clinical medicine practised in hospitals to the provision of control measures in the community, as well as the shift from purely curative to preventive medicine.

#### 9.3 Production of manpower

9.3.1 The resources and facilities required for the regular training of each category of personnel should be allocated in the planning process (see also Chapter 5).

9.3.2 In planning adequate training of personnel, attention should be given to:

- the needs of all components of cancer control, including prevention, early detection, clinical patient management, after-care, rehabilitation and the managerial process;

- all levels of provision of cancer control measures, including care in community settings, at the primary level, in general hospitals and in specialized cancer centres; and
- all categories of personnel, including physicians, nurses and technicians.

9.3.3 Continuing education programmes should be specifically designed for professional groups, including:

- specialists in oncology such as medical oncologists, radiotherapists, oncological surgeons, oncological gynaecologists and cyto-pathologists;
- specialists other than oncologists such as pathologists, internists, surgeons, radiologists and gynaecologists, engaged in cancer patient management outside the specialized cancer control services;
- primary level physicians, who have a key role in diagnosing disease and referring people to the appropriate level of care, and in after-care, rehabilitation and public education;
- nurses in both hospitals and the community; and
- paramedical personnel, such as cytotechnologists and others engaged in mass-screening and early detection programmes

9.3.4 As indicated elsewhere in this document, manpower requirements in management and gathering information for cancer control should also be considered.

9.3.5 Because of the growing importance of public education and lifestyle in cancer control, special attention should be given to the training of health educators and behavioural scientists engaged in cancer control programmes.

9.3.6 Planners should set up a means of cooperation with other health sectors, such as cardiovascular disease prevention and control programmes, planning manpower and evolving curricula for training. For example, different health services could share manpower, in cooperative activities such as integrated programmes for prevention of noncommunicable disease.

9.3.7 The multisectoral planning and training of manpower, particularly for primary cancer prevention programmes may be possible. Efforts should be made to inform people in non-health sectors about the implications of the activities in their own sectors for cancer control.

#### 9.4 Management of manpower

9.4.1 A specialist subcommittee or working group responsible for planning manpower appropriately should be set up within both the national advisory committee and the planning team, to use manpower more efficiently.

9.4.2 Programme managers responsible for the implementation of the cancer control programme and those responsible for training personnel should cooperate in adjusting the production of manpower to the changing needs of the cancer control programme.

9.4.3 Both the changing knowledge on cancer and the advances in technology should be considered in keeping training curricula up to date.

9.4.4 The process of manpower development should be regularly evaluated.

9.4.5 Trained personnel should be placed in the programme where they are most needed and can be most efficient.

9.4.6 In order to guarantee the most efficient management of manpower in cancer control programmes, health services research should discover the best distribution of duties among personnel and the numbers of people necessary to perform them.

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## Annex 1

### RESOURCE ALLOCATION: ECONOMIC APPRAISAL

1. Resource allocation: making a choice. Choices in resource allocation and in cancer control cannot be avoided. To make these choices, planners must ask themselves:

- how to achieve a particular objective
- whether the attempt should be made; and
- how far to pursue the objective.

1.1 Reasons for the need to choose. These questions must be answered because resources are limited, the needs and demands of programmes are greater than can be met with the resources available, and resources should be used as efficiently as possible.

1.2 These three considerations should be examined separately to highlight the economic appraisal techniques that can be used in deciding on the allocation of resources. This annex briefly explains the analytical tools that economists use to try to resolve each of these issues: cost-effectiveness analysis, cost-benefit analysis and marginal analysis. In conclusion, the annex highlights the need for appropriate organizational policies in health care that promote economic appraisal and thereby efficiency.

## 2. Appraisal techniques

### 2.1 Cost-effectiveness analysis

The aim of cost-effectiveness analysis is to determine how a policy is to be implemented. Such analysis should answer two questions. Given an objective, how can it best be achieved? How can a budget for a particular objective best be spent?

Ideally, the requirements of a cost-effectiveness analysis are:

- a clear definition of the nature of the objective in terms of what it will accomplish, such as reductions in morbidity or mortality;
- a list of all the possible ways to meet the objective;
- information on the relative effectiveness of the different options; and
- inclusion and measurement of all costs arising from the options no matter on whom they fall.

Some of the practical issues that arise in using cost-effectiveness analysis include the following. What benefits will be lost because of the rejection of other options? What are the costs of the options being considered, including marginal costs? Will intermediate outputs<sup>a</sup> such as numbers of cases treated, have to be used instead of outcomes<sup>b</sup> or final outputs? Will data on effectiveness be readily available? Finally, are all costs measurable in money?

Cost-effectiveness analysis is relatively simple to apply but it can only address questions of how rather than whether or how much.

### 2.2 Cost-benefit analysis

A cost-benefit analysis should determine whether a policy should be implemented. A policy is valuable only if the advantage gained justifies the sacrifice involved. The aim is thus to maximize the benefit to society from the resources available and to compare disadvantages and advantages in the same terms.

<sup>a</sup> An output is defined here as the amount of benefit or the effect produced as a result of the use of certain resources.

<sup>b</sup> An outcome is the actual result of a certain activity and represents one of the major measures in the assessment of the effectiveness.

The four factors required for cost-effectiveness analysis (see section 2.1) are also requirements for a cost-benefit analysis. Hence, since costs are frequently expressed in money, benefits should be measured in the same terms.

The main practical issues of cost-benefit analysis are the same as those involved in cost-effectiveness analysis (see 2.1), with the additional consideration of the monetary values placed on such health outputs as human life.

In many circumstances the choices are not as uncomplicated as the technique. Measuring benefits and value is difficult but cannot be avoided. There is no denying the necessity of choosing among, and hence of at least tacitly valuing, benefits. Thus if planners decide to allocate a certain amount of money to a programme, then, by implication, they value the benefits of that programme at a sum at least equal to the expenditure.

### 2.3 Marginal analysis

A marginal analysis should determine how far a programme should be pursued. The aim, set in terms of cost-benefit analysis at the margin, is to assist in determining whether more or less should be spent on a particular programme.

The requirements of a marginal analysis are the same as those of cost-benefit analysis (see section 2.2) but concerned with the costs and benefits of changing the overall size of a programme.

The practical issues, given the emphasis on the size of programmes, are the same as those of cost-benefit analysis (see section 2.2).

The principle of marginal analysis is simply that resources should be transferred from one programme or programme component to another until a point is reached where the benefit lost by the decreased expenditure in the first programme or programme component exactly equals the benefit gained by the increased expenditure in the other. This occurs when programmes or programme components have exactly the resources they need to be of maximum benefit, and no more.

2.4 General comments on techniques. If it were possible to measure and value all costs and benefits in money, many of the problems of health care planning would be much smaller. Since it is not, difficulties remain. In the less-than-ideal world in which these techniques are used, the thinking behind the economic appraisal is the most important part of the process.

Judgements are made in any system of resource planning, but these economic appraisal techniques can persuade decision-makers to judge the relevant issues and force them to be explicit about why they value one output more than another. Such clear thinking can be useful in the rational and efficient allocation of scarce health care resources.

3. Applications in cancer control programmes. Although these techniques of economic appraisal are useful in evaluating different elements of cancer control programmes they seem to have been applied in studies of screening programmes and the treatment of cancer quite seldom.

4. Promoting economic efficiency. The desirability of the acceptance of the need for rational evaluation in health care, and especially in cancer control programmes, cannot be overemphasized. Such acceptance requires that the planners and evaluators of cancer control programmes have an increased awareness of the need for economic appraisal in cancer control programmes and an improved knowledge of economic appraisal techniques.

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