

PART I

NPK Vision and Summary
2005-2010

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Part II, published as sub-report (only available in Dutch)

1. Report of the Primary Prevention Working Group
2. Report of the Secondary Prevention Working Group
3. Report of the Cancer Care Working Group
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5. Report of the Research Working Group
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Preface

Whenever someone is diagnosed with cancer, it comes as an enormous shock to the patient and to those close to them. Their life is turned upside down. They generally have to undergo a long and trying period of treatment, with uncertain results.

As a result of 'double ageing' (older people are both increasing in number and living longer) there will be a considerable increase in the number of people developing cancer in the next few years. Survival rates are increasing as a result of improved methods for early diagnosis and treatment. This will further increase the number of people who have, or have had, cancer. New and improved techniques place greater demands on available capacity. In short, there will be a considerable increase in the demand for available resources in the next few years.

These developments prompted five organizations closely involved in cancer control, with the assistance of many others, to set up a 2005 – 2010 National Cancer Control Programme (NPK). The NPK encompasses all aspects of cancer control: primary prevention, secondary prevention, cancer care, patient education and psychosocial care, continuing professional development and research. The aim is to make cancer control more effective and efficient in future, to get the most from the available resources.

There are two parts to the 2005 – 2010 National Cancer Control Programme.

Part I consists of the Programme: a cohesive compilation of bottlenecks, objectives, recommended actions or actions to be taken, based on the reports produced by the six working groups. This Programme was preceded by the 'Vision of the NPK Steering Group', a compact account of ideas, insights, and views which arose from eighteen months of intensive collaboration within the Steering Group. The Vision is definitely not simply a summary of the Programme. The Vision contains distinct accents and provides additional information on specific points.

Part II contains the comprehensive reports produced by the six working groups.

The Steering Group would like to thank all those who, as a member of a working group, as a consultant or in some other capacity, have contributed to the creation of this Programme. We call upon all of those involved in cancer control to join together to make the implementation of this Programme a success.

NPK Steering Group

The Hague, 4 November 2004

The vision of the NPK Steering Group

Large organizations join forces

Since 2003, five organizations working in the field of cancer control have been collaborating on a new National Cancer Control Programme (NPK). They have signed up for a joint programme because partial solutions in sub-fields no longer meet the requirements of multifaceted cancer control in the Netherlands. The five organizations making up the NPK Steering Group are:

- Association of Comprehensive Cancer Centres (VIKC)
- The Dutch Cancer Society (KWF)
- The Ministry of Health, Welfare and Sport (VWS)
- The Dutch Federation of Cancer Patients' Organizations (NFK)
- Dutch Association of Health and Social-Care Insurance Companies (ZN)

Divided into six working groups under the auspices of the NPK Steering Group, various professionals and other interested parties in the field formulated this ambitious programme in just twelve months.

The National Cancer Control Programme is intended to serve as a call to all organizations involved to achieve a number of vital cancer control objectives in the next few years. It is by no means the outcome of a negotiation, instead it is imbued with the ambition and drive for action needed to do justice to this programme during the next few years. Action is now being taken to translate this Programme into the policies of all the organizations involved, including the five that launched the initiative.

Prevent cancer, maintain a healthy lifestyle

It has been shown that lifestyle, environmental factors, and hereditary predisposition have a role in the development of cancer. The risk of developing cancer can be greatly reduced by maintaining a healthy lifestyle. This is certainly true of the relationship between smoking and cancer. The greatest contribution to cancer control, both in terms of individuals and of society at large, is to give up smoking. Those who want to give up smoking should be given as much support as possible, after all, smoking is an addiction. However, a healthy diet, moderate alcohol consumption, an adequate amount of exercise, and sensible sunbathing, can also help to prevent cancer. Sadly, people find it very difficult to change their lifestyle. Even when people understand what is meant by a healthy lifestyle, it does not automatically follow that they will actually adopt a healthier way of life. This is just not enough. Prevention is a matter of credibility, and a process that requires enormous patience. People must come to realize that they can influence their own risk of getting cancer, by making an independent decision to opt for a healthy lifestyle. To this end, people need to be spurred on, stimulated, and rewarded. All of the parties involved – first and foremost the government – must promote the importance of a healthy lifestyle. Such

efforts must be maintained for an extended period of time, presenting the arguments in a way that is both logical and consistent.

Young people's way of life is giving cause for concern ('waste of life'). This is an enormous challenge for the adoption of healthy lifestyles, with the support of the educational system. Schools must be stimulated and rewarded if they can justifiably present themselves as 'healthy schools'. Child Health Centres can also play a more prominent role.

The NPK Steering Group is in favour of a smoking ban in all public places, including hospitality-trade establishments. While this will cause a great deal of commotion among various pro-smoking lobbies and interested parties, it is enormously important in the prevention of cancer and other diseases, such as cardiac and renal diseases. This type of ban has already been introduced in some other countries. Now it is the Netherlands' turn.

Central control for population screening

Some forms of cancer can be detected at an early stage, even before the appearance of symptoms. Some examples are breast cancer and cervical cancer. It is anticipated that, in the next few years, population screening will also become available for other forms of cancer, such as colorectal cancer. Whenever the early detection of a cancer is worthwhile, large-scale population screening is generally involved, for instance all women above fifty years of age. The simplest, most economical, and most effective way of organizing population screening is in the form of national programmes, financed and controlled by the government. If these are organized by the care providers and health insurance companies, it can result in a lower level of coverage (less effective) and to opportunistic screening, i.e. screening for which there is no scientific basis (less effective). There is a reasonable degree of conformity between current population screening practices and these views. The programmes are centrally administered and, from 2006 onwards, they will be directly financed by the government. Three major improvements are possible:

- **Combine** There are considerable benefit to be gained if all population screenings are carried out by a single specialized organization. This would also give improved control.
- **Coordination** The transition from screening to the regular care system is not always ideal. In addition to focusing on the efficient implementation of their screening programmes, the new regional population screening organizations must take special care to achieve consistent coordination with the regular care system.
- **Step-by-step plan** A step-by-step plan is needed at the start of any new population screening programme to make it clear which organization is responsible for providing consultancy services and for decision-making. Each step is assigned a maximum period of time for completion. New scientific insights are assessed in terms of their cost-effectiveness. If the verdict is a favourable one, then they are rapidly put into use on a national scale. Phasing of this kind reduces the risk of premature local initiatives, while guaranteeing the best possible population screening programme.

More care is just the start

Cancer care is a matter (or duty) for patients, medical specialists, GPs, nurses, and caregivers. Cancer care is about diagnosis, treatment, counselling and education. Cancer care also, especially, involves a respectful approach when dealing with patients. Patients must be enabled to make the necessary decisions themselves.

When patients are told that they have cancer, their world is shaken to its very foundations. In addition to medical clarity, patients mainly need something to hold on to, both emotionally and socially. Even in cases where medical intervention is not (or not yet) expedient, patients should still receive psychosocial counselling. Clarity and space in which to deal with this development are essential, they also favourably influence the subsequent medical process.

Since cancer is increasingly curable, increasing numbers of individuals are returning to their 'former' lives after treatment. The make or break issue here is good counselling for the patient and to those close to them by a fixed contact, preferably from day one.

Psychosocial care is inextricably linked to the multidisciplinary chain of cancer care and should be included in the guideline.

Good care has its price

There is still considerable scope for quality improvements in cancer care. Various financial and organizational elements impede collaboration between the numerous individuals and parties who are involved in the treatment and counselling of patients. While population screening and the promotion of a healthy lifestyle are managed by the government, the quality of care is primarily a matter for care providers, health insurance companies, and for patients themselves.

When purchasing care, health insurance companies can impose demands on the care providers. After all, it is the health insurance companies who pay for the care that they provide, on behalf of the patients. A great deal is known about good cancer care, and this is often set out in guidelines and best practices. The same goes for effective education and counselling, including contact with fellow sufferers. Clear standards can and should be drawn up with regard to access to care and to turnaround times. Matters such as working in accordance with guidelines, standards, and best practices should be contractually agreed at the time the care is purchased. The care providers can regulate themselves to a large extent in this regard.

Cancer care is coordinated (chain) healthcare: integrated DTCs

The transition from budgeting on the basis of sub-processes to diagnosis and treatment combinations (DTCs) is a good step. Health insurance companies impose demands regarding functional matters and the care providers are free to select the best and most economical type of organization. However, the current DTCs are highly fragmented, which leads to excessive compartments in the care process. It is for this reason that the

NPK Steering Group is advocating the introduction of 'Integrated DTCs'. These are interdisciplinary and transmural (transmural care is defined as the interface between primary and secondary healthcare) DTCs either for an entire chain or for a section of the chain that can be clearly delimited. They include education, counselling and aftercare, as well as scope for innovation. For many patients, counselling by spiritual counsellors for example is an essential aspect of care.

An integrated DTC of this kind actually describes a complete care process, and it is care processes that are purchased by the health insurance companies. This approach prevents a proliferation of dedicated clinics which only carry out a single treatment without a clear link to other care providers, counselling and aftercare. At the same time, integrated DTCs provide a great deal of scope for innovative initiatives in care. As its demands relate to functional matters, this approach does not reflect the structure of the care provided. The structures of specialized clinics, and their numbers, are a recurring theme in the debate regarding concentration and the allocation of tasks.

If the demands regarding functional matters were extended to include the requirement that treatment providers must provide a minimum number of annual treatments in order to retain their level of experience, this would automatically give rise to allocation of tasks and concentration. This does not require government controls, as it can be handled within the profession. Furthermore, it provides scope for local initiatives.

Best practice

This approach will only work if the integrated DTCs are based on the latest knowledge and insights. New knowledge flows from scientific research. This knowledge is translated into best practices, which are then set out in guidelines (state of the art). These guidelines are combined to form integrated DTCs. Government should play a supportive role in this process, by organizing the drafting of guidelines, monitoring compliance, and coordinating the development of integrated DTCs. In addition, a 'maintenance organization' must be established to assess new knowledge in terms of its applicability and suitability both for incorporation into integrated DTCs and, by extension, into the area of insured care. Here too, the government has a supportive role to play. As with the population screening programmes, a step-by-step plan for the implementation of new knowledge can ensure that the fruits of scientific research are rapidly translated into everyday practice.

Right to information

In addition to tackling the processes via integrated DTCs, patients must be given a more pivotal position in the organization of care. This can be achieved by actively publicizing guidelines and best practices, just like standard times for access, examination and treatment, so that patients know what they can count on in terms of care. The end of 2004 will see the launch of a single recognizable, reliable national portal for information and education about cancer and cancer care. This is a joint initiative by the KWF, the NFK and the VIKC. This portal will also have to be accessible via the portal being developed by the National Institute for Public Health and the Environment (RIVM) at the behest of the Ministry of Health, Welfare and Sport, which will provide reliable information for patients. The NPK Steering Group argues that relevant information from hospitals and specialists/medical partnerships should be rapidly made available to the public. Such information could include five-year post-treatment survival statistics, and the number of treatments per type of cancer. Just measuring patient satisfaction is not enough. Patients' organizations and health insurance companies must also put forward their own stipula-

tions. The role of the health insurance companies in purchasing care therefore gives patients greater influence over their care and their dealings with caregivers.

Cancer research is cancer control

Scientific research into cancer is, essentially, cancer control. Over the past 50 years, thanks to research, the mean five-year survival rate has increased from 25% to well over 50%. Today's discoveries about the origins of cancer form the basis for improved prevention, detection, and treatment tomorrow.

In addition, research into new, targeted methods of detection and treatment can substantially reduce the damage inflicted both by the cancer itself and by the associated treatment. Major improvements in the years ahead will stem from the marked increase in our understanding of cancer, and the associated technological innovations. In order to make progress in the fight against cancer, Dutch cancer research (which still has a top international reputation) deserves a bigger workforce, greater resources, and the ability to make the best possible use of the results obtained. We must recreate a situation in which researchers and qualified clinicians are motivated to opt for a career in cancer research. This will involve expanding opportunities for research and selectively investing in talent in every phase of development. Oncology is multidisciplinary, by definition.

Accordingly, training and continuing education in cancer research and cancer care should emphasize the multidisciplinary research and treatment methods used in leading oncological centres (including those in the university sector).

Translational research and clinical research are vital if patients are to benefit from the results of research as rapidly as possible.

This type of research will generally pay for itself within a relatively short period of time. A major part of the requisite resources should be generated via specific grants (The Dutch Cancer Society, the Netherlands Organization for Scientific Research/The Netherlands Organization for Health Research and Development), extra opportunities for clinical applications (in the context of 'best practices', Dutch Association of Health and Social-Care Insurance Companies) and input by companies (patents, products), incubator funds, subsidies for start-up enterprises (Ministry of Economic Affairs/EZ) and innovation funds.

Researchers and patients (as well as patient organizations) should be more involved in making decisions about research, to ensure that scientific opportunities are well matched to social and medical needs.

In addition to the basic funding provided by the government, researchers can fund their research from a variety of sources such as The Dutch Cancer Society, the Netherlands Organization for Scientific Research (The Netherlands Organization for Health Research and Development), the European Union, and several smaller funds.

In the interests of increased efficiency, more cohesion and transparency is required between the basic funding and the programme or project funding provided by other financiers. What is needed is better harmonization between the major cancer research funds, the government, and the research institutions. This should also result in less stifling legislation, in addition to simple procedures for researchers. Prioritization and assessment should be as transparent as possible. They must be visible to, and testable by, all interested parties.

