

# Dutch Cancer Society Policy Vision 2015 to 2019



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#### I. CANCER AFFECTS US ALL

Cancer affects us all. During their lifetime, one in three Dutch people will become short-term or long-term cancer patients; one hundred thousand people are diagnosed with cancer each year. Each year more than 44,000 people die from cancer (2012). This makes the disease the leading cause of death in the Netherlands. Living with cancer, or life after surviving the disease, can be associated with severe physical and mental problems. The average age of the population of the Netherlands is rising, so the number of new patients is expected to increase still further, to 123,000 in 2020.

#### **Progress and optimism**

The figures shown above illustrate the need to remain fully committed to fighting cancer. To build on what has already been achieved. Improvements in our understanding have helped to clarify the causes and prevention of cancer. This has resulted in improved treatments that are less taxing for patients, and increased chances of survival. In 1949, when the Dutch Cancer Society was founded, only 25% of patients were still alive five years after being diagnosed with cancer. Today's average is 61%. We are also very encouraged by promising developments in scientific research and targed therapies of patients. The Dutch Cancer Society's investment in research and education over the past 65 years has contributed to this.

Our dream is that nobody dies from cancer ever again. We can help to realize this dream by preventing as many people as possible from getting cancer in the first place, by detecting the disease as early as possible, and by improving the treatment of this disease.

#### The Dutch Cancer Society as a social partner

Everyone facing cancer tends to see it as a personal problem: how do I deal with this, can I survive it? However, cancer is also a social problem that affects the whole of society. The fight against cancer is, therefore, a social mission. It is not only important to treat the disease at the level of the individual patient. We also need to fight cancer collectively, as a society. By investing in research and prevention, for instance, and by raising money to fight cancer. In picking up this gauntlet, the Dutch Cancer Society is acting as a social partner in the fight against cancer. We want to be a partner for committed individuals and organizations that share our ideals. We are fighting cancer collectively.

As a partner that cooperates with – and serves – society, we will be making choices, more than ever before, in consultation with patients, with those working in the field of oncology, and with other stakeholders. We will also be encouraging and actively supporting initiatives from society at large to raise money to fight cancer. Such involvement is triggered by our mission, our vision and our expertise. We continually assess the choices we make in the light of state-of-the-art scientific understanding and in terms of the needs and expectations of society.



## II. LESS CANCER, MORE CURE AND A BETER QUALITY OF LIFE - OUR MISSION

The Dutch Cancer Society's ideal world is one in which nobody dies from cancer ever again. We want fewer people to get cancer, more people to cure, and patients to have a better quality of life, during and after the disease.

That's why we fund and facilitate scientific research, influence policy, and share our knowledge about cancer and its treatment.

To make this possible, we raise funds and establish links with other parties involved in cancer control, both here in the Netherlands and elsewhere.

#### III. WHAT WE WANT TO ACHIEVE - OUR GOALS

All of the activities initiated and implemented by the Dutch Cancer Society contribute to one or more of our mission goals: less cancer, more cure, and a better quality of life. We want to fight cancer even faster and better. Which is why we will be introducing a number of innovations over the next few years. In particular, the methods used to fund research are being updated. The goal is to translate the results of research to meet patients' needs, more quickly than ever before. We will be tackling the government, the health sector and industry to influence policy and to ensure that opportunities and sticking points in the fight against cancer are placed firmly on the agenda. We will update our fundraising tools to attract as much funding and support as possible from the people of the Netherlands.

#### **Goal: less cancer**

#### Preventing people from getting cancer by reducing their exposure to risk factors.

The fight against cancer begins with preventing people from getting cancer in the first place. Cancer often develops as a result of factors that are beyond our control, such as a genetic predisposition and old age. In about 35% of cases (this varies from one type of cancer to another), however, prevention is possible, by limiting people's exposure to risk factors. Smoking is the main controllable risk factor for cancer. During this policy period the Dutch Cancer Society will not be slackening its efforts in this area.

