Nederlands
Kanker
Collectief

The Netherlands Cancer Agenda

20 **goals** to reduce cancer's impact on society

Introduction

Cancer is a societal issue

When the 'Nederlands Kanker Collectief' (Netherlands Cancer Collective) launched at the end of 2022, the Netherlands was the only country in Europe that had not yet taken steps towards a national cancer plan. And that while our countriy is facing quite a few challenges.

The number of cancer patients continues to grow. A significant part of these cases are preventable, so we need to pay more attention to cancer prevention. Fortunately, treatment options and survival rates are also growing. This also makes it increasingly important to pay attention to quality of life.

New treatment options are great, but costs grow along with them. The affordability and accessibility of care are under pressure, and many people experience the consequences of staff shortages on a daily basis. Add to this the challenges of an ageing population and alarming health inequalities, plus concerns about sustainability and climate and environmental impact. Then it is clear that we are facing a major societal challenge.

Making a tangible difference together
Many hundreds of parties are already putting their shoulders to the wheel every day. What if we re-organised all these efforts? By working together. The Nederlands Kanker Collectief (NKC) explicitly does not aim to form yet another new initiative. But rather to connect existing initiatives with all their collective thinking and practical skills. And to build on these assets, so we can move up a gear and meet the challenge in a mutually reinforcing way.

This social movement, which is the NKC, comes from the bottom up. From people and organisations who want to lead the way and do things differently. Who are willing to look beyond their shadows and domains. Together, we are seizing the opportunity to reduce the impact of cancer on society.

Together, more than 100 parties drew up the Dutch Cancer Agenda (Nederlandse Kanker Agenda, or NKA) in a year and agreed on 20 goals. Not despite, but because of our broad perspective and the diversity of parties involved, we've managed to create a focus. On issues where we can make a tangible difference on a person's life. We are now working on an approach for five 'featured goals'. The launch of the Netherlands Cancer Agenda is not like reaching the finish line. It is more like a starting point. With a clear, common mission: together improving life before, with and after cancer.

Carla van Laer,
programme manager

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01

The Netherlands Cancer Agenda (NKA)

1.1 What the NKA does

The Netherlands Cancer Agenda (Nederlandse Kanker Agenda, or NKA) is the overall cancer plan for the Netherlands compiled and implemented by the Nederlands Kanker Collectief (Netherlands Cancer Collective, or NKC). It is a living agenda, consisting of 20 ambitious goals and a concrete approach for five featured goals.

This plan is designed with a focus on people before, with or after cancer, regardless of age, gender, background or personal situation. People, citizens and loved ones have a central position in the development and implementation of the agenda.

With this agenda we interpret and implement the EU Beating Cancer Plan in the Dutch context.[1] Until recently, the Netherlands was the only European country without a national cancer plan. Other countries have already successfully deployed national plans, like Denmark which has been working with a structural plan since 2000 and consequently went from laggard to forerunner in Scandinavia in terms of five-yearsurvival rates.[2]

The agenda also ensures a better connection with plans and programmes in Europe, which makes sense as cancer transcends national borders. This connection makes cooperation with other European countries logical and more efficient. Furthermore, the agenda facilitates requesting European funds for research and implementation.

The agenda also provides an overview of the large number of valuable initiatives and promising innovations in the Netherlands that focus on prevention, the patient journey and quality of life. Thanks to this overview, the agenda is able to create synergy between initiatives, to accelerate in order to achieve goals sooner, and add focus an perseverance to underexposed issues.

Moreover, the agenda shows where the biggest impact can be made. This focus provides direction to efforts by all parties in the field. And gives space to better align valuable initiatives and partnerships.

1.2 Where we want to make an impact

When looking at figures, the Netherlands is not in the best of shapes compared to other European countries.[3] Below are some numbers on cancer in the Netherlands. They make it very clear there is a need for a Cancer Agenda in the Netherlands. With a solution-oriented plan and a clear focus, we aim to improve these figures.

The need for the NKA in figures

In the Netherlands, 1 in 2 people get cancer.[4] The number of people who get cancer each year continues to rise. By 2032, 156,000 people are expected to be diagnosed with cancer and more than 1.4 million people are living with or after cancer.[5]

Cancer is the primary cause of death in the Netherlands. Some 46,000 people die from cancer annually.[5] The mortality rate is 8% higher than the European average.[6]

The probability of survival after five years increased from 43% to 65%. But differences between cancer types vary greatly.[7]

For many people who have (had) cancer, rejoining society is difficult. For instance, as many as 1 in 3 people can not function socially as they did before.[8]

You can read more in-depth figures on cancer in the Netherlands in Appendix A.

1 in 2

Dutch people get cancer

Figures only tell part of the story. To better understand the impact of cancer on society, it is important to see these figures in a broader, societal context. The NKA is part of this context and affects it at the same time.

The NKA was created for society. This gives us both a great responsibility and an opportunity to help make the Netherlands future-proof. The agenda is therefore guided by three major social challenges facing the Netherlands: how do we ensure a people-centred, sustainable and durable approach to cancer? These tasks are derived from the Dutch Framework for Appropriate Care ('Kader voor Passende zorg') , but are not limited to healthcare in this broad agenda.[9]

Leading societal tasks for the Netherlands Cancer Agenda

People-oriented

People have different wants and needs and are more than their care or support needs.
This requires seeing the whole person in all their facets. Attention and time are needed for the care recipient and caregiver to decide on the appropriate care.
A people-centred approach also helps to reduce the persistent health inequalities in our country. People with low socioeconomic status and education live fewer years in good health.[10, 11]
The agenda therefore adopts a targeted and inclusive approach and, where necessary, a differentiated approach. Achieving equality sometimes requires treating people unequally.
Female-male differences may also require a different approach to ultimately achieve equal health outcomes.[145]

Social sustainability

Demand for care continues to rise in the coming years, partly due to the (double) ageing population, more complex care needs and new treatment options.[12] Related to this, spending on cancer care is also increasing.[13]
Healthcare providers also report that their job satisfaction and professional space are under severe pressure. To a degree that many (want to) leave the healthcare sector.[14] This puts the financial, human resources and social sustainability of healthcare at risk.
Therefore, the agenda has a sustainable and realistic approach.

Environmental sustainability

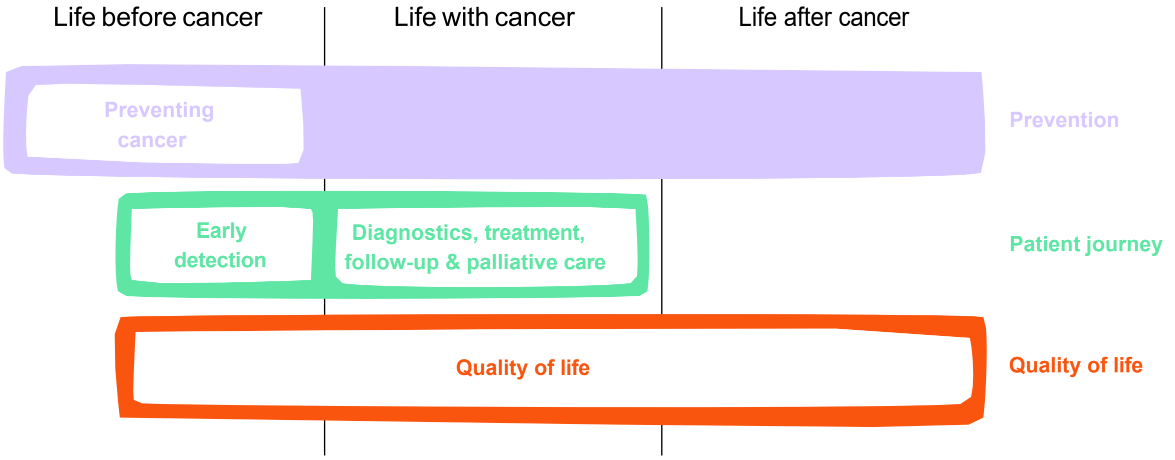
The Netherlands is facing a big sustainability challenge ahead. Also in de field of (cancer) care. Healthcare produces large amounts of waste, releases drug residues into surface water and is responsible for substantial CO_2 emissions.[15] Healthcare must play its part in the energy transition and switch to circular use of materials. The plans of action for the 20 goals on the agenda help reduce environmental impact.

1.3 NKC's view on cancer

Cancer impacts all areas of society and affects almost everyone. It is therefore a social issue that we, as a collective, need to look at with a broad perspective. We do this by making a human life - from beginning to end - the centre of attention. This means we look at the whole continuum of life: before, with and after cancer.

Running right through these three phases are prevention, the patient journey and quality of life. In order to show which issues a person has to deal with, e.g. lifestyle, care or social functioning. Together, this makes the conceptual framework for the Netherlands Cancer Agenda which has a broad perspective.

Conceptual framework NKA



Prevention

As much as 34% of all cancers (excluding basal cell carcinoma) are preventable.[16] So this is a key to reduce the impact of cancer on society. Prevention starts in the phase before cancer and continues through the phases life with and after cancer. The latter two stages are about preventing or reducing symptoms or worsening of the disease.[17]

Patient journey

Within the patient journey, we distinguish early detection (in the phase life before cancer) and diagnosis, treatment follow-up and palliative care* (in the phase life with cancer). We look at quality of care in the entire patient journey. This is done according to six dimensions: effectiveness, quality, patient-centredness, timeliness, efficiency and equality of treatment.[18]

Quality of life

Cancer has a great impact on people's quality of life. Quality of life is seen in this agenda as an integral part of early detection, diagnosis, treatment, aftercare and life after cancer. We also look at quality of life from six dimensions: physical state, mental state, degree of independence and autonomy, social relationships, living environment and personal values and beliefs.[18]

* Throughout this document palliative care means both palliative and supportive care

02

Nederlands Kanker Collectief (NKC)

2.1 The synergy of the collective

The 'Nederlands Kanker Collectief' (NKC) is the Netherlands Cancer Collective. It is an independent and open collective consisting of organisations and initiatives in healthcare and other fields. The collective combines the brainpower, knowledge, capacity, capabilities and resources of its partners. This stems from the belief that cancer is too big a challenge to solve by only one organisation.

The collective's mission is to reduce the impact of cancer on society. And to improve the lives of people before, with or after cancer. This is what connects us and motivates us to work together for the next 10 years.

We did not wait for a government order. We operate independently of political movements. At the same time, we are supported in our approach by a parliamentary majority.

Currently, more than 100 organisations are already working together in the collective. These include patient organisations, healthcare organisations, research institutions, social organisations, (patient) advocates, funders and governments. To successfully implement the Dutch Cancer Agenda, we need everyone's commitment. That is why we work together as partners in the NKC.

The collective's potential lies in thinking and acting from the common interest, connecting people and organisations and bringing together existing and new initiatives from across society. All this is done by crossing the boundaries of regions, domains and specialisms.

The whole is greater than the sum of its parts and together we are able to move forward faster.

2.2 How the collective works together

As a collective, we work together as partners on concrete goals, with a focus on five featured goals. For these we have made action plans which bring solutions closer. The goals are evaluated and recalibrated annually by the collective. Depending on the amount of progress, the focus on the featured goals can shift. Thus, the collective and the agenda continue to evolve and adapt.

Partners contribute to the realisation of the agenda, taking their own role and position. This can be done by aligning existing and new activities with the focus the agenda has indicated. Chapter 5 describes this in further detail. It also states how partners are supported by the NKC hub (programme team).

The collective works together based on these principles:

Fundamentals NKC

- **Openness**
  We work in co-creation, anyone can join in
- **Equality**
  We are all equal and everyone brings a valuable perspective
- **Mission first**
  Decision making is done with a common interest viewpoint
- **Goal oriented**
  We dare to choose, monitor progress and make adjustments where necessary
- **Responsibility**
  We all take responsibility for implementing the agenda

03

Connecting to Dutch and European initiatives

3.1 Dutch initiatives

The Netherlands has many valuable initiatives at local, regional and national level, each of which contribute to reducing the impact of cancer on society in their own way. High-quality scientific research on cancer is also carried out in the Netherlands. The Netherlands Cancer Agenda builds on these initiatives and this research, connects them, brings overview and thus ensures acceleration. An inventory of all current initiatives can be found on the NKC website at the individual goals.

Some examples of key Dutch initiatives that we connect to are the 'Integrated Care Agreement' (IZA), the 'Healthy and Active Living Agreement' (GALA), the 'National Prevention Agreement' (Nationaal Preventieakkoord), the 'National Palliative Care Programme' (Nationaal Programma Palliatieve Zorg) and the initiatives within appropriate care including the 'Appropriate Care Framework' (Kader Passende Zorg) for people with cancer. The 'Taskforce Oncology' and the 'Taskforce Cancer Survivorship Care' work to improve cancer care and enhance integrated care and support for people with or after cancer.

3.2 European Cancer Mission and European Beating Cancer Plan

In 2020, the European Commission drew up the European Cancer Mission (ECM) and, subsequently, in 2021, the European Beating Cancer Plan (EBCP).[1, 19] With the Netherlands Cancer Agenda, we interpret and implement the ambitions described in the ECM and the EBCP.

Through these programmes, the Commission not only encourages decisive action by each European country, but also cooperation between countries. The Commission also wants to reduce inequalities between European countries - so-called cancer inequalities - for example by exchanging expertise and providing resources. This can be accomplished through programmes such as EU4Health, HORIZON Europe and Digital Europe.

The EBCP is structured around four main areas of action: sustainable cancer prevention, improved early detection, high-quality cancer care and improved quality of life for people living with or after cancer. The NKA conceptual framework we described earlier, links to these action areas. Each topic contains some core initiatives (flagships) and several supporting measures. The next page provides an overview of the topics in the EBCP.

3.3 Cancer Mission Hubs

In 2023 the ECHoS project was launched in order to learn from oneanother at a European level, to exchange best practises and start cooperations.[20] This project lays the groundwork for the (continued) development of national Cancer Mission Hubs, as well as a strong European Network of these hubs. These hubs create awareness and organise activities for the benefit of the EBCP. The Dutch Cancer Mission Hub is embedded in the NKC.

