



Progress Report on Cancer Control in the Netherlands

by the Dutch National Cancer Control Programme 2005-2010

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

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Foreword



The reason for the development of the National Cancer Control Programme (Dutch NCCP - *Nationaal Programma Kankerbestrijding*) was the fact that evidence-based guidelines and protocols for diagnosis and treatment were not being employed by all practitioners, institutions and care providers in the care chain, which encompasses primary care (prevention), treatment and aftercare.

Against that background, the Dutch NCCP started on 4 November 2004 as a collaborative venture of five Dutch parties all involved in cancer control from different perspectives with the aim of improving cancer control.

The focus was on improvement of coherence, cooperation and chain care between and with all professionals, organizations, care institutions, insurers, ministries and patients' associations involved in cancer control. Such a goal had never been achieved before and the Dutch NCCP was considered to be a great challenge.

After the implementation of the structure of the Dutch NCCP, the focus moved to the content. This meant not only focusing our attention purely on improved techniques in prevention, screening, treatment and palliative care, but also considering behavioural and psychosocial aspects playing a role. The Dutch NCCP's objective is to tackle the entire combination of human aspects. Psychosocial counselling of patients is after all just as important as clinical technique, as are improved links in the chain of care.

This (holistic) approach appeals to me personally, and it is something I am happy to promote; it is also fully supported by the members of the Dutch NCCP.

The results achieved so far reveal that the Dutch NCCP has contributed to a faster, more complete and more effective chain of care, including prevention and aftercare. Monitoring of achieved goals and the development of future initiatives will need to continue and we will keep discussing the best way to do this.

The goals which have been achieved are described in the present report.

Ir. Hans de Goeij

Chairman of the Dutch National Cancer Control Programme 2005-2010

and former Director-General for Public Health of the Ministry of Health, Welfare and Sport (2002-2009)

Introduction

This report describes the developments regarding the overall goals of the Dutch NCCP and the activities and achievements of the NCCP¹ working groups.

Scope of the National Cancer Control Programme (Dutch NCCP) 2005-2010

In November 2004 the first Dutch NCCP vision and summary for 2005-2010 were published (www.npknet.nl). Both the fact that within 10 years (from 2005 to 2015) the incidence of cancer patients will increase from 78,000 to 95,000 and the fact that in the same period the number of people suffering from cancer will almost double, will engender a major increase in the demand for care. In addition, more than 200 different organizations (besides hospitals) and a tremendous number of individuals are involved in cancer control on a daily basis, bringing their own knowledge, insights and passion to the job. However, they were not operating within a mutually agreed framework on the basis of common priorities or within a comprehensive management structure. Facing the lack of sufficient coherence, the risk of less than optimal performance and the major increase in the cancer burden, the Association of Comprehensive Cancer Centres (VIKC), the Ministry of Health, Welfare and Sport (VWS), the Dutch Cancer Society (KWF Kankerbestrijding; hereafter: KWF), the Dutch Federation of Cancer Patients' Organizations (NFK) and the Dutch Association of Health and Social Care Insurance Companies (ZN) took the initiative to set up the first Dutch NCCP. The Dutch NCCP was not meant to be a means of obtaining more financial support for cancer control. It was to be an initiative that would be neutral in terms of budget and that would realize reallocation on the basis of priorities. The programme, which covers all aspects of cancer control (from prevention, screening and diagnosis to aftercare, psychosocial care, education and research), ensures coherent priorities and measurable objectives. The Dutch NCCP should result in:

- the healthiest possible population;
- less cancer;
- greater likelihood of surviving the disease;
- lower death rates
- optimum quality of life for patients and their family and friends;
- a manageable and efficient system enabling the best possible cancer care.

Based on the more than 150 broad and extensive targets devised within the various domains of comprehensive cancer control, the Dutch NCCP's Steering Committee selected and prioritized seven themes:

- discouraging smoking;
- implementation of colorectal cancer screening;
- improvement of the capacity for translating screening to regular care;
- improvement in the quality and accessibility of cancer care;
- psychosocial care;
- translational research;
- education in oncology for medical specialists and nurses.
- In 2006 and 2007, the Steering Committee set up working groups dedicated to these seven themes.

Why a progress report?

The report aims to help policy makers understand past efforts in cancer control enabling them to better allocate health resources. It highlights the key successes (and failures) in cancer control by showing the results achieved, thus enabling policy makers to better determine the most appropriate strategies for cancer control in the Netherlands.

1 A list of acronyms used can be found at the end of this report.

What's in this report?

The progress report is divided into different chapters: an overview of cancer control in the Netherlands; prevention, screening, quality of care, psychosocial care, education, research and conclusions. Each chapter offers an overview of the objectives based on the Dutch NCCP report 2005-2010 and a description of what has been achieved during this period.

The data and results used have been obtained from various sources (mentioned under the tables and figures) and these sources are responsible for the results used as scientific evidence. All data and results used have been checked with the sources concerned.

Cancer in the Netherlands

In 2009, cancer became the leading cause of death in the Netherlands. In that year more than 42,000 people died of cancer. The proportion of all deaths attributable to cancer has increased over the last decades from 24% in the early 1970s to 32% at present. In 2010, an estimated number of 92,500 new cases of cancer will be diagnosed in the Netherlands: 48,000 in males and 44,500 in females. Survival has increased: of the patients diagnosed between 2003 and 2007, 59% was still alive five years after diagnosis, compared to 47% of the patients diagnosed between 1988 and 1992 (www.kankerregistratie.nl).

Organization and structure of cancer control in the Netherlands

In the Netherlands, the provision of cancer services is the responsibility of each individual hospital. Since the end of the 1970s, nine Comprehensive Cancer Centres (IKCs; network organizations) have been supporting professionals in improving the quality of cancer care. Over time, national associations of (medical) specialists in oncology (medical oncologists: NVRO; surgical oncologists: NVCO, radiotherapists: NVRO, nurses in oncology: NvOV, psychosocial oncologists: NVPO) and many national multidisciplinary tumour working groups in oncology were installed in order to develop more cohesive plans. Patients in need for help, support or information are able to obtain this information via the website or telephone help line of KWF. During the last 10 years the voice of patients, through NFK and cancer-specific patients' associations, have become louder.

Interview with Els Borst-Eilers, chair of the Dutch Federation of Cancer Patients' Organizations



“Psychosocial care has progressed in leaps and bounds”

As chair of the Dutch Federation of Cancer Patients' Organizations (NFK), Els Borst has been involved in the National Cancer Control Programme (Dutch NCCP) since its inception. The former Dutch Minister of Health, Welfare and Sport remains a staunch supporter of a thorough-going plan to tackle cancer. “This disease is a major problem, and major problems require a large-scale approach.”

Els Borst has served as chairperson of the NFK since 1 January 2003. Established in 1991, NFK is the umbrella organization for some 25 cancer patient associations. As stated on its website (www.nfk.nl), “NFK represents the interests of people who either have cancer or have had it in the past. Whenever policy on oncological care is discussed, we are there to take part in the proceedings. We think and speak from the perspective of cancer patients. The patient organizations that make up the NFK represent approx. half a million former and current cancer patients. Around 25,000 of these are members of one of the organizations.”

Borst – who served as Minister of Health, Welfare and Sport in the Dutch government from August 1994 to May 2002 – has only herself to thank for her current position, she says with a wink. “When I approached the end of my tenure as minister, I was of course often asked about my plans for the future. On one of those occasions, I replied that I wanted to get involved with patient organizations. I believed that the position of patients needed to be enhanced, and that the interests of patients could be promoted more effectively.” It came as little surprise, then, that the NFK came knocking at my door shortly afterwards”, asking the retired minister how she would feel about taking up the key position of chairperson.

This was a proposition that Borst did not have to think about for very long. As NFK chair, she would be in a prime position to promote the interests of patients and strengthen their position. Borst also had more personal reasons for accepting the offer. “My husband died of cancer, as have a number of my personal acquaintances. Therefore, I was well aware of the impact that this disease has on patients and their loved ones. In my previous profession as a physician, I have also dealt with patients who suffered from cancer.” Borst will vacate her position as chairperson of Dutch NCCP shortly. After being reappointed for a second four-year period in 2007, she will reach her maximum term at the end of this year and leave NFK.

Borst believes that it was only logical for the NFK to be involved in the National Cancer Control Programme from the start. “After all, you cannot make policy without taking the interests of the patients into account. ‘No decision-making without patient representation’, we say at the NFK. As patients are becoming more assertive and standing up for themselves, the way is paved for patient organizations to play a more prominent role.”

During a conference on smoking cessation organized by the Dutch NCCP and STIVORO (an organization that helps people to stop smoking) on 16 June 2010, Borst presented the previous Dutch NCCP Monitor to Paul Huijts, Director-General of Public Health at the Ministry of Health, Welfare and Sport. The report concluded that most of the targets set in 2006 for combating cancer in the Netherlands have not yet been achieved.

For example, it emerged that none of the targets for the promotion of a healthier lifestyle have been achieved. The incidence of cancer has also risen, predominantly due to the increase in the percentage of senior citizens in the Netherlands.

“Nevertheless, we should not lose heart”, Borst insists. “I am a realistic person. You cannot make the world a better place in a mere five years. At the same time, you have to dare to set your sights high. In a number of areas, we have made considerable progress and there have even been indications of positive developments. For instance, responsibilities in the field of oncological care are now being divided much more effectively and we have developed clear quality standards which are being complied with and monitored. These measures will certainly prove worthwhile. The field of psychosocial care has also progressed in leaps and bounds. Just a few years ago, cancer was approached almost purely from a treatment point of view, paying little attention to the psychosocial aspects. Thankfully this situation has changed, although patients still receive insufficient psychosocial support in my opinion. And these are not the only tangible results achieved by the National Cancer Control Programme.”

The chairperson of the NFK is well aware that there are many steps yet to be taken. One example concerns reducing the number of smokers. “The percentage of smokers was on the decline for years, but has now levelled out at twenty-eight percent. This is still far too high, especially considering that thirty percent of cancer-related deaths are caused by smoking. In short, there is still much to be accomplished in this area. The central issue at the conference was how to improve smoking cessation rates in the Netherlands. A number of foreign experts at the conference were quite critical of the fact that there are still so many smokers here. In many countries the percentage of smokers has declined considerably thanks to a focused, multi-pronged approach. In other words, it *is* possible. We have to devote ourselves more fully to the issue, and that includes addressing the pernicious influence of the tobacco industry.”

Borst believes that the National Cancer Control Programme has provided the oncological care sector with a new sense of energy and direction. “There is now much more cooperation within the sector and all parties are acquainted with one another, which is essential. On the other hand, we have to be careful that the organization does not become overly bureaucratic. I am well aware of the necessity of setting up working groups and writing reports, but once those reports are finished we have to make sure that doctors, nurses and other parties work in the agreed manner. As far as I’m concerned, we need to place more emphasis on this and measure progress in this area from now on.”

The soon-to-be-former chairperson of the NFK hopes that the National Cancer Control Programme will continue beyond 2010. “We should definitely continue with this programme. While many aspects of oncological care have been improved, we are still a long way from achieving our aims. There are still many steps to be taken. In that sense, I am all for a new five-year programme. Long live Dutch NCCP 2!”

Over the last decade, huge changes in the financing of the health care system have increased the responsibilities of health insurance companies and have given them more options to buy care based on quality indicators. As a consequence, the development of a free market health system is being stimulated for the medical as well as the financial outcomes (competition and benchmarking between hospitals). Although the Ministry of Health, Welfare and Sport has been focusing more and more on chain care, the above-mentioned changes are considered to be obstacles for the promotion and facilitation of collaboration between hospitals, between disciplines within a hospital or between hospitals and first-line care.

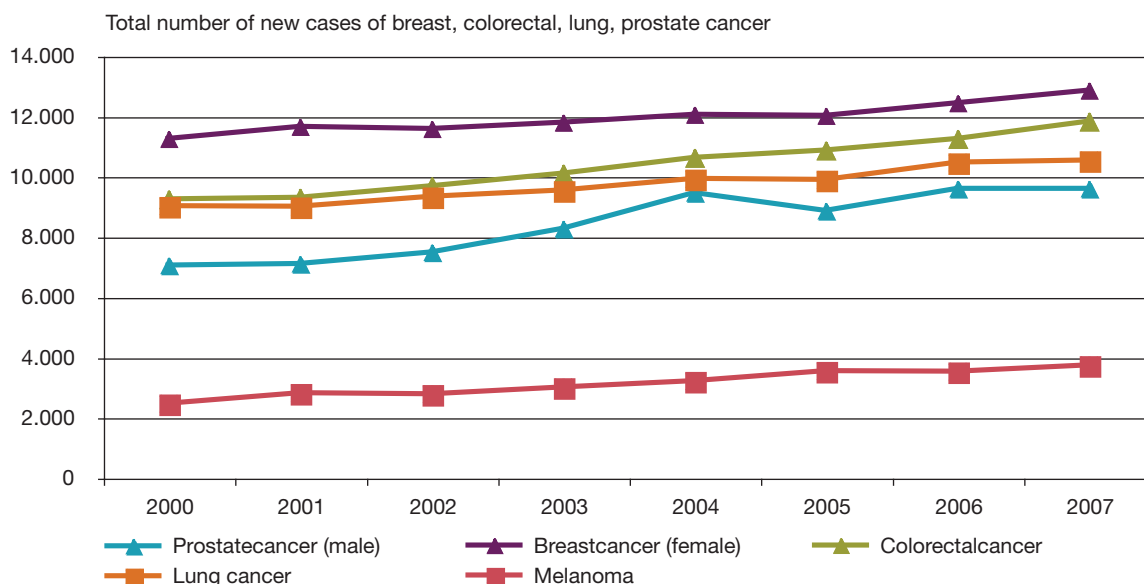
Recently, several reports on the organization and structure of cancer care have been published, including “Zorgketen voor kankerpatienten moet verbeteren” (*Care chain for cancer patients must improve*)¹ by the Health Care Inspectorate (IGZ) and “Kwaliteit van kankerzorg in Nederland” (*Quality of cancer care in the Netherlands*)² by KWF’s Cancer Signalling Committee. The recommendations in these reports promote a more comprehensive management structure, a mutual framework for optimal collaboration in terms of responsibilities, skills, equipment and transparency. Initiatives on transparency by such organizations as the Dutch Health Care Transparency Programme (www.zichtbarezorg.nl), the “Regieraad” and the National Institute of Quality in Health, are all aiming for harmonization and understanding of the quality process of oncological care.

How does the Netherlands compare to other countries?

Only few European countries had an NCCP at the beginning of the year 2000. Due to promotion by and support from the WHO, the UICC and the EU, more and more countries are now aware of their cancer burden and are developing their own cancer plan. Comparison between NCCPs of various European countries (Eurocanplus+: www.eurocanplus.org) showed that most of them did not cover all domains, nor did they formulate the goals in such a way that these could be monitored or evaluated; the NCCPs of the UK and the Netherlands were the exceptions^{3,4}.

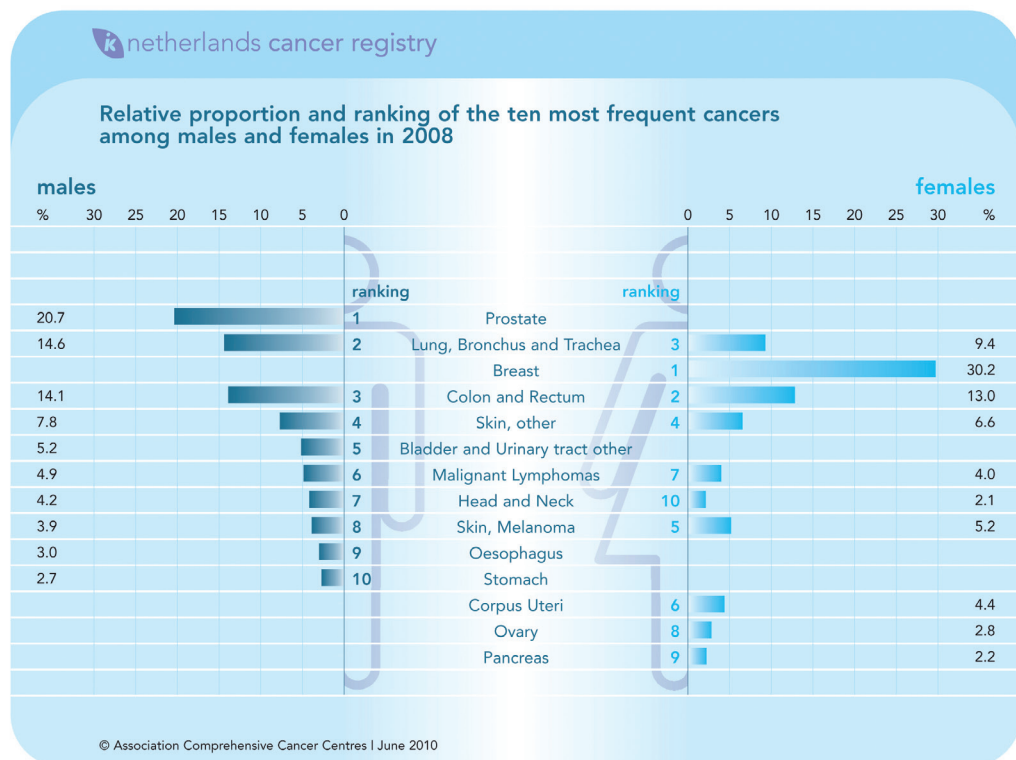
Cancer burden: the Netherlands compared to other countries

The cancer incidence in the Netherlands is high compared to other European countries. This applies especially to smoking-related cancers in women⁵.



