Appropriate Care
Systematic Analysis of neoplasms

Oncology ICD-10:C00-D48

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Status Definitive

Zorginstituut Nederland and Appropriate Care

Taking care of good health care: this is Zorginstituut Nederland's motto. Every insured client must be able to count on receiving good health care. No more and no less than is necessary. And without incurring unnecessary costs. After all, this is something that we all jointly fund.

This is why the Zorginstituut, as a public organisation, keeps an eye on the basic package of health care. We assess, per indication field, whether the way in which diagnostics and therapeutic interventions included in the basic package are deployed is patient-oriented, effective and cost-effective.

We discuss our findings with care professions, patients, health care institutions and health insurers, and together with them we examine what is needed to improve patient care further and avoid unnecessary costs.

The parties in health care are responsible for improving that care. The Zorginstituut provides an overview of points for improvement, promotes cooperation and keeps an eye on the results. This is our way of contributing to good and affordable health care for everyone.

More information about the activities of Zorginstituut Nederland and Appropriate Care can be found on www.zorginstituutnederland.nl.

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1 Introduction

Zorginstituut Nederland published this report within the context of a systematic examination of the insured package.[1] For this report, the investigation started with a systematic analysis of the ICD-10 domain 'Neoplasms' (C00-D48). The analysis focuses specifically on after-care in relation to the five most prevalent malignant diseases. The point of departure of every investigation is the perspective of the patient and the care he or she needs.

Selection of topics for in-depth analysis
In chapter 2 we present the topics that were chosen for an in-depth examination during the next few months on the grounds of the systematic analysis and the input of parties during joint meetings and consultations. [2] We have found signals that opportunities exist in these fields for improving quality by deploying care more appropriately and thus reducing unnecessary health care costs. The Zorginstituut will examine this potential for improvement in close cooperation with the parties.

Method of operation in realising the systematic analysis and in selecting topics for in-depth examination
We designed this systematic analysis and the selection of topics in consultation with care professionals, patients, institutions and health insurers.[2] For instance, an initial meeting took place in which we explained the goal, the approach and the timetable, and gave the parties an opportunity to submit ideas and topics for analysis. Where possible and where interest was displayed, the parties were kept informed, individually and jointly, about interim progress. In the final phase the Zorginstituut gave the parties two opportunities to submit comments and additional topics for examination by means of written consultations.

From ICD-10 domain to a Systematic Analysis of after-care
Within the ICD-10 domain 'Neoplasms', we focussed specifically on malignant neoplasms. The quality of care for these diseases is at a high level in the Netherlands. From an international point of view, the rate of survival for most types of tumours is above average, and many initiatives exist for improving the quality of this care.[3] However, there are also signs that there is room for improvement. For instance, our analysis found differences that demand further investigation between institutions in the care provided. There is also a noticeable lack of data on the quality of oncological care.
Within the domain of neoplasms, we will focus specifically on after-care.
The definition of after-care we use is that of the World Health Council as amended by the KWF. [4][5]
We amended it slightly by replacing the words "after treatment" with "after the first (primary) treatment". Our definition of after-care includes the treatment of cancer

[1] Zorginstituut Nederland is doing this within the framework of the Appropriate Care Programme it was commissioned to carry out by the Ministry of Public Health, Welfare and Sport. The first report published within this framework was the 'Room for Improvement Status Arthritis of the knee/hip' on 30 June 2014. www.zorginstituutnederland.nl
[2] The parties involved are: NIV and NVMO, NVU, NVMDL, NVVH, NVALT, NVDV, NVVR, NVRO, NVT, FMS, NHG, NFU, NVZ, STZ, NPCF, Levenmetcancer [Living with cancer], *the Prostate Cancer* Foundation, Netherlands Lung Cancer, Netherlands Breast Cancer Association, the Melanoma Foundation, Netherlands Intestinal Cancer/SPKS, ZN.
[3] For survival of stomach and renal cancer, the Netherlands scores lower than the European average, but above average for most other types of tumour. IKNL, Netherlands Integral Cancer Centre. Spotlight on Cancer Care. January 2014.
[4] Cancer Signalling Committee of the Netherlands Queen Wilhelmina Fund for combating cancer. Cancer after-care: the role of primary care. May 2011.
[5] Health Council. After-care in oncology. Distinguishing between goals, substantiating content. The Hague, 2007.

that returns after the initial treatment:
"*After-care includes all individual care of patients after their initial (primary) treatment for cancer. It includes providing information, guidance, discussing complaints and symptoms, assessing immediate or late effects of the disease, treatment of recurrences or other manifestations of the disease and treatment and attention to social consequences. Subsequent programmatic checks can be an integral part of after-care. Interpretation depends on the individual situation. The doctor in charge discusses the nature and form of after-care with the patient.*"

We opted explicitly for after-care because a growing number of people are taking advantage of it. Both the incidence and the prevalence of cancer are increasing rapidly. Incidence, the number of people diagnosed with cancer, is increasing mainly because the Dutch population is ageing. And the risk of cancer generally increases with age. Furthermore, patients are living longer due to improved methods of treating cancer; this means that cancer is becoming increasingly chronic in nature. Both factors are causing the number of people making use of after-care to rise. Quality of life and participation in society is important for a growing number of people after oncological treatment. An increase in the costs of oncological after-care is inevitable. The potential impact of implementing appropriate care in this after-care phase is correspondingly on the rise. Furthermore, by opting for after-care, our work is complementary to the many initiatives in the field that focus mainly on the primary treatment of cancer.[6]

Within after-care, we focus on the five most prevalent types of tumour. Skin cancer has the highest prevalence, followed by breast cancer, intestinal cancer, lung cancer and prostate cancer. Together these five make up 64% (65,000) of all newly diagnosed cases of cancer and 73% (347,000) of the number of people who are living with cancer.[7] In 2012 an additional 101,210 people were diagnosed with cancer in the Netherlands. On average the number of new cases increases by about 3% a year.[8] For 2030 expectations are that the number of people with one of these five types of tumours will have increased by half, to about 518,000.