Continuing professional education: a specialization in itself

Effective cancer control is impossible without well trained treatment providers and counsellors. The rapid development of scientific knowledge has created the need for a good infrastructure for continuing education and in-service training, in short, for continuing professional education. Fellow professionals are often the source of new knowledge. Accordingly, in the present situation, continuing professional development is often provided within a given group, and for that group alone.

The NPK Steering Group sees targeted continuing professional development in cancer control as a matter of the utmost importance. To this end, it proposes that this aspect of cancer care should be professionalized. The transfer of knowledge is a specialization in itself. Effective education and training require educational know-how and teaching skills, which can be provided by professional and commercial organizations. When guidelines make new insights mandatory, a nation-wide knowledge transfer system will certainly be required. Professional organizations can be called in, to ensure that the demands made of researchers' time and energy do not get out of hand. Intensive collaboration between professionals and trainers/educators can elevate continuing professional development in cancer care to an entirely new level.

In conclusion

Cancer is already common in the Netherlands and, with an ageing population, it will become even more common in future. Medical-technical capabilities are expanding, and with them the cost per treatment. As a result, cancer control threatens to become a very expensive business. By boosting cohesion and collaboration, the National Cancer Control Programme is attempting to achieve quality improvements, while ensuring that cancer control remains sustainable and affordable. This Programme's ambitions and recommendations will improve all aspects of cancer control, while ensuring that care continues to be affordable in future. They will also ensure that cancer control in the Netherlands continues to rank among the best and most efficient of its kind in the world.

In this way, the present National Cancer Control Programme does justice to the objectives of cancer control:

- Ensure that as few people as possible develop cancer.
- Ensure that those who do develop cancer are timely diagnosed and that they receive adequate treatment, supportive care and aftercare.
- Ensure that patients and those close to them have as good a quality of life as possible.

The NPK Steering Group will monitor the implementation of the recommendations. Each of the five parties involved will use their own area of responsibility to ensure that the recommendations are implemented in a coherent way. They cannot do this if they act alone. This is why collaboration is essential to all those involved in cancer control.

The NPK Steering Group will carry out annual assessments of the implementation, and will formulate follow-up recommendations.

The Hague, 4 November 2004

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Chapter 1 Introduction

The scope of the cancer issue

In 2005, about 78,000 people in the Netherlands will develop cancer. Nearly 40,000 of them will die of the disease. As a result of 'double ageing' (older people are increasing in number and are living longer) there will be a considerable increase in the number of people developing cancer in the next few years. It is estimated that, in 2015, there will be around 95,000 new cases. Increasing survival rates will also produce a considerable increase in the number of individuals who have, or have had, cancer, from around 450,000 in 2005 to nearly 700,000 in 2015. This will produce a major increase in the demand for care.

Incidence

In the year 2000, nearly 69,000 new cases of cancer were diagnosed in the Netherlands. Of the individuals involved, around 35,500 were men and 33,500 were women. Around 10% of these cases had been previously diagnosed with some other form of cancer. Accordingly, in the year 2000 around 62,000 individuals were diagnosed with cancer for the first time. More than 70% of the new patients were below the age of 60. The four most common types of tumour in both men and women are breast cancer (16% of the total number of tumours), colorectal cancer (13%), lung cancer (13%), prostate cancer (10%). Together, these account for more than 50% of all tumours.

Mortality

In the year 2000, almost 38,000 individuals died as a result of cancer. Of these, almost 21,000 were men and 17,000 were women. After cardiovascular disease, cancer is the most common cause of death. It is responsible for 27% of all deaths. In the 45 to 55 age group, cancer is the most common cause of death.

Trends in incidence and prevalence

In view of the sharp increase in cancer incidence with age, the age structure of the population is a determining factor for estimates of future numbers of patients. The number of new tumours will increase from 69,000 in the year 2000, to around 95,000 in the year 2015. This is a growth of 2.7% per annum, and it means that the number of new cancer cases up to 2015 will increase by 40%.

There will also be a sharp rise in the figures for cancer prevalence. While increased prevalence has been observed in all age groups, most of this occurs in men and women aged 65 and above. It is anticipated that from 2000 to 2015, the number of cancer sufferers will increase from around 360,000 to 690,000. This means that the number of cancer sufferers will almost double. More details can be found in the publication entitled 'Kanker in Nederland: Trends, prognoses en implicaties voor zorgvraag' (Cancer in the Netherlands: Trends, prognoses and implications for the demand for care) by the Dutch Cancer Society, which was published in October 2004.

Cancer control in the Netherlands

In general, the quality of cancer control in the Netherlands ranges from adequate to good. Numerous individuals and organizations play a part in this. However, there are also bottlenecks, some well known, others less. It is generally known that there are waiting lists for certain types of examinations and treatments for cancer, and that not all patients have the same access to expensive drugs. The population of the Netherlands is less aware of the fact that the numerous individuals and organizations who are involved in cancer control on a daily basis bring their own knowledge, insights, and passion to the job. They do not operate within a mutually agreed framework, on the basis of common priorities, or within a comprehensive management structure. This carries the risk of insufficient coherence and less than optimum performance. Accordingly, it is by no means sure that we are getting the most out of all the efforts and resources that are devoted to cancer control.

Objective of the National Cancer Control Programme

Given the lack of sufficient coherence and the risk of less than optimum performance, the Association of Comprehensive Cancer Centres (VIKC) has taken the initiative and set up the National Cancer Control Programme (NPK) together with the Dutch Cancer Society (KWF), the Ministry of Health, Welfare and Sport (VWS), the Dutch Federation of Cancer Patients' Organizations (NFK) and the Dutch Association of Health and Social-Care Insurance Companies (ZN). The NPK is a long-range programme (2005 - 2010). It covers all aspects of cancer control, from prevention and diagnosis to aftercare, as well as education, psychosocial care, continuing professional education and research. The Programme offers coherent priorities and measurable objectives. It also indicates how the objectives are to be achieved, and by whom. It also indicates how implementation of the programme will be tackled and monitored, and how the results will be assessed.

The NPK is anything but a one-off event. It is the start of a continuous process of collaboration aimed at the improvement, quality control, and assessment of cancer control in the Netherlands. The creation of the NPK is in line with calls from the World Health Organization (WHO) and the European Parliament for the establishment of national, comprehensive cancer control programmes.

The organization and methods behind the establishment of the 2005 – 2010 National Cancer Control Programme

In 2003, the five above-mentioned parties signed a declaration (Appendix 1) in which they expressed the intention of establishing a national cancer control programme. They also accepted responsibility for the process of setting up the national cancer control programme, and for its content, implementation and assessment. This responsibility was delegated to a Steering Group, which included representatives of these five parties (Appendix 3). In October 2003, the Steering Group appointed six working groups, each of which was to be active in one of the following fields: 'Primary Prevention', 'Secondary Prevention', 'Cancer Care', 'Continuing Professional Education', 'Research' and 'Education and Psychosocial Care'. The working groups were composed of experts in the field in question, and were supported by a number of consultants. The working groups were instructed to

present solutions to the major bottlenecks in each domain. These solutions were to take the form of measurable objectives and actions to be undertaken. The working groups were also required to name those charged with taking the initiative in this regard.

The working groups' provisional findings were discussed and harmonized during a joint working conference of the working groups and the Steering Group, which was held in April 2004. The working groups' reports were completed in June 2004. In mid-2004, a seventh working group was appointed, this was the 'Indicators' working group. This working group includes experts who are involved in the various initiatives and developments in the field of performance indicators and quality indicators in the Netherlands. The working group's assignment is to determine which indicators need to be used to monitor and assess the NPK. The working group will submit its report in the course of 2005.

The financial repercussions of the NPK

The approximate annual cost of cancer care, including population screening and after-care, but excluding primary prevention, continuing professional education and research, amounts to 1.5 billion Euro. This is an enormous sum of money but, for the purposes of comparison, more is spent each year in the Netherlands on the care of those aged 75 and above suffering from cardiovascular disease (> 1.5 million) than on caring for cancer patients of all age groups. (Source: Erasmus/RIVM)

The NPK is not meant to be a way of obtaining more money for cancer control. The assumption is: budgetarily neutral, and reallocation on the basis of priorities. Any budgetary repercussions of policy changes and priority setting within the context of the NPK should, in principle, be financed by the reallocation of existing resources and from efficiency gains. It may not always be possible to achieve this. Nevertheless, nothing ventured, nothing gained, and efficiency improvements generally involve start-up costs and/or investments. Furthermore, essential investments cannot always be held up until savings are achieved elsewhere.

The National Cancer Control Programme 2005-2010

The Steering Group has drawn up the NPK 2005-2010 on the basis of the working groups' reports. Descriptions of the major bottlenecks are included, and as many measurable objectives as possible have been formulated. Furthermore, where feasible, details have been included of specific actions to be undertaken to remove bottlenecks and to achieve objectives. The descriptions of each of the actions to be taken include the organizations charged with implementing the action in question. Other eligible parties will, of course, be involved in these actions. For the record, it should be stated that most of these proposed initiators have yet to be formally approached with regard to this matter. This will take place in the near future.

The NPK 2005-2010 is described in Chapter 2.

Chapter 3 briefly examines the implementation and coordination of the NPK.

Part II consists of the integrated reports of the various working groups, on which the NPK is based.

Chapter 2 National Cancer Control Programme 2005-2010

2.1 Primary Prevention

Primary prevention involves preventing people from becoming ill by eliminating or driving back the causes of disease.

Seventy-five percent of cancer deaths can be attributed to unhealthy behaviour. The risk of developing cancer can be greatly reduced by maintaining a healthy lifestyle. Like overweight, lifestyle factors such as smoking, diet, physical exercise, and alcohol are involved in the development of many other diseases besides cancer. Therefore, in terms of its contribution to public health, healthy behaviour does much more than reducing the risk of getting cancer.

Interventions aimed at promoting a healthy lifestyle are not specific to cancer prevention. This involves health promotion in the wider sense, which should also include aspects such as effective information and education, creating facilities which make it easy and convenient to adopt a healthy lifestyle, as well as introducing rules and regulations, and using price agreements in cases which call for a more authoritative approach. The results of the National Cancer Control Programme should provide a strong stimulus to programmes aimed at promoting a healthy lifestyle, which also make a major contribution to cancer prevention.

The following bottlenecks and recommendations are general in nature and broad in scope. These are followed by an examination of six risk factors for cancer in particular.

Bottlenecks

- Health promotion does not always involve effective preconditions such as a systematic and integrated approach, an optimum mix of interventions, sufficient time and resources, and proportionate joint ventures at local and national level.
- While primary healthcare offers excellent opportunities for prevention, little or no use is made of these.
- Prevention's main purpose often appears to be merely to balance the budget. In recent years, prevention has been allocated two percent of the care budget. From now on, however, less and less money will be available for behavioural prevention programmes.

Actions

- An integrated approach should be used when tackling interventions in the area of primary prevention (involving factors such as the correct mix of interventions, target group segmentation, setting specific, etc.).

Initiators: all organizations which play a part in primary prevention.

- The local health policy memorandum should set out the annual objectives, methods, and budgets dedicated to improving residents' lifestyles, especially those of children, young people, and underprivileged groups.

Initiator: local authorities.

- Throughout primary healthcare, and within GP's practices in particular, the focus should be on promoting a healthy lifestyle. Instruments such as Minimum Intervention Strategies (MIS) should be developed and used to this end. Opportunities for 'Tailor-made advice' should also be exploited.

Initiators: Health-Promoting Institutions (GBIs).

- Mass media campaigns against smoking, overweight, taking an adequate amount of exercise, a healthy diet, reduction of alcohol use, and sensible sunbathing continue to be important. They must be strongly and regularly used in the interests of setting agendas and of promoting awareness. Various prevention activities at local level should be in keeping with these campaigns.

Initiators: HPIs, The Dutch Cancer Society.

- Investment in research is vital, in order to enhance the effectiveness of prevention activities. This involves areas such as research into the determinants of behaviour, success factors for effective interventions, and criteria for implementation.

Initiators: The Netherlands Organization for Health Research and Development, The Dutch Cancer Society

1. Knowledge and perception of risk factors

There is no such thing as totally effective cancer prevention. However, a healthy lifestyle can substantially reduce the risk.

Bottleneck

- People are largely ignorant of the factors that influence the risk of getting cancer. Those who do know something of these risk factors tend to overestimate the contribution made by genetics and environment to the development of cancer, and to underestimate the role of a healthy lifestyle in reducing their own risk of getting cancer.

Objectives

- By 2010, the number of people who will be aware that an unhealthy lifestyle is the major factor behind the development of cancer will have increased by 15%, relative to the 2004 level.
- By 2010, the number of people who take the view that they can influence their own risk of getting cancer by maintaining a healthy lifestyle will have increased by 5%, relative to the 2004 level.

NB: there are, as yet, no recent figures regarding these two objectives.

Actions

- The population of the Netherlands must continually be informed about how cancer can develop, as well as about the types and importance of the factors involved.

Initiators: The Dutch Cancer Society.

- In this regard, it is important that people should be convinced that they can exercise real influence in order to reduce their chances of getting cancer.

Initiators: The Dutch Cancer Society.