Cancer incidence⁶

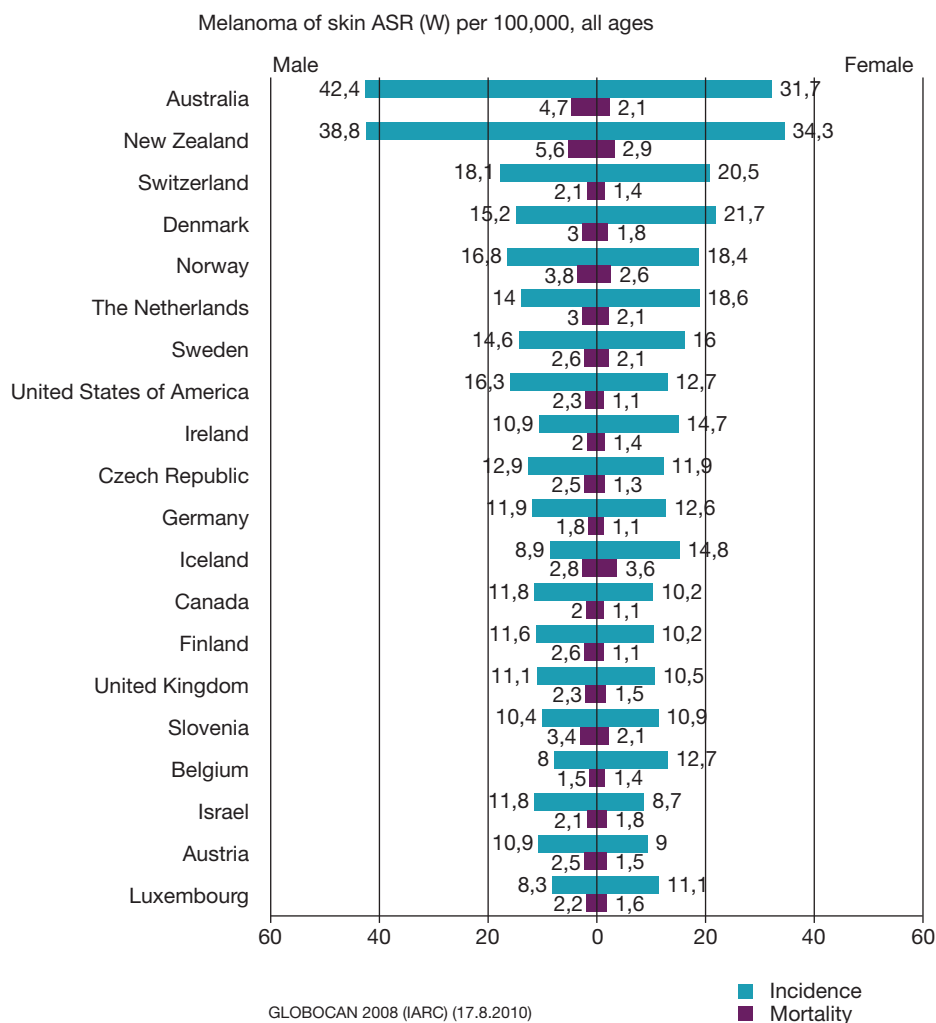
- In 2008, 89,228 new cases of cancer were diagnosed in the Netherlands. During the period 2005-2008 the number of new cancer cases increased by 2.3% per year.
- The increase in the number of elderly people diagnosed with cancer is the main cause of this trend.
- In the Netherlands, cancer remains mainly a disease affecting elderly people. In 2008, 58% of all new cases were diagnosed among persons aged 65 years and older. Less than 1% of all cases occurred among persons under the age of 20.
- The most common types of cancer are breast cancer, colorectal cancer, lung cancer, skin cancer (excluding basal cell carcinoma) and prostate cancer. These five types of cancer combined account for over two thirds of all new cases of cancer in the Netherlands.
- In the Netherlands, as in other countries of the world, breast cancer is the type of cancer diagnosed most frequently in women; in 2008, breast cancer was diagnosed in 13,005 women in the Netherlands (95.3 cases per 100,000 females, according to the World Standardized Rate (WSR)). Worldwide, an estimated 1.38 million new breast cancer cases were diagnosed in 2008 among women (23% of all cancers), and it ranks second overall (10.9% of all cancers). Incidence rates are high (more than 80 per 100,000, WSR) in developed regions of the world (except Japan) and low (less than 40 per 100,000, WSR) in most of the developing regions.



- The absolute incidence of colorectal cancer in the Netherlands was 12,117 in 2008 (6519 males and 5598 females): two thirds of these tumours were located in the colon. Like in the rest of the world, it was the third most common cancer in men (663,000 cases worldwide, or 10.0% of the total number) and the second most common cancer in women (570,000 cases, or 9.4% of the total number) in 2008. Almost 60% of cases occur in developed regions.
- Worldwide, lung cancer has been the most common cancer for several decades, and in 2008 there were an estimated 1.61 million new cases, representing 12.7% of all new cancers. In the Netherlands, lung cancer incidence is still increasing in females: in 2008, 4047 cases were diagnosed (27.7 per 100,000 females, WSR), which represents an absolute increase of

43% from 2005 to 2008. In males, lung cancer incidence decreased by 15% from 2005 to 2008. In 2008, 6729 cases were diagnosed (46.0 per 100,000 males, WSR), making it the second most common cancer in males in the Netherlands. Worldwide it is the fourth most common cancer in women (513,000 cases, or 8.5% of all cancers in 2008) and still the most common cancer in men (1.1 million cases, or 16.5% of the total number). It was also the most common cause of death from cancer worldwide, with 1.38 million deaths (18.2% of the total number). The majority of cases now occur in developing countries (55%).

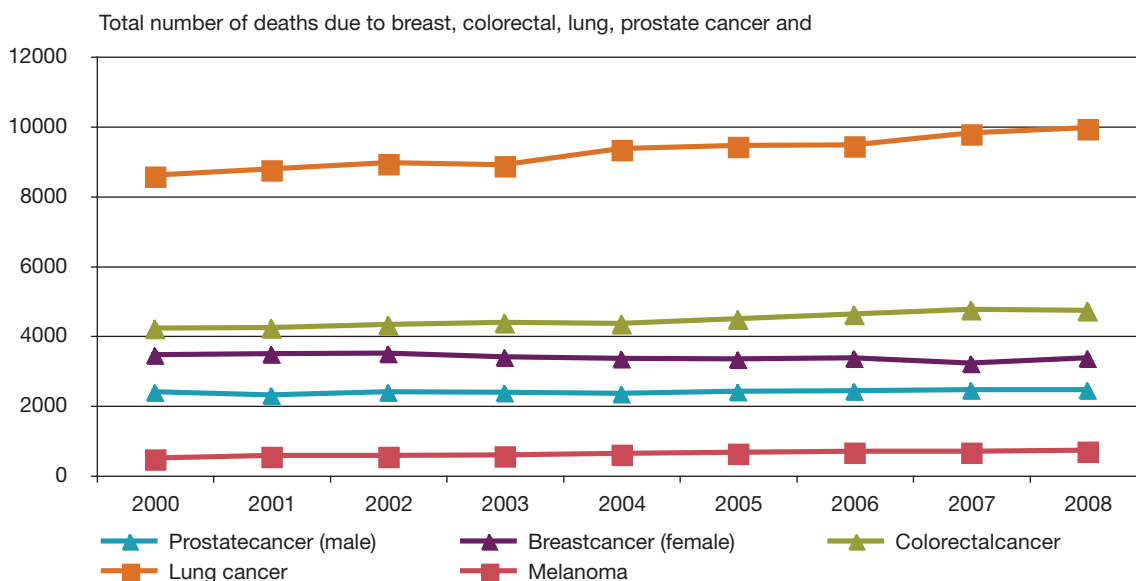
- Skin cancer in general (excluding basal cell carcinoma) increased in the Netherlands to 10,524 new cancer cases in 2008. During the period between 2005 and 2008, melanoma incidence increased by 5% in females to 1437 new cases in 2008 (18.6 per 100,000 females, WSR) and by 6% in males to 1026 new cases in 2008 (14.8 per 100,000 males, WSR). Worldwide, melanoma has an incidence rate of 2.8 per 100,000, with a total number of new cases in 2008 of 197,402.



- Prostate cancer is the cancer most frequently diagnosed in males: in 2008, 9559 cases were diagnosed (66.3 per 100,000 males, WSR). Worldwide, prostate cancer is the second most frequently diagnosed cancer in men (903,000 new cases, or 13.6% of the total number) and the fifth most common cancer overall. Nearly three quarters of the registered cases occur in developed countries. Incidence rates for prostate cancer vary by more than 25-fold worldwide, with the highest rates being observed in Australia/New Zealand (104.2 per 100,000, WSR), Western and Northern Europe, and North America, largely because the practice of prostate-specific antigen (PSA) testing and subsequent biopsy has become widespread in those regions.
- Worldwide, cervical cancer is the third most common cancer in women, and the seventh overall, with an estimated 529,000 new cases in 2008. More than 85% of the global burden occurs in developing countries, with an incidence of more than 30 per 100,000 (WSR), where it accounts for 13% of all female cancers. In the Netherlands, cervical cancer incidence decreased by 1.4% per year from 2005 to 2008, to 699 new cases in 2008 (6.1 per 100,000, WSR).

Cancer mortality⁶

- In 2008, 40,993 people died of cancer in the Netherlands (125.4 per 100,000 person years, WSR).
- During the period 2005-2008, the absolute number of deaths increased by 0.9% per year.
- Corrected for population age and gender, cancer mortality decreased.

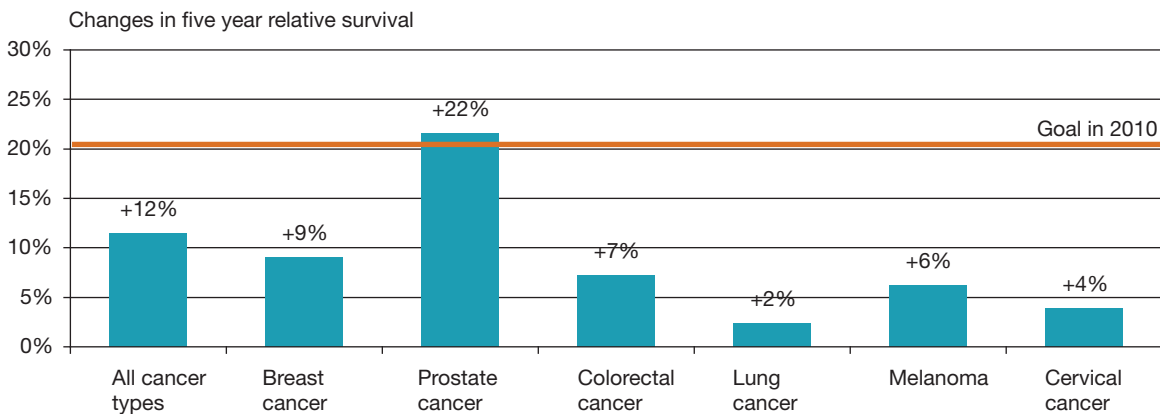


- In the Netherlands, 3327 women died due to breast cancer in 2008 (20.0 per 100,000 females, WSR); this represents a decrease of 13% from 2000 to 2008. Worldwide, the range of mortality rates of breast cancer is much smaller than the range seen in incidence (approximately 6-19 per 100,000, WSR) because of the greater chance of survival of breast cancer in (high-incidence) developed regions. Still, the estimated number of 189,000 deaths is almost equal to the estimated number of deaths caused by lung cancer (188,000 deaths).
- In the Netherlands, the number of deaths due to colorectal cancer was 2466 in males (16.1 per 100,000, WSR) and 2344 in females (11.2 per 100,000, WSR) in 2008. Worldwide, the highest estimated mortality rates in both sexes are in Central and Eastern Europe (20.3 per 100,000 for males and 12.1 per 100,000 for females, WSR).

- Because of the high mortality rate of lung cancer (with a mortality/incidence ratio of 86%) and the lack of variability in survival between developed and developing countries, the highest and lowest estimated mortality rates are found in the same regions as the highest and lowest incidence rates, both for men and for women. In the Netherlands, the lung cancer mortality rate is still increasing in females: in 2008, 3531 women died of the disease (22.2 per 100,000 females, WSR). A decrease was seen in males with 6387 deaths in 2008 (42.0 per 100,000, WSR).
- In the Netherlands, skin cancer caused 766 deaths in 2008, of which 685 deaths were due to melanoma. Melanoma deaths in females increased by 55% in absolute terms to 297 deaths in 2008. In males, death due to melanoma increased by 39% in absolute terms to 388 cases in 2008. Worldwide, 6090 deaths can be contributed to melanoma. Mortality is again highest in Australia/New Zealand (3.5 per 100,000, WSR), followed by South Africa (3.0 per 100,000, WSR). Western Europe has a mortality rate of 1.5 per 100,000.
- Prostate cancer was the cause of death for 2367 males in the Netherlands in 2008 (17.5 per 100,000 males, WSR). Because PSA testing has a much greater effect on incidence than on mortality, there is less variation in mortality rates worldwide (10-fold) than is observed for incidence (25-fold), and the number of deaths caused by prostate cancer is almost the same in developed and developing regions.
- Cervical cancer deaths within the Netherlands decreased by 2.7% per year, to 244 new cases in 2008 (1.6 per 100,000 females, WSR). Worldwide, the mortality/incidence ratio was 52% and cervical cancer was responsible for 275,000 deaths in 2008, about 88% of which occurred in developing countries. In the Netherlands, the incidence/mortality ratio was 26%.

Cancer survival⁷

- Survival increased in the Netherlands: patients diagnosed between 2004 and 2008 survived in 59% of cases compared to 47% of patients diagnosed between 1989 and 1993. In Europe, the five year relative survival rate for all cancers was 52% during the period 1995-1999. Overall, the UK and Eastern Europe showed a somewhat lower survival rate, also for the individual tumour types. The greatest increase in survival over time (from 1990-1994 to 1995-1999) was found for prostate cancer (12.5%), followed by colorectal cancer and breast cancer (both 4.2%).



- In the Netherlands, women have a better survival than men (62% compared to 55%). In general, the lowest stage has the best survival rate for all tumours
- Five year relative survival rate for breast cancer increased to 86% in 2008 (a 9% increase from 1989-1993 to 2004-2008). In Europe, the five year relative survival rate for breast cancer showed an increase in all countries between 1990-1994 and 1995-1999, to 79.5% for patients diagnosed between 1995-1999, with rates ranging from 69.3% (Czech republic) to 87.6% (Iceland).

- Survival of colorectal cancer in the Netherlands increased by 7% from 1989-1993 to 2004-2008. The five year relative survival rates for patients with colon cancer and rectal cancer in the period 2004-2008 were 60% and 63%, respectively. For colorectal cancer, the five year relative survival rate increased by 4.2% to a survival rate of 53.5% in 1995-1999 in Europe in general, with rates ranging from 38.5% (Poland) to 59.7% (Switzerland).
- The five year relative survival rate for lung cancer did not improve significantly and was 15% in the period 2004-2008. Within Europe, the survival of lung cancer showed small improvements in some countries. The highest survival rate was found in Western Europe. The European mean was 10.2% in 1995-1999, with rates ranging from 7.9% (Denmark) to 14.7% (Iceland).
- Prostate cancer patients showed an increase in the survival rate of 22%, from 64% in the period 1989-1993 to 86% in the period 2004-2008, due to earlier detection of the tumour. A significant increase in the survival of prostate cancer patients was revealed in some countries. The survival rate in Europe as a whole was 73.9% and ranged between 47.7% (Denmark) and 84.9% (Austria) in 1995-1999.
- Of all patients diagnosed with melanoma between 2004 and 2008, 87% survived the first five years, compared to 81% in the period 1989-1993. Females had a slightly better survival than males. The five year relative survival rate for melanoma was 85.4% for Europe as a whole during the period 1995-1999 and ranged from 63% (Poland) to 90.35% (Switzerland).
- Cervical cancer had a five year relative survival rate of 66% (2004-2008) compared to 63% in 1989-1993.

Childhood cancer^{8,9}

- In the Netherlands only 0.6% of all cancers are paediatric cancers (children younger than 15 years of age).
- In total, 930 children were diagnosed in 2007/2008 in the Netherlands (161.1 per 100,000 children under 15).
- The types of cancer most frequently diagnosed in 2007-2008 in the Netherlands were lymphatic leukaemia (38.7 per 100,000, according to the European Standardized Rate (ESR)); astrocytoma (14.5 per 100,000, ESR); neuroblastoma/Willms' tumour (11.3 per 100,000, ESR). Within Europe, the highest incidence rates were found for leukaemia, accounting for 34% of all childhood cancers (42.4 per 100,000, WSR), and CNS tumours, accounting for 23% (28.1 per 100,000, WSR). These represent the largest diagnostic groups among the under-15-year-olds.
- In the Netherlands, survival increased by 8% from 71% in 1988-1992 to 79% in 2003-2007. The highest five year survival rate was found in the age group of 5-9 years old (with 81% being alive five years after diagnosis in 2003-2007). The ten year relative survival rate was 75% (for children diagnosed in 1998-2002). For all childhood cancer types an increased five year survival rate was seen. The same increase was seen within Europe, where the survival has risen considerably over the past decades. Regarding the years 1995-2002, the data show an overall five year survival of 81% for Europe and similar values for the USA.

Cancer prevention

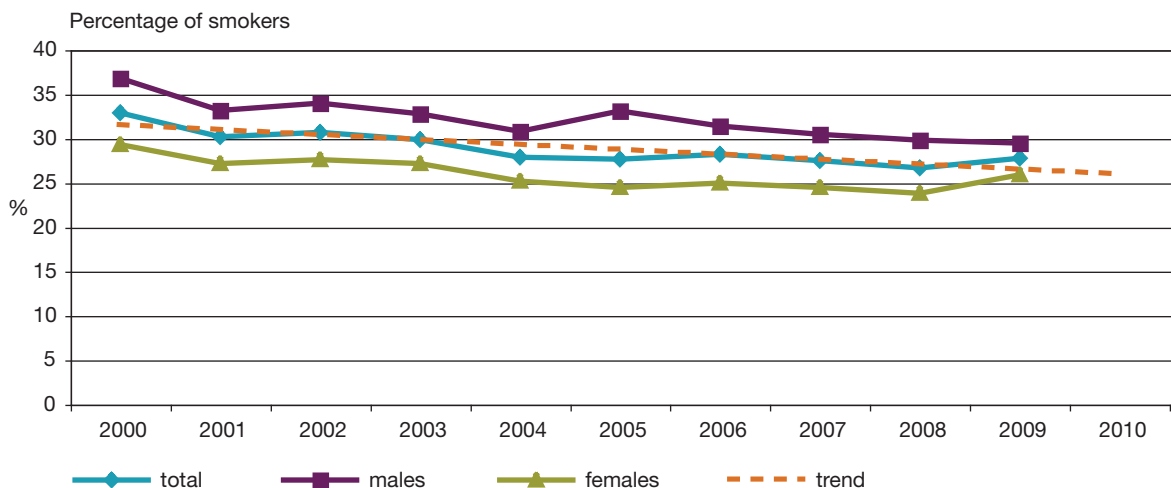
The public health approach

Public health is a broad notion of the health of the total population, based on the recognition that the overall health and well-being is influenced by a wide variety of health determinants. The Dutch NCCP's public health approach has been focused on collaborative actions between the various organizations regarding these determinants across many areas of society.