Figure 1 is a diagramme of the four phases of care for people with malignant neoplasms. The first phase is mainly about complaints and/or phenomena during a visit to the GP or during a population screening (breast cancer and intestinal cancer), that may indicate a neoplasm. Supplementary examination can subsequently determine whether the case really does involve a malignant neoplasm. If this is the case,
then the initial treatment phase commences.

The choice of treatment depends on the type of tumour and the stage of the disease and is determined jointly by the doctor and the patient. The initial (primary) treatment is often comprised of a series of different treatments, also known as courses of treatment or treatment models.

For instance, operative treatment of a tumour can be followed by radiotherapy and/or chemotherapy.

This initial (primary) treatment, whether or not its objective is curative, is followed

[6] Examples of such initiatives can be found in, among others: The Cancer Signalling Committee (SCK) of the KWF for combating cancer. Quality of Cancer Care in the Netherlands. The Hague. July 2010 and in IKNL, Spotlight on Cancer Care 2014. January 2014.
[7] See Appendix 1 Cancer Statistics.
[8] IKNL. Spotlight on Cancer Care. January 2014.

by after-care. This includes all care after primary treatment. This is not just about standard after-checks that focus on discovering new manifestations of the malignant tumour or of (late) consequences of the primary treatment. After-care also includes tests and interventions that are needed for examining or treating new manifestations of the tumour. It also includes combating symptoms such as pain, emaciation or fatigue, as well as treating psychosocial complaints and the need of rehabilitation. In practice, a razor-blade sharp definition of the border between initial (primary) treatment and after-care is not always possible, because treatment and after-care of one treatment model may take place in parallel with that of another treatment model. In this type of situation, the Zorginstituut will opt for a broad scope in searching for opportunities for more appropriate care.

Figure 1: Aspect of care for neoplasms

Naturally, where possible, treatment of cancer focuses on cure. Where this is not (or no longer) possible, the focus is on extending survival and the best possible quality of life. This phase, which no longer focuses on cure, is also sometimes referred to as the palliative phase. We do not use this term however, because in practice its use is not unequivocal. The period of the last phase of life is also a part of after-care.

Conditions for good care
The Zorginstituut's point of departure in systematically examining the package is the perspective of the patient and the care he or she needs with health problems. Our focus is on crucial conditions for good care, such as proven efficacy of medical tests and interventions, the availability and implementation of EBM guidelines, making use of stepped care, communication within and between consultation rooms, shared decision-making and transparency of quality.

In this systematic analysis of oncological after-care, we therefore examined the following topics:

Scientific substantiation of recommendations in guidelines for subsequent controls.
It is important, both for patients and for the quality of care, that professionals agree

on what is good oncological after-care and record this in scientifically substantiated guidelines.

Implementation of recommendations on after-control tests in guidelines
Failing to adhere to the guidelines approved by the professional groups (except in cases of motivated departures) gives rise to a situation in which individual doctors, patients or institutions determine (on vague grounds) which interventions will be used for treating patients. For patients this means arbitrariness in treatment.

Communication in consultation rooms
Not only do patients have a right to know what represents good care, this information is actually a condition for discussions between patients and professionals in consultation rooms. Communication in individual consultation rooms focuses on optimal treatment for every patient. Shared decision-making is important in realising this.

Communication between consultation rooms
This refers to care harmonisation between the various professionals. As a number of disciplines of care-providers are in fact always involved in oncological after-care, communication between the consultations rooms of the various disciplines from primary, secondary and tertiary care is extremely important for quality of care.

Final life-phase
We chose the final life-phase because people's preferences, the need for shared decision-making and good communication between care providers plays an even greater role than in earlier phases. In this phase, the treatment perspective must be re-examined.

Access to expensive oncolytics
One way of improving the treatment of cancer, including when it returns after primary treatment, is by making use of newly developed medicines. It is important that professionals are realistic in estimating the efficacy of new medicines. In addition, patients should receive extensive information, so they can opt for a given treatment based on realistic expectations. The fact that new oncolytics are often expensive gives rise to the fear that their availability could be endangered (in the future). Making the most appropriate use possible of these resources is extremely important both for the quality and the accessibility of health care.

Transparency regarding quality in the after-care phase
High-quality information about oncological care focuses mainly on the diagnostic phase and primary treatment. Transparency regarding the after-care phase is becoming increasingly important because the after-care phase generally lasts much longer and with the passage of time more people will find themselves in this phase.

Structure of this report
In Section 2 we discuss the topics chosen for in-depth investigation. Section 3 describes the accountability for realising this report. In appendix 1, Cancer in statistics, we sketch a picture of the number of cases of cancer in figures.

2 Selection of topics for in-depth analysis

2.1 In-depth topics

In this section we present, with motives, the choice of topics for the in-depth phase. This is about topics that we want to examine in more detail because the systematic analysis [9] gave rise to the suspicion that room exists for improving the appropriate use of care and possibly also for avoiding unnecessary costs. Examination during the in-depth phase should prove whether this is actually the case.

The selected topics are:

1. Appropriate after-control of people treated for breast cancer
2. Appropriate care in the final life-phase of people with lung cancer or intestinal cancer
3. Appropriate use of – and access to – (expensive) oncolytics
4. Appropriate after-control of people with skin cancer
5. Appropriate use of expensive medicines on people with castration-resistant refractory prostate cancer.

Topics that were not selected include:

6. Care in other countries
7. Mohs surgery for facial skin malignancies
8. Active surveillance in cases of low-risk prostate cancer
9. Primary treatment of suspect skin defects
10. Repeat diagnostics

Zorginstituut Nederland arrived at this choice based on a systematic analysis of after-care for patients with breast cancer, intestinal cancer, skin cancer, prostate cancer or lung cancer and based on the responses of the parties. During the consultation, a number of parties provided supplementary arguments to support the choice of certain topics for in-depth examination and/or for new topics. The responses reveal a broad basis of support for the selected topics.

Both shared decision-making and transparency regarding quality, that we included in the analysis, are generic conditions for good care. For this reason, where applicable, these items were always part of the in-depth research of the chosen topics.

In the following paragraphs we discuss the topics chosen for in-depth examination. Where applicable, in our argumentation we present the most important findings from the systematic analysis in making the choices. New topics for in-depth examination which were introduced during the consultations are also discussed here.

