

National Cancer Control Programmes

Policies and managerial guidelines

2nd Edition



World Health Organization

NATIONAL
CANCER
CONTROL
PROGRAMMES

POLICIES AND MANAGERIAL GUIDELINES



WORLD HEALTH ORGANIZATION
GENEVA

WHO Library Cataloguing-in-Publication Data

National cancer control programmes : policies and managerial guidelines. – 2nd ed.

1. Neoplasms – prevention and control 2. National health programs – organization and administration
3. Health policy 4. Guidelines

(ISBN 92 4 154557 7)

(NLM classification: QZ 200)

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Editing, layout and design by Health & Development Networks (HDN) · <http://www.hdnet.org>

Printed in Italy.

Cover design by Marilyn Langfeld.

ACKNOWLEDGEMENTS

The second edition of this monograph has been produced by the Cancer Control Programme of the Department of Management of Noncommunicable Diseases which forms part of the cluster dealing with Noncommunicable Diseases and Mental Health at WHO headquarters, Geneva. It was developed following a meeting on national cancer control programmes in developing countries, held in Geneva in December 2000. Participants in this meeting, and two earlier meetings to discuss national cancer control programmes are listed at the end of this report.

Editorial guidance for both editions has been provided by Anthony Miller. Kenneth Stanley provided editorial assistance for the second edition.

A number of people, who were invited to contribute after the December 2000 meeting, reviewed specific sections and made valuable contributions. These include: David Hunter, Harvard School of Public Health; David Joranson, WHO Collaborating Center for Policy & Communications in Cancer Care; Jacob Kligerman, Brazilian National Cancer Institute; Stener Kvinnsland, International Union Against Cancer; C. Victor Levin, International Atomic Energy Agency; Neil MacDonald, Centre for Bioethics at the Clinical Research Institute of Montreal; Charles Olweny, St Boniface General Hospital; Max Parkin and R.Sankaranarayanan, International Agency for Research on Cancer; Inés Salas, University of Santiago; and, from WHO, Rafael Bengoa, Ruth Bonita, Vera Da Costa e Silva, Maximilien De Courten, JoAnne Epping-Jordan, Silvana Luciani, Nejma Macklai, Maristela Monteiro, Desmond O'Byrne, Sonia Pagliusi Uhe, Pirjo Pietinen, Pekka Puska, Eva Rehfuss, Sylvia Robles, Benedetto Saraceno, Derek Yach, Tokuo Yoshida, and Mohamed Maged Younes.

The team members from the Programme on Cancer Control who worked on this edition were Amanda Marlin, Cecilia Sepúlveda and Andreas Ullrich. Secretarial work was done by Maryann Akpama. The report was edited by Angela Haden and Health & Development Networks. Layout and design by Health & Development Networks.

Executive Summary

MESSAGE FROM THE DIRECTOR-GENERAL OF THE WORLD HEALTH ORGANIZATION

CANCER. The word still conjures up deep fears of a silent killer that creeps up on us without warning. Cancer, evoking such desperation that it has become a metaphor for grief and pain, a scourge straining our intellectual and emotional resources. The numbers are such that each of us will be touched either as a patient, a family member or a friend. There are over 20 million people living with cancer in the world today. The majority live in the developing world.

Yet, there is much that can be done in every country to prevent, cure and relieve this suffering. With the existing knowledge it is possible to prevent at least one-third of the 10 million cancer cases that occur annually throughout the world. Where sufficient resources are available, current knowledge also allows the early detection and effective treatment of a further one-third of those cases. Pain relief and palliative care can improve the quality of life of cancer patients and their families, even in very low resource settings thanks to effective, low-cost approaches.

Understanding and controlling malignant disease have very broad dimensions. It involves scientific knowledge and experience ranging from the complexities of intracellular molecular regulation to individual lifestyle choices. It also requires competent management and the best use of available resources for planning, implementing and evaluating disease control strategies. Cancer prevention and control are among the most important scientific and public health challenges of this era.