What has been achieved?

Tobacco

Tobacco use has been linked to cancers of the lungs, lips, mouth, pharynx, larynx, oesophagus, stomach, pancreas, kidneys, bladder and some types of leukaemia. Tobacco use also increases the risk of some other cancers. Smoking is the single greatest cause of cancer and accounts for about 30% of all cancer deaths. Besides increasing the cancer burden, smoking is associated with most cases of vascular diseases and COPD. This was the main reason why the Steering Committee of the Dutch NCCP identified discouraging smoking as the main objective in primary prevention for the period 2005-2010 in order to have a greater chance of achieving the goal of decreasing the percentage of smokers from 28% in the year 2000 to 20% in 2010.



During that period, two prevention cycles were undertaken. Although the mass campaigns to discourage tobacco use were always organized in collaboration with the Municipal Health Services (GGDs: www.ggd.nl), not all of them participated, even in the second cycle. The GGDs that were active, were supported financially by a national campaign budget. During the Dutch NCCP period, the Dutch College of General Practitioners (NHG) www.nhg.nl publishes its first guideline on "Treatment of tobacco addiction". The national guideline on diagnosis and treatment of lung cancer was updated in 2009 (www.oncoline.nl). Following these guidelines, the care module on the treatment of tobacco addiction was incorporated into the existing care standards.

KWF, the Netherlands Heart Foundation (Nederlandse Hartstichting), the Netherlands Asthma Fund (Astma Fonds) and the Expertise Centre for Smoking Prevention (STIVORO) initiated the National Programme for Tobacco Control (2006-2010). The aim of this programme was similar to the ambition of the Dutch NCCP on tobacco control: reducing the percentage of smokers to 20% by 2010. One of the key networks within this programme was the Public Private Partnership to Promote Smoking Cessation (PPP). This partnership of Dutch stakeholders in the treatment of tobacco addiction has been actively promoting the treatment of tobacco addiction for a long time. During the Dutch NCCP

period, the partnership revised the medical guideline on tobacco addiction (2009), developed the care module for tobacco addiction on the basis of which health insurance companies can contract tobacco addiction treatment (2009) and started the development of a quality register for professionals involved in the treatment of tobacco addiction. This register will be implemented in 2011.

The main achievements concerning tobacco control during the Dutch NCCP period were the realization of a smoke-free hospitality sector as of 1 July 2008 (the smoke-free workplace had already been implemented on 1 January 2004), an tax increase as of 1 July 2008, and the preparation for the reimbursement of tobacco addiction treatment, which will be implemented from 1 January 2011.

- As a result of the introduction of the smoke-free hospitality sector, combined with mass media campaigns and a tax increase on tobacco, the number of smokers decreased from 28% in 2007 to 27% in 2008. In 2009 it went up again to 28%, however. The percentage of smoking in children aged 10-19 years dropped from 24% to 21%. Exposure to environmental smoke dropped from 155 minutes per day in 2007 to 141 minutes in 2008.
- In the preparation for the reimbursement of tobacco treatment, in 2008 a pilot was carried out in Utrecht by one of the main health insurance organizations (AGIS), partly funded by the Ministry of Health, Welfare and Sport. The results of this pilot showed that reimbursement is feasible, will be highly cost-effective and will increase the accessibility of treatment for low-income smokers. These results formed the basis for the recommendation from the Health Insurance Board (CVZ) in April 2009 to reimburse stop smoking programmes under the health insurance system¹⁰. The Minister of Health, Welfare and Sport adopted this recommendation in July 2009, and his decision is implemented on 1 January 2010.

Despite these successes, the Dutch NCCP's ambition to lower the percentage of smokers to 20% by 2010 has not been achieved. There are several reasons for this. One of the reasons is that in 2008 and 2009 the tobacco industry raised a lot of resistance against the law for a smoke-free hospitality industry. Although this resistance was corrected by legal courts in 2010, it resulted in a delay in the implementation of the smoke-free law and the number of smokers increased again, from 27% to 28% in 2009. An international analysis of the Dutch tobacco control policy (by Prof. Stanton Glantz e.a., 2010), concluded that the goals of the National Programme for Tobacco Control were too ambitious and the actions and level of funding did not correspond with the goal. Moreover, the programme failed to recognize the tobacco industry as a crucial vector of disease and an active opponent to the programme. Mass media campaigns focused on cessation rather than targeting non-smokers to reinforce the non-smoking standard. As a result, the non-smoking standard is not yet well-developed in the Netherlands. Future tobacco control should focus more on the non-smoker, demoralize tobacco and tobacco use, and confront the tobacco industry.

Knowledge and perception of risk factors

Objectives

- By 2010, the number of people who will be aware that an unhealthy lifestyle is a 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.

What has been achieved?

In 2006, KWF started a campaign entitled "Six times stronger against cancer" with the aim of increasing public awareness and knowledge about risk factors (especially lifestyle factors) for developing cancer. In 2007, research performed by TNS NIPO showed that 57% of the people

questioned thought that lifestyle plays an important role in the development of cancer. In 2009 this increased to 66%. However, people with an unhealthy lifestyle were found to attribute less importance to these factors than people with a healthy lifestyle. The percentage of people that agree that they can partially influence their own risk of cancer stayed the same between 2007 and 2009: 62%. Evaluation of the effect of this campaign by Maastricht University (financially supported by KWF) showed that it had limited effect.

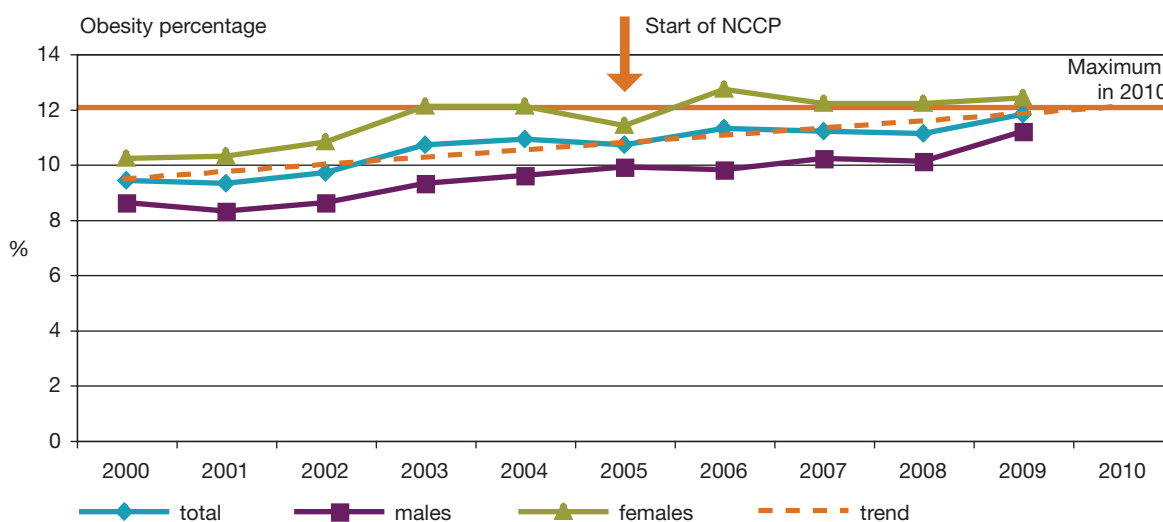
Obesity

Objective

- By 2010, a maximum of 12% of the Dutch population will be obese.

What has been achieved?

In 2005, ten organizations signed the Covenant on Overweight and Obesity. The Ministry of Health, Welfare and Sport, together with the other social partners, aimed to tackle the overweight problem by encouraging exercise. The Covenant did not focus on nutrition. Its main goal was to slow down the increase in the percentage of overweight people to a maximum of 12% in 2010. In 2009 the National Compass showed that 11.2% of men aged 20 years and older and 12.4% of women aged 20 years and older were obese. According to the figure below, the increase is still showing a growing trend. It can be assumed that in 2010 more than 12% of the Dutch population will be obese. In 2000, 9% of the Dutch population was obese (BMI > 30). According to the StatLine database of Statistics Netherlands (CBS), a slight increase in people with overweight (BMI >25) was seen between 2000 and 2009: from 44% to 47%.



Food

Objective

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

What has been achieved?

During the Dutch NCCP period, the Ministry of Health, Welfare and Sport did not focus on preventive activities to promote a healthy lifestyle. The Dutch Nutrition Centre, funded by the Ministry of Agriculture, Nature and Food Quality, and some other organizations promoted the consumption of fruit and vegetables and published some data in 2005-2006. Since then, no other data have been issued. The most recent comprehensive data available (1998) showed that 60% of the Dutch

population eat fruit and 70% of the population eat vegetables on a daily basis. Because of the lack of recent data, it is not possible to say whether the Dutch NCCP's goals for nutrition have been achieved.

Exercise

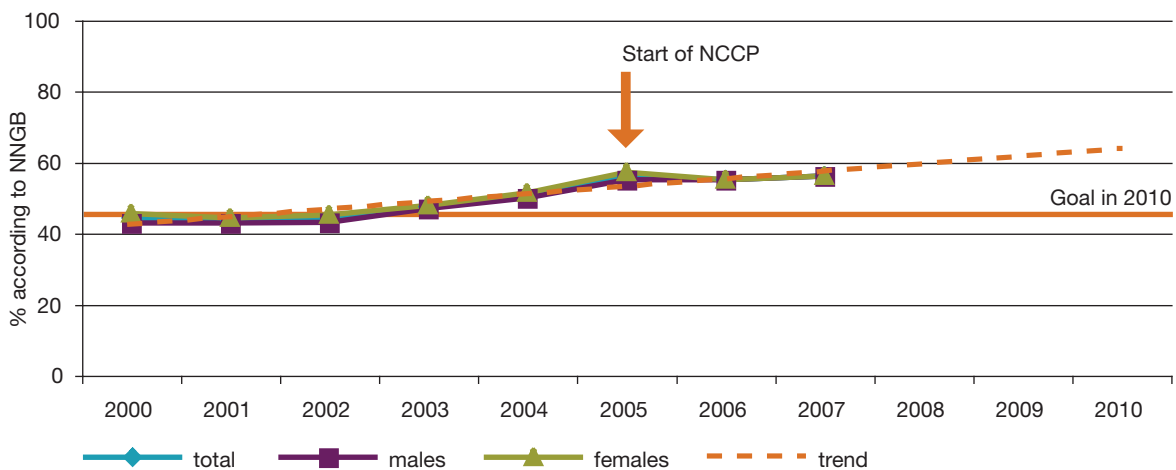
Objective

- By 2010, 55% of the population will meet the Dutch standard for healthy exercise.
- By 2010, up to 8% of the Dutch population fail to get enough physical exercise on any given day.

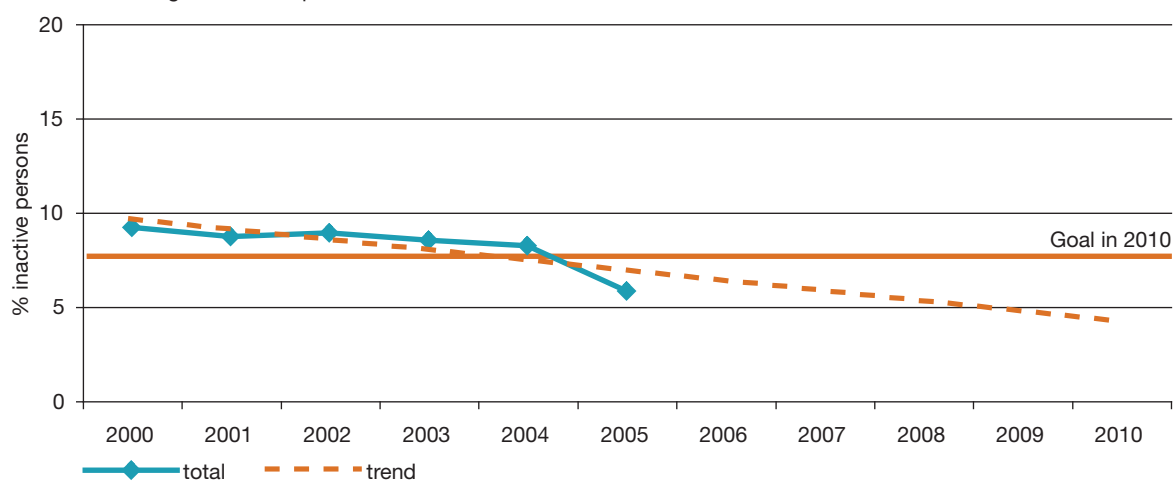
What has been achieved?

For the Ministry of Health, Welfare and Sport, physical exercise has been a spearhead of its policy. An example is the "30 minutes of exercise" campaign. The TNO monitor showed an increase in the percentage of adults meeting the standard, from 44.2% in 2000 to 58.7% in 2007. More recent data are not available. According to the figure below, the set goal had already been achieved in 2005. RIVM's National Compass also revealed that (in 2005) the percentage of the Dutch population aged 18 years and older for physical inactivity varies between 6% in summer and 9% in winter.

Physical activity according to NNGB



Percentage of inactive persons



Alcohol

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 three glasses of alcohol per day. The corresponding figure for girls will be the target value of 8%.

What has been achieved?

The report of VTV, the centre for explorations concerning future public health of the National Institute for Public Health and the Environment (RIVM), reports a steady number of problem drinkers. However, recent data on alcohol consumption among adolescents are not available.

Sunbathing

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).

What has been achieved?

For many years now, KWF has been paying a lot of attention to this topic. Before the year 2000, the campaigns were focused on the general public, while for the last decade more attention has been given to children and adolescents. A study undertaken by KWF showed a decrease of 15% of protection when sunbathing among adults between 2000 and 2009, however. As a consequence, KWF conducted another campaign focused on adults. In 2009, 87% of parents protected their children against sunburn, which is a similar result as in 2000 (86%).

Healthy living also means paying careful attention to your body

Objectives

- By 2010, Dutch people above the age of 55 will be more aware that early detection of cancer means an improved chance of survival. In numerical terms, in 2010 15% more people will be aware of this than was 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 capable of this than was the case in 2004.

Results

From 2007 onwards, KWF has been undertaking an annual campaign on "knowing the nine signs", based on the European signals of the European Cancer Leagues (ECL). Maastricht University evaluated the effect of the campaigns (with financial support from KWF) and found that before the start of the first campaign (2007), 33% of respondents recognized the signals, while after the campaign (2009), 44% did.

The attitude of people aged 55 years and older as regards the importance of watching out for symptoms which might indicate the presence of cancer increased by 10% between 2004 and 2010.

Conclusions

- Although some successes have been achieved, the development of a mutual framework based on common priorities agreed between all partners involved in primary prevention is still in the early stages. Joint priorities, actions and evaluations will help us gain a better understanding of what works and how cancer can be controlled in a more efficient way.
- Tobacco control interventions have not been effective enough. However, the objective to reduce the percentage of smokers to 20% by 2010 was not realistic (see analysis of RIVM (www.rivm.nl/bibliotheek/rapporten/260601004.pdf)). In addition, the tobacco discouragement policy was more or less ad hoc. To be more successful, a comprehensive policy plan spanning some decades will be necessary, including interventions such as intensive campaigns at national, regional and local level, the introduction of the reimbursement of stop smoking programmes and the increase of tax on tobacco.
- The objectives concerning obesity, public awareness of the effects of healthy lifestyles, healthy food and drinks, enough excise and public knowledge of the nine signs seem to have been more or less achieved. This is primarily thanks to the very active role of KWF, the GGDs, RIVM and several NGOs in this field.
- However, to maintain the targets or improve on them, comprehensive, long-term policy agreed between collaborative partners – including trend monitoring – will be necessary.
- Primary prevention requires among others support for the development of an infrastructure and for increasing capacity at national, regional and local level.
- Based on sound research and clinical observations, preventive actions are now the only actions that help reduce the tremendous increase in incidence.

Secondary prevention

Screening attempts to identify cancer or its precursors early on in the disease process, before any symptoms appear. The goal of cancer screening is to reduce morbidity due to the disease and increase the likelihood of survival through early treatment. However, screening will only be beneficial if early treatment options offer some advantage over later treatments. Although it seems obvious that survival rates improve when cancer is detected, this is not always the case.

Organized screening programmes intend to recruit individuals in target groups, to decrease opportunistic screening and to decrease the costs of the healthcare system.

Decision-making associated with population-based screening programmes

Objectives

Before 1 January 2005:

- the Ministry 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.

The Steering Committee considered this a priority and focused on the introduction of colorectal cancer screening.



What has been achieved?

A special working group was installed with the task of identifying the bottlenecks and issuing recommendations with regard to the implementation of colorectal screening. The working group published its report in 2009.

Various well-founded, concrete scenarios for implementation including consequences were outlined in the report. However, in spite of this clear and helpful report, and the conclusions published in the report of the Dutch Health Council (Gezondheidsraad), entitled “Bevolkingsonderzoek naar darmkanker” (*Colorectal cancer screening*)¹¹, which propose starting with the implementation as soon as possible, the Ministry of Health, Welfare and Sport decided on 16 February 2010 to postpone the introduction to a later date, beyond the year 2010.