Making positive choices implies that other topics were not chosen. In order to keep the extent of the in-depth phase manageable, in first instance we are selecting topics where we expect an enormous potential for improvement. For instance, for the topic after-control we chose to focus on the in-depth examination on people with

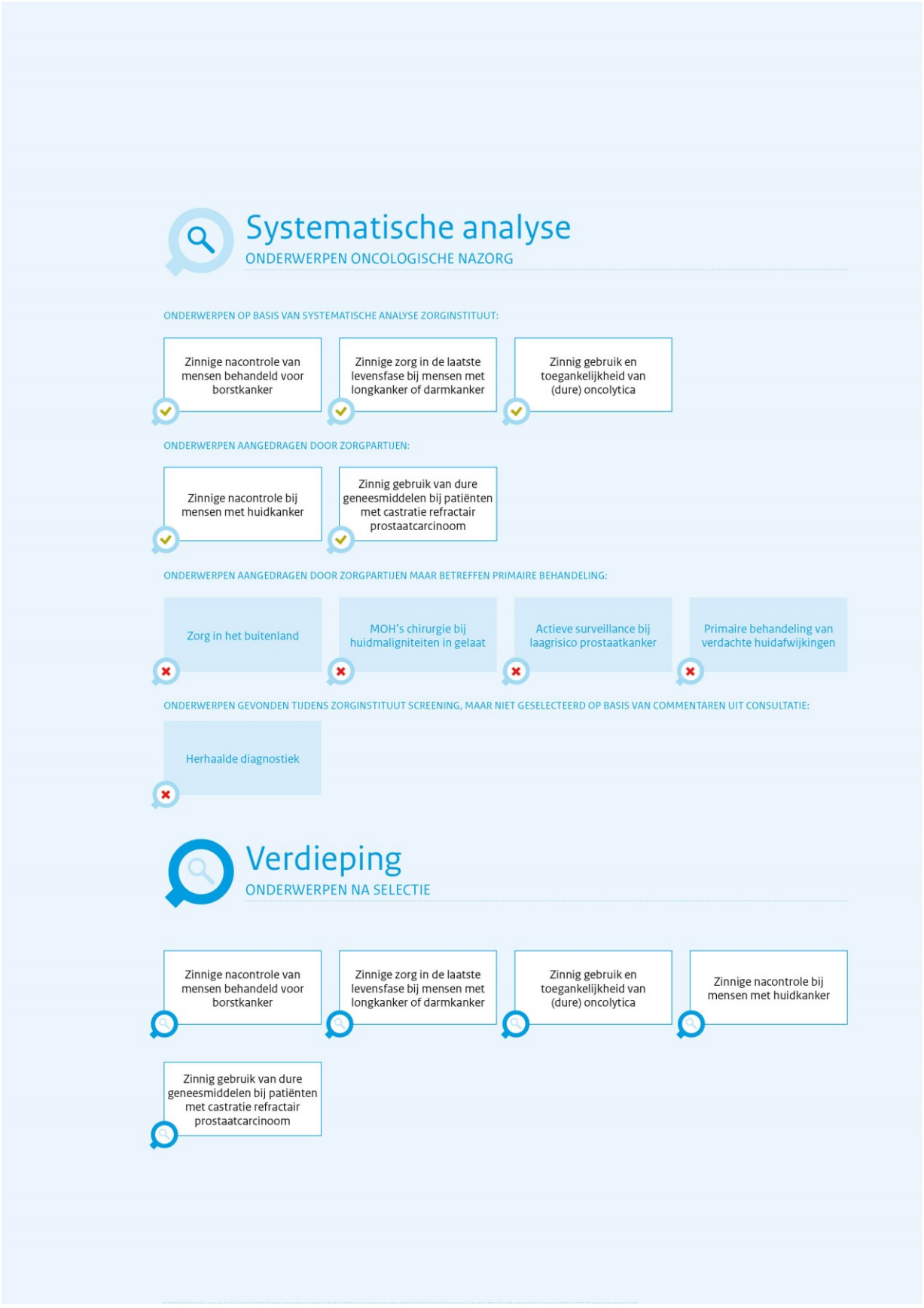
[9] The research carried out by Zorginstituut Nederland is described in the document "Systematic analysis of neoplasms". This document was sent to all parties involved for consultation purposes.

breast cancer, because a relatively large number of them receive after-care due to good survival rates. In the final life-phase we opted for lung cancer and intestinal cancer, because the number of patients who come into contact with oncological care in their final life-phase is (relatively) large due to lower survival rates for these types of tumours.

After an in-depth examination of these types of tumours, we want to examine whether the approach to them and the results achieved can also lead to more appropriate care with other types of tumours. In fact, we are explicitly searching for spin-off opportunities.

Figure 2 is a diagramme of the topics we did and did not choose.
In the following paragraphs we explain the choices per topic.

Figure 2: Selection of topics for in-depth analysis



2.2 Appropriate after-control of people treated for breast cancer

Oncological after-care covers all care after primary treatment. This after-care includes the (protocol-based) after-controls carried out that focus on discovering new manifestations of the malignant tumour or of (late) consequences of the primary treatment. The Dutch oncological guidelines provide recommendations for the frequency of after-controls, carrying out medical tests and the duration/period of after-control.

We chose after-control as an in-depth topic for the following reasons:

- A lack of scientific substantiation for recommendations on after-control in the guidelines has given rise to doubt about the degree of efficacy of medical tests in after-control.[9]
- Claim data reveal differences between hospitals in the use of medical tests that are advised in the guidelines or which are carried out for different reasons.[9]
- During the consultation, a number of parties confirmed the importance of interpreting after-control appropriately.

For the above-mentioned reasons, the same applies more or less to all five types of tumours that we studied. In the in-depth phase we want to focus (in first instance) on one type of tumour, and we have opted for breast cancer. Our assumption is that the analysis and results of the research will be useful for other types of tumours. Eventually we plan to consider whether we still need to examine after-control for other types of tumours in more detail.
Skin cancer was selected as a separate topic for in-depth study, partly because the use of medical diagnostic tests during after-control is strictly limited, with the focus on other matters.