2. Smoking and cancer

Smoking is the single most important avoidable cause of premature death. The contribution made by smoking to the development of cancer is 30%. Each year, well over 20,000 people die of smoking-related diseases. This figure includes well over 7,700 deaths from lung cancer. About 90% of all cases of lung cancer are attributable to smoking. In addi-

tion, smoking increases the risk of a number of other types of cancer. The longer someone has been a smoker, the greater their risk of cancer. The same is true of the quantity of cigarettes smoked, and whether someone drinks alcohol in addition to smoking. Passive smoking can also lead to lung cancer. It increases the risk of getting lung cancer by around 20%. In the Netherlands, several hundred individuals develop lung cancer each year as a result of passive smoking..

Bottlenecks

- Smoking is an addictive disease, even though it has not yet been classified as such by the government. This is an impediment to the treatment of tobacco addiction.
- Tobacco smoke is not listed as a carcinogenic substance.
- While a number of evidence-based interventions are available, no decision has been taken to implement them. The size of the smoking-prevention budget is in stark contrast to the income from tobacco duties.

Objective

- The best way to control cancer is to reduce the number of smokers in the Netherlands. Stringent measures must therefore be taken to reduce the numbers of smokers from the current 28% of the population, to 20% in 2010.

Actions

- Recognize that smoking is an addictive disease, and provide financial remuneration for assistance/support to stop smoking.
Initiators: Ministry of Health, Welfare and Sport.
- Implementation of effective interventions for giving up smoking, such as the Minimum Intervention Strategy for GPs.
Initiator: Public Health and Smoking Foundation (STIVORO).
- Every two years, duty is increased by at least 50 euro cents, above and beyond the correction for inflation.
Initiators: The Ministry of Health, Welfare and Sport and the Ministry of Economic Affairs.
- Classify tobacco smoke as a carcinogenic substance, and introduce a total smoking ban in hospitality-trade establishments as soon as possible.
Initiator: Ministry of Health, Welfare and Sport.

3. Overweight/obesity and cancer

Traditional views on overweight tend to underestimate its contribution to the development of cancer. It was recently calculated that about seven to eight percent of cancers are due to overweight. It is reasonable to assume that this will increase to around 15% during the next few years. Forty percent of Dutch adults are overweight, and ten percent are obese. As regards young people, on average 13% of boys and 14% of girls suffer from overweight. The prevalence of overweight is still increasing. The most rapid rises appear to affect young children aged three and above. It is anticipated that, by 2015, between 15

An individual is said to be overweight if their weight (W) in kg divided by the square of their height (H) in m is more than 25 and equal to or less than 30. Individuals with a value in excess of 30 are classified as obese (extremely overweight).

and 20% of all adults will be obese. Overweight is more prevalent among the poorly educated than among highly educated individuals.

Bottlenecks

- There are few or no evidence-based interventions that can effectively prevent weight gain. Nor indeed are the behavioural determinants and environmental factors that influence overweight fully understood.
- In the Netherlands there is an ‘obesogenic’ environment which encourages people to avoid exercise, and to eat excessive quantities of unhealthy food.

Objective

- By 2010, up to 12% of the Dutch population will be obese.

Actions

- Agreements are being made with food manufacturers to make foods more healthy, both in terms of composition and portion size. Furthermore, agreements are being made concerning better information on labels, and about the advertizing of high-calorie products aimed at children and young people.

Initiator: Netherlands Nutrition Centre Foundation.

- There should be a healthier range of the following products snacks, drinks and meals in companies, schools, hospitals, sports club canteens, fast-food chains, and restaurants.

Initiator: Netherlands Nutrition Centre Foundation.

4. Food and Cancer

The consumption of vegetables and fruit mainly protects against the risk of head and neck cancers, as well as the risk of oesophageal cancer and stomach cancer. It is difficult to quantify the significance of this effect. Only 20% of the Dutch population eat enough vegetables, and only 30% eat enough fruit. It is anticipated that, in future, even fewer people will achieve the standard values for fruit and vegetable consumption.

The Dutch standard is the daily consumption of a minimum of two pieces of fruit and 200 grams of vegetables.

Bottleneck

- Many people tend to overestimate their consumption of fruit and vegetables. The factors involved include a dismissive attitude to healthy food and a lack of motivation to eat adequate amounts of fruit and vegetables. Many people believe that they are not able to eat adequate amounts of fruit and vegetables.

Objective

- By 2010, 30% of the population will eat an adequate quantity of vegetables and 40% will consume two pieces of fruit per day.

Actions

- Under the guide of ‘Catch ’em young’ and ‘Make healthy choices the easy choices’, fruit should be provided free at primary schools. This should be accompanied by a series of lessons about a healthy diet.

Initiator: Netherlands Nutrition Centre Foundation.

- In various settings (including the workplace and schools) interventions should be carried out to promote the consumption of more fruit and vegetables.

Initiator: Netherlands Nutrition Centre Foundation.

5. Exercise and cancer

Lack of exercise is estimated to be responsible for three to four percent of cancer deaths. It is generally agreed that adequate levels of physical exercise can reduce the risk of developing colorectal cancer and breast cancer by 20-30%. In addition, insufficient physical exercise is, indirectly, a risk factor for the development of cancer, after all, insufficient physical exercise leads to overweight.

Despite the fact that people generally agree that physical exercise is beneficial in terms of health, less than half of the Dutch population achieve the Dutch Standard for Healthy Exercise (Nederlandse Norm Gezond Bewegen), in the course of one year. Twelve percent of the Dutch population did not get sufficient physical exercise on any given day during 1998.

Dutch Standard for Healthy Exercise:

- *Adults: at least half an hour of moderately intensive exercise five days a week;*
- *Young people: at least one hour of physical activity each day of the week.*

Bottlenecks

- There are very few evidence-based interventions for the promotion of physical exercise.
- Around two out of three Dutch people believe, incorrectly, that they get enough physical exercise.

Objectives

- By 2010, 55% of the population will meet the Dutch Standard for Healthy Exercise.
- By 2010, up to 8% of Dutch people that fail to get enough physical exercise on any given day.

Actions

- Pupils in both primary and secondary schools should have at least one hour of Physical Education per week, under the supervision of a qualified Physical Education teacher.

Initiator: Netherlands Institute for Sport and Physical activity (NISB).

- There should be an integrated focus on reducing the ‘obesogenic’ environment. This could include redesigning the physical environment.

Initiator: NISB.

6. Alcohol and cancer

Excessive and long-term alcohol consumption leads to an elevated risk of head and neck cancers, as well as oesophageal cancer. Moderate alcohol consumption seldom leads to an elevated level of risk. The risk is further amplified if, besides drinking alcohol, individuals also smoke. There is also a link between long-term alcohol consumption and the development of breast cancer.

The national recommendation with regard to alcohol is that men should consume no more than three glasses of alcoholic beverages per day, and women no more than two glasses per day. This is in addition to the recommendation that people should not drink alcohol on a daily basis.

Eleven percent of adult males drink an average of three or more glasses of alcohol per day. Six percent of adult females drink two or more glasses of alcohol per day. Twenty percent of young men (aged 15-25) drink enough to potentially damage their health. For girls, the figure in question is well over ten percent. Young men do most of their drinking when they go out or when they are on holiday. Furthermore, today's young men are drinking more than their predecessors.

Bottlenecks

- Individuals in the lower income groups drink larger amounts, and more often, than individuals in higher income groups.
- An individual's alcohol consumption is highly dependent on their social setting and on environmental factors.

Objectives

- By 2010, up to 7% of Dutch adults will consume an average of more than three glasses of alcoholic beverages per day.
- By 2010 up to 15% of young men aged between 15 and 25 will consume an average of more than 3 glasses of alcohol per day. The corresponding figure for girls will be the target value of eight percent.

Actions

- Further implementation of school-based programmes that have been shown to be effective.

Initiator: Trimbos Institute (Netherlands Institute of Mental Health and Addiction).

- Primary healthcare offers excellent opportunities for the prevention of excessive alcohol consumption, such as 'tailor-made advice' methods.

Initiators: The Netherlands Institute for Health Promotion and Disease Prevention (NIGZ).

- More interventions should be developed aimed at influencing the physical environment by means of rules, legislation and/or covenants.

Initiator: NIGZ

7. Sunbathing and Cancer

Each year about 25,000 new cases of skin cancer are diagnosed in the Netherlands. The most common form of skin cancer is basal cell carcinoma (80%), followed by squamous cell carcinoma (10%) and melanoma (10%). Each year, the increase in skin cancer increases by an average of three to five percent. Over the past 20 years, female mortality has stabilized while male mortality is still increasing. Approximately 600 patients die of skin cancer each year.

Sensible sunbathing is important to the prevention of skin cancer. This involves avoiding exposure to sunlight between the times of 12.00 and 15.00, wearing protective clothing and a hat, and applying sun lotion to exposed areas of skin.

Bottlenecks

- One out of two Dutch people do not use protection when they are exposed to the rays of the sun. The situation for sunbathers is a little better. Seventy-five percent of sunbathers use some form of protection. Eighty percent of parents apply sun lotion to their children's skin when on the beach or at a swimming pool.
- Many people believe that a tanned skin improves their looks. They are willing to sunbathe (either outdoors or in a solarium) for many hours in order to get a good tan.

Objectives

- By 2010, 85% of the adult population will use some form of protection when sunbathing.
- By 2010, 90% of parents will protect their children against the sun's rays (applying sun lotion, clothing/hat).

Action

- It is worthwhile to initiate an intervention targeting nursery schools. In addition, a series of lessons that have been shown to be effective should be implemented in schools.
Initiator: The Dutch Cancer Society.

8. Healthy living also means paying careful attention to your body

Healthy behaviour also involves a timely visit to the GP at the first sign of a possible problem, such as discovering something in or on the body that might indicate cancer. After all, even individuals with a healthy lifestyle have some risk of developing cancer. For this reason, it is vital that people should be aware of signals produced by the body which may indicate the development of cancer.

Bottlenecks

- People are still not sufficiently well informed about certain symptoms of cancer. As a result, they do not pay enough attention to symptoms that might indicate the presence of these forms of cancer. This in turn means that adequate action is taken less often than it should be.
- In addition, people are not sufficiently well aware of the benefits of being alert to the symptoms of cancer. The barriers involved include 'being worried about the possible diagnosis' and 'having the impression that the GP is not taking you seriously'.

Objectives

- By 2010, Dutch people above the age of 55 will be more aware that the early detection of cancer means an improved chance of survival. In numerical terms, 15% more people will be aware of this than is the case in 2004.
- By 2010, more individuals in this target group will be capable of recognizing symptoms that could indicate cancer. In numerical terms, 10% more people will be aware of this than is the case in 2004.

Action

- A long-term intervention should be initiated with regard to the early detection of cancer.

Initiator: The Dutch Cancer Society

2.2 Secondary Prevention

Secondary prevention is the detection and treatment of diseases at an early stage, before the appearance of actual symptoms. The objective of this type of prevention is to cure diseases at as early a stage as possible or, if that is not possible, to halt or at least delay the disease process.

1. Decision-making associated with population screening programmes

Developments in the field of diagnostic techniques have made it possible to diagnose malignant disorders at ever earlier stages. This has boosted the opportunities for secondary prevention.

Bottleneck

- The introduction of new diagnostic techniques demands adequate decision-making. This applies both to changes in existing population screening programmes and to new population screening programmes that have yet to be introduced. Sluggish decision-making, or a total lack thereof, can lead to uncontrolled proliferation as a result of the independent actions of care providers and care clients, which may have adverse repercussions in terms of effectiveness, efficiency, and the quality of new preventive interventions. This can only be prevented by timely and active teamwork between government and those working in the field. This particularly applies to teamwork between the central parties involved, namely the Ministry of Health, Welfare and Sport, the Health Council (GR), The Netherlands Organization for Health Research and Development (ZonMw) and the Health Care Insurance Board (CVS).
One current issue is the possible introduction of screening for colorectal cancer.

Objectives

Before 1 January 2005:

- the Minister will introduce a strict step-by-step plan which will serve as a focus for decision-making regarding the introduction or amendment of national population screening programmes;
- this step-by-step plan will be applied to decision-making regarding the possible introduction of population screening for colorectal cancer.

Recommendation

- The above-mentioned step-by-step plan must set out clear periods of time, as well as clear roles for each of the parties involved. It is recommended that the following step-by-step plan should serve as a starting point.
Initiator: Minister of Health, Welfare and Sport.

Diagram 1: Step-by-step plan for the introduction or amendment of population screening for cancer¹

Step	Organization	Task	Product	Time factor
1	GR	Regular assessment of the scientific situation.	Description: provisional verdict on feasibility/desirability of certain types of screening; formulating unresolved research questions.	Annual update of description.
2	VWS	Agenda creation with regard to specific screenings, and arranging for a budget for the requisite research.	Agenda for all the relevant actors in a specific screening; establishing framework for a specific experimental population screening programme; making available research budget required for screening programme.	Within 6 months.
3	The Netherlands Organization for Health Research and Development	Throw open research programme; assessment, financing and monitoring implementation of requisite research.	Results of research, cost-effectiveness analyses, and implementation studies.	Throw open and assess within 6 months.
4	GR	Definitive assessment of feasibility and desirability of screening; establish target group, test method, periodicity of screening, policy regarding follow-up diagnosis and treatment. Testing against the Population Screening Act (WBO).	Advice on feasibility and desirability of screening and state-of-the-art method including advice in the context of the WBO.	Within 6 months of completion of requisite screening programme.
5	VWS	Decision in principle on introduction of specific screening.	Decision in principle on whether or not to proceed with screening + request for implementation test.	Within 1 year.
6	CVZ	Assessment of feasibility of including in package and technical aspects regarding the implementation implementation and execution of the specific screening.	Implementation test of inclusion in package and execution variants relating to measure such as calling in professions.	Within 1 year.
7	VWS	(Directing) definitive decision-making concerning specific screening, and arranging for a budget.	Definitive decision + budget implementation and execution.	Within 1 year.