The EU Beating Cancer Plan (EBCP)[1]

Topics	Flagships
Modernising the approach to cancer New technologies, research and innovation serving patient-centred cancer prevention and care • Stimulating change through knowledge and research • Optimal use of data and data digitization	1. Knowledge centre on cancer: coordination of scientific and technical initiatives 2. European imaging initiative
Saving lives through sustainable cancer prevention • Improved health literacy regarding cancer risks • Towards a tobacco-free Europe • Limiting alcohol consumption • Better health through access to healthy food and exercise • Less environmental pollution • Reduced exposure to hazardous substances and radiation • Prevention of infection-induced cancer	3. Eliminate cervical cancer and other HPV induced cancers
Improve early detection • Establish indicators to monitor and assess screening programmes • Screening is based on the latest and available scientific evidence	4. EU Cancer screening schemes focusing on access, quality and diagnostics
Commitment to high-quality cancer care • Improving the quality of care • Ensuring highly qualified professionals • Ensuring access to essential medicines and innovation • Building on personalised medicine for prevention, diagnosis and treatment	5. EU network of accredited nationally integrated cancer centres 6. Access to innovative diagnostics and treatment for all 7. Greater understanding of cancer development (ENCAN)
Improving quality of life for people living with or after cancer and their carers • Improving access to financial services • Improving return to work • Guideline on work-life balance for family carers	8. Initiatives to improve quality of life
Reducing cancer inequalities in the EU • Reducing inequalities in access to prevention and care in the EU • Strengthen and integrate telemedicine and remote monitoring	9. Cancer inequalities registry
Raising awareness of childhood cancer • Adding childhood cancer to European monitoring and research information system • Improve conditions for research and authorisation of new drugs	10. Initiative helping children with cancer

04

The 20 goals of the Netherlands Cancer Agenda

Preventing cancer

1 2 3 4 5 6

Early detection

7 **8**

Diagnostics, treatment, follow-up & palliative care

9 10 11 **12** 13 14

Quality of life

15 16 **17** 18 19 20

00 = Featured goal: on the website, the entire action plan for each featured goal can be found.

4.1 About the goals

In this chapter, we describe the 20 goals of the Netherlands Cancer Agenda. Each goal starts with some facts about the current situation. This is followed by what problem we want to solve, what causes characterise this problem and possible directions for solutions. We conclude each goal with an estimate of where we expect effects for individuals and the society. Because that is what we are doing it for. This estimate includes incidence, mortality, quality of care and quality of life.[18, 21]

All the NKA's goals can also be found on the website. Here you will also find an initial overview of relevant initiatives, reports and stakeholders for each goal.

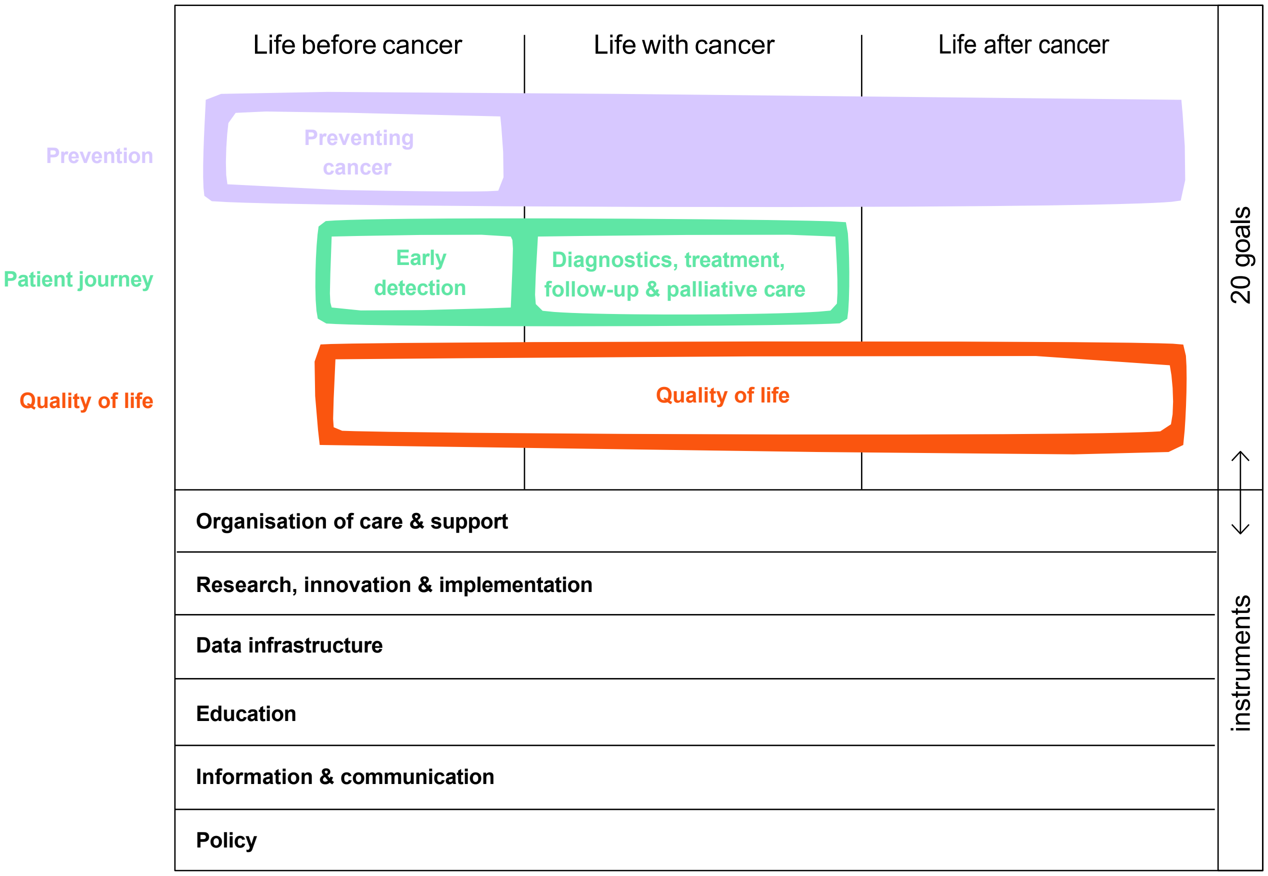
As a collective, we chose to highlight 5 goals: our featured goals. For these goals, we are now working on action plans. Elements of these plans are depicted in this chapter in the pragraphs titled 'what are possible directions for solutions?" On the website, the entire action plan can be found for each highlighted goal. This provides further details on who, what and when. Here, we also share news on the progress of these goals and relevant reports.

In the action plan, we distinguish six instruments: organisation of care and support; research, innovation and implementation; data infrastructure; education; information provision and communication; and policy.

We deploy these resources to realise the NKA's goals. Each goal requires specific activities on one or more resources. Therefore, each of the six resources contributes to several goals, thus creating crossroads where we will be able to attain synergy. All of this is schematically depicted in the framework below.

An example: data infrastructure problems which are well-known are the lack of interoperability of systems and insufficient standardisation. This leads to limited data sharing during the diagnostic, treatment and aftercare process and during the palliative stage. Action is needed in this area in order to achieve several goals of this agenda. And vice versa: multiple goals equally underline the importance of taking action on data infrastructure.

Conceptual framework NKA with instruments



4.2

Preventing cancer

Cancer is prevented by decreasing exposure to risk factors through lifestyle and environment.

Smoking behaviour 1 **Featured**

Alcohol consumption 2

UV radiation 3

Infectious diseases 4

Environmental and air pollution 5

Nutrition and exercise 6

Wanda de Kanter
Smoking Prevention Youth
"Avoidable, not culpable: if tobacco disappears from society, this will result in the greatest possible gain in overall mortality as well as cancer mortality"

Diena Halbertsma
Alliance Nutrition for the Healthy Generation
"We are constantly tempted to eat and drink unhealthy food. This is not good for us and certainly not for our children. Let's work on prevention!"

Bas Henzing
TNO
"Prevention is obviously better than cure, a targeted approach to particulate matter s needed that goes beyond EU and World Health Organisation concentration limits"

Arno Rutte
Steering group Skin Cancer Care Netherlands
"For prevention of skin cancer, there is an easily achievable course of action. We can prevent a lot of misery if we do this tackling together"

1

Featured

Smoking behaviour

By 2032, the number of smokers is reduced to 5% of adults and 0% of young people and pregnant women

Smoking refers to the use of tobacco and nicotine products, such as cigarettes and e-cigarettes.

Description of the current situation

- In 2023, 18% of young people (12 - 25 years) smoked cigarettes every month [22]
- In 2023, 10% of young people (12-25 years) smoked e-cigarettes monthly [22]
- In 2022, 19% of adults (aged 18+) smoked cigarettes [23]
- In 2022, 3% of adults (aged 18+) regularly smoked an e-cigarette [23]
- In 2021, 8% of pregnant women smoked at any time and 5% throughout pregnancy [24]
- In 2019, the percentage of smokers aged over 15 in the Netherlands was lower than in Europe [6]
- Among adults, smoking rates have dropped by about 1 percentage point a year since 2015 [23]
- 72% of Dutch people support a smoke-free country [25]
- 87% of Dutch people think measures should be taken in order for young people to not start smoking [25]
- Tobacco contributes to the development of 12 types of cancer, including throat, bladder and pancreatic cancer [26]
- Every year, 19,095 Dutch people get cancer from smoking [16]
- 86% of lung cancer cases are caused by smoking [27]
- 81% of lung cancer deaths can be attributed to smoking [28]

What do we want to change?

Smoking is harmful to health and nicotine has a strong addictive effect (mentally and physical). The ingredients in the product are so detrimental that - if launched nowadays - it would not be legal to sell.

There is public support for a significant decrease in the number of smokers. We are on our way to a smoke-free generation, thanks to the 'National Prevention Agreement' and the 'Healthy and Active Living Agreement'. Also thanks to the efforts of several organisations such as health funds, knowledge institutes and doctors' associations. And thanks to measures such as reducing points of sale and increasing excise duty. As a result, we are seeing changes, but more is needed.

Smoking is still the norm within certain groups. Also, smoking is still accepted in too many places. In addition, smoking-induced diseases contribute to bogging down healthcare.

Goal 1 continues on the next page

Political and economic interests delay action. Smoking is constantly subjected to delaying political discussions. With every new cabinet the debate on smoking is revisited. The commitment to a smoke-free generation depends on the cabinet's willingness to invest in it.

Therefore, we aim to depoliticize non-smoking. Harm to the individual, healthcare, and society must always be prevented and cannot be a matter of politics. Non-smoking should be the social norm and commitment to it a basic provision. This includes commitment to preventing people from starting smoking and help for smokers who have been made addicted in the past.

What are underlying causes?

- Availability and opportunity - Smoking is possible and accepted in too many places. Promotion and visibility are insufficiently restricted. Tobacco and nicotine products are still for sale in too many places
- Price - Tobacco and nicotine products are too affordable in the Netherlands
- Product development - The tobacco industry is always developing new products which - they suggest - are healthier than smoking, or that refrain smokers from 'real' smoking
- Power of the tobacco industry - The tobacco industry uses many means and tactics to influence politics and media in order to secure their economic interest
- Political discourse - Smoking is renegotiated at the start of every new cabinet. This causes major delays
- Smoking cessation - This does not get enough attention in the docter's office

How are we proceeding now?

- Setting up an up-to-date social harm index. This index reflects the harmfulness of smoking behavior and is used to change the norms surrounding smoking behavior
- Increasing social and political support. By continuing to share knowledge about harmfulness and making comparisons with other drugs that do not enter the market or are removed from the market due to harmfulness. Through this different framing, we further stimulate the social and political debate. In doing so, we pay specific attention to hard- to-reach (target) groups
- Strengthening the quit smoking infrastructure.We let tobacco and nicotine restrictions go hand in hand with stop smoking services. Both within healthcare and outside of it.
    - Regular, substantial price increases are the most effective measure to reduce smoking. Another option is a generational ban on the sale of tobacco and nicotine products.
    - It is crucial that smokers have access to low-threshold effective help during the process of quiting smoking.

What effects do we expect on individuals and society?

● **Incidence**

● **Mortality**

● **Quality of life**
- ● Physical health
- ○ Mental health
- ○ Degree of independence
- ○ Social relationships
- ○ Environment
- ○ Personal values and beliefs

○ **Quality of care**
- ○ Effectiveness
- ○ Safety
- ○ Patient-centredness
- ○ Timeliness
- ○ Efficiency
- ○ Equality of treatment

More on the sub-goals for smoking behaviour can be found in the action plans (Dutch only). The most recent versions can be found here on the website of the Nederlands Kanker Collectief

2

Alcohol consumption

By 2032, pregnant women and under-18s do not drink alcohol; among adults, 65% do not drink alcohol or no more than one glass a day

This goal is in line with the Health Council's advice "Don't drink alcohol or no more than one glass of alcohol per day." [29]

Description of the situation now

- 44% of adults adhere to Health Council advice [30]
- 67% are familiar with the Health Council guideline and 37% know that excessive alcohol consumption increases the risk of cancer [31]
- Alcohol can cause seven types of cancer: oral, pharyngeal, laryngeal, oesophageal, breast, liver and colon [32]
- Every year, 1,140 Dutch people get cancer caused by drinking alcohol [16]
- In 2021, an estimated 600 Dutch people died of cancer caused by drinking alcohol [33]
- Among the Dutch over the age of 15 less alcohol is drunk per year than the EU average.[6] The percentage of Dutch people drinking daily is equal to the EU average [34]

What do we want to change?

Alcohol use has individual and societal consequences. The (problematic) use of alcohol is strongly associated with an increased risk of multiple diseases, including various forms of cancer. Alcohol is also harmful to the growth and development of children and the foetus during pregnancy. As a society, we bear healthcare costs due to alcohol consumption. This is due to illness, as well as addiction and accidents. Therefore, we want to reduce or avoid alcohol consumption.

What are underlying causes?

- Causes of alcohol use include the addictive properties of alcohol, hereditary predisposition, mental influences (such as stress), attitudes towards alcohol and insufficient knowledge about alcohol
- At the level of society, social and cultural norms, availability of alcohol, marketing and advertising and limited enforcement come into play

What are possible directions for solutions?

- Banning or restricting advertising of alcohol
- Limiting outlets
- Introducing price measures
- Mandatory listing of product information and health information and warnings on labels of alcoholic beverages

Goal 2 continues on next page

- Not allowing alcohol in the environment of children and young people such as playgrounds, sports clubs and schools
- Targeted attention to achieve a change in cultural norms
- Targeted attention on alcohol use among pregnant women by healthcare professionals

What effects do we expect on individuals and society?

● **Incidence**

● **Mortality**

● **Quality of life**
  - ● Physical health
  - ○ Mental health
  - ○ Degree of independence
  - ○ Social relationships
  - ○ Environment
  - ○ Personal values and beliefs

○ **Quality of care**
  - ○ Effectiveness
  - ○ Safety
  - ○ Patient-centredness
  - ○ Timeliness
  - ○ Efficiency
  - ○ Equality of treatment

3

UV radiation

By 2032, the number of people applying safe sun behaviour advice will have increased by at least 15%

Advice on safe sun behaviour includes elements on avoiding sun, protective cloathes and using sunscreen.[35] The change in sun protection behaviour is measured relative to 2023 (baseline measurement has yet to take place).

Description of the situation now

- It is unknown to what extent Dutch people follow the safe sun behaviour guidelines. Results of the baseline measurement are expected by the end of 2023
- UV exposure and tanning beds are leading causes of skin cancer [36]
- More than 90% of skin cancer incidence is linked to UV radiation [37]
- Of all new cancer cases, 52% are skin cancers. This makes skin cancer the most common cancer in the Netherlands and has the fastest rising incidence [38]
- Every year, nearly 67,000 Dutch people develop skin cancer. The most common forms of skin cancer are basal cell carcinoma (BCC), squamous cell carcinoma (PCC) and melanoma. 48,000 of these cases involve BCC, 12,300 cases PCC and in 6,200 cases melanoma [36]
- In 25% of people with BCC and 10% of people with PCC, new skin tumours develop within three years of initial diagnosis [36]
- Every year, nearly 800 people die from melanoma and about 130 from other forms of skin cancer [39]

What do we want to change?