Our goal is to reduce the morbidity and mortality from cancer and improve the quality of life of cancer patients and their families, everywhere in the world where the cancer burden is high or there are rising trends of cancer risk factors. We have learned that no matter what resource constraints a country faces, a well-conceived, well-managed national cancer control programme is able to lower cancer incidence and improve the lives of people living with cancer. A comprehensive national cancer programme evaluates the various ways to control disease and implements those that are the most cost-effective and beneficial for the largest part of the population. It should promote the development of treatment guidelines, place emphasis on preventing cancers or detecting cases early so that they can be cured, and provide as much comfort as possible to patients with advanced disease.

We already know that at least one-third of all the new cases of cancer every year can be prevented. Tobacco, the single largest preventable cause of can-

cer in the world today, is responsible for about 30% of all cancer deaths in developed countries and a rapidly rising proportion in developing countries and in underprivileged communities. It is the only consumer product available which kills half its regular users.

In addition to strong, comprehensive tobacco control measures, dietary modification is another important approach to cancer control. Overweight and obesity are both serious risk factors for cancer. Diets high in fruits and vegetables may reduce the risk for several types of cancer, while high levels of preserved and red meat consumption are associated with increased cancer risk.

Our era has seen and continues to see great scientific advances in cancer treatment. Treatment for some cancer sites is becoming increasingly effective, yet poor availability of treatment and delays in seeking medical attention contribute to lower survival rates in many developing countries. Increasing awareness of the signs and symptoms of cancer is important to facilitate early detection of the disease. Where appropriate tests and facilities are available, screening of apparently healthy individuals can disclose cancer in early or precursor stages, where treatment may be most effective. But all too often, limited resources are used to treat patients with far-advanced disease, who really do not benefit from the treatment.

We have also learned important lessons in the field of palliative care. Millions of people around the world suffer not only from cancer, but from other chronic, life-threatening conditions in advanced stages. In these cases where prevention efforts have failed and patients and their families have little access to curative treatment, the devastation is great. These diseases affect people on all human dimensions: physical, psychological, social and spiritual. Solitude and stigma only add to physical suffering. Fortunately, there are low-cost, community approaches that can reduce this suffering and meet this urgent humanitarian need. Measures for good palliative care are essential elements in every national cancer control programme.

WHO's approach to noncommunicable disease prevention and control places emphasis on the rising impact of cancer in low-income and middle-income countries, and the disproportionate suffering it causes in poor and disadvantaged populations. Two years ago we reviewed the progress in implementing national cancer control programmes, as part of a strategy launched about a decade ago. Based on experience from Member States and our collaboration with other partners, we discussed the strengths and constraints of this strategy. While many Member States recognize the need to develop national cancer control programmes, few in the industrialized world and even fewer in developing countries have yet done so. As a result many people die from preventable cancers and suffer unnecessarily from pain and anguish at the end of their lives.

Lack of a comprehensive, systematic approach, weaknesses in organization and priority-setting, and inefficient use of resources are obstacles to effective programmes in both industrialized and developing countries. In far too many cases, primary prevention, early detection and palliative care are neglected in favor of treatment-oriented approaches, regardless of whether they are actually cost-effective or whether they improve patients' quality of life. This happens because of lack of knowledge, lack of political will and lack of national capacity in policy development and programme implementation.

I believe it is the responsibility of the World Health Organization to dig deep to find the best knowledge on cancer control and to facilitate the sharing of successful country experiences among governments and other partners. As the world's leading repository of public health knowledge, we are committed to translating this knowledge into action. But we must work with others – health is a shared responsibility.

We have initiated a process for promoting and reinforcing the development of national cancer control programmes as the best known strategy to address the cancer problem worldwide. Updating and disseminating effective policies and guidelines on national cancer control programmes and providing guidance on the development of these programmes are key components of this strategy.

This document presents WHO's latest recommendations and findings. This edition will provide an updated framework for policy development and programme management that can be adapted to socioeconomic and cultural contexts in all countries. It provides the information needed to guide the development of feasible, equitable, sustainable, and effective national cancer control programmes.

I know what we are seeking to do is not easy. But the constraints and difficulties are far outweighed by the opportunities to reduce the death and suffering caused by cancer. I hope this report makes a contribution to ending the isolation and desperation of cancer patients on the one hand and strengthening national options for comprehensive cancer control on the other. I believe we can act, and we must.