Our ambition is to eradicate smoking in the Netherlands. The World Health Organization's (WHO) Framework Convention on Tobacco Control (FCTC) sets out smoking cessation measures that have been proven to be effective: a coherent package of measures and activities, consisting of education, legislation and pricing policy. On this basis, we will work to promote the introduction of these measures in the Netherlands. This will mainly involve knowledge sharing and advocacy in government and industrial circles. We are also committed to incorporating non-smoking into the care programme of patients. To achieve our ambitions, we cooperate closely with other members of the Dutch Alliance for a Smoke-Free Environment.

Sensible sunbathing is an important measure for limiting the rising number of cases of skin cancer. For this reason, we are sharing our knowledge about exposure to UV radiation. We are also influencing policy in schools and tourist facilities.



In addition to smoking and sunbathing, there are other risk factors that can influence the development of cancer, such as nutrition, exercise, obesity and alcohol. We make this knowledge available to other parties and to the public.

Finally, we fund and facilitate promising developments in prevention research.

#### Goal: more cure

Help to ensure that more people survive cancer, by providing better treatment and by encouraging them to adopt a healthier lifestyle during and after treatment.

On average, the Dutch Cancer Society funds around 475 research projects each year. In recent decades, great strides have been made in efforts to increase people's chances of living longer with cancer, or of surviving the disease. Yet, even now, the harsh reality is that almost 40% of patients still die within five years of diagnosis.

This is something that we can not and will not accept. We must cut this mortality rate. Therefore there needs to be a substantial improvement in the treatment of patients and in the results of such treatment. Scientific research targeting (early) detection, diagnosis, treatment, palliative care and cancer survivorship care are all essential if we are to develop an effective treatment for every type of cancer. The bulk of the Dutch Cancer Society's spending is targeted on research. It is crucially important that all new findings generated by cancer research are translated to meet patients' needs as quickly as possible.

This is a priority in this policy period. In addition to research, it requires advocacy among parties such as the government, research funding bodies, and insurers.

#### Goal: a better quality of life

Improving the physical, psychological and social functioning and well-being of those living with cancer and those who have survived the disease.

The group of those living with cancer and those who have survived the disease is growing rapidly. In the Netherlands, it currently numbers about 700,000 people. Their quality of life is also our concern. Therefore, over the next few years, we devote our full attention to the effects of the disease and its treatment. The Dutch Cancer Society facilitates research into the physical and psychosocial impact of the disease and its treatment. Its aim is to help improve the social functioning and well-being of those living with cancer. Treatments are becoming more intensive every day. For patients and survivors, the balance between living longer and quality of life is becoming increasingly important.

We are committed to the implementation of research findings. For instance, we are committed to making interventions in psychosocial care that have been proven to be effective, available and accessible to every patient who needs them.

The Dutch Cancer Society believes it is important for patients to have access to reliable and up-to-date information. Well-informed patients are better able to make choices (including choices about treatment) and they feel that they have more control over the disease.



#### IV. HOW WE FIGHT CANCER - OUR TOOLS

The Dutch Cancer Society takes three approaches to achieving its mission. These are funding and facilitating cancer research, influencing policy, and sharing knowledge. The Dutch Cancer Society is constantly seeking partnerships with relevant parties.

#### To fund and facilitate cancer research

Scientific research is crucial to progress in the fight against cancer. People in the Netherlands and elsewhere have been investing in research for many years now. As a result, we now know a great deal about what cancer is and how it develops. This has made it possible to significantly improve the treatment of cancer and its outcome. But there is still much to be gained.

Research funding is our strength, which is why the Dutch Cancer Society will be investing heavily in research during this policy period. This inevitably involves making choices. One central pillar of this approach is that research results should be translated to meet patients' needs as quickly as possible. Another aspect is that researchers should be made aware of patients' experiences, to provide a focus for their subsequent research work. During this policy period, to facilitate this process of translating results, we will be thoroughly reorganizing our approach and our funding structure. The Dutch Cancer Society is moving away from a purely funding role to become a facilitator of, and investor in, cancer research.