In the Netherlands, cervical cancer screening started in the 1980s and was performed by the GGDs. From 1995 onwards, collaboration with the IKCs was required. Breast cancer screening was implemented in 1990 at regional IKC level.

Direction and implementation of population screening

Objectives

As of 1 January 2006:

- the two present 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 will maintain close

- relationships 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”.

What has been achieved?

- From 1 January 2010, a single organization has been responsible for the realization of population-based breast cancer and cervical cancer screening, managed by RIVM.
- RIVM supervises the organization, financing, quality policy and monitoring of the screening programmes, according to national criteria.
- Reorganization of the geographical areas resulted in five implementation regions, each with a similar organization based on the principles of “healthcare governance”.



Five regions for breast cancer and cervical cancer screening, integrated into a single national organization, led by RIVM

Transition from population screening to the regular care system

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 will be 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 contacts with 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.



Main results

The Dutch NCCP's Steering Committee prioritized this topic. A working group published a report in 2008 entitled "Aansluiting van screening naar curatieve zorg. Praktische problemen en mogelijke oplossingen" (*Alignment of screening and curative care. Practical problems and possible solutions*), including an analysis of bottlenecks and recommendations.

Main bottlenecks identified

- Referral, following screening, to the hospital/clinic for further diagnostics and treatment is not organized in a structured way.
- Responsibilities of and communication between the various stakeholders are unclear.

Most relevant recommendations

- Monitor the transition between screening and hospital care.
- Identify indicators including waiting times.
- Include these indicators in the project of the Dutch Health Care Transparency Programme (www.zichtbarezorg.nl).
- The screening organizations should conclude agreements with breast cancer and gynaecology cancer outpatients' departments to guarantee short waiting times. In addition, this will ensure that these hospitals will be able to better plan the capacity of professionals.
- Improve in the relationships with GPs.

What else has been achieved?

- The National Breast Cancer Working Group (NABON) identified quality indicators by 2009.
- The Dutch Health Care Transparency Programme has adopted these.
- Collaboration between hospitals has improved the available capacity of professionals.
- Relationships with GPs have not yet been structured.

Population screening and information provision

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 will be so accessible and mutually compatible that to all intents and purposes users will experience it to be a single, integrated information system. Such users should be able to timely the data that they need to perform their duties.

What has been achieved?

- Due to the reorganization of the screening programmes, there was some delay in the provision of data for 2007 and 2008.
- Annual monitoring and results on breast cancer screening are published by Erasmus University Rotterdam.
- In 2010, a first national evaluation of cervical cancer screening was published.
- The linking of data of the five screening organizations and those of the population-based national cancer registry of the VIKC guarantees annual evaluations and will make additional research possible.

Turnout for population screening

Objective

- The population of the Netherlands will be 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.

What has been achieved?

Breast cancer

- The participation rate of breast cancer screening has been $\geq 80\%$ (the highest rate in Europe) since 2000 and is increasing slightly.
- The referral rate has increased from 14 per 1000 screened women in 2004 to more than 18 per 1000 in 2008.
- As a consequence, the percentage of women actually diagnosed with cancer among those referred has decreased from 43 of all referred women to 30 in 2008.

Breast and cervical cancer screening in the Netherlands

	1998-2000	2001	2002	2003	2004	2005	2006	2007	2008
Attendance of breast cancer screening (%)	78,5	78,7	79,1	80,8	80,8	81,7	81,8	82,4	82
Positive predictive value of breast cancer screening (%)	43	38	38	37	35	34	32	31	*
Referral rate (per 1000) after breast cancer screening	10,9	13,8	13	13,1	14,1	14,5	16,1	18	*
Attendance cervical cancer screening (%)	61	62	64	66	65,6	65,5	66	*	*

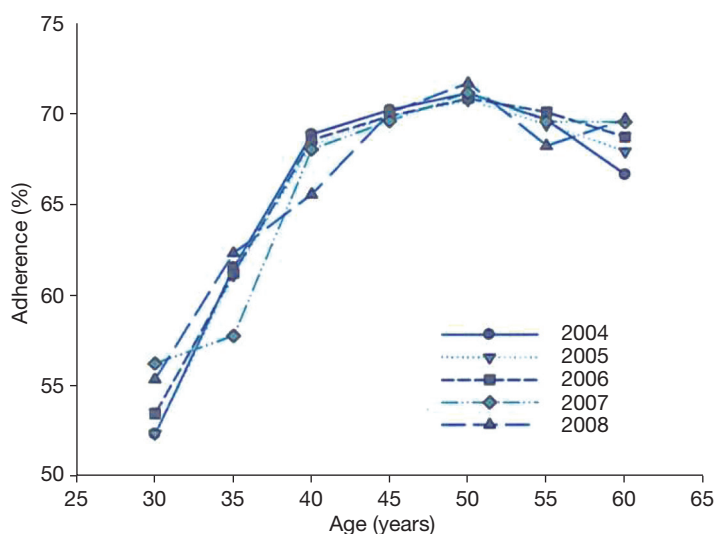
*=not available

Source for breast cancer screening: Landelijk Evaluatie Team Bevolkingsonderzoek Borstkanker (LETB)

Source for cervical cancer screening: RIVM

Cervical cancer

- The participation rate of cervical cancer screening is 66%.
- RIVM is looking for options to make people more alert about the pros and cons of commercial check-ups. This is not yet a high priority.



Percentage of females attending screening by age

(Source: PALGA, CBS)

Financing secondary prevention

Objective

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.

Results

- The centres for clinical genetics focused on cancer have developed evidence-based guidelines.
- The genetic tests are now being structurally financed.

Conclusions

- The reorganization of the screening programmes into a single structure has been realized.
- The journey following breast cancer screening has been improved.
- Indicators to monitor the screening procedures and the outcome have been identified.
- The monitoring results are now published annually, supported by an optimum link between the screening database and the Netherlands Cancer Registry (NKR).
- No attention has as yet been paid to commercial test kits and medical check-ups in private clinics.

Cancer care

Improvement in care: general data

Objectives

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

Five year relative survival of cancer in the Netherlands (age standardized)

	1989-1993	1994-1998	1999-2003	2004-2008	difference between 1989-1993 and 2004-2008
All cancer types	47%	51%	54%	59%	+12%
male	40%	45%	49%	55%	+15%
female	55%	57%	59%	62%	+7%
Breast cancer	77%	80%	84%	86%	+9%
Prostate cancer	64%	77%	82%	86%	+22%
Colorectal cancer	54%	55%	58%	61%	+7%
Colon cancer	55%	56%	58%	60%	+5%
Rectal cancer	52%	56%	57%	63%	+11%
Lung cancer	13%	12%	12%	15%	+2%
Non Small Cell Lung Cancer	15%	14%	14%	16%	+2%
Small Cell Lung Cancer	4%	4%	4%	6%	+2%
Melanoma	81%	84%	86%	87%	+6%
Cervical cancer	63%	64%	65%	66%	+4%

Source: Netherlands Cancer Registry, VIKC

What has been achieved?

The relative five year survival rate for patients with cancer did improve by 5%, from 54% in the period 1999-2003 to 59% in the period 2004-2008.

Cancer patients' satisfaction measurement has not been undertaken nationwide. However, a decision has since been made to develop another, more informative instrument: the CQ index for cancer patients. This instrument will be ready by the end of 2010. A CQ index for breast cancer patients (the most common type of cancer in the Netherlands) has been partially validated and is starting to be implemented in 2010. This is being done in collaboration with the National Breast Cancer Patients' Organization (BVN). In addition, NFK, together with the Haemato Oncology Foundation for Adults in the Netherlands (HOVON), has developed another instrument to measure the information provided to haemato-oncological patients and their experiences during their journey (see the websites www.nfk.nl and www.hovon.nl). The implementation of this instrument started in 2008, and the health insurance companies are aiming to only contract hospitals which use this quality instrument in the future.

Quality and accessibility of cancer care

Working group activities

With regard to cancer care, the Steering Committee decided to select, out of the 39 actions formulated in the NCCP programme for 2005-2010, one spearhead: the quality and accessibility of cancer care. A multidisciplinary working group was set up, which was to approach this theme from various angles.

What has the working group achieved?

Realizing that the oncology landscape will undergo radical changes, the main partners in this field which are represented in the working group – cancer patients (and their associations), professionals and insurance companies – formulated their assignment as follows: *“Which changes in the structure (organization) and quality of oncological care are necessary in order to guarantee the accessibility of optimal cancer care and an optimal care system for all patients in the future?”*

Therefore, five main topics were identified:

- Structure and organization of cancer care
- Quality of cancer care
- IT and communication
- Oncological care and the free market
- Finance and policy



The recommendations were published in the report of Working Group 4, *“Bevorderen kwaliteit en toegankelijkheid kankerzorg” (Promoting the quality and accessibility of cancer care)*.

Most relevant recommendations

- The patient’s journey (pathway) has to be well-defined with regard to the responsibilities of care providers:
- The patient needs to know who their contact person is in the hospital and outside, and this will preferably be limited to only one or two persons.
- Communication between all care providers should be coordinated by these contact persons and will require a better IT system.
- Collaboration between care providers is indispensable in oncological care.
- To ensure better evaluation, structure and organization should be taken into account in addition to volume per hospital. These indicators should be part of the basic cancer registry.
- The Ministry of Health, Welfare and Sport should be asked to support the implementation of the electronic patient file system at national level.
- A future-proof financial system needs to be in place to guarantee optimal accessibility and quality of cancer cure and care.

These recommendations were discussed during the conference “The oncology of the future”, which was held on 22 January 2009 and attended by more than 250 care providers and representatives of these organizations. A summary of this conference is available on www.npknet.nl and can also be found in part II of the progress report. Many of these organizations, including national associations of medical specialists, such as NVMO, NVCO, NVRO, NVvO and national psychosocial oncologists, V&VN, NFK, IGZ, VIKC, KWF and ZN, have adopted some of these recommendations in their policy plans.

Interview with Aart van Bochove, general physician/oncologist

“You always have to ask yourself: what are the interests of the patient?”



One could say that oncological care is in his blood. Aart van Bochove has been working for 22 years as a medical oncologist at Zaans Medisch Centrum (ZMC) in Zaandam. He has also served in many other positions in the field of oncological care and continues to do so today. In his capacity as chairman of a working group on the quality and organization of oncological care, he is closely involved in the National Cancer Control Programme (Dutch NCCP). Van Bochove believes that effective and accessible oncological care is a matter of life and death, both figuratively and literally.

Of course, Van Bochove is not alone in his pursuit of quality and accessibility. It is an ambition that is shared by the Dutch NCCP. Two years ago, the Dutch NCCP working group chaired by the medical oncologist delivered its end product: a vision document on the future of oncology was presented during a Dutch NCCP congress at the beginning of 2009. “Our report is not a blueprint with ready-made solutions; it is a vision document containing a number of statements that are important for oncological care”, says Van Bochove.

One of the most significant concepts that the document puts forward is that the interests of the patient should always be central. “That may sound self-evident, but it’s not”, says Van Bochove. “After all, there are frequently other interests to take into account: those of the physician, the hospital and the health insurer. That’s why we say that as soon as a discussion about a particular aspect of oncological care arises, you have to ask yourself: what are the interests of the patient?”

The document also discussed the size and scope of oncological care. “Due to the fact that some hospitals are simply too small and the field is too specialized, it isn’t conceivable for all hospitals to offer comprehensive oncological care”, says Van Bochove. “On the other hand, it isn’t feasible either for care to be concentrated in just a small number of hospitals. There are simply too many cancer patients to be treated at just a few centres. Ideally, we want to provide care as close to the patient’s home as possible. Therefore, we can conclude that effective cooperation and a clear division of responsibilities between hospitals is extremely important.”

The working group chaired by Van Bochove does not shy away from controversy. “One of our findings was that oncological care does not lend itself to competition in a free-market environment. But this was precisely the approach that the Ministry of Health, Welfare and Sport was promoting in the sector at the time. This very same Ministry is one of the parties involved in the Dutch NCCP, so this conclusion of ours was quite controversial. Thankfully, we have since noted that our message has made quite an impact. These days, there is broad consensus that leaving everything up to the market may not be the best solution after all.”

Van Bochove’s personal involvement in the Dutch NCCP began in spring 2007 when he was asked to chair one of the organization’s working groups. Though he is now a staunch supporter of the Dutch NCCP, he does have a few critical comments. “The main benefit of the Dutch NCCP is that all parties in the oncological care sector are brought together in a single structure. Though this joining of forces is an advantage in many respects, it also represents a risk. It is important that these parties do not remain stuck at the strategic level, but that they achieve practical results.”

In this regard, Van Bochove sees the Dutch NCCP Monitor as an excellent tool because it clearly

indicates the results being achieved in each area across the oncological care sector. The fact that many of the aims and targets set by the programme still have not been achieved does not worry Van Bochove. "You don't start turning a supertanker around in a harbour just like that. It takes time. So there's really no reason for us to be discouraged; we've taken a number of steps in the right direction. What we need to do now is keep working together to hit those targets."

There is certainly still much to be accomplished with regard to lobbying against smoking. "What strikes me is that we take such a haphazard approach to one of the most significant threats to public health in the Netherlands", Van Bochove sighs. "We allow cafe owners to shape the discussion on this important issue. Of course, it's an incredibly complicated subject, but if you see how much damage is being caused by smoking, it's high time that a much stronger position is taken against smoking. This is also one of the ambitions of the Dutch NCCP."

For the Dutch NCCP, cooperation is written with a capital C. Van Bochove, who chaired the Dutch Society for Medical Oncology (NVMO) from 2001 to 2007, has also contributed to this aspect of the Dutch NCCP's activities. As NVMO chairman he was one of the initiators of SONCOS, the Foundation for Cooperation in Oncology. This organization brings together medical oncologists (NVMO), surgeons (Dutch Society for Oncological Surgery working in the field of oncology), and radiotherapists (Dutch Society for Radiotherapy and Oncology). "I strongly supported the merger of the various scientific associations for oncological specialities", says Van Bochove. "As oncology increasingly became a multidisciplinary field, the associations did not cooperate with each other at all. Thankfully this has begun to be rectified with the establishment of SONCOS."

Van Bochove believes that it is essential for the scope of the Dutch NCCP to cover 'current issues' as well as the numerous new developments in the sector. "Despite the good results that we've achieved in the treatment of a number of specific tumour types over the past few years, the fact is that many patients experience relapses or are incurably ill. Although this is not such a glamorous topic, it is imperative that we continue to focus our attentions on this large group of people. Of course, it is much more exciting to report that a treatment has been developed to increase the chance of survival in patients with a certain type of tumour, even if it is a rare type."

"The Dutch NCCP explicitly states that patients who have received treatment and subsequently recovered, at least in an oncological sense, require more effective aftercare", Van Bochove continues. "At the moment this is just not happening enough. Although psychosocial care has indeed improved, there is still much more that can be done in this field. As a physician, you can't just turn and walk away after a patient has been treated successfully. In doing so, you've only completed half the work. There is still a whole aftercare programme to be carried out, which is as critically important for the patient as the successful treatment was."

Other objectives concerning quality and accessibility of care

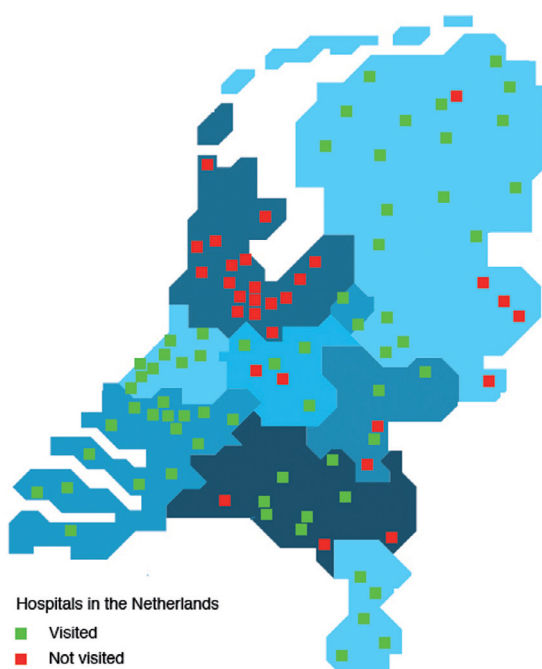
Objectives

- By 2005 the quality criteria for multidisciplinary coordinated chain care will be ready.
- By 2006, an inspection/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 inspection/accreditation of oncological care.

- By 2010, all hospitals in which cancer is diagnosed and/or treated will have undergone inspection/accreditation. Primary care will definitely be included in this process of inspection. The results of this assessment should be available and comprehensible to those requiring care.

What has been achieved

A peer review system and an electronic self-evaluation guide, by way of an internal audit system for the organization of oncological care (according to criteria approved by the medical professionals), have been updated and set up at national level, supported by the IKCs. Most of the hospitals have been peer reviewed during the past few years or are working on achieving this between 2010 and 2012. This system promotes and clarifies the multidisciplinary approach, the communication and agreements between the various organizations (e.g. hospitals and radiotherapy centre, hospital and GP) and the available capacity of specialists, care providers and professionals.



Pilots on tumour-specific pathways have been undertaken by the IKCs since 2007^{12,13}. These pathways serve as an implementation and monitoring tool for all existing national guidelines and indicators and include the recommendations issued by Working Group 4 and by IGZ in its report “Zorgketen voor kankerpatienten moet verbeteren” (*Care chain for cancer patients must improve*)¹; the monitoring system periodically includes patients’ focus groups (at hospital level).

In 2010, KNMG, the Royal Dutch Medical Association, published a support tool with regard to sharing responsibilities in the context of collaboration in care. A checklist with 13 tips summarizes the report entitled “Checklist met 13 concrete aandachtspunten bij afspraken over verantwoordelijkheden” (*Checklist with 13 concrete points for attention in agreeing responsibilities*).¹⁴

Special attention has been given to the terminal phase of patients by developing the “pathway of dying”. In 2009-2010 this pathway is being implemented nationally, supported by the IKCs.