The specific choice of breast cancer was prompted by the following criteria. The longer the survival for a given form of cancer with a high incidence, the greater the number of people in after-control and after-care. This makes it inevitable to opt for a form of cancer with a high incidence and good survival rate, such as prostate cancer, breast cancer or skin cancer, in view of the potential room for improvement by providing more appropriate care.[7] The reason for choosing breast cancer in first instance is partly due to recent scientific publications over this topic and the support of various parties.

During the in-depth phase we want not only to carry out research into the use of medical tests in after-control, but also to take a broader look at an appropriate interpretation of after-care in view of the needs of patients and the evidence on good care during this period. We emphatically included care for not only somatic problems but also psychosocial ones.

Table 1 illustrates the above-named criteria for choosing breast cancer. In the following sub-paragraphs we explain each of the cited arguments for choosing after-control as a separate topic.

Table 1: Characteristics per type of tumour

Kanker type	Borstkanker	Darmkanker	Huidkanker	Longkanker	Prostaatkanker
Incidentie (2012)	14.296	13.408	14.524	11.871	11.158
Prevalentie (per 1-1-2013)	104.213	65.293	81.624	22.115	73.639
5-jaars overleving	86%	61%	87% / 94%	16%	87%
10-jaars-overleving	77%	53%	83% / 88%	9%	77%
Totale kosten 2011 (in mln)	696	488	pm	401	254
Verwachte totale kosten 2030 (in mln)	1.208	1.031	pm	812	583
Gebruik van medische tests	++	++	-	+	+
Aangedragen door partijen	++	+	+	+	++

2.2.1 *The lack of scientific substantiation in the guidelines has given rise to doubt about the degree of efficacy of medical tests in after-control.*

We carried out research into the scientific substantiation of recommendations for after-control in national and international guidelines.[9]
The research took into account a mix of evidence-based and consensus-based guidelines. It seems that the methodological quality of the European guidelines of ESMO, EUSOMA and the EAU is low, and the guidelines of IKNL, KCE and NICE are largely of a good methodological quality. This does not imply that all recommendations from these guidelines have been scientifically substantiated. For medical tests in after-control, even methodologically sound guidelines often do not include a (recent) literature search and there is no link between the recommendations and the underlying evidence. For breast cancer, prostate cancer and non-small cell lung cancer, the guidelines include mainly observational studies or no evidence at all. Also noticeable is that the recommendations in guidelines differ from one another. Based on this research we arrived at the following findings.

The guidelines reveal an almost complete lack of scientific substantiation of recommendations for using medical tests in the after-control of patients who have undergone primary treatment for cancer. Those who draw up the guidelines provide little or no scientific research. This does not necessarily mean no evidence is available for the efficacy of such medical tests. However, the lack of it inevitably does at least raise doubt about the degree of efficacy of the medical tests recommended during after-control.

2.2.2 *Claim data reveal differences between hospitals in the use of medical tests during after-control*

Clearly, in addition to medical tests that are recommended in guidelines and which focus on after-control, medical tests are also carried out for other reasons. In the systematic analysis[9] we formed a picture, based on claim data, of which tests were used on oncological patients (with breast, lung, intestinal or prostate cancer) during the after-control period, three or four years after the year in which they received primary operative treatment (2008 = reference year).[9, 10, 11]

This involved examining the most frequently used tests. Based on available claim data, no distinction can be drawn between tests during after-control and tests for other medical reasons. This resulted in the following picture.

[10] As no medical tests are recommended in the after-control of skin cancer, this form of cancer was not included.

[11] Claim data are registered by hospitals for their claims. These data do not adequately reflect unnecessary care in the daily practice of health care. After all, it is possible that actual actions in a hospital do not correlate with the administration of actions as recorded in claim registers. Claim registers do indicate precisely the provisions for which health insurers were actually invoiced.

Claim data give the impression that differences exist between hospitals in using medical tests during after-control. Hospitals differ both in the percentage of patients who receive medical tests, as well as the average number of tests per patient. These data were examined against recommendations from the guidelines, which revealed variations in implementation percentages. However, due to a lack of substantiation for the efficacy of these tests in guidelines, we are unable to draw any unequivocal conclusions about the quality of care.

Via in-depth research, we want to obtain a clear picture of the underlying causes of these differences between institutions in using medical tests after primary treatment. This can clearly show whether opportunities exist for improving quality by means of more appropriate care.

2.3 Appropriate care in the final life-phase of people with lung cancer or intestinal cancer

We opted for the final life-phase as an in-depth topic for the following reasons:

- The final life-phase is a very special period during after-care due to the need to jointly re-consider the treatment perspective and the completion of a life.
- Available claim data reveal that differences exist between institutions in care during the last three months of life for people with a newly initiated oncological DBC
- A number of parties support the choice of in-depth examination of this topic.

These reasons apply to a greater or lesser degree to all types of tumours studied. In the in-depth phase we want to focus on the care of patients with lung cancer or intestinal cancer. We are assuming that the analysis and results will be useful for other types of tumours. Eventually we plan to consider whether in-depth research is still needed into other types of tumours.

The specific choice of lung cancer and intestinal cancer was prompted by the following criteria. The survival rates for people with lung cancer or intestinal cancer are lower than for people with one of the other types of tumours studied.[7] Our analysis reveals that relatively large numbers of patients are involved and these are also the patients who receive most care in hospital during this final life-phase. We therefore also chose for an in-depth examination of the final life-phase of patients with lung cancer or intestinal cancer.

Table 2 illustrates the above-mentioned criteria for choosing lung cancer and intestinal cancer. In the sub-paragraphs we go into more detail about the above-mentioned arguments.