Gro Harlem Brundtland
Geneva
May 2002

PREFACE FROM THE SECRETARY GENERAL OF THE INTERNATIONAL UNION AGAINST CANCER

CANCER IS AND WILL BECOME an increasingly important factor in the global burden of disease in the decades to come. The estimated number of new cases each year is expected to rise from 10 million in 2000 to 15 million by 2020. Some 60% of all these new cases will occur in the less developed parts of the world.

Improved cancer control will, to a substantial degree, relate to prevention strategies and early detection programmes, including information campaigns and population-based screening programmes. Success of the early detection programmes will rely on effective and optimal use of treatment possibilities. In spite of the explosion in knowledge of tumour biology, another decade will probably elapse before its application through new drugs and treatment principles will significantly reduce cancer mortality. The aspects of cancer control must therefore be seen within the context of a systematic and comprehensive approach, that is, the cancer control plan or strategy.

Forces in the fight against cancer include the government sector, the nongovernmental sector, the private sector and the professional organizations. Their common objective is to reduce morbidity and mortality from cancer. Each sector plays an important role within a national cancer control programme/plan/strategy, though the relative extent of that role varies depending on the situation in the country.

The nongovernmental sector is involved in cancer research, cancer registration, cancer prevention activities, treatment and care facilities, and programmes. This involvement implies either direct provision of the services or acting as funding institutions. Again, the extent of the different activities will vary from country to country. In some countries, funds for treatment come from the national government and funds for disease prevention and screening come from the state government. In other countries, nongovernmental organizations focus on the prevention and early detection of cancer. It is very important for all organizations to be aware of the complexity of cancer control, and of the role they should play in achieving the goals of the cancer control programme or strategy, through a unified effort with other sectors.

The nongovernmental sector is an important source of technical know-how, skills and resources relevant for cancer care and research. Furthermore, nongovernmental organizations provide an important ability to reach out to the professional and public communities. Community participation in

cancer care is essential. This need is particularly acute in the developing countries, given the constrained resources and operational limitations of the government health care systems. Major portions of healthcare budgets in developing countries, which are largely insufficient to begin with, are dedicated to the control of communicable diseases, leaving small margins for allocation to noncommunicable disease control programmes. Nongovernmental and voluntary organizations can, therefore, play a significant role in assisting the efforts of the government health system in reducing disparities in coverage with regard to cancer care services.

In close collaboration with the World Health Organization, the International Union Against Cancer (UICC) promotes the participation of nongovernmental organizations in the development and implementation of national and regional cancer control strategies, and helps to build the capacity in these organizations in the areas of cancer prevention and early detection, particularly through educational and training programmes. By its participation in establishing a national cancer control strategy or plan, the nongovernmental sector will be able to better understand its own role in providing cancer care services, including support of cancer research. The comprehensive and systematic approach to the cancer problem, as presented in a national cancer control programme, gives all providers of cancer care and research the optimal possibility of giving the right focus and proportions to their own work.

The second edition of the WHO publication on national cancer control programmes is an important tool in promoting cancer control strategies. The different elements of a cancer plan are well described, and appropriate organizational aspects discussed. As was the case with the first edition, this publication will be of great value for the establishment and implementation of national cancer control plans.

Stener Kvinnsland
Oslo
May 2002

FOREWORD

THIS MONOGRAPH aims to provide a framework for the development of national cancer control programmes. Its underlying approach is the application of science to public health practice, providing a concise statement of what is feasible and desirable in cancer prevention and control, with the ultimate goal of reducing cancer morbidity and mortality, and improving quality of life in the targeted population. It is intended primarily for policy-makers in health and related fields, but will also be of interest to health ministries and academic institutions and, more generally, to oncologists and other health professionals who need to be aware of developments in cancer control.