2. The steering and implementation of population screening

In the context of cancer control, two major national screening programmes are currently being implemented in the Netherlands, these are the population screening programmes for breast cancer and for cervical cancer. It has meanwhile become clear that the specific characteristics of programmes of this type impose exceptional demands, in terms of coordination and implementation.

¹ Any change to the allotment of tasks will, of course, also involve amendments to the step-by-step plan.

Bottlenecks

- The existence of separate organizations for the implementation of the various population screening programmes is a barrier to the further professionalization of the regional screening organizations, nor is it very efficient.
- The administrative set-ups of the regional screening organizations no longer meets the current requirements imposed by society with regard to transparency, independence, effective management, and effective supervision.
- The management (and, as a result, the screening organizations also) does not stand on an equal position with the Comprehensive Cancer Centres (IKCs) and the Municipal Health Services (GGDs). In a number of cases it appears that a mandatory 'truck system' (payment in credit notes) is involved. This prevents the operation of a free-market in the area of purchasing.

Objectives

As of 1 January 2006:

- the two presently separate organizations for the implementation of population screening for cancer will be replaced by a single organization within which all of the functions for population screening will be integrated. This organization will also be charged with the implementation of a new population screening programme for cancer, which has yet to be designed;
- the new organization for the implementation of population screening for cancer will consist of a national director and nine regional screening organizations, which maintain good relations with the other regional organizations involved;
- the supervision of the various parts of the implementation organization, and their individual accountability, will be based on the principles of 'healthcare governance'².

Actions

- The Minister of Health, Welfare and Sport will appoint a national director for population screening programmes for cancer, who will be charged with the task of setting up a single functional implementation organization before the start of 2006.

Initiator: Minister of Health, Welfare and Sport

- The national director will then proceed with the task in hand, consulting all the other parties involved as the two existing implementation organizations are functionally merged into a single entity.

Initiator: national director

² Report by the Committee of Health Care Governance: Recommendations for effective management, effective supervision, and adequate accountability within the Dutch health service. Leusden, the Netherlands, November 2001.

Responsibilities of the implementation organization

The national director is responsible for:

- *the organization and financing of the various screening programmes, as well as for their quality policy, monitoring and assessment;*
- *the promotion of effective coordination between screening and curative care;*
- *supporting the nine screening organizations as a recognized authority in this field, both for care providers and the general public.*

The national director will be assisted in this by a committee of experts.

The nine regional screening organizations are responsible for:

- *the direct implementation of the population screening programmes, including educating the target group and issuing invitations;*
- *the logistics of the screening programme;*
- *implementing and interpreting the screening test (or arranging for others to do this);*
- *informing the client about the results of the test;*
- *recording the requisite information for the purposes of monitoring and assessment.*

3. Transition from population screening to the regular care system

This is the phase from referral from the population screening programme up to and including the diagnosis and possible treatment in the curative follow-up process. It involves the care of patients with a positive screening result.

Bottlenecks

- In both the breast cancer and cervical cancer population screening programmes, this transition was found to be poorly organized.
- Referral, via the patient's GP, to the regular care system takes too long.
- Referred patients skip their appointments.
- The way in which calls are made for clients for breast-cancer screening programmes (once every two years in each Local Authority area) also produces a bulge in the number of women referred to the regular care system (also once every two years). The regular care system cannot deal with such peak loads.
- The way in which information is exchanged between the various organizations involved leaves much to be desired.
- In order to actually achieve the potential health gains from screening, coordination with (and the quality of) the curative follow-up process must be improved.

Objectives

- In mid-2006, quality criteria will be established and imposed on the transition of patients from population screening programmes to regular diagnosis and treatment. In addition, the responsibilities of all those involved were established, in order to achieve sufficient throughput.
- By the end of 2006, each of the regions will have calculated the capacity that they require (in terms of professionals and facilities) to adequately diagnose and treat the referred patients.
- At the start of 2007, the quality criteria relating to throughput will be incorporated into the conditions governing care contracts with health insurance companies.

- By the end of 2008, the capacity of the regular care system will match the supply generated by population screening programmes, and the quality criteria will have been met.

Actions

- At the start of 2005, a start will be made on the development of quality criteria which the transition from screening to the regular care system must meet.
Initiator: national director.
- At the start of 2005, each of the regions will begin the task of calculating the capacity that they require (in terms of professionals and facilities) to adequately diagnose and treat the referred patients.
Initiator: national director.
- By 2007, when purchasing healthcare, health insurance companies will incorporate the established quality criteria in their conditions.
Initiators: health insurance companies.
- At the start of 2008, a start will be made on assessing compliance with the quality criteria governing the transition from population screening to the regular care system.
Initiator: national director.

4. Population screening and information provision

The effective provision of information is crucial to the success of a population screening programme. The effective provision of information is a prerequisite for the control of quality, effective interaction with adjacent areas of care, and accountability, as well as for the monitoring and assessment of a programme's effectiveness and efficiency.

Bottlenecks

- Current screening programme registries – including those of the regional screening organizations, hospitals, laboratories, comprehensive cancer centres, and Statistics Netherlands (CBS) – are characterized by a lack of mutual compatibility.
- As a result, these registries' users (who include practitioners, the management of the screening organizations, and assessors working on behalf of the national directorate) may not be able to access sufficient data to perform their duties.
- The national assessments in particular suffer from the fact that the gathering and extraction of data from the various registries requires so much knowledge and experience that the result is anything but a free selection.

Objective

- By the end of 2006, the registries and information systems that are vital to the control of population screening programmes and the follow-up process should be so accessible and mutually compatible that, for all intents and purposes, users experience it to be a single, integrated information system. Such users should be able to timely obtain the data that they need to perform their duties.

Actions

- During the first six months of 2005, the national régisseur will start work on making the various registries and information systems more coherent and more accessible. In the course of this process, the régisseur will collaborate fully with all those involved.
Initiator: national director.

- Before the end of 2007, instructions will be issued to assess whether the above-mentioned objectives have been achieved. This assessment will be carried out independently of the implementation organization.

Initiator: Minister of Health, Welfare and Sport.

5. Turnout for population screening

The effectiveness of a population screening programme is dependent on a high turnout. Here we are faced with a conflict of interests. Should we prevail on people to participate in a population screening programme or should we allow them to exercise their own responsibility and freedom of choice? However, once the population screening programme has been initiated, the relevant target groups should then be adequately informed about the programme's merits.

Bottlenecks

- Population screening programmes for cancer usually have a less than ideal turnout. The main reason for this is a low turnout by certain population groups.
- The turnout is also adversely affected by the increased availability of commercial test kits and the possibility of medical check-ups in private clinics.

Objective

- The population of the Netherlands is more aware of the importance of participating in population screening programmes, and of the pros and cons of test kits and of check-ups in private clinics.

Action

- In 2005, an educational campaign will be launched to inform the target groups about the usefulness of population screening programmes, as well as about the pros and cons of test kits and of commercial check-ups.

Initiator: national director.

7. The Financing of Secondary Prevention

The issue of responsibility for the financing of Secondary Prevention needs consideration.

Bottlenecks

- The current financing of population screening programmes, which is based on the Regulation of grants under the Exceptional Medical Expenses Act (AWBZ) and Health Insurance Act (ZFW), is up for discussion. The alternatives, namely budgetary financing or inclusion within the insured healthcare system, are matters of debate. The results of this debate are still uncertain, as are the guarantees for an optimum implementation organization.
- There are insufficient safeguards for the continuity of the periodical monitoring of high-risk groups, as currently implemented by the Centres for Clinical Genetics and promoted by the Foundation for the Detection of Hereditary Tumours (STOET).

Objectives

As soon as possible, but in any event before the end of 2006:

- it will be established how the future financing of population screening programmes will be secured;

- it will be established how the future financing of the activities of Centres for Clinical Genetics and those of STOET in the area of Secondary Prevention will be secured.

Actions

- Even after the introduction of the new Health Insurance Act, funding of the various screening programmes should be organized in such a way that the requisite implementation organization can operate efficiently. Programme-based screening does not tie in with a demand-driven insurance system. For this reason, financing under the direct responsibility of the Minister of Health, Welfare and Sport is indicated.

Initiator: Minister of Health, Welfare and Sport.

- By extrapolation from the previous recommendation: the Minister of Health, Welfare and Sport should be directly responsible for the financing of Secondary Prevention by Centres for Clinical Genetics and STOET.

Initiator: Minister of Health, Welfare and Sport.

2.3 Cancer Care

1. Improvements in care

Each patient has a right to timely, top-quality diagnosis, treatment and care which is in accordance with the most up-to-date guidelines. While the quality and effectiveness of oncological care in the Netherlands can be characterized as reasonably good to good, there is certainly room for improvement.

Objectives

- By 2010, the five-year survival rate for cancer patients will be 20% better than in the year 2000.
- By 2010, cancer patients' satisfaction regarding education, how they are dealt with, their treatment and aftercare will have increased by 20% relative to 2005.

These objectives can be verified on the basis of the cancer registry (provided this is linked to Local Authority's Residents Registry or GBA – see below) and via periodical Patient Satisfaction Surveys (a pilot study has since been carried out).

Actions

- Make periodical measurements on the basis of information contained in the cancer registry.
*Initiator: VIKC**
- Periodical satisfaction surveys among patients.
*Initiator: VIKC**

2. Care: supply and demand

Cancer already imposes a substantial burden of disease, and an ageing population will only exacerbate the problem further. By 2015, the number of new cases of cancer will have increased by 40%, and the number of patients who have had (or still have) cancer will have almost doubled. That will involve a sharp increase in the demands placed on the healthcare system.

New diagnostic techniques, together with new and often intensive treatment techniques, will also place increasing demands on the capacity of the healthcare system.

Bottleneck

- The existence of substantial waiting lists shows that the current capacity of the healthcare system is barely able to meet the existing need for care.

Objectives

- By 2005, a scenario will have been developed for the period from 2005 to 2020. This will indicate the requisite capacity of the healthcare system, based on the anticipated flow of patients from the population screening programmes, the increased numbers of cancer patients. It will also be in accordance with the agreed allocation of tasks and concentration (see below).
- By 2006, an implementation process will be ready.
- By 2010, there will be a good balance between supply and demand in the oncological care sector. This will apply to all cancer patients, and to those for whom a diagnosis of can-

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

cer is being considered. This is measurable through waiting lists, throughput times, and assessment of the implementation of guidelines for diagnosis and treatment.

Actions

- The development of a 2005-2020 scenario for the requisite healthcare capacity.
Initiator: VWS
- The development of an implementation process for 2006.
Initiator: VWS
- The harmonization of supply and demand with regard to healthcare.
Initiator: VWS

3. Coordinated chain care, continuum of multidisciplinary healthcare

During the period of diagnosis, treatment, aftercare and rehabilitation, cancer patients come into contact with a variety of disciplines within the health service are essential. Effective harmonization, coordination and transfer between all of these disciplines are essential.

Multidisciplinary patient discussions: theory and practice

Cancer patients are diagnosed and treated in hospitals throughout the country. Each hospital should have a multidisciplinary oncology committee to initiate and monitor oncological policy at hospital level, to ensure that patients receive the best possible oncological care. Ideally there should be multidisciplinary discussions of all new patients, in addition to patients whose treatment plan has been amended. This multidisciplinary discussion is essential since a variety of professionals are involved in the provision of oncological care. Patient discussions should preferably take place in close consultation with the team of consultants from the (academic or non-affiliated) oncological centre and, if necessary, with the GP.

In practice, the oncology committee's working method and the conduct of patient discussions often appear to deviate from what was originally intended. This emerged from surveys and 'visitatie' projects in the Comprehensive Cancer Centre regions. Some examples: the hospital has no oncological policy plan; only a part of the patients are discussed at a multidisciplinary level; multidisciplinary patient discussions are not always carried out in close consultation with the consultant (or consultants); the topics discussed are not fully recorded in written reports; there is no communication with the patient concerning the recommendations discussed; the GP and other treatment providers are not informed about the recommendations.

Insight into multidisciplinary oncology discussions and consultant services would promote patient satisfaction, improve confidence, eliminate uncertainty, and provide another view on requests for second opinions.

Bottlenecks

- There are both local and regional initiatives for the improvement of coordinated chain care, but people do not appear to make the best use of one another's experience.
- In essence, the bottlenecks in coordinated chain care are not different for oncology patients than are the bottlenecks for chronic disease patients, as formulated in the report issued by the Dutch Health Care Inspectorate (IGZ). The resolution of bottlenecks in coordinated chain care is of vital importance to the promotion of efficiency.