Table 2: Characteristics per type of tumour

Kanker type	Borstkanker	Darmkanker	Huidkanker	Longkanker	Prostaatkanker
Incidentie (2012)	14.296	13.408	14.524	11.871	11.158
Prevalentie (per 1-1-2013)	104.213	65.293	81.624	22.115	73.639
5-jaars overleving	86%	61%	87% / 94%	16%	87%
10-jaars-overleving	77%	53%	83% / 88%	9%	77%
Percentage patiënten met opname-DBC binnen 3 maanden voor overlijden	45,6	47,8	pm	57,6	49,3
Aantal unieke overleden patiënten	3.305	4.974	722	8.840	3.013
Totale kosten 2011 (in mln)	696	488	pm	401	254
Verwachte totale kosten 2030 (in mln)	1.208	1.031	pm	812	583

2.3.1 *The final life-phase is a very special period during after-care due to the need to jointly re-consider the treatment perspective and the completion of a life*

We chose the final life-phase because people's preferences, the need for shared decision-making and good communication between care providers plays an even greater role than in earlier phases. In this phase, the treatment perspective must be re-examined. The parties generally agreed with this. They specifically referred to research into shared decision-making during this last life-phase. During recent years many publications, both scientific and non-scientific, have been published about care during the final life-phase. This regularly raises the question about how far the care offered contributes to a better quality of life and a good completion of a life. The government is paying extra attention to palliative care in a National Palliative Care Programme that started in 2014.[12]

2.3.2 *Available claim data give the impression that differences in care exist during the last three months of life of people with a newly initiated oncological DBC*

Zorginstituut Nederland carried out research into care provided by medical specialists during the last three months of life of people with one of the five types of cancer studied.[9] The research was carried out based on claim data from Vektis. Patients selected for this study had died in 2011 and had at least one newly initiated diagnosis combination treatment (DBC) during the last three months of their life for one of the five oncological diagnoses. We examined which care these patients received from medical specialists during their last life-phase. This care was divided into five care categories: intensive care admission (IC-admission), admission (not IC), chemotherapy (chemotherapy, hormonal therapy and immune therapy), radiotherapy and an operation/surgery. The care given was determined based on all DBCs and intensive care Other Products (IC-OVPs) that commenced during the last three months of a patient's life.[13] Expensive medicines, including oncolytics, were not included in the analysis because in 2011 these medicines were not invoiced via the DBCs.

After this, care was classified according to institution and a care-severity correction was applied based on age, gender and socio-economic class, where relevant.

This research provided the following findings.

[12] http://www.rijksgovernment.nl/onderwerpen/levenseinde-en-euthanasie/palliatieve-zorg/quality-palliatieve-zorg-verbeteren

[13] Newly initiated DBCs and IC-OVPs were chosen because it is certain that this care was provided during the final life-phase. With on-going DBCs and IC-OVPs there is the chance that the care was provided in an earlier period. Opting for newly initiated DBCs and IC-OVPs results in underestimating the amount of care provided.

Claim data relating to care during the last 3 months of the lives of people with cancer give the impression that almost everyone who died during the period studied was under the care or control of a medical specialist. A new DBC was initiated for admission to hospital (some to IC) for more than half of the patients who were in their last life-phase. Patients received chemotherapy, underwent radiotherapy or surgery. This research could not form a picture of the extent to which expensive oncolytics were used. Noticeable is that this (invoiced) care during the final life-phase differs between institutions.

Naturally, people in their final life-phase do require an increasing amount of care. Particularly in the final life-phase it is important that the care provided is in keeping with the patient's wishes. From this perspective it is important to know the backgrounds to differences between institutions in the care offered. We suspect that a role is played here in the way in which decisions about choice of treatment are made in consultation rooms.

2.4 Appropriate use of and access to (expensive) oncolytics

We opted for (expensive) oncolytics as a topic for the in-depth phase and were also commissioned to do this by the Minister of VWS. This is based on the following arguments.

- The introduction of new oncolytics goes hand-in-hand with increased costs, which could endanger the accessibility of care.
- Data currently provide no insight into the appropriate use of expensive oncolytics.

2.4.1 The introduction of new oncolytics goes hand-in-hand with increased costs, which could endanger the accessibility of care.

One way of improving the treatment of cancer, including in cases in which it returns after primary treatment, is by making new medicines available. Expectations are that during the next few years many new and promising oncolytics will come onto the market. As these products are generally fairly expensive, and in view of the limited budgetary scope, access to these could be threatened. Several parties drew attention to this problem and attention was also drawn to this by the KWF report 'Accessibility of expensive cancer drugs. Now and in the future' dated June 2014.[14]

In 2013 733 million euro was spent on cancer drugs in the Netherlands, 519 million euro of which was on expensive oncolytics.[14]

In 2011 these statistics were, respectively, 670 million euro and 415 million euro. This means that of the total expenditure on cancer (4 billion euro at the 2011 BKZ level), 17% is spent on oncolytics, 62% of which is on expensive oncolytics; the latter make up circa 10% of expenditure on cancer (BKZ level).

2.4.2 Data currently provide no insight into the appropriate use of expensive oncolytics.

[14] http://www.kwf.nl/over-kwf/Pages/SCK-report-dure-geneesmiddelen.aspx

A broad in-depth analysis focussing on the appropriate use of expensive oncolytics is currently not possible. Not based on claim data, nor based on clinical registers. The Minister of VWS has commissioned Zorginstituut Nederland to shed light onto more general data on the use of expensive oncolytics. Where possible, insight will be provided into whether use is appropriate or not.

Not only does the appropriate use of expensive oncolytics have positive effects on the health of people with cancer, it can also help to guarantee accessibility by avoiding unnecessary costs as far as possible. Unfortunately, our systematic analysis shows that, based on currently available data, we cannot yet obtain insight into the appropriate use of expensive oncolytics. In-depth research is needed.

2.5 Appropriate after-control of people with skin cancer

The Zorginstituut has opted, based on suggestions of the NVDV, for the topic 'Appropriate after-control of people met skin cancer'. We suspect that potential quality improvement can be realised in this after-control by drawing up (properly substantiated) transmural guidelines. In comparison with the other four types of tumours, skin cancer is a special disorder due to the visibility of skin tumours, the generally good prognosis and the fairly limited diagnostic and therapeutic interventions. The results of the in-depth analysis topic 'Appropriate after-control of people treated for breast cancer' are not applicable to skin cancer, which is one of the reasons why the Zorginstituut has opted for both topics.

- Based on recent research, the Dutch Association for Dermatology and Venereology (NVDV) expects quality improvement will be possible in diagnosing all forms of skin cancer by improving how this care is organised.
- Skin cancer is the most prevalent form of cancer. Many people attend after-control due to the fairly good prognosis.