UV radiation can cause skin damage through burning and accumulation of sun exposure over a long period of time. This damage can cause skin cancer later in life.[40] This results in higher healthcare costs and has a negative impact on people's quality of life. Therefore, we want to encourage safe sun habits and reduce UV exposure.

What are underlying causes?

- Causes of unsafe sun and tanning behaviour include insufficient knowledge of the (long-term) dangers, insufficient awareness of one's own behaviour such as exposure during outdoor work and sports
- Insufficient knowledge of and/or access to protection options (shaded areas, clothing and sunblock)
- Aesthetic ideals and cultural norms

What are possible directions for solutions?

- Facilitate healthy sun behaviour by adapting the environment, e.g. by creating shaded areas and providing sunscreen

Goal 3 continues on the next page

- Gaining insights on existing solar behaviour by performing structural measurements
- Educating and training healthcare professionals
- Developing information material
- Developing public campaigns to increase knowledge about sunbathing and cancer
- Focusing on specific (high-risk) target groups: children up to 18 years and their parents, carers and teachers, outdoor athletes, outdoor workers and sunbed users

What effects do we expect on individuals and society?

● **Incidence**

● **Mortality**

● **Quality of life**
- ● Physical health
- ○ Mental health
- ○ Degree of independence
- ○ Social relationships
- ○ Environment
- ○ Personal values and beliefs

○ **Quality of care**
- ○ Effectiveness
- ○ Safety
- ○ Patient-centredness
- ○ Timeliness
- ○ Efficiency
- ○ Equality of treatment

4

Infectious diseases

By 2032, infections with the HPV virus, and other infectious diseases that can lead to cancer, are prevented as much as possible

This goal focuses on viruses and bacteria that have a direct relationship with cancer. There are also infectious diseases that affect the immune system and therefore increase the risk of cancer, such as HIV infections.

Description of the situation now

- Of all people, 80-90% become infected with HPV [38] one or more times in their lifetime.
- Infections with HPV can lead to cancer of the cervix, anus, vagina, penis, mouth and pharynx [41]
- Every year, 1,622 Dutch people get cancer from HPV [16]
- Infections with hepatitis B and C can lead to liver cancer. In 2021, 1,167 people were diagnosed with liver cancer and over 1,200 people died of liver cancer [42]
- Infections with Helicobacter pylori can lead to stomach cancer, in about 1 in 100 infected people. In 2021, over 1,100 people were diagnosed with stomach cancer and nearly 1,200 died of it [42, 43]

What do we want to change?

Infection with HPV, hepatitis B and C or Helicobacter pylori increases the risk of several diseases, including several cancers. Infection also affects sexual health. This puts pressure on healthcare costs and people's quality of life in society. That is why we want to prevent infection with a bacterium or virus as much as possible.

What are underlying causes?

- Causes of HPV virus infection include sexual contact, reduced immunity and lack of HPV vaccination due to unfamiliarity about HPV, religious beliefs, fear of side effects, distrust of vaccination or practical considerations
- Causes of hepatitis B and C infections include sexual contact, lack of hepatitis B vaccination in high-risk groups such as healthcare workers or lack of hepatitis B vaccination due to similar reasons as HPV vaccination
- Causes of Helicobacter pylori infections include oral-fecal transmission, improper food preparation and/or food storage

What are possible directions for solutions?

- Lowering the barrier to participation in the HPV vaccination programme for girls and boys in the year they turn 10. For example, through accessible locations and education of children and their parents
- Enable free HPV (catch-up) vaccinations and encourage risk groups to take part i (e.g. in cases of reduced resistance due to organ transplants)

Goal 4 continues on the next page

- Set up targeted campaigns to promote available free vaccinations for hepatitis B for specific target groups (immigrants, sex workers, care workers)
- Develop public education on transmission of HPV and hepatitis B and C through sexual contact
- Screening certain groups (including first-generation migrants) for hepatitis B and C

What effects do we expect on individuals and society?

● **Incidence**

● **Mortality**

● **Quality of life**
- ● Physical health
- ○ Mental health
- ○ Degree of independence
- ○ Social relationships
- ○ Environment
- ○ Personal values and beliefs

● **Quality of care**
- ○ Effectiveness
- ● Safety
- ○ Patient-centredness
- ○ Timeliness
- ○ Efficiency
- ○ Equality of treatment

5

Environmental and air pollution

By 2032, people are less exposed to environmental and air pollution

This goal focuses on air pollution because of its impact on society as a whole. The ambition is to reduce exposure to air pollution by reducing particulate matter, measured as PM$_{2,5}$ by 44%.[44] At a later stage other forms of environmental pollution, such as PFAS, asbestos, benzene and microplastics, may be included.

Description of the situation now

- The average exposure index of PM$_{2.5}$ is 8,9 µg/m^3. This is below the European standard of 20 µg/m^3 en below the European target value of 14,4 µg/m^3 [45]
- WHO's annual average advisory value (5 µg/m^3 for PM$_{2.5}$) is exceeded throughout the country [45]
- In the Netherlands, 18% of lung cancer cases are caused by PM$_{2.5}$ [16]

What do we want to change?

Exposure to air pollution increases the risk of multiple diseases, including several forms of cancer. This puts pressure on healthcare costs and people's quality of life. The limited individual influence on the causes of air pollution causes great unease among people and in society. Therefore, we want to reduce air pollution and exposure to it.

What are underlying causes?

Exposure to PM$_{2.5}$ occurs in several places:

- Indoor spaces, e.g. due to poor ventilation
- During work, e.g. due to emissions from machinery
- Outdoor air, e.g. emissions from industry, agriculture and traffic

What are possible solution directions?

- Implementing the commitments in the 'Clean Air Agreement'
- Expand Clean Air Agreement partners, including municipalities
- Reduce emissions from polluting sectors (aviation, agriculture, industry, inland navigation and ports, restaurants, traffic) through, for example, sustainability, better use of available techniques and regulations on emission requirements
- Reducing wood burning through education, appropriate regulation and enforcement
- Specific focus on highly exposed areas and high-risk (occupational) groups
- Mapping air quality: where, when and from which sources

Goal 5 continues on the next page

- Gaining insight into where and how many people have been exposed to polluted air by linking anonymised mobile data to air quality data
- Deploy sensors for real-time measurements to alert people when limit values are exceeded
- Using the above insights to take targeted action
- Determining the health relevance of a particulate mixture, e.g. through determining chemical reactivity and oxidative potential

What effects do we expect on individuals and society?

● **Incidence**

● **Mortality**

● **Quality of life**
- ● Physical health
- ● Mental health
- ○ Degree of independence
- ○ Social relationships
- ● Environment
- ○ Personal values and beliefs

○ **Quality of care**
- ○ Effectiveness
- ○ Safety
- ○ Patient-centredness
- ○ Timeliness
- ○ Efficiency
- ○ Equality of treatment

6

Nutrition and exercise

By 2032, people eat healthier and exercise enough

The 'Health Council's' good nutrition guidelines form the basis for a healthy diet. These include eating fruit and vegetables and reducing processed and/or red meat.[29] The Health Council's exercise guidelines indicate what constitutes sufficient exercise. This includes intensive exercise and muscle and bone-strengthening activities.[46]

Description of the situation now

- The number of adults following the good nutrition guidelines varies between 10 and 50% depending on the product group. Almost 30% of adults eat enough vegetables and almost 20% eat enough fruit [47]
- Adults eat an average of 483 grams of red and/or processed meat per week. The 'Nutrition Centre' recommends a maximum of 500 grams of meat per week, of which a maximum of 300 grams should be red meat [47]
- Of all Dutch people, 44% meet the exercise guideline [48]
- Half of Dutch people aged 18 or over are overweight [49]
- Healthy diet and adequate exercise reduces the risk of developing cancer, including breast and colon cancer [46, 50]
- Every year, 6,452 cancer cases can be attributed to unhealthy diet. Too little fruit and vegetables contribute the most, followed by too little dietary fibre and too much processed meat [16]
- Annually, 4,995 cancer cases are attributable to obesity and 2,228 to insufficient exercise [16]
- Compared to other European countries, the Dutch eat less fruit and vegetables. However, more people do exercise every day [6]

What do we want to change?

An unhealthy diet and insufficient exercise are related to an increased risk of various diseases, including several forms of cancer. In addition, unhealthy eating and insufficient exercise can lead to energy imbalance, which increases the risk of obesity increased. Being overweight leads to metabolic dysregulation and poses an additional risk of developing cancer.[51] Therefore, we aim for people to eat healthier and exercise more, according to the Health Council's good nutrition and exercise guidelines.

What are underlying causes?

Causes of unhealthy diet and insufficient exercise are:

- Insufficient awareness and knowledge, insufficient financial resources, cultural and social influences and mental influences such as stress

Goal 6 continues on the next page

- Unhealthy environment, e.g. high availability and accessibility of unhealthy food, its promotion with pricing and marketing techniques and limited exercise facilities

What are possible directions for solution?

Nutrition

- Improve availability and accessibility of healthy food, e.g. through pricing measures, water points in public places and substantially increasing the share of healthy products in supermarkets, educational institutions and sports canteens
- Reduce availability and accessibility of unhealthy food, e.g. through pricing measures, visibility and placement of products and reduction of outlets
- Improve food compositions by reducing calories, sugar, salt and saturated fats in products and reducing portion sizes
- Simplify product information on food labels
- Reducing marketing for unhealthy food, especially to children
- Conduct public campaigns on healthy eating and obesity and focus on nutrition in schools

Movement

- Setting up an exercise-friendly living environment, e.g. through cycle paths and greenery in the neighbourhood
- Lowering the threshold for use of exercise and sports offers, e.g. through free membership of sports clubs
- Launch campaigns on exercise and obesity and focus on exercise in schools and workplaces

What effects do we expect on individuals and society?

● **Incidence**

● **Mortality**

● **Quality of life**
- ● Physical health
- ● Mental health
- ○ Degree of independence
- ○ Social relationships
- ○ Environment
- ○ Personal values and beliefs

○ **Quality of care**
- ○ Effectiveness
- ○ Safety
- ○ Patient-centredness
- ○ Timeliness
- ○ Efficiency
- ○ Equality of treatment

4.3

Early detection

Cancer is detected early where possible, making treatment more effective and less stressful.

Hereditary load
7

Early detection
8
Featured

Kim Hulscher
Olive Foundation
"Both prevention and participating in population screening can save someone a lot of misery. There is a need to prevent cervical cancer and the long-term consequences of it"

Hereditary predisposition

By 2032, people who may have a hereditary predisposition can make informed choices for hereditary testing

How is the situation now?

- 5% of all cancers are due to hereditary predisposition, including pancreatic, colon, bladder, breast, prostate, ovarian and stomach cancers [52]
- A hereditary test usually consists of a referral to a clinical geneticist, collection of family data and DNA testing [53]

What do we want to change?

Hereditary research contributes to knowledge of whether cancer is caused by an inherited mutation. This enables tailored treatment and follow-up. For people, it is important to know whether they have an inherited mutation. If so, preventive approaches can be considered, such as checkups to detect cancer at a preliminary or early stage or surgery. Therefore, it is important that healthy people with an inherited mutation are detected. So they are informed in a timely and accessible way about the possibilities of hereditary testing to make an informed choice.

What are underlying causes?

- A lack of knowledge and awareness about hereditary testing among people with cancer, their families and healthcare professionals
- Low health literacy
- Mental, cultural and social influences such as fear of the consequences of hereditary predisposition
- Limitations in the healthcare system such as privacy issues, financial barriers and insufficient referrals

What are possible solution directions?

- Promote accessibility of clinical genetic care through commitment to more requests for DNA testing by non-clinical geneticists (mainstreaming)
- Creating appropriate privacy policies
- Inclusion of preventive measures for people with hereditary predisposition in specialist medical guidelines
- Setting up centres of expertise for professional guidance on preventive measures for people with hereditary predisposition

Goal 7 continues on the next page

- Providing a free initial appointment with a clinical geneticist or other physician for people with limited financial resources
- Setting up training programmes for (healthcare) professionals on heredity and communication on the subject with different target groups
- Investigate the psychosocial and social consequences of having knowledge about hereditary predisposition for this group of people, their family members and relatives

What effects do we expect on individuals and society?

○ **Incidence**

● **Mortality**

● **Quality of life**
- ● Physical health
- ● Mental health
- ○ Degree of independence
- ○ Social relationships
- ○ Environment
- ● Personal values and beliefs

● **Quality of care**
- ● Effectiveness
- ○ Safety
- ● Patient-centredness
- ● Timeliness
- ○ Efficiency
- ● Equality of treatment

8 **Featured**

Early detection

By 2032, disadvantages and barriers to participating in early cancer detection are reduced

This goal focuses on early detection by means of population screening. These are systematically offered in the Netherlands for breast, cervical and colon cancer. Self-examination is also a form of early detection. Future developments and innovations within early detection - such as opportunities to detect cancer in blood or urine - may give cause to adapt the current form of population screening.

Description of the current situation

- Participation in population screening in 2022 was 68% for colon cancer and 71% for breast cancer. For cervical cancer, participation rises from 46% after one year to around 65% after five years. The total number of people participating in population screening is declining slightly anually [55-57]
- Participation in population screening for colorectal cancer and breast cancer is above the European average in the Netherlands. Participation in the population screening for cervical cancer is below the European average [6]
- Of all people participating in population screening in 2022, 1.2% were diagnosed with (a preliminary stage of) colon cancer, 0.8% with breast cancer and 1.1% with (a preliminary stage of) cervical cancer [58]
- Population screening aims to prevent or detect cancer early. For colon cancer, the number of new diagnoses has been decreasing every year since 2016.[59] In cervical cancer, the number of new diagnoses has been increasing since 2015 - just before the introduction of primary HPV screening. Despite the increase, mortality decreased [60] For breast cancer, the risk of mortality is reduced by half if someone has participated in population screening [61]

What do we want to change?

Population cancer screening is of a high standard in the Netherlands and leading in Europe and beyond. But what is good, can be even better. This includes participation, disadvantages in execution and lead time of research and innovation.

- Participation in population screening is declining. Non-participation is not problematic, if preceded by a well-informed choice. It is known that not all target groups are reached equally well. For instance, participation is lower among people in lower income groups and those with a non-Dutch cultural background.[59, 62] To better reach the target group, it is important to remove existing barriers to participation as much as possible.
- Conducting population screening also comes with drawbacks. Examples include mental and/or physical strain on participants. For example, due to the testing method used, falsely positive and falsely negative test results or overdiagnosis and overtreatment in cases where cancer is found but would not have

Goal 8 continues on the next page

resulted in symptoms. Population screening also contributes to the burden on the healthcare system and the environment. By reducing disadvantages of participating in early detection, the burden on people, the healthcare system and the environment is avoided wherever possible.