- coordinated chain care requires effective steering. There should be national quality criteria for multidisciplinary harmonization and for the conduct of the entire healthcare process: allocation of tasks and responsibilities for those involved in caring for the patients, agreements between the professionals concerning conveyance, agreements about access times, throughput times, preferably per type of tumour.
- Quality requirements must be imposed on the oncology committee and the multidisciplinary patient discussion, in terms of their effectiveness, efficiency, and working method.
- Patients, GPs and other treatment providers should be informed about patient discussions, and about the results of such discussions.
- The requisite exchange of data between the various professionals can be safeguarded by the effective use of Information and Communications Technology (ICT).

Objectives

- By 2005, the quality criteria for multidisciplinary coordinated chain care will be ready.
- By 2006, a visitation/accreditation system will be ready, and the implementation of these criteria will be tested in a pilot study. In addition, the working methods of the oncology committees, the multidisciplinary patient discussions, and the consultant services will be assessed at national level.
- By 2006, work will have been completed on a description of the tasks and responsibilities of professionals, with regard to education and psychosocial care for patients in hospitals. This will be part of the multidisciplinary assessment, or visitation /accreditation of oncological care.
- By 2010, all hospitals in which cancer is diagnosed and/or treated will have undergone visitation/accreditation. Primary care will definitely be included in this process of visitation.
The results of this assessment should be available and comprehensible to those requiring care.

Actions

- Develop quality criteria for multidisciplinary coordinated chain care as soon as possible. At the very least, there should be quality criteria for the following components
 - for the multidisciplinary harmonization and conduct of the entire care process: allocation of tasks and responsibilities for those involved in caring for cancer patients, agreements between the various professionals concerning transfers, agreements about access times and throughput times, preferably per type of tumour.
*Initiator: VIKC**
 - for the oncology committee and the multidisciplinary patient discussions, in terms of their effectiveness, efficiency, and working method; patients, GPs and other treatment providers should be informed about patient discussions, and about the results of such discussions.
*Initiator: VIKC**
- Prepare a visitation/accreditation system for the purpose of testing the implementation of these criteria.
*Initiator: VIKC**

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

- A description of professionals' tasks and responsibilities in relation to medical care, education and psychosocial care for patients in hospitals – as part of multidisciplinary assessment, visitation /accreditation of oncological care.

*Initiator: VIKC**

- All hospitals in which cancer is diagnosed and/or treated will undergo visitation/ accreditation.

*Initiator: VIKC**

4. The allocation of tasks in coordinated chain care

Concentration of the (further) diagnosis and treatment of rare tumours and complex, multidisciplinary oncological care will enhance the quality of such care. There are various ways in which concentration might be achieved. The Health Council made recommendations on this topic well over ten years ago, and the Netherlands Cancer Institute (NKI) has recently published a discussion document on the subject. Optimum allocation of tasks, harmonization and collaboration – set out in clear and feasible mutual agreements between hospitals, and with GPs and other extramural carers – are conditions for fully effective coordinated chain care. Within hospitals, agreements about the allocation of tasks are vital to the effectiveness of procedures, logistics, communication protocols between professionals (or with patients).

Bottleneck

- Although there have been effective initiatives at local level, national control is needed in order to achieve an optimum concentration, which in turn will produce a transparent, mandatory, and testable allocation of tasks.

Objectives

By 2005, a committee will have been appointed and tasked with:

- developing quality criteria for the allocation of tasks and concentration in oncology;
- drawing up a plan in relation to implementation, and assessing implementation on the basis of these criteria;
- indicating the repercussions if the criteria have not been met;
- producing a report, which will include details of what is expected of each of the actors involved in implementation.

Action

- An authoritative, national committee of independent experts should be appointed as soon as possible, and tasked with publishing an advisory report. This report will deal with the issues of how concentration and the allocation of tasks can best be achieved, who will control this process, who will test the agreed quality criteria, and what action should be taken in cases which do, or do not, meet these criteria.

Initiator: VWS

By 2006, the assignment will have been completed and the results set out in a report. The process of implementation will also have been set in motion.

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

5. Development of guidelines

With regard to the diagnosis and treatment of patients, there are currently 15 tumour-specific guidelines at national level and another 50 at regional level. In addition, there are various NHG standards for client-oriented (differential) diagnosis and for targeted referral in connection with cancer. Diagnosis and treatment should, as far as possible, be conducted in accordance with evidence-based guidelines.

There are regional and (sometimes) national initiatives for the implementation and assessment of guidelines. Both implementation and assessment will be carried out by organizations that were involved in developing guidelines.

There is more to creating guidelines than development alone. They also need to be adjusted, as appropriate, on the basis of the latest scientific insights (evidence-based medicine). The procedures involved in the development, adjustment, implementation and assessment of national guidelines (particularly multidisciplinary and transmural guidelines) are far from simple. Nor is it always clear who bears responsibility for this point during the various stages of guideline development.

Objectives

- By 2005, procedures will be available for the development, adjustment, implementation and assessment of guidelines, both in terms of methodology and content. The guideline focuses on a number of specific components, such as:
 - education
 - elderly patients (co-morbidity).
 - During implementation, consideration is also given to:
 - allocation of diagnosis, counselling and follow-up tasks between primary and secondary healthcare;
 - familiarizing primary healthcare providers with the guidelines.
 - A procedure will be established for familiarizing individuals with new and updated guidelines.
- By 2005, it will be clear which actor (or actors) bear responsibility for overall control.
- By 2005, the collected guidelines will be available via www.oncoline.nl. There will also be links to the monodisciplinary guidelines and the NHG standards (www.nhg.nl).
- By 2005, the financing of multidisciplinary guideline development will have been clarified.
- By 2005, a national summary of the guidelines that have been assessed (including the results) will be available via iKCnet.
- By 2007, the procedures will have been assessed.
- By 2005, the cancer registry will be able to collect the additional data required for the assessment. There is a plan for the efficient assessment of the guidelines. This plan is updated annually.
- By 2005, there will be a link between the cancer registry and the GBA, to display details of patient survival.

Actions

- Describe the procedure for the development, adjustment, implementation and assessment of guidelines, both in terms of methodology and content.

*Initiator: VIKC**

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

- Designate the steering organization of the above action, for the implementation.
Initiator: VWS
- Publish the guidelines at www.oncoline.nl or link through to the NHG standards.
*Initiator: VIKC**
- Financial basis for the development of the multidisciplinary guideline.
*Initiator: VIKC**
- Drawing up a national summary of the guidelines that have been assessed (including the results).
*Initiator: VIKC**
- Draw up a plan for the efficient assessment of guidelines, making use of the cancer registry.
*Initiator: VIKC**
- A limited number of indicators should be developed, per guideline.
*Initiator: VIKC**
- Modifying the cancer registry to enable the additional data to be processed and analyzed.
*Initiator: VIKC**
- Create a link between the cancer register and the GBA.
*Initiator: VIKC**
- Assess the procedures.
*Initiator: VIKC**

6. Diagnostic phase

While this section focuses specifically on diagnosis, it should nevertheless be viewed in the light of sections 3, 4 & 5.

Considering or eliminating a diagnosis of cancer is part of daily practice of GPs and (non-oncological) medical specialists.

Bottlenecks

- Better coordination is needed between population screening programmes and the health service, also in terms of the capacity for further diagnosis.
- GPs, non-oncological medical specialists and dentists are often involved in the early detection of cancer and in patient referral. There is room for improvement, particularly when it comes to who is responsible for which part of the diagnosis.

Objectives

- By 2005, a summary of the (European) cancer code for the early diagnosis of cancer will be available at iKCnet.
- By 2005, there will be an implementation plan for such early detection.
- In 2007 there will be an initial assessment of people's familiarity with this topic. It will be possible to measure this in terms of doctors-related delay (referral) and through the trend analyses of tumour stages.
- From 2005, as part of the development and adjustment of national guidelines, there will be a systematic focus on the allocation of tasks in terms of early and later diagnosis.

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

- From 2007 onwards, as part of the educational programmes (and in-service training) for GPs, non-oncological medical specialists and dentists, there will be a systematic focus on the detection and diagnosis (including early detection and diagnosis) of the various forms of cancer.

Actions

- A summary of the (European) cancer code for the early diagnosis of cancer will be available at iKCnet.

*Initiator: VIKC**

- Development of an implementation plan for such early detection.

*Initiator: VIKC**

- Preparation and implementation of an initial assessment.

*Initiator: VIKC**

- Modify the content of the guideline's with regard to the sections early and specific diagnosis. (including the associated allocation of tasks).

*Initiator: VIKC**

- Incorporate the sections dealing with the early and more specific diagnosis of various forms of cancer into educational programmes for GPs and dentists. This should be included in the educational programme's final attainment levels.

Initiator: Universities

7. Treatment phase

While sections 3, 4 & 5 dealt with treatment as such, this section explains participation in trials.

Bottlenecks

- Trials are often not applicable to more elderly patients, given the frequent occurrence of co-morbidity. Increasing ageing of the population will mean that the majority of these patients cannot be treated in accordance with a guideline, as there is no evidence-based information available. For patients, participation in trials is important in terms of their survival and quality of life.
- The current organization of trial management has room for improvement. Furthermore, there is no summary of current local, regional, national and international trials.
- There are too few development opportunities for independent, commercially unattractive, clinical cancer research.
- In addition, it takes a long time before the results obtained from clinical scientific research are implemented in practice.

All patients should be encouraged to take part in trials, by improving the provision of information about trials and by providing greater administrative support.

Objectives

- By 2005, there will be a national coordination point for oncological trials. Its responsibilities will include keeping the trial summary up to date, and access via Internet.
- By no later than 2006, agreements will have been made concerning the adequate financing of data management and the responsibilities of the parties involved with regard to the conduct of research and data management.

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

- The procedure for drawing up and amending guidelines speeds the flow of results from clinical scientific research to daily practice.
- In 2007, more than five percent of trials should partly or entirely focus on patients above the age of 70.

Actions

- Establishment of a national coordination point for oncological trials.
*Initiator: VIKC**
- Reach agreement concerning the adequate financing of data management and the responsibilities of the parties involved with regard to implementation and data management.
*Initiator: VIKC**
- The procedure entitled 'drawing up and amending guidelines' ensures that the flow of results from clinical scientific research is quickly translated into daily practice.
*Initiator: VIKC**

8. Aftercare

For quite some time after completing their course of treatment, cancer patients continue to visit their specialist for routine check-ups. These follow-up visits serve various purposes: counselling and support for the patient, the early detection of recurrence tumours or metastases, and assessment of the long-term effects of treatment.

Essential elements of cancer care include adequate pain relief and, for patients with progressive or terminal illnesses, palliative care and end-of-life-care.

Bottlenecks

- As yet, the usual oncological follow-up does not focus on the early detection of late adverse effects. Nor have any guidelines yet been developed for this purpose. Thus, in some hospitals, there are no checks whatsoever for the occurrence of adverse effects in patients, while other centres screen for disorders in which this is not effective.
- Further improvements are possible in palliative care and end-of-life-care. In this connection, clarity in communication with patients is very important.

Unexpected relapses and complications may occur after the treatment phase (sometimes many years later). For this reason, it is very important, both in terms of care provision and of clinical scientific research, that medical files are stored in an adequate way, for a sufficient period of time.

Objectives

- From 2005 onwards, a new chapter on aftercare will be added to the procedure for drafting new guidelines or updating existing ones. This will address the issues of when and how screening will be carried out, and for what. This follow-up screening includes an assessment of the patient's psychosocial situation and the later effects of treatments, relapses and metastases.
- During implementation of the guideline, the allocation of screening-related tasks between primary and secondary healthcare is determined at local level. This involves

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

who does what and when, and how is this communicated to other professionals and to the patient.

- From 2005 onwards, where relevant, the process of developing, implementing, and adjusting guidelines will include consideration of palliative and terminal care, and the adequate handling of issues surrounding euthanasia.

Actions

- A new chapter on screening during follow-up should be added to the procedure for drafting new guidelines or updating existing ones. This chapter should also set out the allocation of tasks between primary and secondary healthcare during this screening: who does what and when, and how is this communicated to others.

*Initiator: VIKC**

- Drafting guidelines for palliative and terminal care in general and, where necessary, developing, revising, implementing and assessing guidelines per type of tumour.

*Initiator: VIKC**

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

2.4 Continuing professional development

Care for cancer patients demands that educational programmes, in-service training, and continuing education focus on knowledge and skills in the fields of somatic symptoms and psychosocial aspects. Other requirements are competencies in the fields of palliative care and of influencing individual high-risk lifestyles. Consideration should also be given to spirituality and to giving meaning to life. This is why great demands are placed on practitioners charged with the treatment and counselling of cancer patients. When a disease becomes incurable, and enters the chronic, palliative or terminal phase, it is especially important that patients can aspire to their own wishes, expectations and preferences. While patients can often realize these wishes in their home environment, they may still require support from informal carers as well as professional and informal carers on a number of specific points. The practitioners must have adequate interpersonal skills, to enable them to discuss sensitive issues with patients, such as their future prospects and specific wishes. This requires a degree of coordination between different carers, so that patients are not presented with contradictory information.

1. General terms for continuing professional development

Bottleneck

- Various professions, such as medical specialists and nurses, still have no cohesive system of final attainment levels, no testing of competencies at initial registration and thereafter, no register, no system of accredited continuing education and in-service training, no re-registration system in general or for the specific area of oncology.