As the Ministry of Health, Welfare and Sport is in favour of care standards (due to favourable experiences with care standards for diabetic patients) it presented NFK with the opportunity to

analyze the possibility of a cancer care standard for cancer patients, something that resulted in the NFK report “Verkenning Zorgstandaard Kankerzorg” (*Explorations for a care standard for cancer care*)¹⁵. As a result of this analysis, NFK, together with other partners, will be trying to realize a generic standard. To avoid duplicates, the participants in the two projects on care standards and pathways are collaborating intensively.

The development and registry of indicators on process, structure and outcome have been realized by the collaborative project of the Dutch Health Care Transparency Programme on breast cancer. VIKC is responsible for facilitating the process of development and registry of the indicators on cancer. Since 2008 the IKCs have been giving an overview of several indicators on the quality of oncological care per hospital (the so-called “ONCOMONITOR”, www.ikcnet.nl). The indicators take volume and outcome into account and are based on the items which are registered in the NKR in relation to the main tumour groups. These data are provided nationally in aggregated way. The hospitals obtain their own data.

Concentration of treatment

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 the above-named 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 parties involved in implementation.

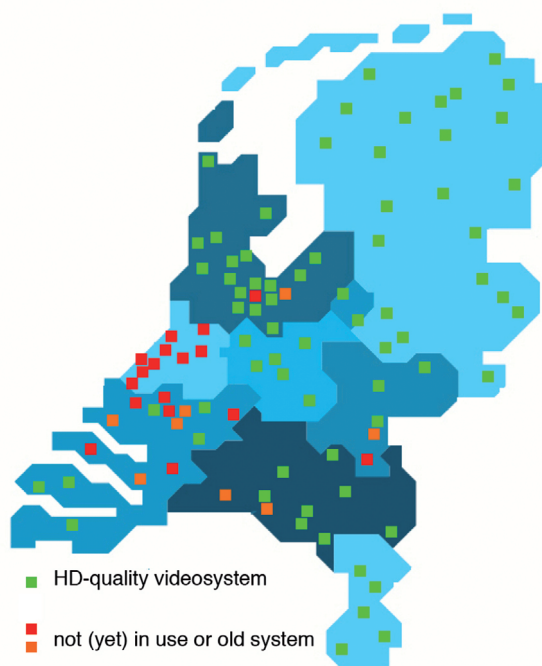
What has been achieved?

This issue is still unresolved as not enough quality criteria are available to decide which main factors are responsible for good outcome, NVCO, the Dutch Society of Surgical Oncology, is urging more and more for the concentration of treatment of complex and less common tumours.

The report “Kwaliteit van kankerzorg in Nederland” (*Quality of cancer care in the Netherlands*) by KWF’s Cancer Signalling Committee (published in 2010) states recommendations on concentration of treatment. Concentration should take place on the basis of criteria concerning hospital infrastructure, volume and degree of specialization, and demonstrably good care outcomes. The report includes a plan with a more detailed description of the parties involved and of the tasks and responsibilities in the implementation.

In some IKC regions, managed clinical networks (agreements between hospitals about who is doing what, how and in which situation) have recently been set up for oesophagus cancer, pancreatic cancers and ovarian cancers. Thanks to the super specialization of medical specialists, multidisciplinary teams of experts in certain types of cancer are being formed and they are increasingly providing advice to the general hospitals through videoconferencing, facilitated by the IKCs.

This shift in consultancy services will have its implications for the structure and organization of general hospitals.

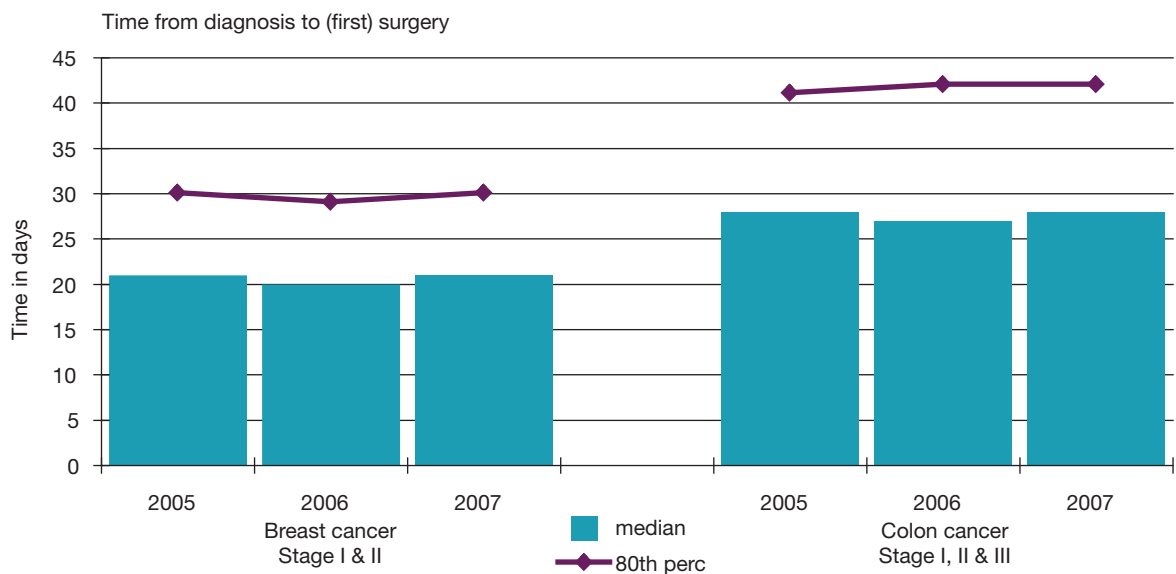


Hospitals with videoconference equipment to support consultancy services.

Care: supply and demand

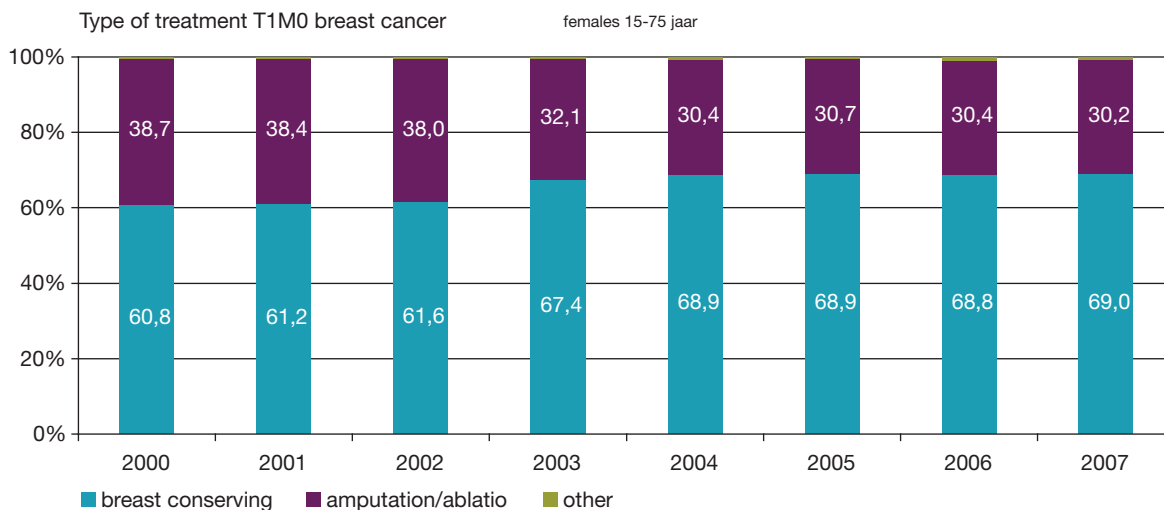
Objectives

- 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 and the increased number of cancer patients.
- By 2006, an implementation process will be ready.
- By 2010, there will 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 cancer is being considered. This is measurable through waiting lists, throughput times, and assessment of the implementation of guidelines for diagnosis and treatment.



What has been achieved?

- Waiting times and throughput times are part of the indicators registered for some tumours in VIKC's NKR; they are also being registered separately by hospitals and insurance companies.
- Treatment according to guidelines can be measured through the NKR and the indicators defined by the national multidisciplinary working groups.



Source: Netherlands Cancer Registry, VIKC

Guideline for adherence per cancer type

	Percentage in agreement with the guideline (2007)
Guideline for colon cancer	
At least 10 lymph nodes investigated/resected	65.1%
Adjuvant chemotherapy	73.1%
Guideline for rectal cancer	
Pre-operative radiotherapy	82.6%
Guideline for bladder cancer	
Radical lymph node dissection	27%

Development of guidelines

Objectives

By 2005, procedures will be available for the development, adjustment, implementation and assessment of guidelines, in terms of both methodology and content. The guidelines will focus on a number of specific components, such as:

- education;
- elderly patients (co-morbidity).

During implementation, consideration will also be 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 party or parties will 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 www.ikcnet.nl.
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 will be a plan for efficient assessment of the guidelines. This plan will be updated annually.
By 2005, there will be a link between the cancer registry and the Local Authority's Residents Registry (GBA), to display details of patient survival.

What has been achieved?

- The procedures for the development, implementation and evaluation of guidelines are available and are being used by VIKC, in support of the multidisciplinary oncological guidelines (www.oncoline.nl). See also part II. These procedures are ranked among the top three of procedures available in Europe (www.cocancpg.eu).
- More than 150 national guidelines are publically available on www.oncoline.nl, www.pallialine.nl, www.herstellenbalans.nl, www.ikcnet.nl/sib and www.stg.nl/index.php?page=271&lang=1.
- The financing of multidisciplinary guideline development has been clarified but the costs are far from being covered. The monodisciplinary medical associations, the Ministry of Health, Welfare and Sport and the IKCs are each providing financial support for part of the development and updating of guidelines.
- Evaluation of guidelines and survival data (by linking the NKR with the GBA) are available on www.npknet.nl/monitor and www.ikcnet.nl/cijfers.

Diagnostic phase and staging

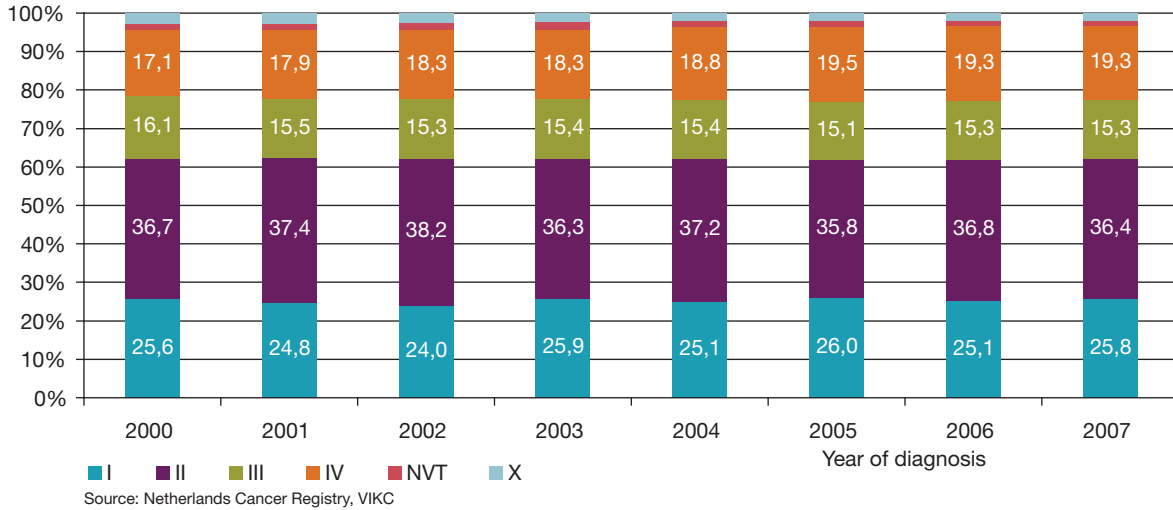
Objectives

- By 2005, a summary of the (European) cancer code for the early diagnosis of cancer will be available on www.ikcnet.nl.
- 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 doctor-related delay (referral) and through 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.

Goals achieved

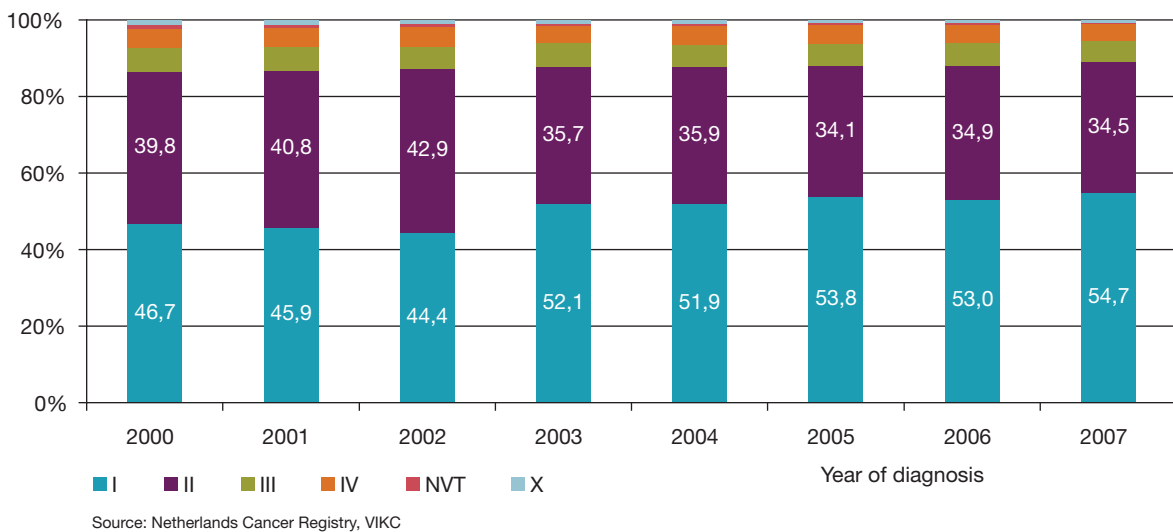
- The European cancer code "Know the 9 signs" (see primary prevention chapter) has been adopted by KWF and related campaigns are now part of its policy plan.
- Tumour stages have been collected by the NKR since 1989.

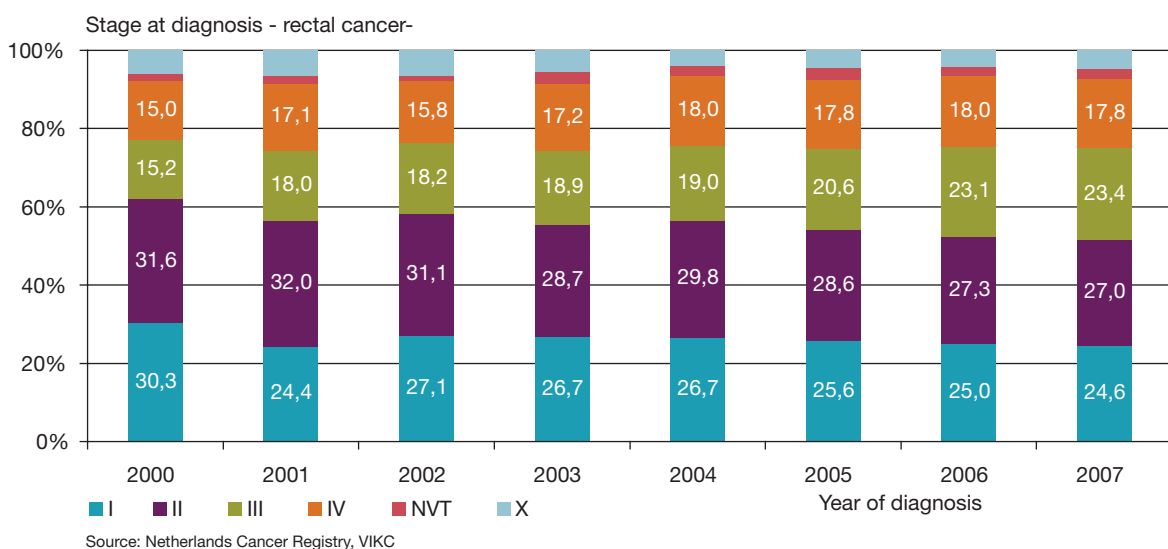
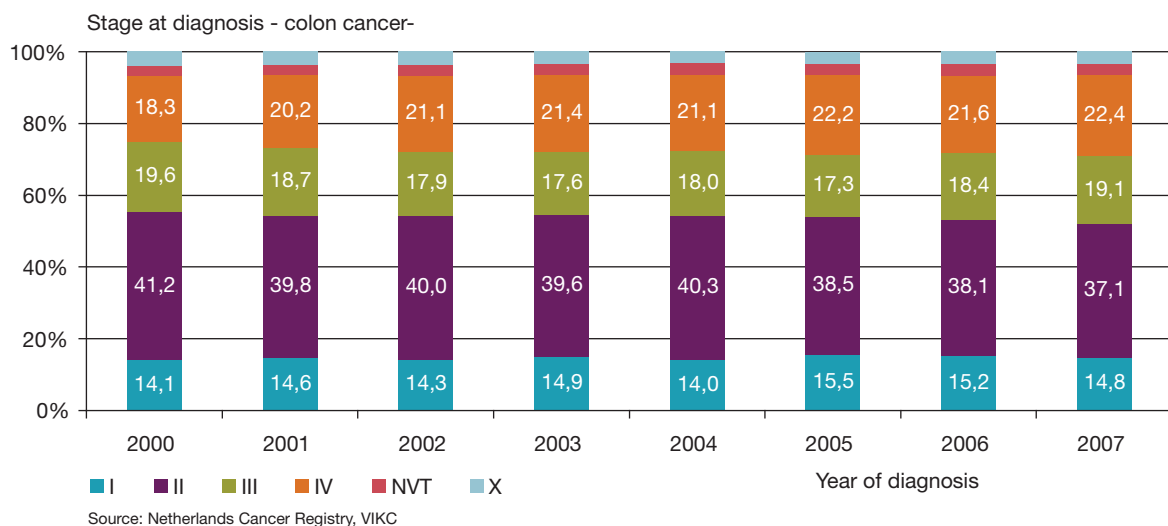
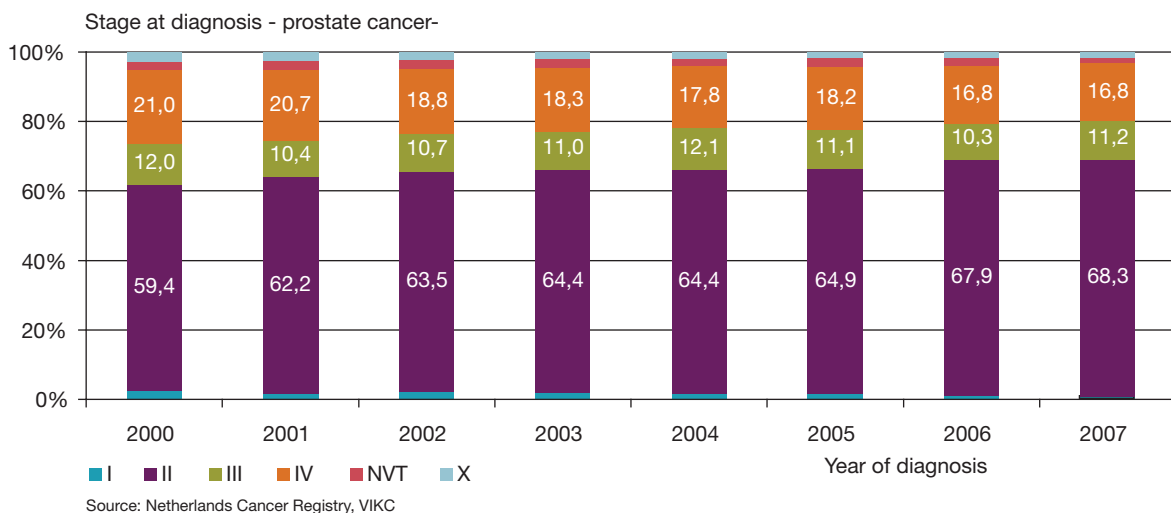
Stage at diagnosis - top 4 tumours-