In view of the focus on the after-care phase, Zorginstituut Nederland wants to make use of the above-mentioned advice for the diagnostics of after-control for patients with skin cancer. In collaboration with the NVDV, Zorginstituut Nederland wants to search for quality improvement by improving substantiation and realising transmural guidelines.

The three most prevalent forms of skin cancer are melanoma, basal cell carcinoma and squamous cell carcinoma. The joint incidence of these forms of skin cancer is about 15,000 persons a year. Expectations are that the incidence will continue to rise. Excessive exposure to sunlight is one of the reasons for this. Many people attend after-control because of the good prognosis with skin cancer, particularly basal cell cancer.
Expectations are that in 2030 the incidence of skin cancer will be about 43% higher than in 2012.[7]

2.6 Appropriate use of expensive medicines by patients with mCRPC

The Zorginstituut has opted for the in-depth topic proposed by the NVU, 'Appropriate use of expensive medicines by patients with castration-resistant prostate carcinoma'. In collaboration with the NVU, this in-depth analysis will focus explicitly on research into the appropriate use of expensive oncolytics for this form of prostate cancer.

- The Dutch Urology Association expects quality improvement will be possible in the use of expensive oncolytics for men with castration-resistant prostate carcinoma (mCRPC) and wants to study this in collaboration with Zorginstituut Nederland in the in-depth phase.
- The Zorginstituut chose this topic because the collaboration with professionals offers a unique opportunity for developing a good method for forming a picture of the appropriate use of expensive oncolytics.

The NVU has indicated a willingness to research whether quality improvement is possible in cases where oncolytics are given to patients with mCRPC who may not benefit due to their limited life expectancy.

Prostate carcinoma is the most prevalent form of cancer in men in the Netherlands. Treatment for metastatic disease comprises hormonal therapy, the objective of which is to suppress testosterone, an important growth factor for prostate carcinoma. The tumour generally becomes progressive within two years after starting hormonal therapy. This is known as castration-resistant prostate carcinoma m(CRPC). Recently a number of important medicines, particularly expensive oncolytics, were added to the treatment of mCRPC.
Annually about 3000-4000 men are diagnosed with mCRPC. (NKR data)

2.7 Topics not selected for in-depth analysis

Topics that were not selected include: Care abroad, Mohs surgery for skin malignities in the face, Active surveillance for low-risk prostate cancer, primary treatment of suspicious skin defects and Repeat diagnostics

2.7.1 Care in other countries

The topic 'Care in other countries' was proposed for in-depth analysis during the first round of consultations. The NVVH stated that: "experience teaches that patients who do not receive in the Netherlands the treatment they expected or which they would like, sometimes seek solace in one of the neighbouring countries". We carried out prospective research into data on care abroad and came across the in-depth research of IBO.[15]

The research shows that very little is known about the factors that lead to obtaining care abroad or about its effects. Furthermore, little insight exists into expenditure on cross-border care. A significant reason for this is the lack of (consistent) information.
If more information about cross-border care becomes available via the IBO research, Zorginstituut Nederland will consider analysing this topic in more depth.

2.7.2 Mohs surgery for skin malignancies of the face, Active surveillance of low-risk prostate cancer, primary treatment of suspicious skin defects

As this systematic analysis focuses on care for cancer patients in the phase after primary treatment, the above-mentioned topics – which relate to primary treatment – are beyond the scope of our analysis and are not eligible for in-depth analysis.

[15] IBO has done Inter-departemental Policy Research (IBO) into cross-border care since the start of 2014. This type of policy research is commissioned by the Cabinet and is carried out by inter-departmental work-groups. They develop alternatives for existing policy and cover broad fields of policy involving several Ministries.

2.7.3 Repeat diagnostics

People who are treated for cancer are often confronted with several care professionals, such as surgeons, medical oncologists, radiotherapists, MDL doctors and GPs. If they also have other (chronic) disorders, even more professionals will be involved. We understand, from signals from patients' associations, that greater harmonisation is needed between care providers; patients still often have to listen to every specialist giving his/her own story or recommendations. This can cause confusion and uncertainty in patients. And it raises doubts about appropriate care. This is emphatically not only about harmonisation between care professionals in the second line, but also about harmonisation between the lines.

The exchange of data (communication) between care professionals can facilitate making all diagnostics carried out on a patient available for another care provider, where this is medically possible. This means that patients do not have to undergo potentially taxing investigations.

Research carried out by Zorginstituut Nederland shows that medical tests are frequently repeated: almost one in five tests studied was repeated within three months.[169] The reasons for repeating these tests could not be determined based on claim data. Claim data can only reflect that a repeat took place but do not explain the medical necessity for this repeat. Parties, particularly scientific associations, state that in most cases, there will be medical indications and plausible explanations for repeating the tests.

Zorginstituut Nederland did not select the topic 'repeat diagnostics' for in-depth analysis because, based on their study and the responses during consultations, few indications were found for improving quality.

A study of the claim data leads to a picture whereby, in almost one in five of the diagnostic interventions studied, the same test was repeated within 3 months after the first test. Differences do exist in the number of repeated tests per institution. Professionals give a number of plausible explanations for repeating tests and expectations are that the scope for improving quality for this topic is limited. No (large) communication problem seems to exist between consultation rooms in respect of this topic. This is probably because most repeat tests take place within the same institution.

[16] A variety of medical tests were studied. These included, among others, X-rays, CT-scans and PA examination.

3 Accountability

Zorginstituut Nederland started the Appropriate Care programme at the end of 2013. This programme involves a systematic examination of the insured package. All so-called ICD-10 fields will be analysed in a five-year cycle, the objective being to improve quality and where possible avoid unnecessary costs by using care more appropriately. In implementing the programme, the Zorginstituut is collaborating with all parties in health care: patients, care professionals, care providers and health insurers. The systematic examination will be carried out as far as possible in consultation with them.

This section is a description of how we collaborated with the parties and an examination of the main outlines of the working method of the Appropriate Care Programme. We should comment here that this working method is still currently being developed and can therefore be amended. We aim to ensure optimum quality of analysis, argumentation and underlying information.