- The Netherlands has a good position in Europe in the field of early cancer detection. Maintaining this position in the future requires attention to the speed with which the value of new and innovative methods and techniques is assessed and implemented. Connecting population screening to follow-up testing after a positive test also requires attention.

What are underlying causes?

Below are some causes that provide a starting point for change.

- The choice to participate in population screening can be influenced by a wide range of factors. Examples include insufficient or incorrect knowledge, low literacy, distrust, fear and cultural beliefs
- Population screening is currently designed uniformly, with people being invited based on age and/or gender. However, there are other factors hat can help determine cancer risk. Examples include previous test results, biological, genetic and lifestyle factors
- The method used in population screening can lead to strain due to fear, pain or shame [62]
- To ensure the quality of population screening high standards of evidence are set. This extends the time between research and implementation
- The infrastructure and capacity to do research with data from population screening is limited. This increases the lead time of studies. Also, using data from population screening is difficult because participants are not yet explicitly asked for consent

How are we proceeding now?

There are several initiatives in the Netherlands which aim to make existing population screening even more effective and further develop early detection. One such initiative is the development agenda for the population screening programmes that 'RIVM' is working on, together with relevant parties. This population screening development agenda is expected to address several of the above points.

The activities below are complementary to the population screening development agenda:

- Reaching specific target groups better and supporting in informing about risk-based screening. Thus, existing public education can be extended to these target groups.
- Co-funding scientific research and infrastructure that align with the realisation of risk-based applications within the development agenda
- Improving accessibility of existing data from population screening
- Providing input for the design of relevant laws and regulations, such as Wbo and AVG

What effects do we expect on individuals and society?

● **Incidence**

● **Mortality**

● **Quality of life**
- ● Physical health
- ○ Mental health
- ○ Degree of independence
- ○ Social relationships
- ○ Environment
- ○ Personal values and beliefs

● **Quality of care**
- ● Effectiveness
- ○ Safety
- ○ Patient-centredness
- ● Timeliness
- ○ Efficiency
- ● Equality of treatment

More on the sub-goals for early detection can be found in the action plans (Dutch only). The most recent versions can be found here on the website of the Nederlands Kanker Collectief

4.4

Diagnosis, treatment, follow-up & palliative care

Care according to the latest insights for all people with cancer improves survival rates and quality of life.

Diagnostics	Treatment	Innovations	**Rare cancers**	Palliative care	Lifestyle support
9	10	11	**12** **Featured**	13	14

Hans Nijman
Quartermaster cancer network and expert care
"The challenges we face in healthcare require courage, leadership and creativity from all of us"

Mara van Stiphout
Knowledge Centre for Pediatric Palliative Care
"By 2032, all children with incurable cancer will have an Individual Care Plan (IZP) to record all agreements and wishes around care, treatment and quality of life and dying "

Sophia Sleeman
Patient Advocate
"Starting from the diagnosis, we need to focus on who someone is as a person. What is important to that person? When we postpone addressing this until aftercare, many people will keep ending up in a dark place after treatment."

Warnyta Minnaard
Mission Tumour Unknown & World CUP Alliance
"Precision oncology offers hope and opportunities for more cancer patients, therefore I find it inspiring and important that this is also reflected within the Netherlands Cancer Agenda"

Baukje van den Heuvel
Fit4Surgery
"Lifestyle has an important role in the onset, progression and treatment outcomes of cancer. Improving health should be an integral part of any cancer treatment"

Eveliene Manten
AYA Care Network
"No tumour care without person-centred patient care"

Mariët Bouwmeester
Platform Rare Cancers
"Where I am 5 years after being diagnosed with a rare form of cancer?
I'm still searching, wandering or sitting in a waiting room. Thankfully not dead yet. Many people with rare cancers are not that lucky after 5 years"

9

Diagnostics

By 2032, people with cancer will have a personalised diagnosis (more) quickly with minimal burden

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Description of the situation now

- In 1989, nearly 56,000 cancer diagnoses were made. In 2019, there were 118,000 and by 2032, this will be around 156,000 new diagnoses [5]
- The median duration between GP visit with first cancer symptoms and hospital referral is one day for breast cancer, 8 days for colorectal cancer, 13 days for lung cancer, 14 days for prostate cancer and 8,5 days for melanoma [63]
- The median time between referral to hospital and diagnosis for breast cancer is 6 days, for colon cancer 26 days, for lung cancer 21 days, for prostate cancer 51 days and for melanoma 20 days [63]
- The SONCOS standard states that the time between the first outpatient visit and diagnosis is a maximum of three weeks [64]
- Every month of delay in cancer treatment results in a 6-13% higher risk of mortality [65]

What do we want to change?

We want to make the right diagnosis as soon as possible so that appropriate treatment can be started quickly. This takes into account the wishes, values and preferences of people with cancer. Currently, there are differences in outcomes and lead times of diagnostic processes between hospitals. Data on these are not available for all tumour types. The use of molecular diagnostics has proven added value for certain patient groups, for example for Primary Tumour Unknown (PTO) and rare cancers. This is not known for all other patient groups. Molecular diagnostics are also not offered in all hospitals. The use of technology and innovations can make the diagnostic pathway more efficient. This potential is currently insufficiently exploited.

What are underlying causes?

(Please also check the paragraph on resources in section 4.1)

- There are national diagnostic protocols. Their use is not mandatory and a protocol is not available for every tumour type.[66] This creates differences in diagnoses made
- Molecular diagnostics are of limited availability, partly due to cost and expertise required
- Currently there is insufficient understanding of efficiency and outcomes of molecular diagnostics [67]

Goal 9 continues on the next page

- A proportion of people do not recognise early symptoms sufficiently or too late and/or go to their GP with general complaints [63]

What are possible directions for solutions?

- Conduct research into the causes of variation in lead times and outcomes of diagnostic processes between GPs and hospitals and between hospitals themselves
- Making expert care in complex diagnostics available and accessible
- Coordinate (comprehensive) molecular diagnostics to improve lead time and accuracy of diagnosis. And in doing so, giving an impulse to the further development and implementation of new techniques, in line with the quality standard 'organisation of molecular diagnostics' [68]
- Investigate for which specific patient groups molecular diagnostics have proven added value [67]
- Further develop national diagnostic protocols for all tumours and mandate the use of (existing) protocols
- Develop AI applications and imaging techniques for proper diagnosis and prognosis

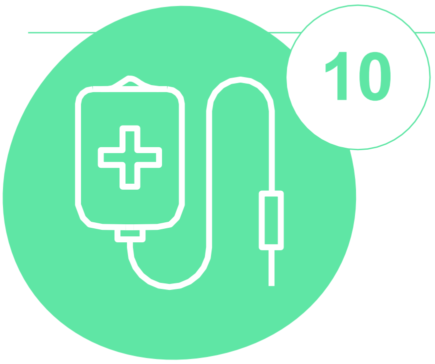
What effects do we expect on individuals and society?

○ **Incidence**

● **Mortality**

● **Quality of life**
  ○ Physical health
  ○ Mental health
  ○ Degree of independence
  ○ Social relationships
  ○ Environment
  ● Personal values and beliefs

● **Quality of care**
  ● Effectiveness
  ○ Safety
  ● Patient-centredness
  ● Timeliness
  ● Efficiency
  ● Equality of treatment



Treatment

By 2032, people with cancer will have access to the best possible personalised treatment with minimal burden

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Description of the current situation

- Overall 5-year survival in the Netherlands has increased from 43% (1990) to 66% (2022). Differences between cancer types are large [7, 69]
- The 5-year survival rate for children with cancer is currently 83% [70]
- The time between the first outpatient visit and the start of treatment is maximum 6 weeks and set in the SONCOS standardisation. Each month of delay in cancer treatment results in a 6-13% higher risk of mortality [65]
- With 15% of people with or after cancer, the GP discussed what he/she considers important in life and what impact treatment may have on it [71]
- About half of healthcare professionals say they make decisions together with the person with cancer, while only 37% of these people say they actually experience this [72]
- 34% of people who died of cancer experienced potential overtreatment. For young adults, this percentage is around 39 % [73]
- Practice variation can be seen between hospitals.[74] These include differences in treatments, treatment combinations and prescription behaviour [75]

What do we want to change?

We want the most appropriate treatment at the right time for everyone with cancer. The outcome of treatment should not be influenced by where it takes place.[75] Over- and undertreatment should be prevented. And quality of life should be given a more prominent place in any treatment. The wishes and preferences of people with cancer should be leading in making treatment decisions. Providing people with cancer and their loved ones with information they can understand is essential for this.

What are underlying causes?

(See also the paragraph on resources in section 4.1)

- Treatments are sometimes insufficiently tailored to specific target groups. For example, children and AYAs have different needs than adults and tumour characteristics may be different [73, 76]
- In research, certain groups are underrepresented, including women, people from non-Western backgrounds and the elderly.[77-79] As a result, treatments are less well-suited to these groups and less effective

Goal 10 continues on the next page

- Which precision treatment under which conditions is most effective for a specific person is not always clear. These treatments are costly and not available to all people with cancer[80]
- There is insufficient knowledge about practice variation and the impact of practice variation on people with cancer
- Deciding together on treatment options is not always applied in practice
- The consequences of treatment are not always discussed, while this can affect the treatment preferences of people with cancer[71, 72]

What are possible directions for solutions?

- Creating a treatment plan that takes into account personal values and needs for all people with cancer
- Deciding together in all treatments and taking time-outs in the care pathway so that a person goes through treatment better informed and loved ones are appropriately involved
- Setting up the multidisciplinary consultation from a broad perspective with attention to co-morbidity, the long-term impact of treatment and the wishes of people with cancer
- Commitment to expert care, concentration and distribution of care
- Making hospitals' specific expertise accessible to all
- Investigating and understanding needs of specific target groups and implementing specific interventions for these target groups
- Monitoring the effect of treatments through real-world evidence based on real-world data and using this data for broad research into the effectiveness of treatments
- Development and application of prediction models for determining appropriate treatment and impact on quality of life
- Evaluate treatment using Patient Reported Outcome Measures, including the impact of over- and under-treatment

What effects do we expect on individuals and society?

○ **Incidence**

● **Mortality**

● **Quality of life**
- ● Physical health
- ● Mental health
- ○ Degree of independence
- ○ Social relationships
- ○ Environment
- ● Personal values and beliefs

● **Quality of care**
- ● Effectiveness
- ● Safety
- ● Patient-centredness
- ● Timeliness
- ● Efficiency
- ● Equality of treatment

11

Innovations

By 2032, innovative and effective diagnostic and treatment methods are more readily available

This goal is about market access and reimbursement of innovative and effective diagnostic and treatment methods.

Description of the situation now

- Many new cancer diagnostic and treatment methods have entered the European market in recent years and many more are set to follow in the coming years [81]
- About 1 in 5 European-approved drugs is placed in the so-called lock in the Netherlands for market access. The majority involve oncology drugs [82-84]
- Following approval of innovative cancer treatments on the European market, they are reimbursed in the Netherlands after 234 days on average. However, a big difference can be seen between treatments. The timeframe can also go up to around 700 days [85]
- A systematic review of authorisation of new oncology treatment methods by the European Medicines Agency on the European market found that for 39 of 68 (57%) methods, there was no evidence of improved survival or quality at the time of authorisation of life. At least 3.3 years after market authorisation, this evidence was still not there for 33 out of 39 methods [86]

What do we want to change?

Compared to other European countries, it takes a relatively long time in the Netherlands for innovative and effective diagnostic and treatment methods to become widely accessible to people with cancer.[85] Not all innovative treatment methods that are admitted to the European market and reimbursed in the Netherlands actually prove effective. [86] The long time to market and lack of effectiveness can lead to negative effects for people with cancer, such as lower survival rates and/or lower quality of life. It is therefore important that new diagnostic and treatment methods become available and effective as soon as possible.

What are underlying causes?

- European countries have different evidence requirements for authorisation of new diagnostic or treatment methods. Also, the criteria countries use for the cost-effectiveness of these methods are unclear and ambiguous. Market access may take longer as a result [85]

Goal 12 continues on the next page

- Determining reimbursements for new diagnostic and treatment methods in the Netherlands can be a lengthy process
- After national approval on reimbursement, each hospital still makes its own arrangements on this with insurers. These negotiations also take time [85]

What are possible directions for solutions?

- Improved European and/or international cooperation on development, authorisation and procurement of innovative and effective diagnostic and treatment methods
- Reviewing assessment criteria and prices of innovative and effective diagnostic and treatment methods and making them more transparent
- Better public-private cooperation during the development and research phases of innovative diagnostic and treatment methods to achieve faster market access
- Increasing awareness of the importance of phase 4 studies, including appropriate access arrangements. As sometimes small patient groups are included in phase 3 studies, phase 4 studies give a more realistic picture of the effectiveness of the method
- Increased use of real-world data in trials and in practice for evidence generation

What effects do we expect on individuals and society?

○ **Incidence**

○ **Mortality**

○ **Quality of life**
  ○ Physical health
  ○ Mental health
  ○ Degree of independence
  ○ Social relationships
  ○ Environment
  ○ Personal values and beliefs

● **Quality of care**
  ● Effectiveness
  ○ Safety
  ○ Patient-centredness
  ● Timeliness
  ● Efficiency
  ○ Equality of treatment

12

Featured

Rare cancers

By 2032, survival of people with or after a rare form of cancer has improved

A cancer type is rare when there are fewer than six diagnoses per 100,000 people annually.[87] For each rare cancer type, this equates to a maximum of 1,000 new diagnoses per year in the Netherlands. This covers solid and non-solid tumours.[88]

Description of the situation now

- 1 in 5 new cancer diagnoses involves a rare cancer. Rare cancer as a group is therefore not rare [88]
- Every year, more than 20,000 Dutch people are diagnosed with a rare form of cancer [89]
- On average, a GP sees less than three new people with a rare form of cancer each year [88]
- Over the period from 1995-1999 to 2015-2019, the 5-year survival of rare solid cancers increased from 46% to 53%. In the same period, the 5-year survival of non-rare solid cancers increased from 57% to 70% [90]
- People with a rare form of cancer are more likely to experience a lower quality of life than those with a non-rare form of cancer [89]

What do we want to change?

The rare nature hampers the timely and correct recognition of these cancers. This causes a delay in making the (correct) diagnosis. Delayed diagnosis can have adverse effects on the stage of the tumour and the timely initiation of treatment, and thus increase the risk of mortality.[65] People with rare cancers with recurrence and/or metastases do not have access to comprehensive molecular diagnostics, including Whole Genome Sequencing (WGS). There are also too few (evidence-based) treatments available for people with rare cancers. There is relatively little research into new treatment methods, compared with non-rare cancers. Much of the data on rare cancers is hereby collected in different silos, both within and between countries. This hinders development of new treatment methods.