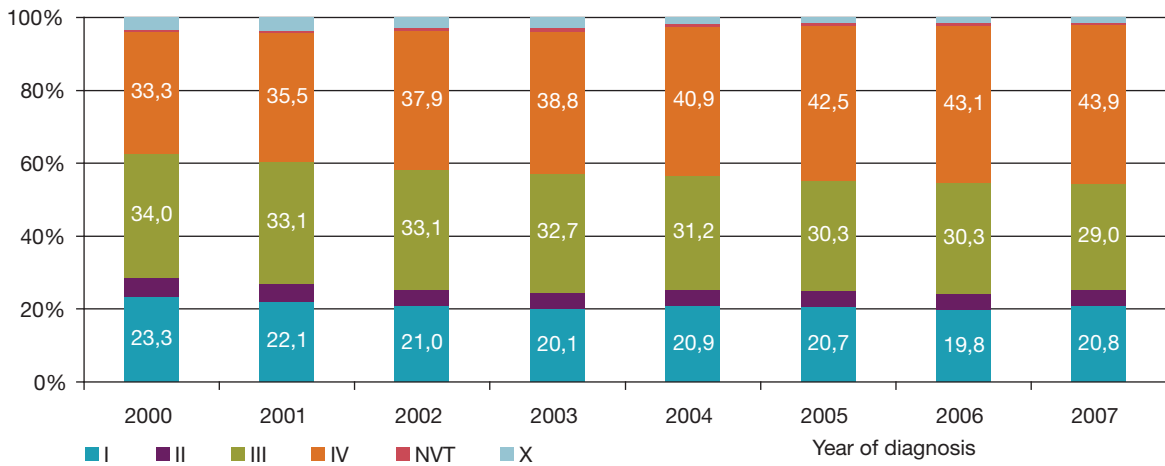
- No major stage changes have been observed over the period 2000-2007.
- The increase in the percentage of stage I in breast cancer is mainly due to a change in the definition of the stage (TNM Wittekind 2004).
- The increase in the percentage of stage I in prostate cancer between 2000-2007 is related to the increased use of PSA detection.
- For colon cancer, no relevant changes in staging were observed over the period 2000-2007. For rectal cancer, the percentage of stage I-II patients decreased, something that mainly reflected a stage migration due to improved staging procedures (CT scan, MRI, endo ultrasound).
- The percentage of stage IV in lung cancer is increasing, mainly due to the introduction of the PET scan, which has improved the detection of metastasis compared to the conventional CT scan.

Stage at diagnosis - breast cancer-



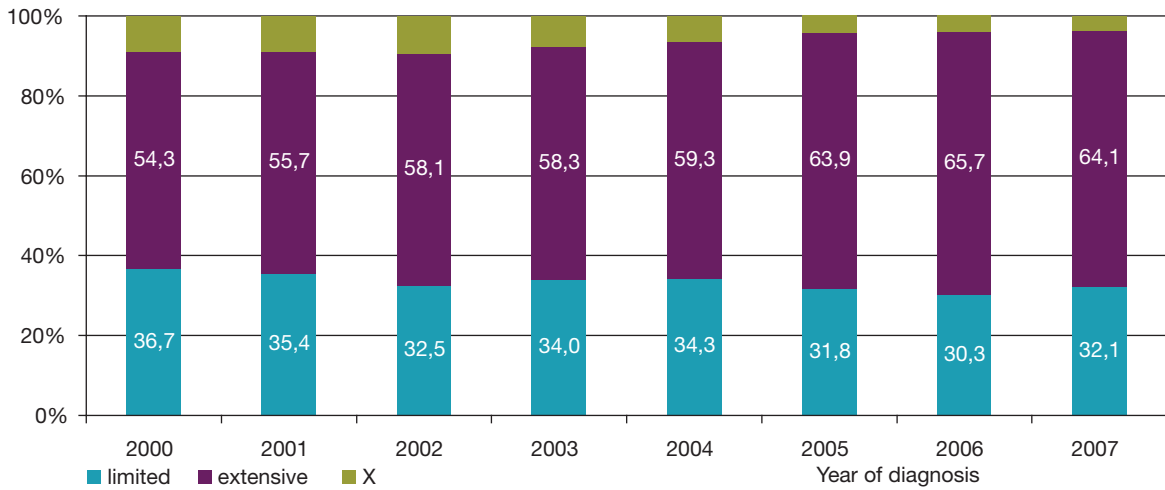


Stage at diagnosis - non small cell lung cancer (NSCLC)-



Source: Netherlands Cancer Registry, VIKC

Stage at diagnosis - small cell lung cancer (SCLC)-



Source: Netherlands Cancer Registry, VIKC

Treatment phase

Objectives

- By 2005, there will be a national coordination point for oncological trials. Its responsibilities will include keeping the trial summaries up to date and accessible via the Internet.
- By no later than 2006, agreement will have been reached concerning the adequate financing of data management and the responsibilities of the parties involved with regard to the performance of research and data management.
- The procedure for drawing up and amending guidelines will speed up the flow of results from clinical research to daily practice.
- In 2007, more than five percent of trials will focus entirely on patients above the age of 70.

What has been achieved?

- VIKC is playing a role in the coordination of investigator-driven trials. KWF is funding data management.
- Concerning adequate financing of data management and parties conducting research and data management, important steps have been taken.
- More and more attention is being paid to the development of trials for elderly patients.
- A regional trial database informing patients on ongoing trials has been developed as part of a pilot project. The trial database is currently being expanded to the national level

Aftercare

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. The follow-up screening will include 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 will be determined at local level. This will involve who does what, and when and how this will be communicated to other professionals and to the patient.
- From 2005 onwards, where relevant, the process of developing, implementing and adjusting guidelines will include consideration for palliative and terminal care, and the adequate handling of issues surrounding euthanasia.

What has been achieved?

- National guidelines on rehabilitation www.herstelenbalans.nl / www.oncoline.nl, on going back to work and on detection of the need for psychosocial support using the Distress Thermometer (Lastmeter: www.lastmeter.nl) are available.
- The development of the guideline on aftercare is only in its early stages but is broadly supported.
- Survivorship is receiving more and more attention as the prevalence of survivors is increasing enormously.
- The allocation of tasks has not yet been described in all guidelines.
- The IKCs have supported not only the development but also the updating (in late 2010) and implementation of guidelines for palliative care.

Conclusions

- Many different associations and organizations have included objectives into their own policy plans recognizing the bottlenecks of these recent years.

- Survival rates are improving but not as fast as in other developed European countries.
- Important steps forward with regard to structural and organizational aspects are being taken and implementation can be expected in the near future (peer review, pathways, cancer care standards).
- Monitoring systems using indicators and available registry systems have been developed and the first results are available.
- Guidelines on diagnosis, treatment, aftercare and palliative care are available and the procedures to develop these are of very high quality.
- The structure of data management and the implementation of trials have been improved.
- However, to guarantee optimal quality of cancer care and accessibility with a view to:
 - an increase in the absolute number of cancer patients;
 - an increase in the absolute number of survivors;
 - an increase in refined and more sophisticated diagnostic and treatment possibilities;
 - financial bottlenecks,
- the priorities defined by Working Group 4 will need to be translated to concrete objectives and actions.

Interview with Chiel Bos, former director of the Dutch Association of Healthcare Insurance Providers



“Funding has to be linked much more effectively to quality of care”

As director of the Dutch Association of Healthcare Insurance Providers (Zorgverzekeraars Nederland, ZN) from early 1999 until spring 2008, Chiel Bos was one of the initiators of the National Cancer Control Programme (Dutch NCCP). Although many of the programme’s aims have not yet been achieved, Bos focuses on the positive side of things. “Without a doubt, oncological care has improved thanks to the Dutch NCCP. The main change for the better lies in the fact that the various disciplines now work together much more effectively than before. People used to say that you could only receive high-quality oncological care in university hospitals and that other institutions didn’t count. Thankfully, we’ve come down from our ivory towers on this issue.”

Bos has gained plenty of recognition within the healthcare sector. He is now working as an independent advisor and can draw on a wealth of managerial experience. Bos is also vice-chairman of the National Council on the Quality of Healthcare, and is investigating the possibilities for the establishment of an ‘eHealth’ programme at VU University in Amsterdam. Bos is a man with vision and an outspoken opinion, and he is not afraid to share either of them.

“What’s great about the Dutch NCCP is that this is an initiative of the sector itself. The Dutch Cancer Society, the Dutch Federation of Cancer Patients’ Organizations, the Association of Comprehensive Cancer Centres and various health insurers have committed to working together to ensure the best possible oncological care throughout the sector, and throughout the country. The Ministry of Health, Welfare and Sport declared its support for the initiative and wanted to play an active role in the programme. The great benefit of the Dutch NCCP lies in ensuring that the patient is represented much more effectively and is of central importance within the oncological care sector.”

The Dutch NCCP asserts that both the quality and accessibility of care has to be the same for everybody. “The level of care should be the same for every patient, regardless of whether you live in the provinces or next to Antoni van Leeuwenhoek Hospital in Amsterdam”, says Bos. “Patients should be able to receive care as close to home as possible and be referred to a specialist centre if

necessary. Standardization is also an important principle. It's not acceptable for a patient with a tumour that in one hospital he would be operated, while in another he would undergo radiotherapy for the same tumour."

Bos believes that it was only logical for the Dutch Association of Healthcare Insurance Providers – of which he was director at the time – to be involved in the Dutch NCCP from its inception in 2005. "It was at this time that healthcare insurers were also starting to set their own requirements regarding the quality of care. We didn't just want to collect premiums and pay care institutions; we also wanted to discuss the accessibility and content of the care provided. Our emphasis on, for example, accessibility played a prominent role in the establishment of special breast cancer outpatient clinics. These clinics allow patients to be diagnosed within a day."

The health insurers are not only one of the five parties participating in the Dutch NCCP; they also finance the programme together with the Ministry of Health, Welfare and Sport. However, as far as Bos is concerned, this has never led to a conflict of interests. "Not at all! It's very simple: if you wish to have high-quality care, someone has to pay for it. It's better to provide a patient with the best treatment possible rather than opt for a cheaper solution that doesn't have the desired effect. Why? Because in the end, it'll end up costing more. Not to say that effective treatment has to be expensive, of course. What is expensive, anyway? Psychosocial treatment costs a lot of time and, by extension, money, but it benefits the patient's mental condition and therefore his health as well." Bos knows what he's talking about due to his position as chairman of the Dutch NCCP working group on psychosocial care. "Health insurers have included psychosocial care in their reimbursement schemes since 2006. This recognition is very important for the development of this form of care, which is one of the spearheads of the Dutch NCCP. In addition to treating the physical disease, attention must also be paid to the psychosocial problems experienced by patients after finding out they have cancer. After an operation, it can sometimes take years for a patient to regain his mental balance. Nurses and psychologists can play an important role in ensuring that the path to recovery is as easy as possible."

Bos is critical of the Dutch NCCP's apparent lack of activity of late. "After an ambitious start, in which much was accomplished in a short period of time, the programme seems to have lost steam. The parties involved have to provide new impetus and energy to the programme. The best way of doing this is to develop a new five-year programme with new spearheads. What sort of spearheads do I mean? One example is more efficient use of modern communication technology, such as utilizing electronic patient files in order to exchange information quickly and easily. Other spearheads could include improving the system that refers patients to specialist centres and changing regulations pertaining to costs and funding."

"Funding has to be linked much more effectively to quality of care", Bos emphasizes. "The wrong incentives have arisen over the past few years due to the introduction of so-called 'Diagnosis Treatment Combinations'. Something is wrong if a hospital opts to perform an operation instead of radiotherapy just because it receives more money by carrying out the former option. As a hospital you should never be tempted to do this!"

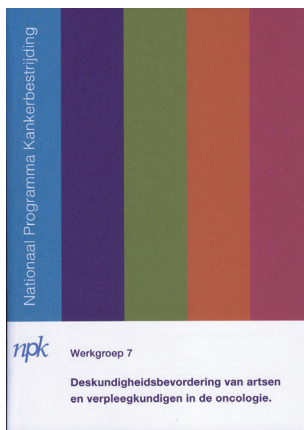
Bos really hopes that the National Cancer Control Programme will continue. "The best course of action would be for the Ministry of Health, Welfare and Sport to promote and facilitate the Dutch NCCP much more than at present, for example through a different form of funding. It is also important for the Ministry to promote the Dutch NCCP's recommendations and to avoid allowing the agenda to be set by comments made in the Lower House of Dutch Parliament, which are often fuelled by action groups representing their own particular interests. These 'rearguard actions' are not in the interests of cancer patients. On that level, we still have some work to do."

Bos ends on a telling anecdote. "A friend of mine recently told me that he had to go to hospital for an operation. As he had already been to another hospital some time previously and had had X-rays

taken there, he thought it would be practical to ask for these X-rays to be sent to the hospital where he was now being treated. It turned out that the hospital was unable to do this. He could pick the X-rays up himself, but it would cost him eleven euro. In the end he caught the train to the hospital and was eventually handed a CD with the X-rays on to take to the next hospital. When I heard this story I was quite saddened. As professionals working in the healthcare sector, we should be thoroughly ashamed of ourselves that such things happen!"

Continuing professional education

Care for cancer patients requires professionals and care providers to have been basically educated in the medical, psychosocial and palliative aspects of cancer in terms of knowledge and skills.



Working group

However, to remain sufficiently competent, continuing education and experience is also required. Therefore, the Steering Committee of the Dutch NCCP considered this topic to be a major priority and installed a working group “Education”. Although the actions mentioned in the Dutch NCCP 2005-2010 were much broader, the working group decided to focus on the education of medical professionals and nurses. The results and recommendations were published in the report “Deskundigheidsbevordering van artsen en verpleegkundigen in de oncologie” (*Improvement of the professional expertise of physicians and nurses in oncology*) in 2008.

Medical specialists

Some conclusions

- Well-described oncological education, requirements and specific registration with regard to knowledge and skills in oncology are not available for all medical specialists
- For those super specializations such as medical oncology, gynaecological oncology, surgical oncology, haematological oncology, head and neck oncology, urologic oncology, neurologic oncology, and paediatric oncology, general and sub competences have not always been well-formulated, neither harmonized.

Some recommendations

- Can Meds is the tool medical specialists use to define the competencies needed; this tool should take oncology into account.
- During medical specialists’ education, practical training focusing on diagnostics and treatments should be compulsory, under the supervision of a dedicated, registered specialist oncologist.
- The national associations of scientific medical specialists should apply uniform re-registration requirements with regard to the recognized super specializations (e.g. annual hours for continuing education, participation in multidisciplinary teams).

Nurses and nurse practitioners

Some conclusions

- The basic education for nurses (levels 4 and 5) is not sufficient for looking after cancer patients. To obtain the required level, an adequate education effort must be delivered.

Some recommendations

- In departments which mainly accommodate cancer patients, care should be provided by nurses who have received nationally recognized post-education in cancer.
- This training programme needs to achieve the optimum relation between theory and practice and must be taught by competent teachers.

- Home care for cancer patients must be provided by home care nurses who have received supplementary education in cancer and palliative care (according to national criteria).
- The basic education for nurses at intermediate (MBO) and higher (HBO) vocational level needs to incorporate basic knowledge and skills with regard to cancer as they will all come across cancer patients at some point. This should be added to the report “Gekwalificeerd voor de toekomst, kwalificatiestructuur en eindtermen voor verpleging en verzorging” (*Qualified for the future. Qualification structure and final terms for nursing and care*).¹⁶

As the specialized education for nurse practitioners in cancer is quite recent, much more attention should be paid to the educators themselves, in terms of uniformity at national level and registration.

Cohesive plan for continuing professional development

Objectives

- By 2005, details will be available concerning the institution (or websites) via 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. After that, care providers, physiotherapists, dieticians, social workers, etc., will be involved.

Unfortunately, not enough manpower has been available to elaborate these objectives.

Education for other professionals and caregivers

- Psychologists have developed a post-graduate training programme in oncology and registration. See <http://www.nvpo.nl/index.php?option=content&pcontent=1&task=view&id=30&Itemid=58>
- A master class in palliative care for spiritual counsellors has been piloted and might be rolled out nationally. More attention will need to be paid to cancer.
- For informal carers, local training programmes focused on cancer are sometimes available, but in general these programmes are more oriented towards palliative care.