3.1 Parties involved

This report is the result of a systematic analysis of part of a ICD-10 care domain, namely oncological after-care for the five most prevalent forms of cancer. It includes the topics selected for in-depth analysis. This is the first report that the Zorginstituut has published within the framework of a screening phase.

This systematic analysis was realised after consulting care professionals, patients, institutions, health insurers and the government. For example, an initial meeting took place in which we explained the approach, planning and goal of the systematic analysis, asked for support and gave the parties an opportunity to make suggestions and introduce topics. Where possible and where interest was displayed, the parties were kept informed about interim progress on an individual basis. Before the first written round of consultations, an informative meeting was held with the parties in which the Zorginstituut explained the findings of the systematic analysis. In the final phase, the Zorginstituut gave the parties two opportunities to submit comments and suggestions by means of a written consultation.

The responses of the parties contributed additional nuances and clarification of our analysis. We included the parties' suggestions for topics for in-depth analysis in Section 2. Furthermore, all parties received an individual written response to their contribution.

3.2 Working method of the Appropriate Care Programme

The Zorginstituut designed a working method for the Appropriate Care Programme in order to systematically examine the way in which care in the insured package is consumed. The key is to identify and combat ineffective and/or unnecessary care, thus improving the quality of care for patients, increasing health benefit and avoiding unnecessary costs. We do this based on a circle of improvement as illustrated below. This circle is comprised of the four sequential phases:

1. Screening phase
2. In-depth analysis phase
3. Implementation phase
4. Monitoring phase

Figure 3. Circle of improvement for Appropriate Care

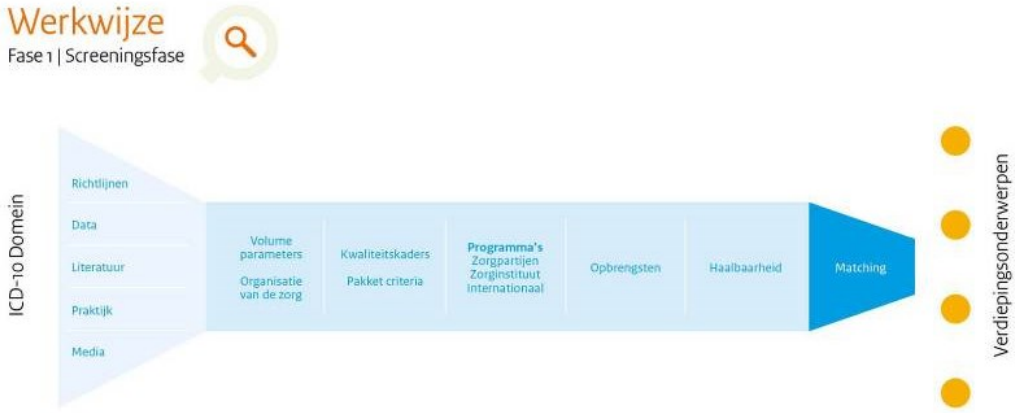
Screening phase
The objective of the screening phase is to select a number of topics for in-depth analysis with a potential for improving the quality of care and avoiding unnecessary costs by using care more appropriately. These topics will be recorded in a 'systematic analysis' report and send to the Minister of VWS.

Steps in the screening phase are:
- Identifying stakeholders (relevant care parties)
- Describing epidemiology
- Collecting sources (guidelines, data, literature, practice, innovations)
- Analysing these sources jointly

The selection of topics for in-depth analysis was based on systematically analysing (the 'snapshot' of the situation) the domain being studied. The following diagramme

represents how the systematic analysis processed and analysed the various sources (guidelines, signals, literature, data) in order to arrive at a good choice of topics for in-depth analysis.

Figure 4. From sources to topics for in-depth analysis



In-depth analysis phase
The in-depth phase comes after the screening phase. The objective of this phase is to to make the method for achieving the potential for improving the selected topics as concrete as possible.

Per topic, detailed analyses were carried out and gaps in knowledge were completed with extra data-analyses, an examination of practice and/or a literature study. The Zorginstituut also collaborated closely with the parties involved during this phase. The final results have been recorded in a so-called 'Room for improvement status'. This states which improvements in care and in health, in respect of both content and extent, are considered possible, and an estimate is given of the amount of avoidable costs. The Zorginstituut will also send the Room for Improvement Status to the Minister of VWS.

Implementation phase
The implementation phase is primarily a task for the parties in health care: patients, care professionals, institutions, health insurers and the government. The objective is to actually realise the possible improvements recorded in the Room for Improvement Status. In the implementation phase the Zorginstituut can play a supportive and facilitative role, for instance, by organising meetings, providing data and feedback and by carrying out additional research. Periodically, the Zorginstituut reports progress made to the Minister of VWS.

Monitoring phase
During the Monitoring phase, the Zorginstituut examines progress, together with the parties involved, and reports on it.

3.2.1 Important elements of the working method

Regular use is made of information within the Appropriate Care Programme. The following is an explanation of key elements of how we process the information.

The Zorginstituut Nederland carries out research into how care included in the basic package is used in practice on the basis of care-related questions. To this end, we collect information from many sources: from discussions with stakeholders to scientific publications, from statistics of the RIVM to claim data.

These are, in part, quantitative data. The Zorginstituut takes various measures to ensure that security and privacy are guaranteed when using data.

For example, the Zorginstituut uses pseudo-anonymous personal data over several years and obtains from various sources that are eventually combined. This is what makes it possible to determine, for instance, whether a patient received medicinal treatment from a GP before undergoing surgery. Or to see which type of long-term care patients receive after an intervention. Combining data sources also makes casemix-corrections possible.

We use claim data from the Declaration Information System (DIS) and from Vektis in order to obtain an impression of care practice. Claim data reflect registration practice and do not always reflect actual care provided. Nevertheless, these data are an important source of information, sometimes the only source, and they can provide valuable signals about the quality of care. A detailed examination of the possibility of using other sources of data is a topic of research, in collaboration with VWS and other parties in health care.