The organisation of expert care - from (pre-)diagnosis and treatment to aftercare or palliative care is not well regulated. As a result, people with are cancers do not have sufficient access to expert care.[89] There is also relatively little awareness of the issues surrounding the care of people with rare cancers.

To bring more perspective to people with rare cancers, it is important to increase (international) cooperation, doing more research, improving the organisation of care, increase access to diagnostics and treatments and raise awareness of rare cancers.

Goal 12 continues on the next page

What are underlying causes?

- Delays in the diagnostic pathway are caused by insufficient awareness among people with cancer and healthcare professionals, a lack of knowledge and insufficient use of and referrals to centres of expertise
- There is low evidence on the impact of comprehensive molecular diagnostics; meeting the assessment framework 'current state of science and practice' is not feasible for rare cancers
- There is still too little awareness among people with cancer and healthcare professionals about the added value of comprehensive molecular diagnostics, including WGS, for guidance to targeted treatment in rare cancers
- There is a lack of prioritisation in time and money from private and public parties to invest in rare cancer research due to the low numbers characteristic for this group. As a result, there are fewer treatment options for rare cancers and too few (new) treatments are added
- There is a limited amount of (approved or candidate) drugs that are registered for rare cancers whilst originally being indicated for more common cancers (drug repurposing)
- Doing scientific research with small populations is difficult, so trials do not get off to a good start
- Direction around centres of expertise is lacking, resulting in poor alignment of existing initiatives - multidisciplinary working groups, SONCOS, regional networks, European reference networks, centres of expertise for rare diseases (ECZA)
- Existing agreements around expert and network care are too 'non-binding'. As a result, people are not treated in the right hospital and/or are treated without involvement from a centre of expertise. Agreements, including future agreements on volume standards, are not binding
- Knowledge about specific problems faced by people with rare cancers is limited. For example, when it comes to unmet needs and quality of life
- There is insufficient structured data available on diagnosis, treatment and quality of life of people with rare cancers
- Opportunities to make connections and collaborate on research and initiatives on a European level are still underused
- It is insufficiently known that people with a rare form of cancer account for a fifth of all people with cancer and that survival of this group is lagging behind

How are we proceeding now?

10 sub-goals have been formulated with a focus on solid rare cancers. The next step will include a focus on non-solid rare cancers.

- There is an understanding of the causes and consequences of delays in the diagnostic pathway of people with rare cancers and an approach has been developed to speed this up
- Uniform and comprehensive molecular diagnostics are deployed for all people with rare cancers
- There is faster authorisation of and better access to (new) drugs for all people with rare cancers
- Expert care is available throughout the care pathway for all people with rare cancer, by embedding it in visible and functioning networks
- There is an understanding of the conditions for optimal diagnosis and treatment for people with rare cancers, contributing to appropriate care
- There is an understanding of how we can translate breakthroughs and improvements in the care of common cancers into the care of rare cancers
- There is an understanding of the support needed by people with rare cancers and their loved ones regarding unmet needs and quality of life throughout the patient journey
- There is an understanding of how we can maximise learning from people with rare cancers, partly through the use of innovative research designs and structurally collected prospective data. Where possible and necessary, we collaborate in a European context
- We can learn from every person with rare cancer by including molecular, clinical and quality-of-life data in 'linkable' databases (both national and international)
- Urgency to improve care for people with rare cancers is widely supported

Goal 12 continues on the next page

What effects do we expect on individuals and society?

○ **Incidence**

● **Mortality**

● **Quality of life**
- ● Physical health
- ● Mental health
- ○ Degree of independence
- ○ Social relationships
- ○ Environment
- ○ Personal values and beliefs

● **Quality of care**
- ● Effectiveness
- ● Safety
- ● Patient-centredness
- ● Timeliness
- ● Efficiency
- ● Equality of treatment

More on the sub-goals for rare cancers can be found in the action plans (Dutch only). The most recent versions can be found here on the website of the Nederlands Kanker Collectief

13

Palliative care

By 2032, people with incurable cancer will receive proactive palliative care and support based on their values, wishes and needs

The palliative phase starts the moment healing is no longer possible.

Description of the situation now

- More than 38,000 people are diagnosed with metastatic cancer every year [91]
- More than half of people with metastatic cancer experience clinically relevant high symptom burden of pain, tightness and fatigue in the last three months of life (eQuiPe study)
- 62% of people with incurable cancer feel the need to talk about their end-of-life [93]
- A study of 43,067 people with cancer found that 34% received potentially 'non-appropriate care' in the last phase of life [94]
- People with cancer who receive timely palliative care are five times less at risk of receiving potentially non-appropriate care than people with cancer who receive no palliative care or only in the last 30 days of their lives [94]

What do we want to change?

Stopping cancer treatment and accepting that life is finite is difficult for most people with cancer and loved ones. Death is often still a taboo. Many people find it difficult to talk about the end of their life with others. Partly as a result, healthcare professionals are not always aware of the values, wishes and needs of people in the palliative phase and their loved ones. As a result, different choices are made than subsequently appeared to be desirable. Thereby, care training is more focused on cure and treatment. It is vital to provide proactive palliative care and support based on personal preferences to people with incurable cancer. This ensures that they can live and die with dignity.

What are underlying causes?

- No proper handover of the agreements made regarding personal wishes and needs of the person with cancer and his/her relatives between 'primary and secondary care' [95]
- No proper handover and cooperation between formal care, informal care and the social domain
- Transmural palliative care is currently not sufficiently facilitated by funding and laws and regulations. The main goal is to ensure continuity of care for the person with cancer and his/her loved ones and in his/her preferred location

Goal 12 continues on the next page

- There is a delicate balance between stopping life-extending treatment and entering the palliative phase. This requires expertise.[96] Not all (healthcare) professionals have this expertise, as palliative care is not structurally embedded in training courses

What are possible directionsfor solutions?

- More commitment to proactive care planning according to the guideline.[97-99] So that more people receive more approppriate care in the last phase of life [94, 100-103]
- Facilitate transfer between 'second and first line care' and between 'first line and informal care', e.g. by establishing a transmural multidisciplinary consultation
- Embedding palliative care in (transmural) care pathways
- Integrate palliative care into the basic education of healthcare professionals and provide continuing education pathways for current healthcare professionals
- Organising a nationwide range of support (physical, psychological, social and spiritual) for people in the palliative phase and their loved ones [54]
- Visibility of available regional informal care provision and its value
- Providing reliable information on quality of care and life in the palliative phase of cancer
- Breaking the taboo and creating space to talk to each other about being incurably ill and dying with dignity, fitting cultural values, wishes and needs

What effects do we expect on individuals and society?

○ **Incidence**

○ **Mortality**

● **Quality of life**
- ○ Physical health
- ○ Mental health
- ○ Degree of independence
- ○ Social relationships
- ● Environment
- ● Personal values and beliefs

● **Quality of care**
- ● Effectiveness
- ○ Safety
- ● Patient-centredness
- ● Timeliness
- ○ Efficiency
- ○ Equality of treatment

14

Lifestyle support

By 2032, people with or after cancer are supported to maintain or acquire a healthy(er) lifestyle

This goal focuses on care-related prevention during the diagnostic, treatment, aftercare and palliative stages.

Description of the current situation

- Among people living with or after cancer, 11% smoke and 51% of women and 76% of men drink alcohol. In the general population, more people smoke and drink [8]
- 30-50% of all cancer patients experience malnutrition [104]
- Healthy diet reduces the risk of developing or recurring colon cancer. Only 36% of people who have had colon cancer change diet [50]
- A healthy lifestyle helps reduce the chances of cancer coming back [105, 106]
- Prehabilitation programmes can reduce complications by 40-50% and achieve a reduction of two bed days after surgery [107-107]

What do we want to change?

An unhealthy lifestyle has a negative impact on treatment outcome, recurrence risk and quality of life for people with or after cancer.[110-112] An unhealthy lifestyle also has negative social consequences, such as higher healthcare costs and a reduction in work capacity. Adapting lifestyle is complicated for many people. This is where they need help. This help is now insufficiently available during the diagnostic, treatment, aftercare and palliative care process.

What are underlying causes?

- A healthy lifestyle is not a regular part of treatment for people with or after cancer [98]
- Due to lack of evidence of the effectiveness of lifestyle interventions on cancer treatment, they are usually not funded [98]
- Healthcare professionals sometimes lack the knowledge to assist people in healthy lifestyle support. For example, healthcare professionals are not always aware of effective lifestyle programmes and lifestyle support offerings
- Cooperation between (healthcare) professionals in the field of lifestyle support is sometimes difficult, partly due to a lack of clarity about the division of roles

What are possible directions for solutions?

- Discuss the topic of lifestyle during treatment, focusing on seeking appropriate lifestyle programmes and promoting and supporting self-care

Goal 14 continues on the next page

Lifestyle support

- Including lifestyle advice in medical specialist guidelines and care pathways and in the individual (after)care plan
- Educating (healthcare) professionals on the importance of healthy lifestyles and their role in it
- Clarifying the division of roles between (healthcare) professionals in 'first, second and third line' in the field of lifestyle support, to improve cooperation
- Realise cross-domain reimbursements for lifestyle programmes and interventions
- Researching the effects of healthy lifestyles and using the results to implement effective lifestyle interventions
- Implement prehabilitation programmes prior to surgery and major systemic therapies in high-risk groups

What effects do we expect on individuals and society?

● **Incidence**

○ **Mortality**

● **Quality of life**
- ● Physical health
- ● Mental health
- ○ Degree of independence
- ○ Social relationships
- ○ Environment
- ○ Personal values and beliefs

● **Quality of care**
- ● Effectiveness
- ○ Safety
- ○ Patient-centredness
- ○ Timeliness
- ○ Efficiency
- ○ Equality of treatment

4.5

Quality of life

Everyone living with or after cancer and their loved ones experience optimal quality of life and can continue to participate in society.

(Late) consequences
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Education and cancer
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Work and cancer
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Financial implications
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Relatives and informal care
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Social-emotional support
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Jourik Gietema
Cancer Surivorship Care Taskforce
"When designing oncological treatment, possible late or long-term effects should be part of the discussion of the treatment plan - which is jointly decided on with the patient"

Anneke Eikelenboom
Youth and Cancer Foundation
"Everyone who is diagnosed with cancer should have the opportunity to pursue an education suited to his/her capabilities and coping ability"

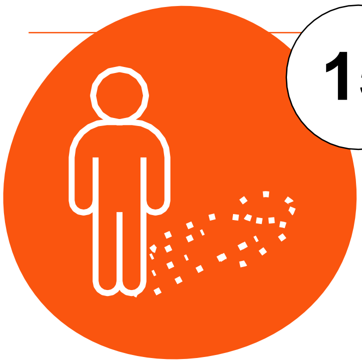
Cherine Mathot
Association for Children's Cancer Netherlands
"Fortunately, with the right aftercare, guidance and support, I have learned to see what I'm still capable of. And that I am much more than just an ex-childhood cancer patient. "

Roger Lam
Experience expert
"Run, jump, fly, dive, fall, get up and keep going. This is what working with cancer feels like to me"

Desiree Dona
Radboud UMC
"Ensuring worry-free work in the future starting from the diagnosis"

Cora van Horssen
NIBUD
"During your illness or recovery you don't want to be preoccupied with money. But help with finances is crucial to avoid losing grip and money trouble at this time."

Wieke Hengelveld
MantelzorgNL
"Carers are indispensable for someone with cancer, good support is indispensable for carers"



15 **Featured**

(Late) effects

By 2032, good care and support is available for people who live with or after cancer to prevent and reduce the impact of the (late) effects of cancer

The availability of care and support applies to both before, during and after treatment.

Description of the current situation

- 35% of people who live with or after cancer report that long-term effects were not discussed by healthcare provider(s) [113]
- A large proportion of people with or after cancer who struggle with late effects, recover well with the help of basic care, lifestyle advice and online self-help programmes [8]
- 25% of people who live with or after cancer are expected to need some form of monodisciplinary or medical specialist rehabilitation care for the problems they experience [8]
- Variations in late outcomes are due to e.g.: cancer type, treatment type, co-morbidity, gender, age, education, lifestyle, quality of life knowledge, PTO and rare tumors [8, 88, 114]
- 75% of children who have had cancer experience one or more health problems in adulthood [115]
- Physical: 54% of people with or after cancer have reduced physical fitness, 68% experience fatigue and 44% struggle with sexual problems.[116] 38% of people with or after cancer experience neuropathy [8]
- Cognitive: nearly 50% of people with or after cancer experience cognitive effects. For example, 40% have problems concentrating and 37% have memory problems [8, 116]
- Psychological: nearly 50% of people with or after cancer experience anxiety symptoms; 33% experience symptoms of depression.[8] 10-40% of children who have had cancer experience more mental problems than their peers [117]

What do we want to change?

A large part of people with or after cancer do not receive appropriate care and support aimed at preventing, identifying, treating and coping with the (late) effects of cancer (treatment). Currently, we know too little about the (late) effects of cancer and how they can be prevented and/or reduced. The knowledge that does exist does not yet appear to be sufficiently implemented in practice. A large part of people with or after cancer experience (late) effects of cancer. The impact on daily functioning can be significant. For example, it can affect family roles, social interactions, leisure activities and the ability to work.[116]

Goal 15 continues on the next page

Therefore, we want to increase attention to these effects during treatment and afterwards, and to the possibilities of care and support when it coms to late effects. Which will result in people who are living with or after cancer being helped to live their daily lives in the best way possible, despite the obstacles they experience due to the (late) effects of cancer.

What are underlying causes?

- Insufficient alignment of care and support with the individual wishes, needs and preferences of people with or after cancer
- Insufficient cross-domain and cross-line organisation of care and support
- People with or after cancer often do not have the right information at the right time about the (late) effects of cancer, and the range of care and support available
- Insufficient implementation of existing knowledge to prevent, detect, treat or appropriately deal with (late) effects of cancer
- Knowledge deficit on (late) ceffects: around preventing, detecting, treating and managing (late) effects, especially in certain specific areas (see Kennisagenda Kanker & Leven) [118]

How are we proceeding now?

Five sub-goals have been formulated based on the above causes.