The first edition of this monograph was produced following the meeting of a Working Group on National Cancer Control Programmes, 25–29 November 1991, at WHO headquarters in Geneva, Switzerland. The second edition of this monograph has been produced by the Cancer Control Programme of the Department of Management of Noncommunicable Diseases, WHO, following a meeting on national cancer control programmes in developing countries, held in Geneva in December 2000. Editorial guidance for both editions has been provided by Professor Anthony B. Miller. Dr Kenneth Stanley provided editorial assistance for the second edition. We would also like to acknowledge the seminal work of Dr Jan Stjernswärd, former Chief of the WHO Cancer Unit. While it is not possible to acknowledge all contributions of the countless individuals and organizations that gave so freely of their expertise, the participants at the major WHO meetings on the theme of this monograph are listed at the end of this report.

The timeliness of this updated publication is underlined by the fact that the World Health Organization has designated noncommunicable diseases, including cancer, as a priority area. Moreover, WHO Member States, in their work towards health for all, are continuing to formulate and implement national health strategies, of which plans for cancer control must form an increasingly important part. The WHO regional offices, and the WHO country representatives throughout the world, are providing valuable technical assistance for these initiatives.

In developing national cancer control programmes, it will be important for each country to create optimal conditions while undertaking a strategy development process for cancer control. These conditions include politi-

cal will and commitment, collaboration among key national organizations, participatory processes in programme planning, critical assessment of the scientific evidence and costs of proposed programmes, and an approach based on maximizing the desired outcome, principally reduction in mortality from cancer. WHO can play a facilitating role with member countries that decide to develop or revise a national cancer control programme, by collaborating with them to advocate cancer control as a priority public health issue, by providing technical assistance during the development and implementation of cancer control guidelines, interventions and strategies, and by assisting with evaluation of programmes.

While this monograph provides guidance about what elements should be taken into account in establishing and maintaining national cancer control programmes, we are conscious that it does not provide comprehensive operational models for how to implement these recommendations. Although many countries will be able to successfully adapt the present guidelines to their particular situations, others, especially those with complex realities and constrained resources, will need further guidance in applying effective, operational methodologies for assuring adequate and sustainable performance of national cancer control programmes.

Considering this, and the suggestions from experts involved in revising this monograph, efforts will be made in the near future to develop a complementary volume that will focus on the “how”, based on successful demonstration areas and specialized expertise. We are certain that such an initiative will be useful for those facing more challenging settings.

Cecilia Sepúlveda
Coordinator, Cancer Control Programme
World Health Organization
Geneva

EXECUTIVE SUMMARY

THIS MONOGRAPH outlines the scientific knowledge that is the basis for national cancer control programmes, and offers guidance on their establishment and organization. Much of its content derives from experience gained in the various countries that have already instituted or are planning their own national cancer control programmes.

Enough is now known about the causes of cancer and means of control for suitable interventions to have a significant impact. At least one-third of the 10 million new cases of cancer each year are preventable by such means as controlling tobacco and alcohol use, moderating diet, and immunizing against viral hepatitis B. Early detection, and therefore prompt treatment, of a further one-third of cases is possible where resources allow. Effective techniques are sufficiently well established to permit comprehensive palliative care for the remaining, more advanced, cases. The establishment of a national cancer control programme, tailored to the socioeconomic and cultural context, should allow countries to effectively and efficiently translate the present knowledge into action.

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

The nature of cancer

The term cancer is used generically for more than 100 different diseases including malignant tumours of different sites (such as breast, cervix, prostate, stomach, colon/rectum, lung, mouth, leukaemia, sarcoma of bone, Hodgkin disease, and non-Hodgkin lymphoma). Common to all forms of the disease is the failure of the mechanisms that regulate normal cell growth, proliferation and cell death. Ultimately, there is progression of the resulting tumour from mild to severe abnormality, with invasion of neighbouring tissues and, eventually, spread to other areas of the body.

The disease arises principally as a consequence of exposure of individuals to carcinogenic (cancer-causing) agents in what they inhale, eat and drink, and are exposed to in their work or environment. Personal habits, such as tobacco use and dietary patterns, rather than inherited genetic factors, play

the major roles in the etiology of cancer, as may occupational exposure to carcinogens and biological factors such as viral hepatitis B infection and human papillomavirus infection. Knowledge of many of these factors can serve as the basis of cancer control. Vaccination against hepatitis B, for instance, can protect against liver cancer.