#### New funding structure and approach

Over the next few years, a new and more flexible funding structure will be introduced. This will enable us, together with those working in the research field, to meet our mission goals more effectively. Directing matters in this way requires transparency: we are becoming increasingly successful at clarifying the impact of our research spending. This allows us to work more effectively and to be better at showing others what we do and what we achieve in this way.

Our present approach to assessing grant requests is to focus on the scientific quality of the project or programme in question. From now on, we will place greater emphasis on the potential of the research in question to make a genuine contribution to our mission. The only way to obtain a clear picture of this is to examine each study in terms of its strategy for developing the results obtained into new treatments for patients. This calls for flexibility in the types of funding used: every effort must be made to ensure that the results genuinely reach patients. Throughout the entire research chain, from the laboratory to the patient, those working in the research field put forward research proposals, and we facilitate the flow of results. There is still a substantial focus on basic cancer research, as this is the source of new insights. Yet there is also scope for promising initiatives in the field of infrastructure, for example. And we continue to encourage young talent to get involved in cancer research. This effort too is based on high quality research proposals that contribute to our mission. By taking on the role of a partner, and by maintaining an ongoing dialogue with those working in the field, we are expanding our understanding of the trends, opportunities and knowledge gaps in the field of cancer. The Dutch Cancer Society initiates and then funds research in these areas. We are boosting cooperation with other bodies that fund research. The goal is to generate more money for research and to deliver results faster, through substantive coordination.



The Netherlands Cancer Institute (NKI) remains an important partner for the Dutch Cancer Society, building on our long-term association in the fight against cancer. As a national knowledge centre in the centralization of tasks in the field of research infrastructure and training, and in the implementation of policy-based innovation, we expect the NKI to adopt a pioneering role.

Private parties have an important part to play in the translation of knowledge from research to applications for patients. Now, more than ever before, the Dutch Cancer Society is seeking partnerships with these parties to make the process of moving from the laboratory to the patient as streamlined as possible. In this policy period, we will be pursuing this goal by developing an approach that will facilitate collaboration with private parties while allowing income to be channelled back.

#### Influencing policy

Using the funds entrusted to it, the Dutch Cancer Society endeavours to make the greatest possible contribution to the fight against cancer. However, the effect of this on cancer control is not determined solely by the Dutch Cancer Society's own efforts and policies. Government policy and that of other parties, such as political circles, health insurers, medical professionals, health institutions and industry, all play a part in determining the potential and effectiveness of cancer control.

For this reason, the Dutch Cancer Society has decided to make greater use than ever before of its network and position, to influence the policies of these institutions. As a respected and independent organization with a strong social support base, we are able to identify relevant themes and sticking points, to ensure that these are placed firmly on the agenda, and to solve them together with stakeholders. In the area of prevention, we are focusing on smoking cessation measures. We are also committed to ensuring that there is sufficient funding for high-quality oncology research, for implementing new findings from scientific research more quickly and more widely, and for safeguarding comprehensive care – both physical and psychosocial. In addition, we are identifying and debating issues in society that impact the fight against cancer.

#### Sharing knowledge

Providing and disseminating information about cancer is a basic service that the Dutch Cancer Society renders to the Dutch public and to people with cancer and their close friends and relatives. Providing patient information can add to a patient's understanding, and to that of their close friends and relatives. It also enhances their capacity for self-management. Those working in the field of healthcare, patient organizations and other educational initiatives make an important contribution to effective information provision. Together with the digital platform Kanker.nl, the Dutch Cancer Society sees to it that up-to-date and reliable knowledge about cancer is available and that it can be shared. Kanker.nl is a partnership between the Comprehensive Cancer Centre of the Netherlands (IKNL), the 'Levenmetkanker' (living with cancer) patient movement and the Dutch Cancer Society.

This electronic platform contains information about cancer, about the range of treatments available, about living with cancer and about life for cancer survivors. There are also details about ongoing clinical trials in which patients can participate. Kanker.nl is a place where those who have faced cancer can share details of their experiences and where the views of the target group can be widely disseminated.