- Better tailoring care and support to the individual wishes, needs and preferences of people with or after cancer
    - Activities include: applying shared decision-making; creating awareness and knowledge about (monitoring) (late) consequences of cancer among (healthcare) professionals and people living with or after cancer; and creating space for personalised care and aftercare in guidelines
- People with or after cancer receive appropriate care and support for (late) consequences of cancer. This calls for establishing lineless and cross-domain care and support for a streamlined offer
    - Activities include: commitment to transmural care pathways and connection between the lines (informal-formal, first-second-third line); creating a comprehensive offer within 'line-free care'; and making care and support more accessible (including paying attention to funding challenges, such as the deductable threshold)
- Making information on the (late) effects of cancer accessible and findable for (care) professionals and people with or after cancer, including information on available care and support offerings
    - Activities include: reducing fragmentation and diversity in the quality of information; focussing on findability and comprehensibility of information for vulnerable target groups; and supporting people to make good choices in the range of care and support offered at the right time (possibly with the help of a dedicated point of contact)
- Reduce the knowledge gap on (late) effects, increasing understanding of how to prevent, detect, treat or manage (late) effects of cancer
    - Activities include: focussing on cooperation between researchers, structurally collecting data (also in the long term and for specific patient groups) and linking existing (PROMS) data
- Implement existing knowledge and innovations aimed at preventing, detecting, treating and managing (late) effects of cancer
    - Activities include: integrating care for the (late) effects of cancer in both healthcare and the social domain, applying proactive care planning, nationwide implementation of developed evidence-based innovations or interventions, include knowledge in quality standards, increase availability and findability of knowledge for (healthcare) professionals, deploy lifestyle adaptations and connect to current funding streams

Goal 15 continues on the next page

What effects do we expect on individuals and society?

○ **Incidence**

○ **Mortality**

● **Quality of life**
- ● Physical health
- ● Mental health
- ● Degree of independence
- ● Social relationships
- ○ Environment
- ○ Personal values and beliefs

● **Quality of care**
- ● Effectiveness
- ○ Safety
- ● Patient-centredness
- ● Timeliness
- ● Efficiency
- ○ Equality of treatment

More on the sub-goals for late effects can be found in the action plans (Dutch only). The most recent versions can be found here on the website of the Nederlands Kanker Collectief

16

Education and cancer

By 2032, people living with or after cancer can be educated according to their own wishes, needs and coping ability

This goal concerns children and (young) adults who (want to) receive an education or training and people with or after cancer who want to enter a reskilling programme.

Descripton of the current situation

- Every year, 600 children (0-18 years old) are diagnosed with cancer. The 5-year survival rate is above 80% [119,120]
- Every year, more than 4,000 young adults aged 18 to 39 get a cancer diagnosis. More than 32,000 young adults are living with or after cancer and this number is increasing [73]
- People with cancer have symptoms such as fatigue (68%), difficulty concentrating (40%) and memory problems (37%) [116]
- The risk of attaining a lower education and unemployment is 2-5 times higher in people who had cancer as children compared to peers [121]
- 45% of young adults report experiencing fewer work and career opportunities [73]
- Virtually no figures are known about education attendance by people with or after cancer

What do we want to change?

Education appears to be an under-researched topic in relation to cancer. We know that people experience symptoms during and after (a) cancer (treatment). Through experience, stories we know it can be difficult to pursue education with these symptoms. For instance, we know that people can face emotional, cognitive and physical limitations as well as social isolation. We also know that students with or after cancer experience barriers in attending education. More research is needed to provide good support for people with or after cancer in pursuing an education.

What are underlying causes?

- Necessary treatment for cancer contributes to reduced ability to pursue an education. Treatment takes time, energy and affects **taxability through**, for example, side effects
- Even after treatment, **load capacity** is often lower due to (late) effects
- Limited knowledge about (the need for) supporting pupils with or after cancer

What are possible directions for solutions?

- Taking stock of perceived bottlenecks
- Increasing knowledge about the effects of cancer on education attendance among deans and (teaching) staff
- Creating practical manuals with support options (e.g. digital education) so appropriate education can be continued

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- Appoint a permanent point of contact at each educational institution to whom students can turn during a period of illness and afterwards
- Consider the needs of pupils when formulating guidelines in care
- Setting up schemes, for example around student grants, to support pupils who are ill
- Facilitating a good transition from education to work for people with or after cancer with a focus on (changing) career opportunities and/or job retention

What effects do we expect on individuals and society?

○ **Incidence**

○ **Mortality**

● **Quality of life**
- ● Physical health
- ● Mental health
- ● Degree of independence
- ● Social relationships
- ○ Environment
- ○ Personal values and beliefs

○ **Quality of care**
- ○ Effectiveness
- ○ Safety
- ○ Patient-centredness
- ○ Timeliness
- ○ Efficiency
- ○ Equality of treatment

17

Featured

Work and cancer

By 2032, people living with or after cancer will be able to work according to their own wishes, needs and ability to cope

People with or after cancer (of working age) are in both the 'disease process' and the process of 'absenteeism to return to work'. 'Disease process' refers to diagnosis, treatment, aftercare and palliative care. 'Absenteeism to return to work' means: recovery, rehabilitation, reintegration and sustainable return to work. In this goal, caregivers also include people in the work environment. Depending on the study target group, research findings below on the work situation of people with or after cancer vary.

Description of the current situation

- 88% of people with or after cancer and 73% of caregivers indicate that the work situation changes (temporarily) after diagnosis. Of these people with or after cancer, 24% work (temporarily) less and 27% have (temporarily) stopped [122]
- In 18% of people with cancer aged between 18 and 65 years, the work situation changes after diagnosis, with 41% working less and 30% quitting [8]
- 60% of people with or after cancer report that the impact of cancer on work was not discussed by healthcare professionals in the hospital [123]
- People with or after cancer often have a long absence period, which is associated with high costs for both employer and employee [124]
- Employer acceptance rates are lower for people with or after cancer than for people with other chronic conditions [125]
- People after cancer are more likely to be unemployed than healthy people (33.8% vs 15.2%) [126]
- People with or after cancer without paid work have a higher risk of financial problems than people with or after cancer with paid work (27% vs 16%) [8, 127]
- 45% of AYAs report experiencing fewer work and career opportunities [73]

What do we want to change?

People with or after cancer experience barriers in returning to work, staying at work and/or finding a (different) job. We want people to be able to get and keep a job, both during and after cancer treatment. Both (healthcare) professionals, the employer, colleagues, loved ones, and the person with cancer themselves pay too little attention to the impact of cancer (treatment) on work. Reliable information on cancer and work, including available care and support, is of limited findability and accessibility. In addition, current laws, regulations and funding of work-related care impede support for people with or after cancer in (returning to) work.

Working contributes to quality of life, has a positive impact through distraction and meaning, leads to (new) social contacts and is important for one's financial situation. Utilising the labour potential is also important for society because of a tight labour

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market, the high cost of absenteeism and disability. Therefore, there should be work support throughout the disease process. This should be tailored to the goals and wishes of people with or after cancer and their loved ones.

What are underlying causes?

- People with or after cancer and their loved ones are insufficiently aware of the importance of work (retention) and do not pay enough attention to it. This also applies to the possibilities of work-related care and support throughout the disease process
- There is a lack of personalised work-related support. The personal circumstances and problems of people with or after cancer and their loved ones do not receive sufficient attention. This is especially the case with vulnerable groups, such as people with a distance to the labour market, a low social economic status (SES), a rare form of cancer, self-employed people and AYAs
- Working people with or after cancer and their loved ones experience insufficient support from employers or the work environment. This is partly due to insufficient awareness of the impact of cancer on work. Incorrect perceptions can also contribute to this
- (Healthcare) professionals do not pay enough attention to the impact of cancer (treatment) on work. This is partly because 'work as a treatment' is not an integral part of the whole disease process
- Different professionals involved in return to work or job retention do not co-operate well enough. These include professionals in the employment domain, the social domain and healthcare primary, secondary and tertiary care professionals
- Bottlenecks in (applying) laws and regulations hinder people with or after cancer from retaining employment or finding a new job
- There is no adequate funding to support working people with or after cancer throughout the disease process
- There is limited findability of and access to reliable information and effectively proven interventions for people with or after cancer, relatives, (care) professionals, employers and work environment regarding cancer and work

How are we proceeding now?

Eight sub-goals have been formulated for this goal:

- People with or after cancer and their loved ones are aware of the importance of work retention and the possibilities of work-related care and support
    - Activities include: boosting collaborative decision-making with a focus on (the impact of treatment at) work
- Personalised work-related support is available. Especially for vulnerable groups, attention is needed to personal circumstances and problems
    - Activities include: identifying problems in these vulnerable groups, developing and offering personalised work-related support from absenteeism to return to work
- Employers and/or the work environment are aware of the impact of cancer (treatment). They offer appropriate support to working people with or after cancer and loved ones
    - Activities include: researching appropriate support from employers and the work environment, providing education to employers and/or HR professionals with the aim of achieving appropriate HR policies
- 'Work as a treatment' is integral to the whole disease process, making (healthcare) professionals more attentive to the impact of cancer (treatment) on work
    - Activities include: implementing the generic module 'labour participation' in specialist medical guidelines; and including cancer and work in foundation and specialty training of medical specialists, nursing specialists and general practitioners connecting and expanding existing networks with the social domain and informal care
- Professionals co-operate better to provide good (work-related) care and support, both in transmural care (primary, secpondary and tertiary), as well as cross-domain care (labour and reintegration domain and social domain)
    - Activities include: connecting and expanding existing networks with the social domain and informal care
- Laws and regulations support working people with or after cancer and loved ones
    - Activities include: breaking down barriers between care and labour including associated legal frameworks and funding;

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    and increasing knowledge about laws and regulations surrounding illness and (long-term) absenteeism of people with or after cancer, HR professionals, occupational health and safety professionals

- Funding is adequate to support employed people with or after cancer with tailored support through the disease process and in the work place
    - Activities include: proposing changes to financing structures
- High-quality reliable information, effectively proven interventions for cancer and work, and the range of work-related care and support are centrally findable and accessible for people with or after cancer, loved ones, (care) professionals, employers and the work environment
    - Activities include: compiling online information on cancer and work (which is already available); and promoting the sustainable deployment (and funding) of effectively proven interventions

What effects do we expect on individuals and society?

○ **Incidence**

○ **Mortality**

● **Quality of life**
○ Physical health
● Mental health
● Degree of independence
● Social relationships
○ Environment
○ Personal values and beliefs

● **Quality of care**
○ Effectiveness
○ Safety
● Patient-centredness
○ Timeliness
○ Efficiency
● Equality of treatment

More on the sub-goals for work and cancer can be found in the action plans (Dutch only). The most recent versions can be found here on the website of the Nederlands Kanker Collectief

18

Financial implications

By 2032, people living with or after cancer experience as few negative financial consequences as possible

This goal does not focus on the impact of cancer on work. Loss of income is included in this goal.

Description of the current situation

- 76% of people with or after cancer experience adverse financial impact of their illness. This includes less income and/or extra expenses [128]
- Of those who experienced a decline in income, 60% of people with or after cancer have a permanent declining income [128]
- 50% of AYAs experience problems with insurance, loans or mortgage [73]
- In 2021, the 'clean slate scheme' was introduced in the Netherlands with a table of terms indicating when you don't have to disclose your cancer history for insurance purposes [129, 130]
- 27% of people with or after cancer need financial help or support. 33% of them have actually received help or support, especially from loved ones [128]
- 33% of people with or after cancer who have experienced financial consequences do not find it easy to talk about these consequences [128]

What do we want to change?

People living with or after cancer often experience financial consequences due to their illness. It is not clear what support is best for them, and accessibility and findability prove to be insufficient. It is important that people do not face (greater) financial problems because of their illness. That is why we want more attention for the financial consequences of cancer.

What are underlying causes?

- People with or after cancer may face a drop in income (especially after 2 years) due to fewer hours worked because of decrease in work capacity and/or time needed for treatment
- Barriers to getting insurance due to cancer history
- Not being able to take out death benefit insurance when you take out a mortgage can lead to residual debt after death
- Barriers to claiming benefits. Young people usually cannot get 'Wajong' benefits and also 'WIA' benefits
- Seeking help or support for financial consequences is not a habit for many people. This is also not facilitated by the taboo on talking about finances and limited availability of people in their own network to talk about it

Goal 18 continues on the next page

What are possible directions for solutions?

- A roadmap for (care) professionals for referral to appropriate financial support, similar to the 'Werk en Wijzer' for care providers [131]
- Setting up and deploying (low-threshold) support for a changing financial situation, such as online tools
- Understanding which groups fall between the cracks in terms of legal arrangements. Setting up schemes for these specific groups in order to avoid this
- Continuously update the table of terms of the 'clean slate scheme', e.g. based on medical developments
- Investigate whether the principle of the clean slate scheme can be applied to other insurance policies, such as disability insurance

What effects do we expect on individuals and society?

○ **Incidence**

○ **Mortality**

● **Quality of life**
- ○ Physical health
- ● Mental health
- ● Degree of independence
- ○ Social relationships
- ● Environment
- ○ Personal values and beliefs

○ **Quality of care**
- ○ Effectiveness
- ○ Safety
- ○ Patient-centredness
- ○ Timeliness
- ○ Efficiency
- ○ Equality of treatment

Loved ones and informal caregivers

By 2032, care and support for loved ones and informal caregivers is available

By loved ones, we also mean the bereaved.

How is the situation now?
Support for people with or after cancer from loved ones and informal caregivers

- 83% experience a lot of emotional support during treatment from their loved ones [132]
- 49% experience emotional support for late or long-term effects by loved ones [132]

Support for loved ones, informal carers and bereaved

- 92% gave extra support or help to their loved one after he or she got cancer [133]
- 98% of loved ones take it for granted to give support or help [133]
- 55% of loved ones completely adapt their own life to that of their loved one with cancer [133]
- 73% of loved ones and 96% of parents indicated that their work situation was (temporarily) adjusted because of their loved one's cancer (treatment) [134]
- 36% of loved ones need professional support in their work. Among parents, this is 65%. In both groups, 1 in 6 did not receive this support [133]
- 90% of loved ones report that they themselves also need care or support [133].
- 26% of loved ones need information about what it is like as a loved one; 22% need emotional help from an expert (only 38% of them received this) [133]
- For 91% of loved ones, the professional support they received helped more or less [134]
- 14% of visitors to centres for living with and after cancer are loved ones; 18% are the bereaved [135] At psycho-oncology centres, 19% of visitors are loved ones [136]
- When losing a partner or child, 73% do not function well for an extended period, 23% experience burn-out and 14% lose their job [137].

What do we want to change?
Relatives and informal carers currently do not always experience sufficient support. This concerns practical, psychological and social support. Informal care has an effect on how one fills one's day. Caring for someone with or after cancer is tough. This impact is also great for loved ones. It is therefore important to provide loved ones and informal caregivers with sufficient support, appropriate to their needs, so that they can continue to provide optimal support.

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What are underlying causes?

- During treatment and afterwards, attention is focussed mainly on the person with cancer. Loved ones and informal carers are seen as an important pillar of support, but not always the same attention is given to the support they need
- There is sometimes shame around seeking help or support as a loved one, carer or bereaved caregiver
- The supply of targeted care and support for relatives and informal carers is limited and what is available is not easy to find for all groups

What are possible directions for solutions?