Research

In the Dutch NCCP 2005-2010, three main subjects were highlighted:

- To improve researchers' career prospects and the funding of cancer research from 2005 onwards.
- To enhance the opportunities for the implementation of scientific findings in the clinical situation.
- To review the current legislation concerning the performance of clinical studies.

The development of improved treatments for cancer patients requires that basic scientific discoveries are translated into clinical applications. In spite of an increased interest in translational research in the Netherlands, multiple obstructions are preventing the smooth progression 'from bench to bedside'. The Dutch NCCP and KWF acknowledge that cancer patients should benefit faster from scientific results and have prioritized translational research as their main topic. KWF has promoted translational research by:

- increasing the budget for translational research projects;
- increasing the budget for education and substantial expansion of the educational programme for scientists throughout their careers;
- performing an inventory of the regulatory/legislative factors that are obstructing the performance of translational research (in collaboration with the Collaborative Healthcare Funds (Samenwerkende GezondheidsFondsen);
- performing the Dutch NCCP project "Translational Research".

The Dutch NCCP project "Translational Research" was initiated to help facilitate translational research, focusing on the steps involved in the development of therapeutic products up to phase I studies, in particular for those discoveries that are not rapidly taken up by the pharmaceutical industry. The development of these products requires an alternative route to ensure that they become available for clinical application.

Objectives of the Dutch NCCP project "Translational Research"

- To make an inventory of the numbers and types of scientific discoveries with potential clinical applications that were aborted during the development process (analyses of KWF research project files).
- To identify factors that are currently slowing down the development process (interviews with scientists and organizations working in the field of translational cancer research).
- To intervene in four translational research projects that were already engaged in product development but had encountered obstructions which were halting progress, and to test whether possible solutions will indeed optimize the development process.
- To clear the confusion surrounding the regulations concerning the production of non-classic (cellular) therapeutics and the performance of clinical studies.

What has been achieved?

- The inventory shows that about 10% of the KWF research project files studied describe a product that is potentially clinically relevant. The majority of these research projects describe discoveries that can be classified as "tailor-made" (mainly immunological) therapeutics.
- Obstacles have been identified in the production of therapeutics and the availability of facilities, the regulations concerning the production of therapeutics and the performance of clinical studies, and it has been observed that there is the lack of translational research funding.
- The case studies show that relatively small interventions and investments can remove obstructions encountered on the route from bench to bedside:

- the desire and possibility to develop clinical products in an academic setting are present;
- collaboration between research groups, the availability of knowledge, additional financial support and guidance for research projects are important factors in promoting the translational process;
- collaboration with research groups and pharmacists has resulted in the development of a model-IMP (Investigational Medicinal Product Dossier) for non-classic (cellular) therapeutics, to assist scientists and pharmacists with regulatory issues. This model-IMP should contribute to uniformity and transparency regarding the information required to speed up the procedure for ethical review by the Central Committee on Research Involving Human Subjects (CCMO).
- The current infrastructure in the Netherlands is insufficiently equipped to offer these solutions on a structural basis.

Former VIKC chairman Boi Jongejan

“Collaboration and continuity in cancer care remain essential”



The first step towards establishing a National Cancer Control Programme (Dutch NCCP) was taken just under ten years ago at the offices of the Association of Comprehensive Cancer Centres (VIKC). Boi Jongejan, then vice-chairman and secretary of the VIKC, and Renée Otter (then director of IKN and now chairwoman of the VIKC) came to the conclusion that collaboration within the broad spectrum of cancer care was both essential and inevitable. Jongejan looks back on the birth and early years of the Dutch NCCP with much satisfaction. He believes that the time has come for a fully mature National Cancer Control Programme.

“Renée Otter and I were talking one day and noted that, while much was happening in the field of cancer care, there was little coordination. The Netherlands is a small country in which a large number of people and organizations do different things at different times. We saw opportunities for improvement. We wanted to introduce more structure and cohesion, to establish priorities and to bundle strengths where appropriate. Moreover, it is important to be able to present a joint front to the government, which not only determines policy but is a major source of funding. The same applies to communication with the general public. There are many organizations and professionals involved in cancer care. It would be good to present a clear, unified message through a single channel. We started to discuss our ideas for a national programme within our own organizations, where we received substantial support, and then went on to contact other organizations with a view to collaboration.”

Direction

That it was the comprehensive cancer centres which initially proposed the Dutch NCCP was only logical, believes Jongejan, who would later go on to become chairman of the VIKC. “The VIKC exists to serve common interests and is primarily a support organization. We were therefore the ideal party to manage and direct the process. It took some time to get all five partners ‘on board’. Each had its own interests and priorities, but we focused on the things that we have in common.”

The Dutch Cancer Society (KWF) and the Dutch Federation of Cancer Patients’ Organizations (NFK) were the first to join the VIKC’s initiative. “The NFK was keen from the very outset,” recalls Jongejan. “They thought it an excellent idea. The KWF was a little more hesitant. As a large organization, it was used to doing things itself and being in control.”

The next partner to join was the Ministry of Health, Welfare and Sport (VWS). “Again, it took a little time to get the ministry involved. It had no previous experience in developing a broad approach to one specific disease. Cancer care was a first in this respect, but not the last. We now see a similar broad approach to diabetes, for example.”

Lobbying

Jongejan, who in addition to his work for IKW and VIKC became chairman of the CBO (Institute for Health Care Improvement) and is currently director of the Oranje Kruis first-aid organization, clearly remembers the lobbying that was needed to win the ministry over. “I think the fact that the Netherlands was about to take up the presidency of the European Union played an important role. Because we had oriented ourselves internationally during the preparation stage, we knew that some other countries already had a national cancer control programme in place. We therefore suggested to the Minister of Health, Hans Hoogervorst, that it might not be appropriate for the country leading the entire EU to be without one. I think this was a decisive argument.”

At the suggestion of the ministry, the Dutch Association of Healthcare Insurance Providers (ZN) became the fifth and final partner to join the initiative. “This was very quickly arranged following a meeting with its chairman, Hans Wiegel,” states Jongejan. He believes that the Dutch NCCP has made a huge difference. “There is now far more contact between the partners, and hence much better cooperation. In a multidisciplinary field such as oncology, this is a very important development. Moreover, we have succeeded in establishing certain priorities and in focusing on specific aspects of cancer care. Take translational research, for example, which is extremely important. Thanks to the Dutch NCCP, it has been possible to move scientific research out of the laboratory and into clinical practice more quickly. That is certainly a very welcome development.”

Patience

Nevertheless, Boi Jongejan concedes that several aspects of the Dutch NCCP could be improved. “It will be a long and difficult process, not least because there are so many different people and organizations involved. There have to be meetings and consultations, which inevitably cause delays. That is frustrating, since one always prefers to see immediate results. It is often a question of patience. We have proposed a national screening programme for intestinal cancer, for example. Unfortunately, the Minister of Health, Ab Klink, has yet to approve the idea but this should not be reason for pessimism. After all, a ‘no’ today is not necessarily a ‘no’ forever. And if we look at smoking, we are still not where we want to be but at least the smoking ban in public places is a step in the right direction.”

Jongejan is most impressed by the Dutch NCCP spearheads of psychosocial and palliative care for cancer patients. “Sadly, we cannot prevent or cure every form of cancer. It is therefore extremely important that we continue to devote attention to those who are living with the disease. After all, we are talking about a very large group of people who wish to live out their remaining days in comfort and dignity. It’s all about the quality of life.”

Although Boi Jongejan no longer has any professional involvement with the Dutch NCCP, his personal interest and engagement remain strong. “I hope that the National Cancer Control Programme will be continued. Collaboration and continuity within cancer care remain essential. You cannot just ‘pull the plug’ and stop encouraging lifestyle changes or supporting translational research. I fervently hope that the Dutch NCCP has established a recognized position among the policy-makers. It should be seen as an essential component of our health care system. Cancer care can only benefit if the programme is given an even stronger position – and isn’t that what we all want?”

Patient education and psychosocial care

Introduction

The disease cancer and its treatment not only give rise to physical symptoms, but often also to fear, depression, insecurity, impairment of self-esteem and a sense of lack of control. In addition, there are social consequences, such as loneliness or dependency. The confrontation with cancer may also lead to an existential crisis, which raises questions about what is meaningful and significant. And although work for most cancer patients is an important source of emotional support and financial independence, many cancer patients experience problems with their return to work. The burden cancer patients can experience on an emotional, physical, social, spiritual or practical level can be summarized by the term distress.

In the Dutch NCCP, the mission of the working group “Psychosocial care and education” is stated as follows: “Patients and their relatives should be able to trust that the information, care and assistance they need to cope with the disease and its consequences are available to an optimal degree. (...)

Psychosocial problems should be prevented and if they do occur, appropriate care must be provided.” (Dutch NCCP 2005-2010). To achieve these goals, a programme has been designed to ensure that every cancer patient in the Netherlands will receive good information and psychosocial care when this is needed.

In the field of education, many parties in the Netherlands are already actively involved. In particular, the role of KWF is prominent. Moreover, patient organizations like NFK and the Dutch Patient Consumer Federation (NPCF) play an active role. This has resulted in many initiatives to ensure adequate information provision to both individual patients and the general public. The increased use of the Internet warrants guidelines for reliable information sources. As there was no need to involve extra parties, these challenges in the Dutch NCCP were left to KWF and NFK.

With respect to psychosocial care there seems to be an ongoing loop (a vicious circle). Research has shown a discrepancy between cancer patients’ needs in terms of professional care and the care they actually receive (Report of the Health Council, (Gezondheidsraad), 2004). This is not surprising when we consider the elements of the vicious circle of psychosocial oncology referred to. Psychosocial problems in cancer patients are not systematically identified. As a result, those patients are often not provided with the care that is needed. As this care is provided only to a limited degree, it is difficult or impossible to investigate and measure the effectiveness of such care. As a result, not enough evidence is available to develop evidence-based care. Because the evidence base has not been sufficiently developed, it is not possible to develop evidence-based guidelines. This makes it difficult for insurers to determine what care should be financed. Because the funding does not come off the ground, it is difficult for patients to obtain the care they need and as they are not systematically screened for psychosocial problems, their distress is not identified... And so on.

To break this circle, significant progress should be made in all areas. To achieve this, close cooperation of all parties involved was needed. On this basis, working group “Integration of psychological care” (specially installed by the Dutch NCCP to focus on psychosocial oncology) formulated five targets which, when realized, should lead to the availability of the best possible care: screening, evidence, guidelines, education of professionals and funding of psychosocial care for all people with cancer in all stages of the disease. Later, monitoring of the goals was added as a target.

Patient information

Objectives from the Dutch NCCP

From 2007 onwards, patient information will meet the following criteria:

- Information will be provided in accordance with established ‘best practices’, as set out in a guideline. The requirements imposed by the Dutch law on medical treatment will also be included.
- The topic of providing effective information to – and communication with – cancer patients will be incorporated into the basic educational programmes of all of the relevant care professions.

Current situation

A great deal of high-quality information for patients has become available, both on paper and through various websites, including the websites of KWF, the cancer patients’ organizations and their umbrella organization NFK, the IKCs and those of university medical centres. KWF, NFK and the IKCs are undertaking a project to coordinate, link and, where possible, combine all available information. The provision of information in accordance with established ‘best practices’ has been explored and needs further study.

Psychosocial care

Objectives

By 2010:

- A validated, cost-effective screening instrument capable of determining the need for specialized psychosocial assistance will be available and will have been widely introduced. This will enable all patients who need specialized psychosocial care to be detected and offered help.
- Evidence for the effectiveness of psychosocial care will have been collected, reviewed and made available.
- Effective forms of psychosocial care will have been incorporated into the guidelines for oncological care.
- Training in effective psychosocial care and communication will have been incorporated into the basic educational programmes for all of the relevant professions.
- Effective psychosocial care and rehabilitation will have been incorporated into the standard health insurance package.

Current situation

The Dutch NCCP’s Steering Committee considered psychosocial care to be one of the main priorities of the Dutch NCCP 2005-2010. The working group “Integration of psychosocial care” was set up in order to elaborate all objectives. The Dutch Society for Psychosocial Oncology (NVPO) made the realization of the NCCP goals the main target of its policy for 2005-2010. The results achieved were due to the active participation of many members of NVPO.

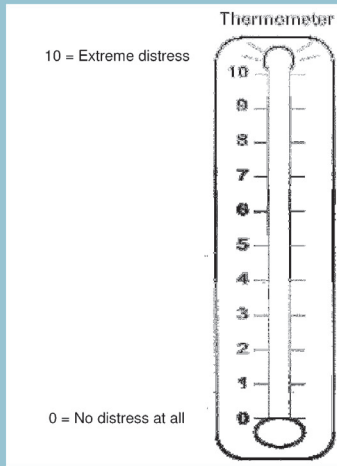
Screening

- A validated screening instrument has been developed by NVPO and the Comprehensive Cancer Centre North-East (IKNO) based on the Distress Thermometer. Its national implementation started in 2009, supported by the VIKC (www.lastmeter.nl).
- The guideline “Detection of the need for psychosocial care” was published on www.oncoline.nl in June 2010, with the help of KWF.
- A baseline inventory was made in 2009 to explore the current situation and the needs for the future.
- A nationwide training programme for professionals of all hospitals (nurses, psychosocial professionals and staff) was developed and applied in 2009 and 2010 through the IKCs . Follow-up training is planned for 2010 and 2011.

Distress thermometer and problem list

Date of today: (day-month-year)

First, please circle the number on the thermometer that best describes how much distress you have been experiencing in the past week (including today) physically, emotionally, socially, practically and religiously.



Source NCCN, USA
© CCCNE, the Netherlands

Problem list

Second, please indicate by checking yes or no if any of the following has been a problem for you in the past week (including today). Be sure to check YES or NO for each.

- | Yes | No | Practical problems |
|--------------------------|--------------------------|--------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | child care |
| <input type="checkbox"/> | <input type="checkbox"/> | housing |
| <input type="checkbox"/> | <input type="checkbox"/> | housekeeping |
| <input type="checkbox"/> | <input type="checkbox"/> | transportation |
| <input type="checkbox"/> | <input type="checkbox"/> | work/school/study |
| <input type="checkbox"/> | <input type="checkbox"/> | financial |
| <input type="checkbox"/> | <input type="checkbox"/> | insurance |

- | Yes | No | Family / social problems |
|--------------------------|--------------------------|-----------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | dealing with partner |
| <input type="checkbox"/> | <input type="checkbox"/> | dealing with children |
| <input type="checkbox"/> | <input type="checkbox"/> | dealing with friends/family |

- | Yes | No | Emotional problems |
|--------------------------|--------------------------|--------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | keeping emotions under control |
| <input type="checkbox"/> | <input type="checkbox"/> | memory |
| <input type="checkbox"/> | <input type="checkbox"/> | self confidence |
| <input type="checkbox"/> | <input type="checkbox"/> | fears |
| <input type="checkbox"/> | <input type="checkbox"/> | depression |
| <input type="checkbox"/> | <input type="checkbox"/> | tension/nervousness |
| <input type="checkbox"/> | <input type="checkbox"/> | loneliness |
| <input type="checkbox"/> | <input type="checkbox"/> | concentration |
| <input type="checkbox"/> | <input type="checkbox"/> | feelings of guilt |
| <input type="checkbox"/> | <input type="checkbox"/> | loss of control |
| <input type="checkbox"/> | <input type="checkbox"/> | dependence on others |

- | Yes | No | Religious/spiritual concerns |
|--------------------------|--------------------------|------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | meaning of life |
| <input type="checkbox"/> | <input type="checkbox"/> | trust in God / religion |

- | Yes | No | Physical problems |
|--------------------------|--------------------------|-------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | appearance |
| <input type="checkbox"/> | <input type="checkbox"/> | changes in urination |
| <input type="checkbox"/> | <input type="checkbox"/> | constipation |
| <input type="checkbox"/> | <input type="checkbox"/> | diarrhoea |
| <input type="checkbox"/> | <input type="checkbox"/> | eating |
| <input type="checkbox"/> | <input type="checkbox"/> | feeling swollen |
| <input type="checkbox"/> | <input type="checkbox"/> | fever |
| <input type="checkbox"/> | <input type="checkbox"/> | mouth sores |
| <input type="checkbox"/> | <input type="checkbox"/> | nausea |
| <input type="checkbox"/> | <input type="checkbox"/> | nose dry/congested |
| <input type="checkbox"/> | <input type="checkbox"/> | pain |
| <input type="checkbox"/> | <input type="checkbox"/> | sexual |
| <input type="checkbox"/> | <input type="checkbox"/> | skin dry/itchy |
| <input type="checkbox"/> | <input type="checkbox"/> | sleep |
| <input type="checkbox"/> | <input type="checkbox"/> | shortness of breath/breathing |
| <input type="checkbox"/> | <input type="checkbox"/> | nausea |
| <input type="checkbox"/> | <input type="checkbox"/> | speech/talking |
| <input type="checkbox"/> | <input type="checkbox"/> | taste |
| <input type="checkbox"/> | <input type="checkbox"/> | weight change |
| <input type="checkbox"/> | <input type="checkbox"/> | tingling in hands/feet |
| <input type="checkbox"/> | <input type="checkbox"/> | bathing/ dressing |
| <input type="checkbox"/> | <input type="checkbox"/> | daily activities |
| <input type="checkbox"/> | <input type="checkbox"/> | fatigue |
| <input type="checkbox"/> | <input type="checkbox"/> | out of shape/condition |
| <input type="checkbox"/> | <input type="checkbox"/> | muscle strength |

Other problems?

Would you like to talk with someone about your problems?

- yes maybe no

If yes, with whom?