In addition to making information about cancer (and its treatment) available, we also see it as our duty to inform our stakeholders and the Dutch public, clearly and transparently, about our methods and results (including our research results). For instance, free online access to research publications (open access) will be one of the conditions attached to our grants.

#### Joining forces

The complexity of cancer and cancer control requires cooperation and excellence in vision, strategy and execution. Cancer can be more effectively controlled by combining the strengths of various parties at national and international level. The Dutch Cancer Society wants to actively and intensively engage in partnerships with parties who support our mission goals. Not only at national level, but also internationally: cancer is a worldwide problem. We want to continue our efforts to cut the rates of cancer, as a global disease, in the years ahead. We will do this in partnership with organizations such as the Union for International Cancer Control (UICC) and the Association of European Cancer Leagues (ECL). Through cooperation with international organizations such as the International Cancer Research Partnership (ICRP) and the European Network on Translational Cancer Research (Transcan), we are expanding our understanding of cancer research and sharing knowledge.

#### In partnership with patients

In this policy period, patients and ex-patients will have much greater influence at every level of the organization. The Dutch Cancer Society will listen to their accounts of what they have experienced and, in the years ahead, will give people with cancer official input into its core activities and into the development of its policies. To this end, we are cooperating with our patient advisory committee, with Kanker.nl, with the Levenmetkanker (living with cancer) movement, and with any patients (or ex-patients) who would like to contribute. The Dutch Cancer Society considers it essential that patients are supported and that their voices are heard. This is why we are helping the cancer patient organizations who have joined forces in the framework of 'Levenmetkanker' to grow into a powerful, autonomous patient movement. Based on their shared goals, the Dutch Cancer Society and 'Levenmetkanker' are seizing opportunities to join forces and to engage in co-creation.

## V. THE LINK IS OUR STRENGTH – FUNDRAISING AND OBTAINING TIME COMMITMENTS

The Dutch Cancer Society is entirely dependent on community involvement and donations. To achieve our mission, we engage in fundraising activities, mostly together with the thousands of people in the community who are committed to making cancer control possible. From the cyclists and sponsors of Alpe d'HuZes to fundraising by school pupils, and from those who participate in the Relay For Life to the Dutch Cancer Society's collectors. The Dutch Cancer Society fosters, encourages and actively supports this commitment. It engages in a lasting relationship with volunteers, with those who initiate events like the Alpe d'HuZes, and with our more than one million donors, large and small. That link is our strength as a social partner.

However, the scope for fundraising is under pressure from legislation, from economic factors, and from the critical views held by some members of the public. Our target – in four years' time – is to stabilize our revenue at a level of 136 million euros per year, through the commitment of our volunteers and donors.



#### Lasting relationship

For Dutch Cancer Society volunteers, the departmental structure will continue to shape the organization's presence throughout the country. For some years, we have been investing in improving the departmental structure, in terms of increased efficiency and resilience. Our goal is to create a model based on large, merged departments and smaller units. Each department will obtain the level of service and support that is appropriate to its needs. Over the next few years, the national door-to-door collection campaign in every first week of September will continue to be a major source of income and an important expression of public support for cancer control and for the Dutch Cancer Society.

Over the next few years, the Dutch Cancer Society will not only focus on encouraging and supporting campaigns and volunteers but also on recruiting and on retaining donors and on acquiring income from legacies.

Here too, undertaking lasting relationships will be the prime consideration. As a way of boosting the commitment of donors and campaign workers, we will be offering more opportunities for donations to be specifically targeted. To this end, we are setting up an online portal in which we will present a range of studies and projects for 'targeted donations'.

#### Partnership for innovation

Society is changing fast. This challenges us to invest in innovation. Thus, over the next few years, we will be actively looking for new and inspiring types of campaigns and fundraising concepts.

We will also continue to publicize our ideals, methods and results in a way that is both transparent and clear. We will actively engage in discussions with anyone who cares about cancer control. Together with them, we will achieve our mission.

The substantive, financial and organizational consequences of this policy vision will be refined into a strategic and operational plan.