Cancer is profoundly associated with social and economic status. Cancer risk factors are highest in groups with the least education. In addition, patients in the lower social classes have consistently poorer survival rates than those in the higher social classes.

The burden of cancer

Of the 10 million new cancer cases each year, 4.7 million are in the more developed countries and nearly 5.5 million are in the less developed countries. Although the disease has often been regarded principally as a problem of the developed world, in fact, more than half of all cancers occur in the developing countries. In developed countries, cancer is the second most common cause of death, and epidemiological evidence points to the emergence of a similar trend in developing countries.

Cancer is currently the cause of 12% of all deaths worldwide. In approximately 20 years time, the number of cancer deaths annually will increase from about 6 million to 10 million. The principal factors contributing to this projected increase are the increasing proportion of elderly people in the world (in whom cancer occurs more frequently than in the young), an overall decrease in deaths from communicable diseases, the decline in some countries in mortality from cardiovascular diseases, and the rising incidence of certain forms of cancer, notably lung cancer resulting from tobacco use. Approximately 20 million people are alive with cancer at present; by 2020 there will probably be more than 30 million.

The impact of cancer is far greater than the number of cases alone would suggest. Regardless of prognosis, the initial diagnosis of cancer is still perceived by many patients as a life-threatening event, with over one-third of patients experiencing clinical range anxiety and depression. Cancer can be equally if not more distressing for the family, profoundly affecting both the family's daily functioning and economic situation. The economic shock often includes both the loss of income and the expenses associated with health care costs.

Prevention of cancer

Prevention means eliminating or minimizing exposure to the causes of cancer, and includes reducing individual susceptibility to the effects of such

causes. It is this approach that offers the greatest public health potential and the most cost-effective long-term cancer control.

The present and potential burden of tobacco-induced cancer is such that every country should give highest priority to tobacco control in its fight against cancer. Tobacco use in all forms is responsible for about 30% of all cancer deaths in developed countries, and this percentage is rising steadily in developing countries, particularly in women. The best approach to preventing tobacco-related cancer is preventing the uptake of tobacco. Tobacco dependence is listed in the WHO ICD-10 as a chronic condition. Tobacco is responsible for 80–90% of all lung cancer deaths, and probably some of the deaths from cancer of the oral cavity, larynx, oesophagus and stomach. In some Asian countries, oral cancer is a common tumour, and is associated with tobacco chewing habits. A comprehensive strategy involving legislative action to raise the tax on tobacco products and limit access and promotion, education of youth and adults to promote healthy life styles, and cessation programmes has a demonstrated ability to reduce tobacco consumption in many countries.

In recent years, substantial evidence has pointed to the link between overweight and obesity to many types of cancer such as oesophagus, colorectum, breast, endometrium and kidney. It is therefore strongly recommended to control weight and to avoid weight gain in adulthood by reducing caloric intake and by performing physical activity. The latter has also been seen to have a protective effect in reducing the risk of colorectal cancer. The composition of the diet is also important since fruit and vegetables might have a protective effect by decreasing the risk for some cancer types such as oral, oesophageal, gastric and colorectal cancer. High intake of preserved meat or red meat might be associated with increased risk of colorectal cancer. Another aspect of diet clearly related to cancer risk is the high consumption of alcoholic beverages, which convincingly increases the risk of cancer of the oral cavity, pharynx, larynx, oesophagus, liver and breast.

Thus, conducting a cancer prevention programme, within the context of an integrated noncommunicable disease prevention programme, is an effective national strategy. Tobacco use, alcohol, nutrition, physical inactivity, and obesity are risk factors common to other noncommunicable diseases, such as cardiovascular disease, diabetes, and respiratory diseases. Chronic disease prevention programmes can efficiently use the same surveillance and health promotion mechanisms.