- | | |
|--|---|
| <input type="checkbox"/> nurse | <input type="checkbox"/> pastoral worker |
| <input type="checkbox"/> dietician | <input type="checkbox"/> psychologist |
| <input type="checkbox"/> physiotherapist | <input type="checkbox"/> patient association |
| <input type="checkbox"/> social worker | <input type="checkbox"/> another, namely..... |

Evidence

- A Cochrane review financed by KWF on the efficacy of professional psychosocial care one year after diagnosis has been conducted. More than 3000 publications (3380, published between 1990 and 2009) were studied and rated for their scientific quality based on 15 criteria (e.g. randomized case control study design). Only 12 studies met the criteria. Results show that psychosocial care has a positive effect in diminishing distress in cancer patients. However, more research is needed to find out which intervention is most effective for which patient/problem. A national research agenda was recommended. Publication in the Cochrane library is expected in 2010.

Psychosocial care in tumour-specific guidelines

- NVPO and the IKCs agreed in 2006 to work on structural involvement of psychosocial experts in the development of evidence-based tumour-specific guidelines. However, in the recently adopted structure for guideline development, only the most urgent topics are addressed. Psychosocial care is rarely seen as urgent enough by medical experts to meet the criteria for inclusion in guidelines.
- To obtain an overview of the number and contents of tumour-specific guidelines with reference to patient information and psychosocial care, a search was conducted with financial support from KWF. Results show that in 50% of all tumour-specific clinical guidelines (www.oncoline.nl) references to optimal patient information and communication and to detection of psychosocial needs and psychosocial care are included as part of the implementation of evidence-based oncological guidelines.
- To facilitate the implementation of psychosocial topics in the tumour-specific guidelines, recommendations for the incorporation of psychosocial topics have been made available. Development of quality of care criteria for guideline development and implementation of patient information, screening procedures and psychosocial care are being considered.

Finance

- Structural financing of psychosocial care has been improved. Psychosocial oncological care has been included in the standard health insurance package.
- Psychosocial care in specialized centres is now available without costs being charged to the patient. However, structural financing and availability of psychosocial care in hospitals and rehabilitation are still poorly organized.
- To explore the specific problems and barriers, an invitational conference was organized on April 2nd 2009 and was attended by the most important stakeholders in the field: 25 representatives of societies for cancer care professionals, care managers, insurance companies, the Ministry of Health, Welfare and Sport, and cancer patients' organizations. The conference provided a clear insight into the bottlenecks and some possible solutions for the financing of psychosocial care. As a follow-up, the working group conducted further explorations with stakeholders of the health financing system and hospital management. The working group will publish a detailed report on the successes and challenges by November 2010.

Education of professionals in psychosocial oncology

- Two specialized psycho-oncological education programmes have been developed and successfully implemented since 2007: one for medical psychologists in collaboration with the Central RINO group Utrecht (post-master education) and one for social workers in collaboration with HAN University of Applied Sciences.
- Specialized psychosocial oncology centres (IPSO) and the 'visitatie' system on oncological care of IKCs have adopted these education programmes as the professional standards for psychologists and social workers working with cancer patients.
- A registration system has been developed by NVPO for professionals who have completed the programme; the registry is now available via the NVPO website.
- A communication training programme in psychosocial oncology for medical specialists was developed in 2009. Two pilots were completed in 2009 and evaluated (positively) in 2010.

Assurance

- Standards for psychosocial support and screening have been included in the IKCs' peer review system 'visitatie' on oncological care, as have standards on the educational level and the proportional formation of psychosocial staff/care providers.

Experiences of health professionals with the Distress Thermometer



“Definitely an asset”

Teuna Esser and Jantien van der Sluis, nurse practitioners at Antonius Hospital in Sneek, think the Distress Thermometer (“lastmeter” in Dutch) is definitely an asset for cancer care, especially for the psychosocial aspects. “It is an excellent tool to discuss psychosocial problems. For both the patient and the doctor it is immediately clear how heavy the burden is and in what areas the patient is having difficulty. Based on the Distress Thermometer, direct action can be triggered,” said Teuna Esser. “The patient always has the lead in determining what will follow, which issues need addressing and what action will be taken.”

More acceptable

“A great additional advantage is that thanks to the list of topics one does not forget things,” continued Jantien van der Sluis. “And it is much easier for us to address certain problems one

usually does not dare to ask about, such as finance or sexuality. These areas, like many other topics, are simply mentioned in the problem list of the Distress Thermometer.”

Additional resultant development

- The guideline “Rehabilitation after cancer” has been developed and will be available as of December 2010 (www.oncoline.nl, www.herstellenbalans.nl).

Conclusion

With its commitment to improving psychosocial care in oncology in the Netherlands, Working Group “Integration of psychosocial care”, adopted a multi-focus approach. This approach was successful thanks to the collaboration within the Dutch NCCP. Psychosocial care is becoming a more integrated part of oncology care, but the opportunities for applying screening and psychosocial care are often not exploited, despite the recognized need for them by patients. Continued collaboration in a national programme is therefore important.

The following points should receive attention as regards the near future.

Screening

- Nationwide implementation of the guideline in hospitals.
- Possible deployment of the guideline in first-line care.
- Mapping of beneficial and harmful factors for deployment.
- Adjustment of the guideline based on these experiences.
- Monitoring of the extent to which this deployment is successful by recording in the national cancer registration system whether or not screening has been applied.

Evidence

- For further strengthening of evidence, the following has been proposed:
 - to establish a research agenda to which researchers can be invited.
 - This requires that the constraints are formulated on the basis of quality and cooperation.
 - These consultations can take place in collaboration with KWF and ZonMw (the Netherlands Organization for Health Research and Development) regarding opportunities for expansion of that research agenda.
- Psychosocial care in all tumour-specific guidelines needs to be given further attention. Based on the inventory of directives made in 2010, the goals will be:
 - to achieve both substantive and procedural agreement on the integration of psychosocial aspects in tumour-specific guidelines.
 - To formulate a 'guideline for guidelines' with respect to generic psychosocial components in tumour-specific guidelines.
 - In addition: to develop and implement a guideline concerning the establishment of specialized high-quality psychosocial care.

Finance

- For the accessibility of healthcare, its funding as part of the basic health insurance is a prerequisite. Bottlenecks that need to receive attention in the future are 1)
 - The financing of psychologists and social workers in hospitals.
 - The financing of communicative interventions (screening), and 3) the distribution of psychosocial care outside the hospital across the country.

Professional education

- A growing number of people will be confronted with the diagnosis of cancer during the next few decades. To meet the need for qualified care, recommendations on further expertise are:
 - Setting quality standards for education and psychosocial care for each occupational group, both specialized psychosocial professionals and clinicians (doctors, nurses, and paramedics).
 - Establishing a registration system for specialized psychosocial professionals.
 - Training of a sufficient number of experts in psychosocial oncology to meet the needs of the growing number of cancer patients.

Assurance

- Finally, to ensure true integration of psychosocial oncology, it is important that:
 - the indicators for good care are defined;
 - a standard of care is achieved in which the patients' need for psychosocial care is met and integrated.

Support

The working group was able to achieve the results mentioned above with the help of many supporters. Financial support was received from:

- Porticus Foundation, RCOAK and Ingeborg Douwes Foundation for a coordinator of the working group (2007-2010);
- KWF for development of the screening guideline, for the exploration of psychosocial aspects in all tumour-specific guidelines and for the Cochrane review.
- The IKCs supported the development and implementation of the screening guideline, the guideline "Rehabilitation after cancer" and the incorporation of standards for psychosocial care in their Hospital Inspection Standards (2010).
- The Ministry of Health, Welfare and Sport supported an invitational conference on the funding of psychosocial care (2009).

Harm Jan Roelants, former member of the Dutch NCCP project team



“The bottom line is that the patient must benefit”

Harm Jan Roelants is the former director of the Dutch Federation of Cancer Patients’ Organizations. He is also one of the original architects of the National Cancer Control Programme 2005 – 2010 (Dutch NCCP). He and Henk Hummel (formerly of IKN and now with IKNO), formed the project team which provided the momentum for the entire programme. Roelants looks back on this period with much pleasure, but also has some critical comments about the way in which the Dutch NCCP was developed.

“We started work as a project team in 2003,” Roelants recalls. “Much of the necessary preparation had by then been undertaken by a steering group made up of the five partners: the Dutch Cancer Society (KWF), the Dutch Federation of Cancer Patients’ Organizations (NFK), the Association of Comprehensive Cancer Centres (VIKC), the Dutch Association of Healthcare Insurance Providers (ZN) and the Ministry of Health, Welfare and Sport (VWS). The early days were marked by many meetings and ongoing consultation, but little actual progress was made. It was therefore decided that a project team should be appointed to professionalize the process. That task fell to Henk Hummel and myself. We produced a project plan which set out exactly who was going to do what and when we were going to do it.”

Not a simple process

Although the five partners were relatively quick to make agreements regarding a broad-based, joint approach to cancer care, putting those agreements into practice proved rather more difficult. “It was not a simple process,” Roelants admits. “The partners had very different backgrounds and very different ideas. Of course there were also some differences in outlook, but that is good. All that really mattered was to get the programme up and running, and eventually we did so very successfully. We may have made a few mistakes along the way, but that is hardly surprising given the enormous scope of the Dutch NCCP project. We had no example to follow. A few other European countries, Denmark and the United Kingdom for example, had national cancer control programmes. We studied them to see what we could learn, but soon realized that we could not merely ‘transplant’ them into the Dutch situation. After all, every country has its own culture and its own way of structuring health services.”

It was in late 2004 that the National Cancer Control Programme was finally launched with the publication of a report. “The intention was that we would then make a start on the actual implementation, but little or nothing happened straight away,” Roelants recalls with some regret. “It was not until half 2005 that firm action was taken. Why the delay? Well, it was chiefly due to the way in which the project was organized. There was no shortage of plans and ambitions, but the partners could never seem to reach consensus.”

Roelants, who had devoted so much energy to setting up the programme, was unhappy with the way things were going. “In November 2004, Henk Hummel and I were thanked for our input and we thought that was the end of the matter. However, a few months later we were asked to return and pick up where we had left off. The programme was then brought under the wing of the Ministry of Health, which meant that funding and support were secure. The implementation of the plans could finally begin in 2006. In effect, we had lost twelve months.”

Essential

Roelants remains a fervent supporter of the broad approach to cancer care in all its facets. “There are hundreds of organizations and tens of thousands of professionals who are involved in cancer

care to a greater or lesser degree. We are talking about huge numbers. Encouraging cooperation and coordination is therefore a condition sine qua non. For this reason alone, I would like to see a successor to the National Cancer Control Programme. That said, I also think that there are some aspects which should be modified.”

“In my view, the Dutch NCCP has been too ambitious. It gave rise to more expectations than could be met. At least a hundred different action points were formulated, but there were no firm plans for implementation for all of these. The necessary preconditions were not always put in place or the resources not made available. The parties who would be responsible for each initiative were named, but they included organizations other than the five original programme partners; in some cases those organizations failed to make any firm commitment that they would indeed do what had been asked of them.”

Roelants stresses that he continues to support the joint approach. “There are of course many projects that have been realized or at least put in motion. Topics which had previously enjoyed little or no attention have now been placed on the agenda. It’s just a shame that the successes are overshadowed by all the things which have not yet been accomplished.”

A successor to the Dutch NCCP

Asked whether the National Cancer Control Programme should be continued, Roelants does not have to think twice. “Yes, absolutely! But, as I have already said, a different approach is required. For example, at present there seems to be a clear demarcation between the programme and developments in the rest of the oncological field. I see that as a highly undesirable situation. For example, people say, ‘the Dutch NCCP achieved this, no one else – just us!’ It is entirely irrelevant who does what. What is important is that it gets done at all.”

Roelants believes that the key requirement is a well-functioning platform group in which all the main players within cancer care are represented. “That means that the health care professionals must also be involved. How do I see the role of the platform? It must set the agenda, identify the obstacles, lobby, monitor, communicate and educate. It must develop new initiatives and take responsibility for the actual implementation of essential activities. The aim should not be an all-embracing programme but rather a realistic approach geared to actual results. And the patient must notice the difference. After all, that’s what it’s all about. The bottom line is that the patient must benefit, in every sense of the word. Only when that is so, and when it is seen to be so, can you claim success.”

Overall conclusions

This progress report on the developments relating to cancer control in the Netherlands in the period 2005-2010 shows that there have been substantial changes in cancer control over the last five-year period. On the whole, survival rates have improved and mortality rates have decreased. Awareness of healthy living among the public at large has increased. The screening organizations have been reorganized and the degree of attention paid to screening programmes is high. Chain care, psychosocial care and palliative care have been supported by enormous incentives. For most of the various kinds of cancer, national guidelines are now available. Progress has been made in the monitoring of indicators for process, structure, organization and outcomes of cancer care. Focus on translational research facilitates the identification of further steps to be undertaken.

Within these developments, the Dutch NCCP has been the first comprehensive effort to optimize cancer control in the Netherlands. It has played an agenda-setting role and has set many activities in motion. Although many of the objectives of the NCCP have been met, a significant number of goals have yet not been achieved. As the incidence and prevalence of cancer in the Netherlands will increase enormously over the next ten years, a comprehensive cancer plan remains essential.

Members of the working groups

Working group "Tobacco control"

- L. van Gennip

Working group "Population-based screening of colonic cancers: scenarios for proper implementation"

- E. van der Wilden-van Lier, Erasmus Medical University Rotterdam, chairwoman
- N. Baselmans, VWS
- M. Bloemers, ZonMW
- T. Drenthen, NHG
- J. van den Eijnden-van Raaij, IKZ
- D. Habbema, Erasmus MC
- E. Kuipers, Erasmus MC
- A. Lock, RIVM
- J.W. Schouten, ZN
- C. Smit, NPCF

Working group "Alignment of screening and curative care. Practical problems and possible solutions"

- H. Feenstra, De Friesland, Health insurance company, chairman
- J. van Leeuwen, Stichting Olijf
- K. van Schoonhoven, RIVM
- G. van der Heide-Schoon, Breast Cancer Association
- M. Gort, IKNO
- M.J. Steinbusch, Limburg Population Screening Programmes
- Ch.J. Maats, KWF Cancer Signalling Committee
- Luijk, ZN

Working group "Promotion of the quality and accessibility of cancer care"

- A. van Bochove, NVMO, chairman
- E. Borst - Eilers, NFK
- C.C.E. Koning, NVRO
- J. Paulides, VIKC
- R. Otter, VIKC
- J. Lambriks, nurses' organization V&VN, Oncology department
- P.D. Siersema, NVvO
- R.A.E.M. Tollenaar, NVCO

Working group "Improvement of the professional expertise of doctors and nurses in oncology"

- B. Meyboom-de Jonge, UMCG, chairwoman
- R. Otter, VIKC
- P.F. Roodbol, UMCG
- D.T. Sleijfer, UMC

Working group "Integration of Psychosocial care"

- J.C.J.M. de Haes, AMC-UVA, chairwoman
- E. Bleiker, NKI
- A.M. Van Dulmen, NIVEL
- N. Golsteijn, V&VN
- J.E.H.M. Hoekstra-Weebers, VIKC
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Acronyms used

AMC-UVA	Amsterdam Medical Centre / University of Amsterdam
BVN	National Breast Cancer Patients Organization
CBS	Statistics Netherlands
CCMO	Central Committee on Research Involving Human Subjects
CVZ	Health Insurance Board
DBC	Diagnosis/Treatment Combination
ECL	European Cancer Leagues
ESR	European Standardized Rate
GBA	Local Authority's Residents Registry
GGD	Municipal Health Service
GP	General Practitioner
GR	Health Council of the Netherlands
HBO	Higher Vocational Education
HOVON	Haemato Oncology Foundation for Adults in the Netherlands
IGZ	Dutch Health Care Inspectorate
IKC	Comprehensive Cancer Centre
IMPd	Investigational Medicinal Product Dossier
IPSO	Institute for Psychosocial Oncology
KNMG	Royal Dutch Medical Association
KWF	Dutch Cancer Society ('KWF Kankerbestrijding' in full)
LEBA	National Evaluation Team on Cervical Cancer Screening
LETB	National Evaluation Team on Breast Cancer Screening
LUMC	Leiden University Medical Centre
MBO	Intermediate Vocational Education
NABON	Dutch National Breast Cancer Consultation
NCCP	National Cancer Control Programme
NCR	Netherlands Cancer Registry
NIVEL	Netherlands Institute for Health Services Research
NFK	Dutch Federation of Cancer Patients' Organizations
NHG	Dutch College of General Practitioners
NKI-AVL	Netherlands Cancer Institute / Antoni van Leeuwenhoek Hospital
NKR	Netherlands Cancer Registry of VIKC
NNGB	Dutch Standard for Healthy Physical Activity
NPCF	Federation of Patients and Consumer Organizations in the Netherlands
NVCO	Dutch Society of Surgical Oncology
NVMO	Dutch Society of Medical Oncology
NVOV	Dutch Society of Oncology Nurses
NVPO	Dutch Psychosocial Oncology Society

NVRO	Dutch Society of Radiology and Oncology
NVvO	Dutch Oncology Society
PSA	Prostate-Specific Antigen
RCOAK	RCOAK charitable foundation
RIVM	National Institute for Public Health and the Environment
RPCF	Dutch Patient Consumer Federation
STIVORO	National Centre of Expertise for Smoking Prevention
TNO	Dutch Research Organization of Industry and Government
TNS NIPO	Market research company
UICC	Union for International Cancer Control
UMC	University Medical Centre
UMCG	University Medical Centre Groningen
VIKC	Association of Comprehensive Cancer Centres
VWS	Ministry of Health, Welfare and Sport
V&VN	Association of Nurses and Care Providers
WGBO	Medical Treatment Agreements Act
WHO	World Health Organization
WSR	World Standardized Rate
ZN	Dutch Association of Health and Social Care Insurance Companies
ZonMw	Netherlands Organization for Health Research and Development

Relevant websites

www.cocancpg.eu
www.eurocanplus.org
www.ggd.nl
www.herstelenbalans.nl
www.hovon.nl
www.ikcnet.nl
www.ikcnet.nl/sib
www.ikcnet.nl/cijfers
www.kankerregistratie.nl
www.kwfkankerbestrijding.nl
www.lastmeter.nl
www.nfk.nl
www.nhg.nl
www.npknet.nl
www.npknet.nl/monitor
www.oncoline.nl
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www.rivm.nl
www.stg.nl
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www.zichtbarezorg.nl
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