Objectives

- Medical specialists who are qualified to practice in the field of oncology should take a supplementary educational programme in oncology whose final attainment levels in the areas of education, psychosocial care, and communication are both uniform and cohesive. This must be achieved in 2008. It should be linked to a re-registration system. Once they have entered the job market, practitioners should regularly demonstrate that they have been practising their profession and that they still satisfy the criteria.
- By 2007, the Association of Oncology Nurses (VvOV) and the Dutch Psychosocial Oncology Society (NVPO) will have implemented the final attainment levels of the oncology registration. This will also apply to mamma-care nurses and nurse practitioners in oncology. This will be linked to a registration and re-registration system.
- The accreditation of continuing education and in-service training programmes will be embedded in the practitioners' accreditation and re-registration system. Accredited continuing professional development will also take place in the workplace, during peer review and supervision meetings.

Actions

- Drawing up final attainment levels in the areas of education, psychosocial care, and communication, and linking these to a system of re-registration for the medical specialists who are involved in caring for cancer patients.

Initiator: Committee for the Registration of Medical Specialists (MSRC)

- Implementation of the final attainment levels of the oncology registration by the VvOV and the NVPO. This will be linked to a registration and re-registration system.

Initiator: VvOV, or NVPO

2. Cohesive plan for continuing professional development

Bottleneck

- The parties who are directly and indirectly involved in cancer care have no cohesive plan for continuing professional development, nor do they have overall insight into the range and quality of the available continual professional development activities. Partly in the light of the patients' perspective, these parties should make their policy clear to all concerned, particularly where it touches on the area of continuing professional development. What is their competence, their responsibility, what expertise is available, and what resources? These parties must collaborate in the area of continuing professional development.

Joint solutions should be found for existing bottlenecks.

Objectives

- By 2005, details must be available concerning the institution (or websites) from which this overview can be accessed.
- From 2006 onwards, there will be a central national overview of the annual plans (for continuing professional development in the area of oncological care) drawn up by the various parties involved in cancer care. The highest priority will be assigned to GPs, nursing home physicians, medical specialists, nurses and psychologists. Following on from this, the caregivers, physiotherapists, dieticians, social workers, etc will be involved.

Actions

- Publishing a overview of the websites of the various parties involved.
*Initiator: VIKC**
- The establishment of a central national overview of the annual plans (for continuing professional development in the area of oncological care) drawn up by the various parties involved in cancer care.

*Initiator: VIKC**

3. Caregivers

A caregiver's work focuses on the patient's quality of life and on support in their home environment. It is extremely relational in nature. Besides caring for patients, caregivers in oncology also have the job of alerting other professionals.

Bottleneck

- In order to effectively alert others to the health problems caused by the cancer, the treatment and the adverse effects, caregivers (who deal with numerous cancer patients) require additional knowledge of oncology.

Objective

- By 2006, a national overview will have been drawn up of the existing supplementary educational programmes for caregivers in the area of palliative care and/or oncology. Any gaps in specific fields must have been eliminated by 2008.

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

Action

- The establishment of a national overview of the existing supplementary educational programmes for caregivers in the area of palliative care and/or oncology.

*Initiator: VIKC**

4. Nurses

Bottlenecks

- As yet, nurses in the Individual Health Care Professions Act (BIG) register are not obliged to re-register. In-service training and continuing education are not mandatory. Nor are any requirements imposed on current practical experience.
- In order to ensure that there will be no shortages of care-sector professionals in the years to come, changes will need to be made to the way in which both educational programmes and the professions are structured.
- Oncological diagnosis is continually changing. There is a rapid rise in the use of combined treatments, with a corresponding increase in the complexity of care. Treatments are increasingly determined on a case by case basis. Given the complex nature of the care involved, effective diagnosis by nursing staff is essential. Nursing staff are currently insufficiently competent to deal with this.
- Little oncology nursing research is conducted in the Netherlands, and research results are poorly implemented in practice. Evidence-based nursing care is essential to the quality of care.
- There is too little continuity of care between primary and secondary healthcare, and vice versa. Cooperation between nursing staff in primary and secondary healthcare should be intensified and improved.

Objectives

- By 2005, the extensive range of educational programmes for oncology nursing staff will have been published on the Web.
- By 2006, a system of re-registration will have been set up.
- Reallocation of duties – from physicians to nursing staff (and oncology nursing staff) and other practitioners – must also take place with regard to the treatment of cancer patients. This is part of the ‘*visitatie*’ which is aimed at the organization of multidisciplinary oncological care (see chapter entitled ‘Cancer Care’).
- Oncological diagnosis by nursing staff must be developed additionally, then implemented in a straightforward way. Oncology nursing staff should seek to expand their knowledge, to enhance their diagnostic skills and then make use of them in practice.
- By 2006, a detailed plan will have been drawn up for the initiation, execution and implementation of oncology nursing research. Adequate training and supervision are needed, to encourage and support the use of evidence-based procedures in oncology nursing.
- The continuity of care between primary and secondary healthcare nursing staff (and vice versa) must be safeguarded.

Action

- Draw up a plan for oncology research.

Initiator: VvOV

Most of the objectives will be translated into actions in other chapters and sections.

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

5. GPs

Bottlenecks

- On average, guidelines are followed in approximately 75% of cases. Nevertheless, there is a sizeable and unacceptable amount of interphysician variation.
- GPs do not make enough use of effective preventive strategies, such as the Minimum Intervention Strategy (MIS) for helping people to stop smoking.

Objectives

- By 2007, testing will be carried out for the purpose of benchmarking, which will reveal the degree of interphysician variation. By 2010, this variation will have been reduced by 20%.
- By 2010, MIS must be actively used in 50% of GP practices.

Actions

- Establishment of a benchmark instrument, to monitor GP compliance with guidelines/standards.
Initiator: NHG
- Implementation of MIS in institutions such as GP practices.
Initiator: GPs

6. Medical specialists

Bottleneck

- There are still medical specialisms and subspecialisms for which no final attainment levels (for the purpose of periodical testing) with regard to the subjects communication and psychosocial support have yet been established. Accordingly, the patients of such specialists have no guarantee that the physician in question has kept his knowledge and skills up-to-date.

Objectives

- By 2007, final attainment levels and re-registration criteria will have been formulated for communication, social psychology, ethics, multidisciplinary case review meetings, and transfer to other disciplines.
- From 2007 onwards, in line with the conclusion from 'de arts van straks' (the physician of the future), 'visitaties' will focus much more on the content of care.

Actions

- As soon as possible, the MSRC must decide to establish general and discipline-specific final attainment levels, per specialism.
Initiator: MSRC
- A re-registration system supported by accredited continuing education activities is required, along with the formal testing of specialists using the formulated final attainment levels.
Initiator: MSRC
- Final attainment levels and re-registration criteria have been formulated for the fields of communication, social psychology, ethics, multidisciplinary case review meetings, and transfer to primary healthcare and nursing homes.
Initiator: MSRC

- The ‘visitaties’ for medical specialists will incorporate more elements related to the content of care.

Initiator: Dutch Society of Medical Specialists (OMS)

7. Social workers

Bottlenecks

- The basic programmes devote scant attention to the subject of caring for clients with a serious somatic disease such as cancer.
- In none of the advanced courses for social workers is sufficient consideration given to psychosocial oncology.
- In the Netherlands, there is no integrated system of continuing education and in-service training for social workers in the field of psychosocial oncology.

Objectives

- From 2006 onwards, the structure of the basic programmes should be modified to include a greater emphasis on ‘working in the health service’. This should include a knowledge of the fundamentals of psychosocial oncology.
- From 2006 onwards, the structure of the two post-HBO (higher vocational education) advanced programmes must be modified to include the counselling of people with a serious physical illness, including cancer sufferers.
- By 2007, a psychosocial oncology course will have been developed for social workers who wish to undergo further training in this field.

Actions

- Embed psychosocial oncology in the basic programme for medical social work.

Initiator: basic programmes for medical social work

- Embed psychosocial oncology in the two post-HBO advanced programmes.

Initiator: HBO programmes

- Develop a psychosocial oncology course for social workers who wish to undergo further training in this field.

*Initiator: VIKC**

8. Psychologists

Bottlenecks

- By no means every university with a clinical psychology programme includes topics such as ‘working in the health service’ and ‘the psychosocial aspects of serious physical illness’.
- Postgraduate programmes in healthcare psychology and clinical psychology devote little or no attention to the psychosocial problems resulting from a serious physical illness like cancer.
- In the Netherlands, there is no complete and integrated system of continuing education and in-service training for psychologists in the field of psychosocial oncology.

Objectives

- From 2006 onwards, universities must include topics such as ‘working in the health service’ and ‘the psychosocial aspects of serious physical illness’ in their basic programmes in clinical psychology.

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

- From 2006 onwards, the structure of postgraduate programmes in healthcare psychology and clinical psychology must be modified to include themes involving sickness and health, and the counselling of people with a chronic physical illness.
- From 2006 onwards, a more complete and cohesive programme of continuing education and in-service training in the field of psychosocial oncology will have been developed for psychologists.

Actions

- Psychosocial aspects of serious physical illness and working in the health service will become fixed components of the basic programme in clinical psychology, and of the postgraduate programmes.

Initiator: Faculties offering programmes in clinical psychology

- The NVPO will compile (and keep updated) a summary of cohesive programmes of continuing education and in-service training.

*Initiator: NVPO/VIKC**

9. Spiritual counsellors

Bottlenecks

- The advanced programme in spiritual counselling devotes too little attention to aspects of sickness and health.
- The in-service training and continuing education available to spiritual counsellors primarily focus on the counselling of patients during the palliative phase. However, there is also a need for care in other phases of the disease process.

Objective

- As soon as possible, the advanced programme in spiritual counselling, as well as in-service training and continuing education, will place greater emphasis on the entire process of 'being ill'.

Action

- Develop continuing education and in-service training programmes in the area of cancer care, for spiritual counsellors.

*Initiator: VIKC**

10. Volunteers

Bottlenecks

- The extent to which volunteers receive courses of instruction when preparing to take up their duties and whether, if necessary, they receive any in-service training.
- The financing of training for volunteer work needs to be placed on a firm footing.

Objectives

- From 2005 onwards, institutions which supply volunteer workers must see to it that they receive proper courses of instruction and in-service training.
- The financing of courses of instruction and in-service training for volunteers must be secured as soon as possible.

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

Action

- Establish courses of instruction and in-service training for volunteers.

*Initiator: VIKC**

11. Informal carers

Informal carers are individuals who provide care to cancer sufferers on an occasional basis, rather than in a professional capacity. Such informal carers are usually members of the patient's social circle, someone with whom the patient has an emotional bond. While they did not opt for the role of carer, informal carers consider it to be their duty or obligation because the cancer sufferer is someone close to them. There is a broad understanding of the type of support required by the informal carers of cancer patients.

Bottleneck

- Informal carers are often confused about the types of support programmes that are available, about their quality, and about how various elements are financed.

Objectives

- Education about cancer should also address the needs of informal carers. It must also identify effective sources of support. This must be achieved in 2007.
- From now on, professionals must provide informal carers with information about potential sources of support.

Actions

- Make a list of where informal carers can obtain support, and from which institutions.

*Initiator: VIKC**

- Make this summary available to all professionals.

*Initiator: VIKC**

* By definition, this is carried out in consultation with NVZ, VAZ, OMS, LHV, AVVV, NVPO, VvOV, LVT and national scientific associations.

2.5 Research

Today's cancer research effort promises to make the prevention, diagnosis, and treatment of cancer still better tomorrow. Over the past 50 years, thanks to research, the five-year survival rate has increased from 25% to well over 50%. Developments in the field of genetics are providing just some of the new opportunities for further improvements. This particularly applies to the technology of DNA chips and protein chips, in the context of genomics and proteomics. The preliminary spin-offs of this fundamental and clinical research will be the more accurate diagnosis and prognosis of cancer, followed by more targeted and effective therapy.

*The term **Genomics** is derived from 'genome': the sum total of genes contained in an organism's DNA. The international Human Genome Project has led to the identification of all of the genes stored in human DNA (approximately 32,000). This has given rise to new technology, in the form of the DNA micro array technique. Using this technique, it is possible to identify the DNA profile of any given tumour biopsy. Various DNA profiles are now available for a number of tumours (including breast cancer and certain types of leukaemia), as is data concerning the tumour's clinical course and its response to treatment. Clear similarities between patients' DNA profiles indicate similarities in the type and clinical behaviour of the tumour. If patient data is available concerning the tumour's course and its response to treatment, this can be informative for the prognosis and for the treatment of each new tumour with a comparable profile.*

*The term **Proteomics** is derived from protein. The new domain of proteomics involves the large-scale analysis of proteins derived from a tumour, which are then compared to the proteins derived from other tumours. It is anticipated that these protein profiles will eventually provide valuable information about a patient's prognosis and the response of the tumour to treatment.*

New, better targeted drugs are currently in various phases of clinical trials, and existing therapies will be perfected. Research in the fields of epidemiology and behavioural science will provide increased opportunities for prevention such as risk group identification and effective guidelines for a healthy lifestyle. Dutch cancer research still ranks among the best in the world. In order to make the most of these opportunities for the benefit of cancer patients, and in the interests of the prevention or early detection of cancer, investment is required in all areas of cancer research and a number of obstacles must be eliminated. This requires action and effective teamwork between the actors and institutions involved. In this context, the following areas have been identified: 'people and resources', 'from knowledge to product' and 'legislation and implementation'.