Occupational and environmental exposure to a number of chemicals can cause cancer of a variety of sites; examples include lung cancer (asbestos), bladder cancer (aniline dyes), and leukaemia (benzene). A number of infections or infestations cause certain types of cancer: viral hepatitis B and C cause cancer of the liver, human papilloma virus infection causes cervical cancer,

the bacterium *Helicobacter pylori* increases the risk of stomach cancer, while in some countries the parasitic infection schistosomiasis increases the risk of bladder cancer, and in other countries liver fluke infection increases the risk of cholangiocarcinoma of the bile ducts. Exposure to ionizing radiation is also known to give rise to certain cancers, and excessive solar ultraviolet radiation increases the risk of all types of cancer of the skin.

National policies and programmes can be enacted to reduce exposure to these risks and implement preventive interventions. Care needs to be taken to ensure that the public has a clear understanding of these major risks and is not overwhelmed by the minor risks that are described in their local media on a virtually daily basis.

Early detection of cancer

Early detection comprises early diagnosis in symptomatic populations and screening in asymptomatic, but at risk, populations. Increasing awareness of the signs and symptoms of cancer contributes to detection of the disease in less advanced stages. Where tests for cancer of specific sites are available, and facilities are appropriate, screening of apparently healthy individuals can disclose cancer in early or precursor stages, when treatment may be most effective. Early detection is only successful when linked to effective treatment.

With early detection, there is a greater chance that curative treatment will be successful, particularly for cancers of the breast, cervix, mouth, larynx, colon and rectum, and skin. It is therefore critical that people are taught to recognize early warning signs of the disease, such as lumps, sores that fail to heal, abnormal bleeding, persistent indigestion, and chronic hoarseness, and urged to seek prompt medical attention. This can be promoted in all countries by public health education campaigns and through training of primary health care workers.

Population screening (mass application of simple tests to identify individuals with asymptomatic disease) is another approach to early detection. However, screening programmes should be undertaken only when their effectiveness has been demonstrated, when resources (personnel, equipment and so on) are sufficient to cover nearly all of the target group, when facilities exist for confirming diagnoses and for treatment and follow-up of those with abnormal results, and when prevalence of the disease is high enough to justify the effort and costs of screening. At present, in countries with high levels of resources, screening can be advocated only for cancer of the breast and cervix. Efforts should concentrate on women at greatest risk of developing invasive cancer: those aged 35 years and over for cervical cancer and those aged over 50 years for breast cancer. In developing countries, organized screening should only be considered for cervical cancer and should

focus primarily on providing a limited number of screenings with maximum population coverage, because the women at greatest risk for cervical cancer are in general the last to approach the health care services.

Diagnosis and treatment of cancer

Cancer diagnosis is the first step to cancer management. This calls for a combination of careful clinical assessment and diagnostic investigations including endoscopy, imaging, hystopathology, cytology and laboratory studies. Once a diagnosis is confirmed, it is necessary to ascertain cancer staging, where the main goals are to aid in the choice of therapy, prognostication, and to standardize the design of research treatment protocols.

The primary objectives of cancer treatment are cure, prolongation of life, and improvement of the quality of life. A national cancer control programme should therefore establish guidelines for integrating treatment resources with programmes for early detection, and provide therapeutic standards for the most important cancers in the country.

Care of cancer patients typically starts with recognition of an abnormality, followed by consultation at a health care facility with appropriate services for diagnosis and treatment. Treatment may involve surgery, radiation therapy, chemotherapy, hormonal therapy, or some combination of these. An initial priority, especially in developing countries, should be the development of national diagnostic and treatment guidelines to establish a minimum standard of care, and promote the rational use of existing resources and greater equity in access to treatment services.

Optimal treatment of people diagnosed with certain types of cancer detected early, for example, cancers of the uterine cervix and corpus, breast, testis, and melanoma, will result in 5-year survival rates of 75% or more. By contrast, survival rates in patients with cancer of the pancreas, liver, stomach, and lung are generally less than 15%. Some treatments require sophisticated technology that is available only in locations with substantial resources. Since the cost of establishing and maintaining such facilities is high, it is desirable that they should initially be concentrated in relatively few places in a country to avoid draining resources that could be devoted to other aspects of the national cancer control programme. Facilities can be expanded when additional resources are available.

Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identifica-