- Gain insight into the needs and wishes of loved ones and informal carers through 'loved ones journeys'. This maps out what a loved one or informal carer has to deal with throughout the disease process of the person with cancer
- Develop and/or improve guidance for loved ones and informal carers, appropriate to their wishes and needs
- Improve the findability of what can be offered to loved ones and informal carers, such as psychosocial care and practical relief such as respite care
- Raise awareness of the psychosocial and physical effects for loved ones and informal carers and the impact on their lives and work
- Introducing regulations that facilitate support from loved ones and informal carers
- Improve care leave and extend bereavement leave for bereaved carers

What effects do we expect on individuals and society?

○ **Incidence**

○ **Mortality**

● **Quality of life**
- ○ Physical health
- ● Mental health
- ● Degree of independence
- ● Social relationships
- ○ Environment
- ● Personal values and beliefs

○ **Quality of care**
- ○ Effectiveness
- ○ Safety
- ○ Patient-centredness
- ○ Timeliness
- ○ Efficiency
- ○ Equality of treatment

20

Social-emotional support

In 2032, people with or after cancer and their loved ones feel socially and emotionally supported by society

This goal is about making it easier for people in the Netherlands to talk about cancer and, in doing so, giving support to people with or after cancer and those who will not get better.

How is the situation now?

- 84% of people with cancer experience a lot of emotional support from those around them after diagnosis and 83% experience this during treatment. After treatment, this is 62% [132]
- 49% of people after cancer experience support for the late or long-term effects of cancer [132]
- 37% of people with cancer experience some to many barriers in social functioning [8]
- 25% of people with or after cancer do not feel understood by those around them [132]
- 23% of AYAs feel that family and/or friends do not sufficiently understand the impact of cancer for them [73]
- 48% of people with or after cancer say they do not want to bother those around them with their illness [132]
- People with rare cancer experience relatively less support from their environment [138]. Moreover, they experience lower social functioning in the palliative phase than people in this phase with non-rare cancers [139]

What do we want to change?

People with or after cancer and their loved ones regularly experience insufficient understanding of the impact of cancer on their lives. They need socio-emotional support, such as practical help or conversation. The desire to talk about dying can be great among people with cancer who are not getting better and their loved ones. Talking about it can be very supportive.

What are underlying causes?

- There is insufficient knowledge in society about the impact of cancer on daily life. This makes us socially awkward when someone close to you gets cancer. Many people assume that someone will be back to their old self once treatment is over
- Insufficient network support or wider circle due to lack of understanding or taboo on cancer
- People hesitate to ask for help, or experience self-perceived burden. It's not always easy to have the conversation about life with or after cancer
- People do not like to talk about a life with limitations and the finality of life

What are possible solution directions?

- Increasing knowledge about the impact of cancer on life in society through campaigns

Goal 20 continues on the next page

- Conducting social dialogue on living with cancer
- Conducting social dialogue on dying (as a result of cancer)

What effects do we expect on individuals and society?

○ **Incidence**

○ **Mortality**

● **Quality of life**
- ○ Physical health
- ● Mental health
- ○ Degree of independence
- ● Social relationships
- ○ Environment
- ● Personal values and beliefs

○ **Quality of care**
- ○ Effectiveness
- ○ Safety
- ○ Patient-centredness
- ○ Timeliness
- ○ Efficiency
- ○ Equality of treatment

05

After the launch

5.1 A new phase

An important step has been taken with the launch of the Netherlands Cancer Agenda on 27 November 2023. After a year of working in co-creation, there isa shared agenda of 20 goals, with action plans for the five featured goals. The launch marks the transition to a new phase for the NKC: implementing the agenda.

The collective will continue to consist of participating parties (partners) who want to contribute to the realisation of the goals on the Netherlands Cancer Agenda. New parties can join the moment they see added value and can add value themselves. We need the strenght of the collective to realise the goals of the agenda. And we need partners to take their own role and responsibility.

5.2 Partner activities

Within the collective, we have formed so-called acceleration teams for the featured goals; they are the frontrunners, working together on the action plans and thus realising the highlighted goals. The website contains the most up-to-date versions of the action plans for the highlighted goals.

Partners in the collective are already actively working on all 20 goals. With their own programmes, projects and initiatives that contribute to the realisation of a goal on the agenda. Here, the NKC wants to provide an overview and map this work on the website: who is doing what, what milestones are there, how does this contribute to a goal? In this way, we can more easily connect and cooperate more effectively.
In addition, participating parties can initiate new activities themselves to contribute to the realisation of the goals. For example, developing an action plan for a non-featured goal with other partners.

5.3 The NKC hub

The collective is supported by the so-called NKC hub: a small, agile and efficient project team, led by the NKC programme manager. The hub's role in the collective is instigating and coordinating and is characterised by a clear, no-nonsense project approach. The hub supports the collective and the acceleration teams and is responsible for involving all partners in the collectively for the implemention of the agenda. The hub can also support initiatives for non-featured goals. Each request will be assessed to determine if and how it will be met.

5.4 Hub activities

The hub will initiate the following activities after the launch to realise the goals on the agenda:

Hub activities

Supporting developing action plans

- Coordinate the development of action plans for the highlighted goals
- Support the development of the plan at content level and the implementation of action plans including how to contribute to solutions for the societal challenges (people-oriented, sustainable and durable)
- Develop tools for partners to work out other goals and action plans themselves

Sharing knowledge

- Sharing relevant existing and new initiatives from the Netherlands and Europe
- Sharing information on relevant grants in the Netherlands and Europe
- Sharing information on agenda progress and realising goals
- Post relevant news on the website, in the newsletter and via LinkedIn

Connecting and accelerating

- Organising NKC meetings for partners around a goal or theme
- Organising good liaison with Dutch and European initiatives
- Involve partners who can actively contribute to the goals
- Communication and lobbying in order to realise the goals
- Facilitating the social dialogue on moral, ethical and economic issues that relate to the goals in the agenda and affect everyone in our society. Topics such as:
  - Individual freedom of choice versus social interest
  - Distribution of financial resources between cancer and other diseases
  - Distribution of financial resources between (cancer) care and other sectors, such as education, infrastructure and the social domain
  - Socially acceptable prices for treatments
  - The limits to treatment
  - Solidarity between different generations and groups in society
  - Living and dying with dignity
  - Dealing with mortality

Monitoring

- Developing a dashboard to monitor progress on targets

Evaluating

- Initiating the annual review of the Netherlands Cancer Agenda

Annex A

Figures on cancer in the Netherlands

Cancer is increasingly common
An increasing number of people are living with or after cancer. The number of people succumbing to the effects of the disease is increasing as well. 1 in 2 Dutch people get cancer.[4] In 2022, 124,000 new diagnoses were made.[42] This number will rise to about 156,000 by 2032.[5]

Every year, 46,000 people die from cancer. This number rises to 54,000 by 2032. One third of these people die before the age of 69.[5]

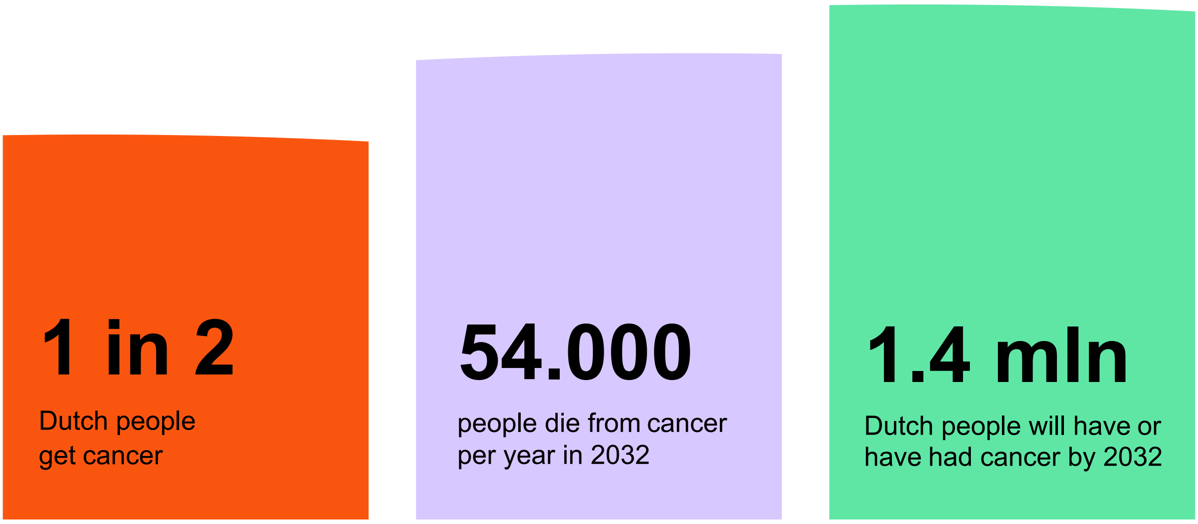
Some 850,000 people are living in the Netherlands who have (had) cancer. By 2032, this will be nearly 1.4 million.[5]

Age distribution
More than half of people with cancer are 70 years or older. About 75% of people who develop cancer are 60 years or older.[140]

Of those diagnosed with cancer in 2022, [140]

- 53% were older than 70 years
- 45% was between 30 and 70 years
- 1% was under 30 years of age

Cancer is increasingly common [4, 5]



Most common cancers

Prostate cancer is the most common cancer in men. In women, it is breast cancer. This is followed by skin cancer and lung cancer, in both men and women.[69]

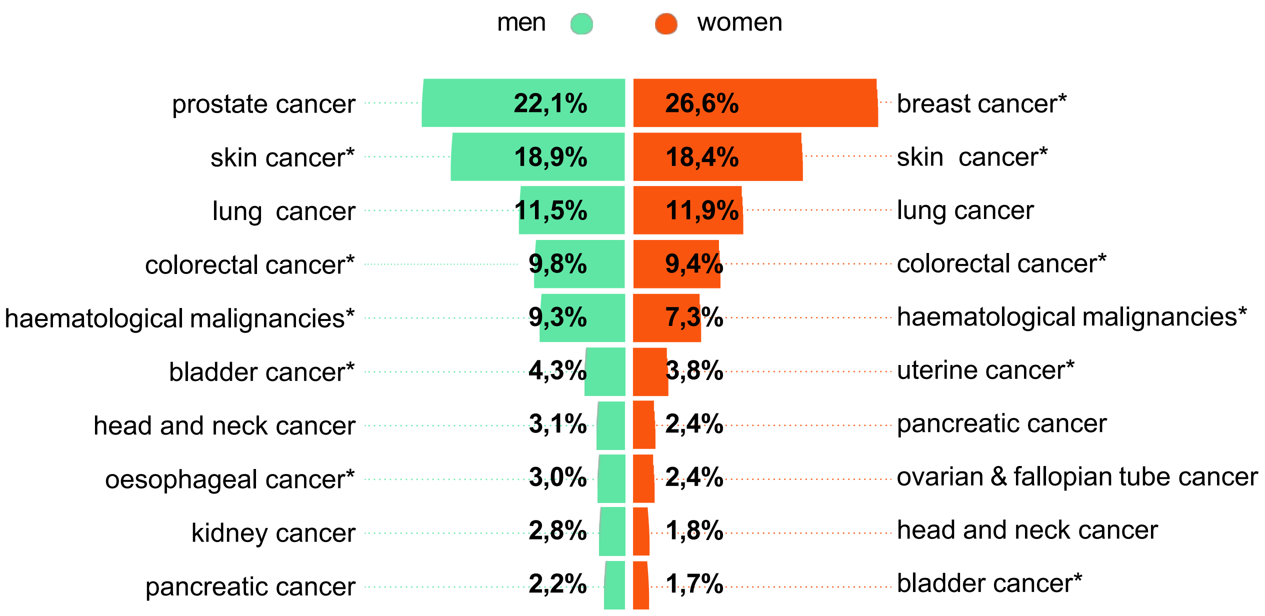
Impact of cancer

The impact of cancer on patients and loved ones is significant. It affects the quality of life during, but also after treatment. The impact does not stop when treatment stops. Of people who have (had) cancer:

- 65% experiences late effects; including sexual problems (44%) and concentration problems (40%) [116]
- 88% experiences adverse impact on their work [143]
- 76% experiences adverse financial impact (some of which are permanent and some of which are additional expenses) [128]

Almost 20% experiences many limitations (more than the average population) in performing daily activities.[8] Also, 35% feels lonely because of their illness.[132]

Ten most common cancers [69] Based on diagnoses made in 2022



skin: excluding basal cell carcinoma
colorectal: colon and rectal cancer
haematological malignancies: leukaemia, lymphoma, multiple myeloma and other forms of bone marrow cancer
bladder and other cancers of the urinary tract: renal pelvic cancer, ureteral cancer, non-muscle-invasive bladder cancer, muscle-invasive bladder cancer, urachus cancer, cancer of the urinary tract, others
oesophagus: excluding cardia

*

breast: invasive mammary carcinoma
skin: excluding basal cell carcinoma
colorectal: colon and rectal cancer
haematological malignancies: leukaemia, lymphoma, multiple myeloma and other forms of bone marrow cancer
endometrial: endometrial cancer **bladder and other cancers of the urinary tract**: renal pelvic cancer, ureteral cancer, non-muscle-invasive bladder cancer, muscle-invasive bladder cancer, urachus cancer, cancer of the urinary tract, etc

Cancer diagnoses versus cancer deaths

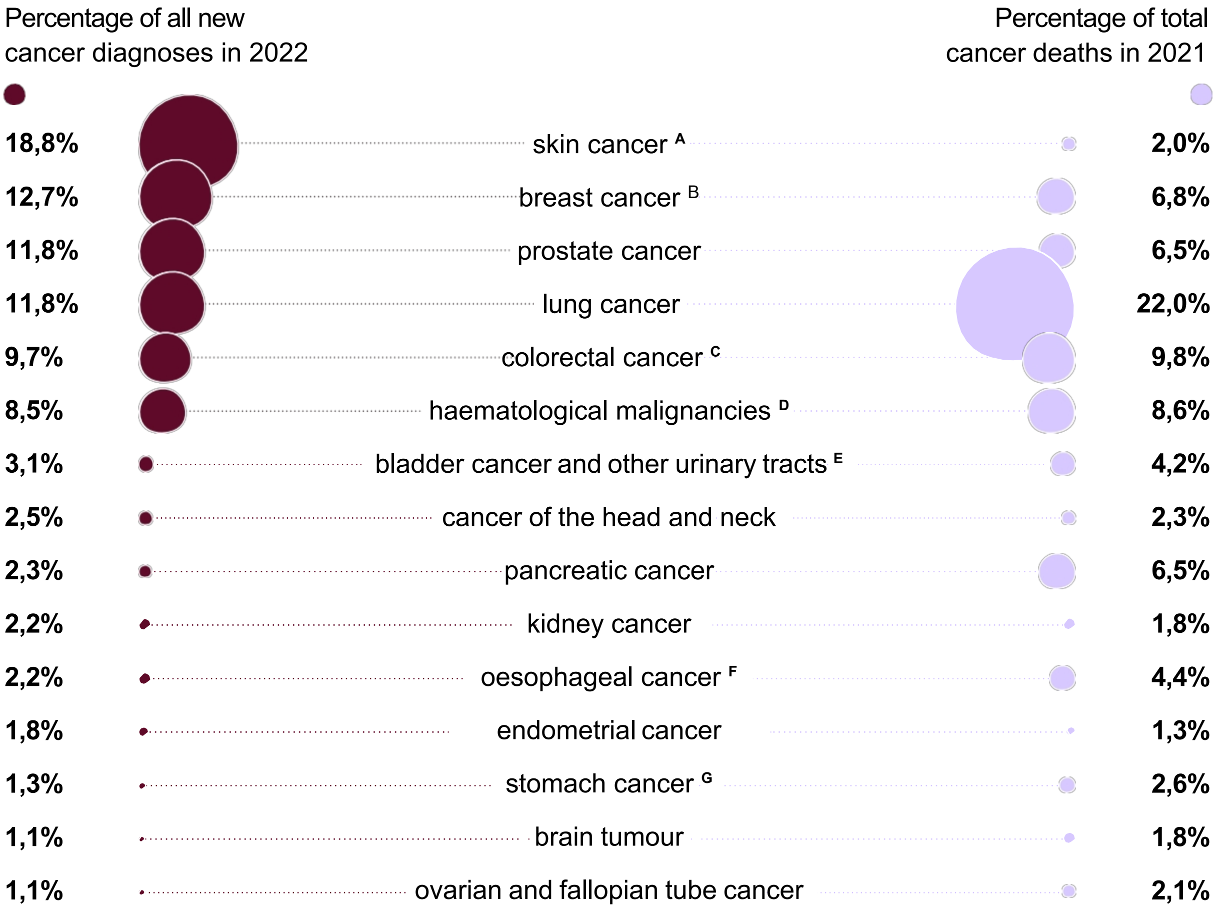
Skin cancer, breast cancer, prostate cancer and lung cancer accounted for more than 50% of new cancer diagnoses in 2022. Lung cancer caused the most deaths at 22%.[69]