1. People and resources

Numerous analyses, including the 'Discipline Plan' by the Royal Netherlands Academy of Arts and Sciences (KNAW) have shown that while Dutch cancer research ranks among the best in the world, this reputation is currently under threat.

Bottlenecks

- Too few young people are opting for a career in science. This is because unfavourable terms and conditions of employment, and adverse conditions for research, have made the career prospects unattractive.
- The funding of research (including cancer research) in the Netherlands by the government³ and industry is lagging behind that of other European states, the US, and Japan. It has fallen below the minimum necessary to maintain the Netherlands' leading position in cancer research.
- Clinicians have too little time for research. As a result, fundamental, translational and clinical cancer research have suffered. And this at a time when, in combination with valuable patient materials, unique opportunities (from sources such as the 'omics' research) hold the promise of a breakthrough in the fight against cancer.

Objective

- To improve researchers' career prospects and the financing of cancer research from 2005 onwards.

Actions

- Improved terms and conditions of employment for researchers, including more opportunities for bonuses and, for researchers of proven quality, better chances of obtaining a permanent position.

Initiators: The Association of Universities in the Netherlands (VNSU)/Association of University Hospitals (VAZ) in consultation with the research institutions.

- Expanding the opportunities for financing (for direct and indirect government funding) research (including cancer research) by investing larger sums of money.

Initiator: government

- Those funding research should invest selectively in talent during all phases of development.

Initiators: The Dutch Cancer Society, NWO/ZonMW and the government

- More ringfenced time for qualified clinicians to conduct research, via a modified collective labour agreement (CAO).

Initiators: research institutions

- Action, initiated by the political authorities, to boost the numbers of students in the pure sciences (in accordance with the Deltaplan bèta/techniek – a white paper on human resources in science and engineering)⁴ by elevating the social status of research and of researchers.

Initiator: government

- Improving the fringe benefits for researchers by a more flexible appointment policy, less bureaucracy, and more support.

Initiators: research institutions.

Some of the requisite resources can be obtained from innovation funds (joint government and industry, according to recent plans drawn up at Lisbon, within a European framework), partly from health insurance (where patients stand to benefit directly) and partly by reallocation (selective investment in innovation and talent, 'Bottom-up' control of science).

³ TOF total research funding from the Ministry of Education, Culture and Science: <http://www.minocw.nl/wetenschapsbudget/voortgang/10.html>.

⁴ The Deltaplan bèta/techniek will form part of the memorandum on knowledge workers by the Ministry of Education, Culture and Science, the Ministry of Economic Affairs, and the Ministry of Social Affairs and Employment.

2. From knowledge to product

The route leading from scientific discovery to product (or clinical application) is often long, expensive, and riddled with pitfalls.

Bottlenecks

- Insufficient use is made of the opportunities for translating a scientific result into an application that is of benefit to patients (translational and clinical research). This is due to a lack of specific knowledge, expertise and resources.
- That which is scientifically possible often fails to match the patient's needs, as some common types of cancer are not particularly amenable to experimentation. Nevertheless, recent tools derived from the molecular sciences represent a considerable improvement in this area.
- Research and treatment are becoming increasingly multidisciplinary in nature. This places great demands on coordination and on people's readiness to appreciate one another's expertise, capabilities and limitations.

Translational research

Rather than the development or expansion of scientific knowledge, this type of research is aimed at converting a scientific discovery into a clinical application. The starting point for translational research is a scientific discovery. The end point (objective) is a standard operational product (e.g. a usable chemical compound, or cell population) or standard operational procedure (a clinically applicable procedure) which can be tested in preclinical research. Translational research may include a toxicity study, as well as the validation of new techniques, the implementation of new diagnostic tests and the production and scaling-up of new medicinal products.

Objective

- Enhanced opportunities for the implementation of scientific findings in the clinical situation in the period from 2005 to 2010.

Actions

- The opportunities for translational research must be expanded through specific types of subsidies, and simplified legislation. Educational programmes in exact science and medicine should give greater emphasis to translational aspects, while universities must be better able to capitalize on clinical applications and commercial translation.
Initiator: consultations between research institutions, government and The Dutch Cancer Society.
- When making particular choices in cancer research, the scientific options must be in line with social and clinical needs. This means that researchers and patients (as well as patient organizations) must be involved ('bottom-up'). Furthermore, scientific quality must be a priority.
Initiators: The Dutch Cancer Society and NWO/ZonMw.
- Educational programmes should give greater emphasis to the current (multidisciplinary) mode of research and treatment. One way in which this can be done is by means of special Master Classes, 'shadowing' assignments, continuing education, and programmes, which are both up-to-date and which offer good options.

To this end, there are various university oncological centres where the requisite degree of broad-based expertise has been gathered together in the appropriate places. This aspect should be taken into account in the funding of research and education.

Initiators: research institutions

- The long and expensive route from discovery to medicinal product should be kept as short as possible, by modifying legislation and implementing cost-cutting measures. Insurance health funds and flexible legislation should make it possible for clinical trials to proceed in cases where funding from the pharmaceutical industry is unavailable.

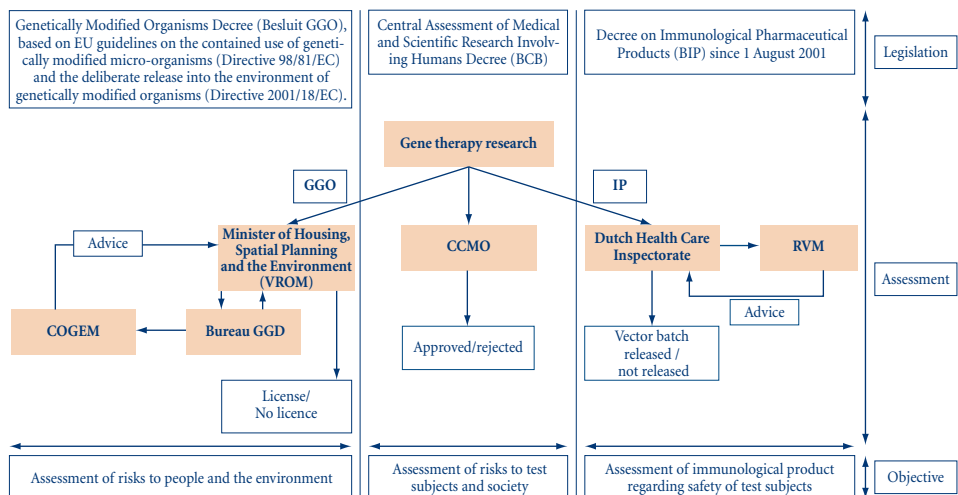
Initiators: government, industry and the health insurance companies.

Translational research will generally pay for itself within a relatively short period of time. The greater part of the requisite resources should therefore be generated via input from companies (patents, products), incubator funds and grants for business start-ups (Ministry of Economic Affairs).

3. Legislation and implementation

The western world is characterized by an increasing tendency to bring lawsuits. The field of biomedical research has also been affected by this trend, which has impeded important cancer research. The research field is pressing for fewer rules and less bureaucracy, to enable the interests of patients, the population, experimental animals, and the environment to be considered in a balanced, efficient and well-considered way.

The figure below illustrates how a complex network of advisory bodies and organizations is involved in granting a licence for clinical gene-therapy research.⁵



Bottleneck

- Major areas of clinical and fundamental cancer research are either severely impeded or made completely impossible by excessive, suffocating legislation. A number of existing or planned rules (retention time for medical records, availability of patient materials) are either counterproductive or are to the detriment of cancer research. This increasing tendency to bring lawsuits must be stopped.

⁵ Haanen J, Te complexe regelgeving obstakel voor klinisch onderzoek met DNA-vaccins [Overly complex legislation an obstacle to clinical research into DNA vaccines], Conceptuur (2003), 37; 16-18

Objective

- Review of current hierarchical legislation, including reducing the number of executive government bodies and increasing the involvement of the research sector and patients (as well as patient organizations) from now on.

Actions

- Existing rules must be simplified (e.g. broad informed consent).
Initiator: government
- Testing and permission for clinical studies and for experimental animal studies, for example, should, as far as possible, be obtained via a single contact point (in accordance with the 'government's outline coalition accord'), in which the core of the problem is that too many different organizations must be tackled.
Initiator: government
- More consultation with those most closely involved (scientists and patients) is needed when establishing new legislation. Those working in the field must be prepared and assisted well in advance, and there must be more harmonization of laws and regulations in a European context.
Initiator: government
- Finally educational programmes in exact science and medicine should give greater emphasis to all aspects of setting up and performing good clinical studies.
Initiators: research institutions.

2.6 Patient Education and Psychosocial Care

The following are ranked below education and psychosocial care: a) information provision and communication; b) support for the rehabilitation of patients; c) screening for psychosocial problems; and d) providing specialized psychological assistance in the form of counselling, Psycho-education, psychotherapy and psychiatric treatment.

1. The social and emotional repercussions of cancer and its treatment

There is plenty of evidence to show that when an individual contracts cancer, their life is radically disrupted in physical, emotional and social terms. Besides physical symptoms, the disease and its treatment often give rise to fear, uncertainty and depression, as well as impairment to a patients' feeling of self-worth and control. Disfiguring treatments, as well as cancer of the reproductive organs, can adversely effect sexuality. Patients may be affected by social effects if the disease causes them to become lonely or dependent. Besides being an important source of support, partners, parents and children can also experience highly unpleasant emotional repercussions. Each will have their own individual problems, which require appropriately tailored care.

The basic principle is that psychosocial problems of this kind must be avoided wherever possible, and that assistance with such problems should be provided wherever it is needed. Patients and those close to them must be able to rely on getting the information, care and assistance that they need to cope as effectively as possible with the disease and its effects. Psychosocial care and education remain relevant throughout the entire course of the disease (the diagnostic phase, the treatment phase, the disease-free period, the palliative phase, and the terminal phase). The next of kin may also need care. Aside from the disease itself, the often drastic treatments may generate a need for specific types of psychosocial care.

For many such patients (70-75%), effective education, communication and support during rehabilitation may be particularly helpful. Accordingly, help of this kind will enable them to tackle the problems associated with the disease themselves. The remaining patients (estimated at 25% to 30%) require specialized psychosocial care.

2. Patient information

Cancer patients and those close to them benefit from retaining as much control over their lives as possible, and of being able to make carefully considered choices. The provision of care must do justice to the autonomy of the patient and those close to them. Adequate information is indispensable in this regard, not just during the course of the disease, but also before and afterwards.

Bottlenecks

- The educational activities of care providers and their organizations and the information they give to the patients are not always perfectly in keeping with each other. There is too little coordination.
- There is a lack of clarity with regard to harmonization with the Medical Treatment Agreements Act (WGBO).

- The wide range of written and digitally-available educational and information material displays a lack of clarity and organization in terms of quality, completeness, topicality, and accessibility.
- Currently available information resources and the way in which information is provided are not sufficiently well tailored to the information needs by specific target groups.

Objectives

From 2007 onwards, at the very latest, patient information / education must satisfy the following criteria:

- Provide information / education generally takes place in accordance with established 'best practices'.
- These 'best practices' are set out in guidelines. The requirements imposed by the WGBO are also included here.
- The topic of effective education for - and communication with - cancer patients will be incorporated into the basic educational programmes of all of the relevant professions.

Actions

- By 2005, effective models for education (best practices) will have been identified.
Initiators: KWF, NFK, VIKC jointly.
- By 2006, a method of effective education and details of how to comply with the requirements of the WGBO will have been set out in guidelines.
Initiators: KWF, NFK, VIKC jointly. VIKC will see to it that the professions demonstrate commitment.
- 2005 will see the launch of an ongoing campaign aimed at incorporating 'education' and 'communication' into the basic educational programmes of all of the relevant professions.
Initiators: professional groups.
- In 2005, a start will be made on the (systematic and continuous) improvement and updating of the written and digitally-available information / educational material.
Initiators: KWF, NFK, VIKC jointly.

3. Alerting others to the need for extra psychosocial care

A patient's need for psychosocial care should be recognized. Alerting others is part of integrated care: treatment providers must determine that there is a need for additional care. A screening instrument can be of use in this regard.

Bottlenecks

- The regular care system is not equipped to detect psychosocial problems.
- No generally accepted instrument is available to screen for psychosocial problems.

Objectives

The following situation will have been achieved in 2010:

- A validated and cost effective screening instrument capable of indicating the need for specialized psychosocial assistance will be available and will have been widely introduced.
- This will enable all patients who are in need of extra psychosocial care to be detected and offered help.

- Screening for psychological and social problems, as well as those related to giving meaning to life has been included in the national guidelines for oncological care.

Actions

- At the beginning of 2005, a start will be made on the selection or development of a validated and cost effective screening instrument.

Initiator: Dutch Psychosocial Oncology Society (NVPO).

- Between 2007 and 2010, the screening instrument will be introduced throughout the country. One way in which this will be done is to incorporate the use of this instrument into the national guidelines for oncological care.

Initiator: NVPO.

4. Evidence for – and the provision of - specialized psychosocial care

Once an alert has been issued, the patient in question must have access to good-quality psychosocial oncological care. This is already provided in some places, but there is under-diagnosis and under-treatment at the national level.

Bottleneck

- The effectiveness of some treatments is supported by the available evidence, but high priority should be assigned to the further elaboration and organization of care.

Objectives

By 2010, the following will have been achieved:

- Effective forms of psychosocial care will have been incorporated into the guidelines for oncological care.
- Effective psychosocial care will have been incorporated into the basic educational programmes of all of the relevant professions.
- Effective psychosocial care and rehabilitation will have been incorporated into the standard health insurance package.

Actions

- During 2005 and 2006, research will have produced additional evidence to determine which forms of psychosocial care are effective for cancer sufferers.

Initiators: NVPO and ZonMw.

- Between 2007 and 2010, effective forms of specialized psychosocial care will be incorporated into the national guidelines for oncological care.

Initiators: relevant professional groups, NVPO and VIKC.

- 2007 will see the launch of an ongoing campaign aimed at incorporating effective psychosocial care into the basic educational programmes of all of the relevant professions.

Initiators: professional groups.

- From 2007 onwards, effective specialized psychosocial care will have been incorporated into the standard health insurance package.

Initiators: professional groups, health insurance companies.

2.7 Indicators

An adequate and manageable core set of indicators is needed to refine and better monitor the demand for care, the care process and treatment results. Furthermore, these will need both national and local input. The results of regular and systematic surveys (feedback from patients) should also be included in this. While simplicity and measurability (with as little extra effort as possible) are fine objectives, they are less easily achieved when it comes to essential, less readily accessible indicators. For the general public, there is a need for transparency and candour in relation to indicators and performance. The indicators are primarily useful for self-assessment exercises conducted by departments and institutions, which enable them to measure themselves against national trends. However, they can also be used for external assessment and international comparisons.

Bottlenecks

- No such set of nationally applicable indicators is available.
- As yet, death certificate data from the GBA cannot be used in the cancer registry. Consequently, it is not possible to supply effective and efficient survival figures.

Objectives

- By mid-2005 a set of indicators will have been established that is suitable for monitoring progress towards achieving the objectives of the NPK.
- By the end of 2005, the national set of indicators will be operational.
- By 2005, a link will have been set up between the cancer registry and the GBA, for the purpose of transferring survival figures efficiently and effectively.

Actions

- Establishing a set of indicators (checklist) to monitor progress towards achieving the objectives cited in the NPK report;
Initiator: NPK 'Indicators' working group.
- Indicate how and where the set of indicators for assessing the level of the quality of oncological care in the Netherlands can be derived.
Initiator: NPK 'Indicators' working group.
- The Netherlands Cancer Registry (NKR) will expand its data to include treatment type and location, and death-certificate data. This should provide information on cancer prevalence and survival, by tumour type and institution. This will require an amendment of the regulations, since institution-specific figures are not yet available.
Initiator: VIKC

Chapter 3. Implementation and Coordination

The establishment of the National Cancer Control Programme 2005 – 2010 will be followed by implementation, monitoring, assessment, and (where necessary) amendment. The NPK Steering Group takes the view that these activities fall within its remit. Action is now being taken to translate this Programme into the policies of all the organizations involved, including the five that launched the initiative.

In addition, starting in 2005, the Steering Group will draw up an annual action plan. This will be discussed with other organizations, and adjusted accordingly. The implementation of these action plans will also be assessed on an annual basis.

The Steering Group will establish a set of indicators in 2005. This work will, of course, take place in relation to existing indicator sets. These indicators will be used for monitoring and evaluating progress. They will also be included in the Steering Group's progress reports.

The National Cancer Control Programme aims to achieve tangible cohesion, collaboration and results. Hardly a sinecure, given the numerous parties involved and all those ambitions. This initiative, which originates from within the sector, demands that responsibility for its implementation is borne by the sector itself. Moreover, government support is indispensable.

Effective coordination is needed, if the requisite cohesion and progress are to be achieved. The Steering Group takes the view that these activities also fall within its remit. Change, collaboration, the promotion of cohesion – all demand leadership and the best possible support. Taking its inspiration from other countries' experiences the Steering Group recommends the appointment of a leading, widely respected professional in the field of oncology. Like those occupying posts such as National Cancer Director or Chief Executive of Cancer in other countries, this top official would promote implementation of the programme on behalf of the Minister of Health, Welfare and Sport. Given the scope of the cancer control network, an individual occupying a pivotal role can make the difference between sluggish progress and renewed zest. However, this can only be achieved if, in addition to possessing personal authority, the individual is acting as an ambassador on behalf of the minister. This person must tackle the problem by maintaining a dialogue, by presenting examples, making recommendations, but most of all by continuing to emphasize the intended objective, and to flesh it out.

Appendix 1

Declaration of Intent

The Association of Comprehensive Cancer Centres (VIKC), the Dutch Federation of Cancer Patients' Organizations (NFK), the Dutch Cancer Society/Queen Wilhelmina Fund (KWF), the Dutch Association of Health and Social-Care Insurance Companies (ZN) and the Minister of Health, Welfare and Sport (VWS) hereby declare their intention to join forces in establishing a National Cancer Control Programme (2005-2010) and to define measurement criteria and targets for such a programme. This programme has evolved from the discussion document 'Cancer control: towards the formulation of a medium-to-long term policy', published in April 1989 by the then Ministry of Welfare, Health, and Culture (now known as the Ministry of VWS). This programme also answers European and international calls from such bodies as the WHO and the European Parliament for the establishment of a national 'Comprehensive Cancer Control Programme'.

Based on a collective commitment and level of ambition, the said parties are responsible for the process, the content and also the evaluation of the National Cancer Control Programme.

Considering the need for:

- more effectiveness (through the pooling of knowledge and resources);
- greater efficiency (by avoiding duplication of effort and seeking a better allocation of tasks);
- cost control;
- a cohesive overall picture (with regard to both the public and professional sectors);
- coordination with regional, national and international developments (including European initiatives);

the parties have concluded that optimization of cancer control in the Netherlands in all its aspects (from prevention and diagnosis to aftercare, and also continued professional development, research, counselling and psychosocial care) is of eminent importance. This can be achieved on the basis of cohesion and cooperation between the institutions and organizations involved in cancer control in a policy-making and executive capacity.

The aforementioned parties – each having a specific role – will endeavour to establish a National Cancer Control Programme, within which policy will be formulated with a view to optimizing cancer control. Their efforts to achieve this goal will be subject to the financial and political circumstances prevailing at the time, with the following objectives being paramount:

- to assist in optimizing the health of the population;
- to reduce the incidence of cancer;
- to improve cancer survival rates;
- to decrease cancer mortality;
- to optimize the quality of life of patients and those close to them;
- to create a manageable and efficient system of optimal oncological care.

To achieve this, the following criteria must be fulfilled:

- availability of relevant epidemiological data;
- a high level of basic and applied research;
- rapid translation of research results into innovation and clinically usable services and products;
- a high standard of information provision and constant availability of continued professional development;
- optimal availability and accessibility of early detection methods for cancer;
- optimal availability and accessibility of optimal treatments for cancer;
- optimal availability of quality systems and effective methods of assessment, or alternatively the availability of reliable indicators.

The National Cancer Control Programme will be characterized by:

- broad-based participation at national and international level;
- outline objectives (which will, in principle, be measurable);
- concrete objectives;
- clearly defined priorities;
- a clear division of responsibilities;
- agreements with regard to continuity, implementation and assessment

Date: 23 October 2003

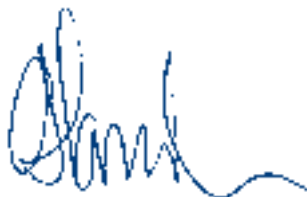
The Dutch Federation of Cancer
Patients' Organizations
E. Borst-Eilers, Chairperson



The Association of Comprehensive
Cancer Centres
B.A.J. Jongejan, Chairperson



The Dutch Cancer Society
A.G.J.M. Hanselaar,
Managing Director



Dutch Association of Health and
Social-Care Insurance Companies
M.A.J.M. Bos, Care Director

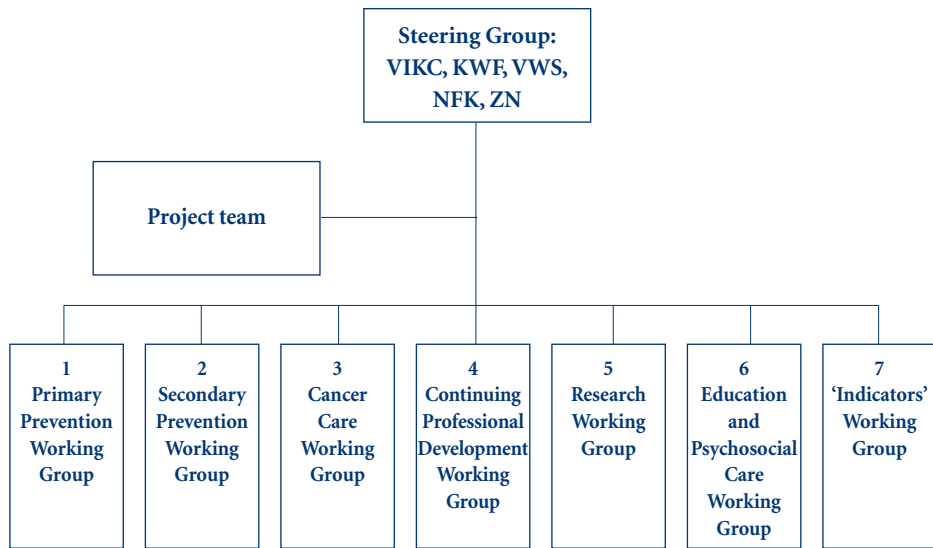


Ministry of Health, Welfare and
Sport
J.F. Hoogervorst



Appendix 2

NPK organization chart



Appendix 3

Composition of the Steering Group

On behalf of the Association of Comprehensive Cancer Centres, Utrecht

Dr R. Otter, Board of Management, North Netherlands Comprehensive Cancer Centre, Groningen

B.A.J. Jongejan, Director, Comprehensive Cancer Centre West, Leiden Region

On behalf of the Dutch Cancer Society, Amsterdam

Ms C. Honing, Head of education and counselling

Dr A.G.J.M. Hanselaar, Managing Director

On behalf of the Ministry of Health, Welfare and Sport, The Hague

L. Kootstra, Prevention and Public Health Directorate

J.S. van Vliet, Prevention and Public Health Directorate, Head of Disease Prevention

On behalf of the Dutch Federation of Cancer Patients' Organizations, Utrecht

Dr E. Borst-Eilers, chairperson

Dr P. Huijbregts, Director

On behalf of The Dutch Association of Health and Social-Care Insurance Companies, Zeist

C. Bos, Care Director

Project team

H. Hummel, North Netherlands Comprehensive Cancer Centre, Groningen

Ir. H.J. Roelants, Amsterdam

Appendix 4

Abbreviations used

AVVV	The Dutch Association of Nurses and Care Workers
AWBZ	Exceptional Medical Expenses Act
BCB	Central Assessment of Medical and Scientific Research Involving Humans Decree
BIG	Individual Health Care Professions Act
BIP	Decree on Immunological Pharmaceutical Products
CAO	Collective labour agreement
CBS	Statistics Netherlands
CCMO	Central Committee on Research Involving Human Subjects
COGEM	Netherlands Commission on Genetic Modification
CVZ	Health Care Insurance Board
DBC	Diagnosis Treatment Combination
EZ	Ministry of Economic Affairs
GBA	Local Authority's Residents Registry
GBI	Health-Promoting Institution
GGO	Genetically Modified Organisms
GGD	Municipal Medical and Health Service
GR	Health Council of the Netherlands
HBO	Higher Vocational Education
ICT	Information and Communications Technology
IGZ	Dutch Health Care Inspectorate
IKA	Comprehensive Cancer Centre, Amsterdam Region
IKC	Comprehensive Cancer Centre
IKZ	Comprehensive Cancer Centre, Southern Region
KNAW	Royal Netherlands Academy of Arts and Sciences
LHV	National Association of General Practitioners
LVT	National Association for Home Care
MIS	Minimum Intervention Strategy
MSRC	Committee for the Registration of Medical Specialists

NFK	Dutch Federation of Cancer Patients' Organizations
NHG	Dutch College of General Practitioners
NISB	Netherlands Institute for Sport and Physical activity
NIGZ	Netherlands Institute for Health Promotion and Disease Prevention
NKI	Netherlands Cancer Institute
NKR	Netherlands Cancer Registry
NPK	National Cancer Control Programme
NVPO	Dutch Psychosocial Oncology Society
NVZ	Netherlands Association of Hospitals
NWO	Netherlands Organization for Scientific Research
OMS	Dutch Society of Medical Specialists
RIVM	National Institute for Public Health and the Environment
STIVORO	Public Health and Smoking Foundation
STOET	Foundation for the Detection of Hereditary Tumours
VAZ	Association of University Hospitals
VIKC	Association of Comprehensive Cancer Centres
VROM	Netherlands Ministry of Housing, Spatial Planning and the Environment
VSNU	Association of Universities in the Netherlands
VvOV	Association of Oncology Nurses
VWS	Ministry of Health, Welfare and Sport
WBO	Population Screening Act
WGBO	Medical Treatment Agreements Act
WHO	World Health Organization
ZFW	Health Insurance Act
ZonMw	Netherlands Organization for Health Research and Development
ZN	Dutch Association of Health and Social-Care Insurance Companies