Metastatic cancer

In 1 in 5 people diagnosed with cancer, the cancer has spread at the time of diagnosis. Every year, about 21,000 people are diagnosed with metastatic cancer. In total, there are about 38,000 people living with metastatic cancer in the Netherlands.[91]

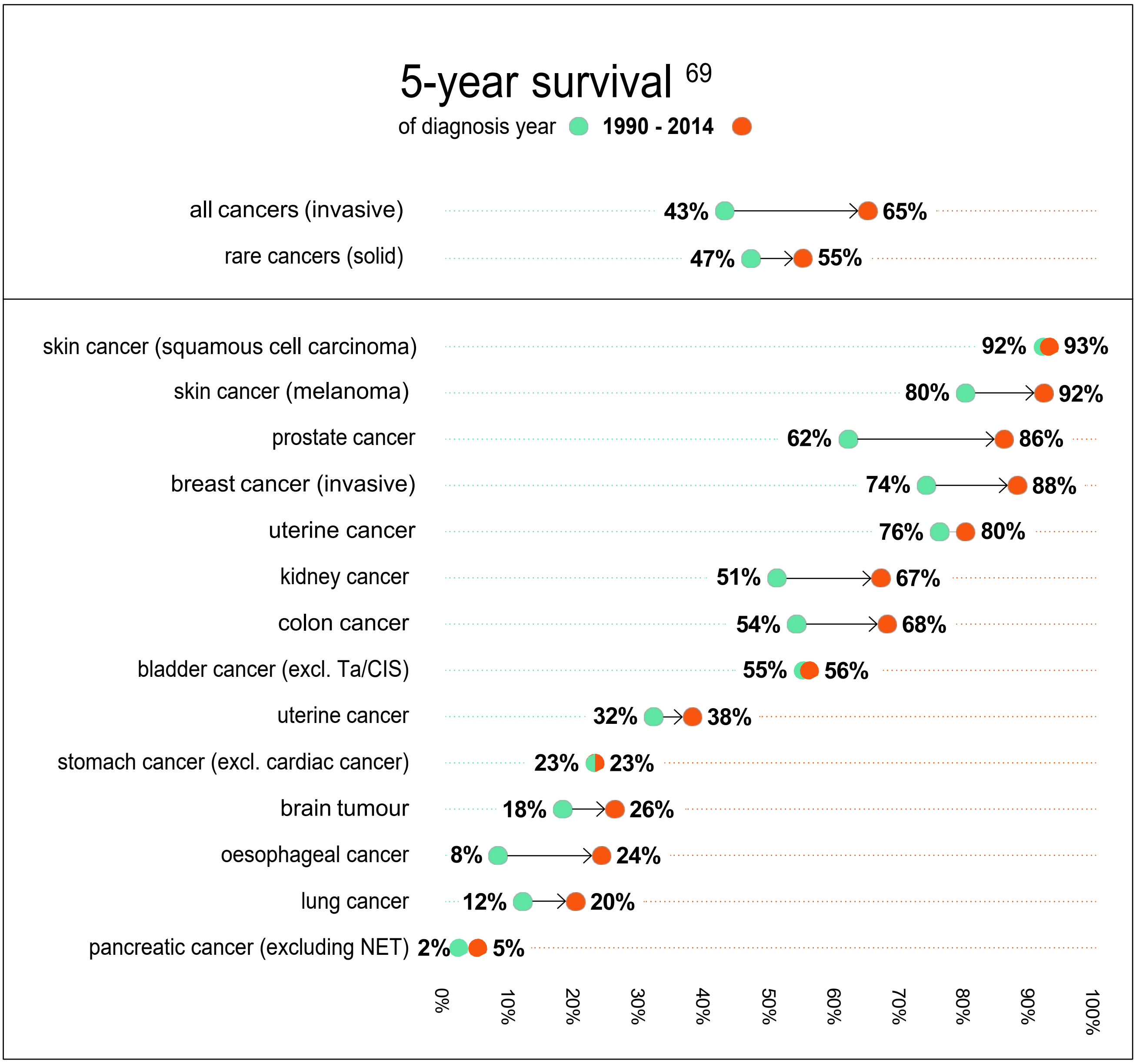
The most metastatic cancers at diagnosis are pancreatic, lung, stomach, bile duct and gall bladder cancer. The largest group of people with metastatic cancer involves those with lung cancer. The group with metastatic prostate cancer is also large. This is not so much because this cancer metastasises quickly, but mainly because of the large group of people with prostate cancer.[91]

Cancer diagnoses versus cancer deaths [69]



A. excluding basal cell carcinoma, **B.** invasive mammary carcinoma, **C.** colon and rectal cancer, **D.** leukaemia, lymphoma, multiple myeloma and other forms of bone marrow cancer, **E.** renal pelvis cancer, ureteral cancer, non-muscle-invasive bladder cancer, muscle-invasive bladder cancer, urachus cancer, cancer of the urinary tract other, **F.** excl. cardiac cancer, **G.** incl. cardiac cancer

5-year survival
Overall 5-year survival has increased from 43% (1990) to 66% (2022).[7-69] 5-year survival has increased for almost all cancer types, but the differences are large. For example, 5-year survival for skin cancer is 93% and for breast cancer 88%. For pancreatic cancer, it is only 5%.[69] Over the past 30 years, 5-year survival has increased to 70% for women and 66% for men.[5]



5-year survival compared to EU
Compared to other EU countries, the Netherlands has a number of cancer types in which the 5-year survival is higher than the EU average. This applies to prostate cancer, childhood leukaemia, breast cancer, cervical cancer, colorectal cancer and lung cancer.[6]

5-year survival compared to EU [6]

Prostate cancer
Netherlands: **88%**
EU-24: **87%**

Childhood leukaemia
Netherlands: **90%**
EU-24: **82%**

Breast cancer
Netherlands: **87%**
EU-24: **83%**

Cervical cancer
Netherlands: **67%**
EU-24: **64%**

Bowel cancer
Netherlands: **63%**
EU-24: **60%**

Lung cancer
Netherlands:17%
EU-24: **15%**

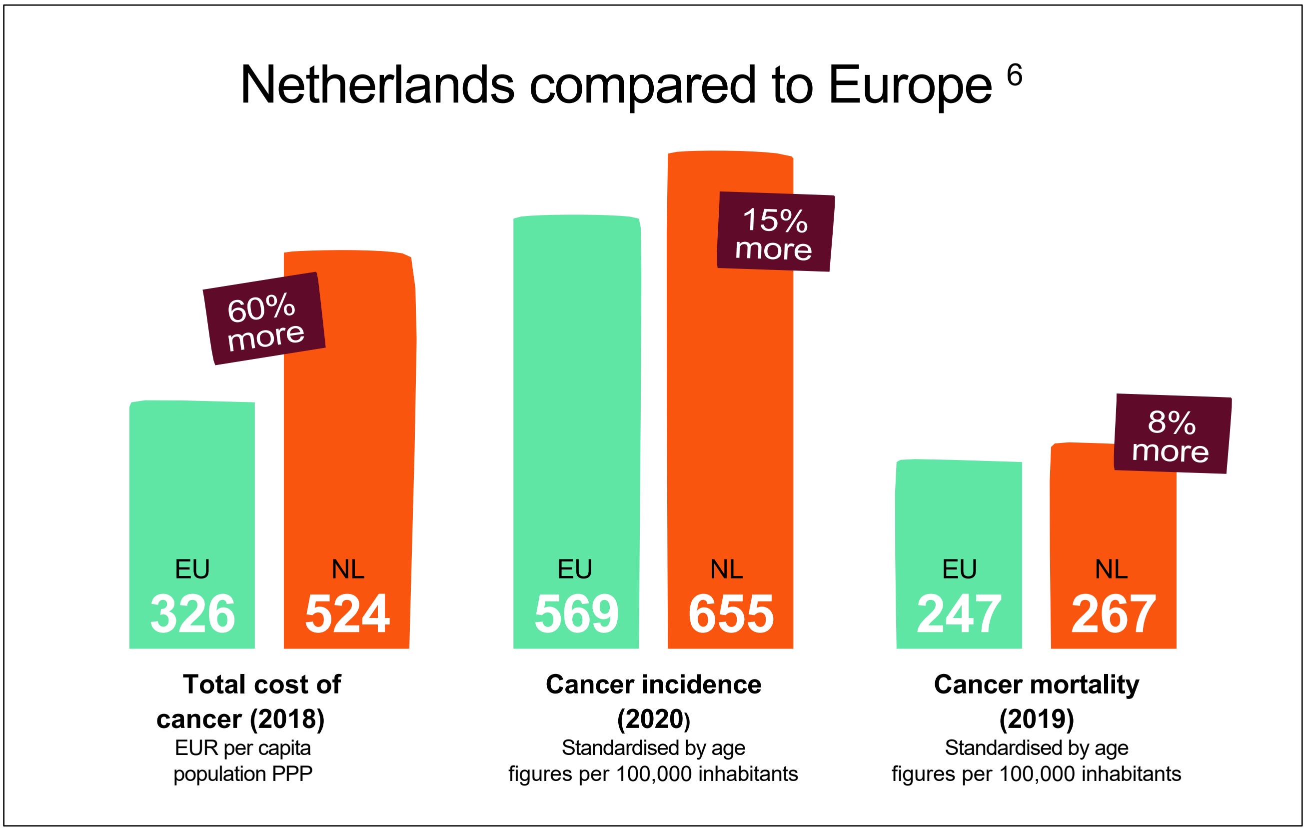
Note: Data refer to people diagnosed between 2010 and 2014
Childhood leukaemia refers to acute lymphoblastic cancer

Netherlands compared to EU
Mortality rates in the Netherlands have improved in recent years, but are still above the European average.[6, 141]

Compared to the 26 other EU countries, the Netherlands in particular has a high incidence rate. For men, it is around the European average but women have the third highest rate among all EU countries.[3] This high position may partly be an effect of higher participation in population screening and better screening methods[142] in the Netherlands.

Cost of cancer
Cancer care costs were about 7% of total healthcare costs in 2019 in the Netherlands. This amounts to about EUR 6.5 billion. Of this amount, most was spent on hospital care, at EUR 5.5 billion (84.6%). These costs include spending on expensive drugs that are used in hospitals. This was followed by spending on drugs and aids at EUR 225 million (3.5%).[144]

The cost of cancer care in the Netherlands is high compared to other EU countries.[6] We spend 60% more than the EU average.[6] Despite this, Dutch mortality rates are 8% above the average of all EU countries and incidence is 15% higher than average.[6]



Annex B

The process explained

The Netherlands Cancer Agenda was developed in a year of co-creation. Individuals from more than 100 organisations contributed to it.

Kick-off
In November 2022, we launched a kick-off focusing on the urgency and need for a Netherlands Cancer Agenda.

More information on the outcome of this meeting can be found on the website.

Step 1:
Setting goals
In March 2023, participants of the Nederlands Kanker Collectief formulated goals for the next 10 years. To set these goals, it is important to first have an overview of where the problems are. Prior to the meeting, participants received an overview of figures and bottlenecks in the Netherlands, based on literature research. Interactive working sessions were then held for each of the three phases: life before, with and after cancer. After each meeting, the output was emailed to participants, asking them to respond and add to it. In the end, we arrived at 41 goals.

Feedback from these sessions can be found on the website.

Step 2:
Prioritising and singling out goals To provide focus, we collectively prioritised 41 goals in June 2023 using three parameters. These were impact, attention and urgency. By using multiple parameters, we reduce the risk of confirmation bias.

- **Impact**
  How does a cause contribute to reducing the impact of cancer on our society? We always consider impact qualitatively and where possible quantitatively. Here, we looked at: cancer incidence, mortality and survival, quality of care and quality of life.
- **Attention**
  Which goals should we pay more attention to in the Netherlands? We mapped current activities in the Netherlands that contribute to achieving the goal. These include task forces, partnerships, programmes, agreements, action plans, campaigns, research and grant programmes and tools.
- **Urgency**
  What goals should we as a collective start with now?

Prior to the meeting, participants were given the 41 goals, with each goal complemented by the potential impact and ongoing initiatives on a goal. In preparation, participants were asked to individually prioritise the goals before the meeting. During the meeting, participants exchanged arguments for the choices made and were able to adjust their choices.

In a post-consultation, organisations that could not attend were given the opportunity to prioritise. All prioritisations, the underlying arguments and suggestions were then brought together. Also the suggestion to merge some goals and tighten up the wording. This yielded 20 goals, five of which scored high on the three parameters. We call these the five highlighted goals.

The overview of the 20 goals and five highlighted goals can be found on the website.

Step 3:
Defining approaches for the highlighted goals

At the September 2023 meeting, we started making plans of action. The basic for these plans is the 'Theory of Change'.[146] This method makes it clear what the underlying problems are, what activities you want to deploy on them and what the intended results are.

With smaller acceleration teams from different partners, further elaboration was taken up after the meeting. The degree of elaboration varies per highlighted goal, matching the size, complexity and corresponding pace of the goal.

You will find the latest versions of plans of action on the website. These are listed under the highlighted goals.

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s.d. = "without date"

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