Zorginstituut Nederland

Chairman of the Executive Board

Arnold Moerkamp

Appendix 1 cancer in statistics

This appendix provides a picture of the amount of cancer in the Netherlands. We look at how many patients live with cancer, mortality rates, chances of survival and which care costs are incurred. We will do this for the total of all forms of cancer and for the five selected forms of cancer: lung cancer, breast cancer, intestinal cancer, prostate cancer and skin cancer. We have included data from 2011 and 2012, but also sketch expected developments in 2030.[17]

The rapidly increasing prevalence of cancer is noticeable, as also is the expected growth in care costs. In 2030 the number of people living with one of the five types of cancer studied is expected to increase by almost 50%, from circa 347,000 at the start of 2013 to more than 518,000. This is largely because the Dutch population is ageing, which increases the chance of cancer. It is also because we are better able to treat people with cancer, so they are living longer. For many patients, the disorder cancer takes on a chronic character, which means they rely on oncological after-care. For them it is important that after-care is efficiently customised to meet their needs and that it is of a high quality.

In 2011 care for cancer cost in total more than 4.8 billion euro, which is 5.3% of the total care costs in the Netherlands.[18] An increase in the number of people getting cancer and who live with it will also increase care costs. Expectations are that in 2030 the total costs for oncological care will have almost doubled, reaching 9.1 billion euro. The costs of the five types of tumours selected for this systematic analysis are 1.8 billion euro (2011). Expectations are that this expenditure will also more or less double, reaching circa 3.6 billion euro in 2030.

Unfortunately, there is no way of knowing what proportion of this goes on oncological after-care. Nor do we know how many people with cancer actually make use of after-care, let alone which form and for how long. The prevalence statistics provided should be regarded as an estimate. Where pressure increases on oncological after-care due to the growing number of patients making use of it, costs will rise (more than) accordingly. The focus of appropriate care on this oncological after-care clearly shows that insufficient data are currently available to be able to make a more precise estimate of the costs of after-care covered by basic insurance.

Epidemiology and burden of disease

Prevalence

At the start of January 2013 almost half a million people had cancer (all types). In 2012 more than 100,000 new cancer cases were diagnosed in the Netherlands. Together the five types of cancer selected for this report make up 64% of all new cancer cases in the Netherlands and 73% of the number of people who live with cancer (prevalence of almost 347,000). Expectations are that the prevalence of these five types of tumours will increase by almost 50% to more than 518,000 in 2030.

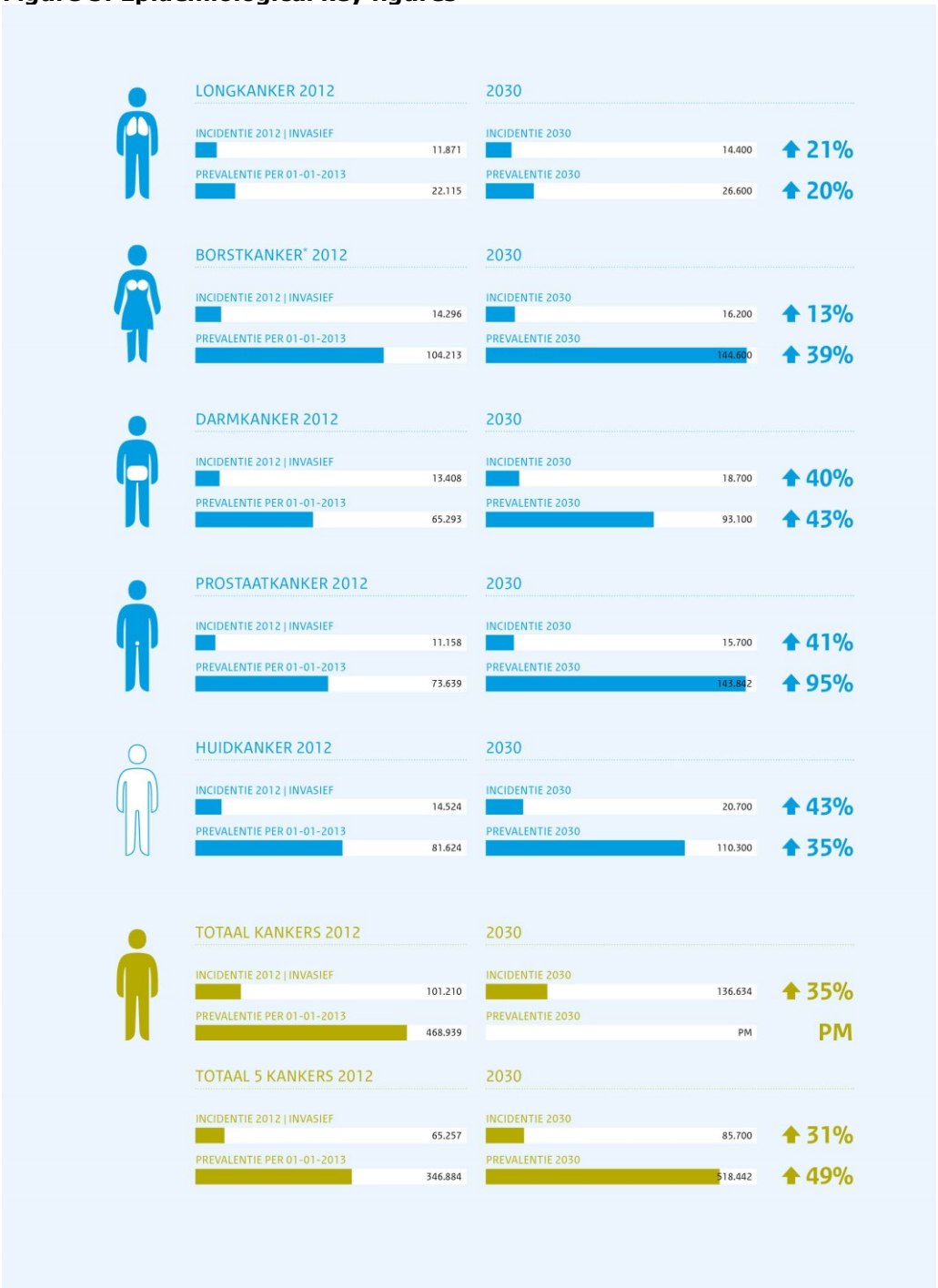
Figure 5 provides an overview of epidemiological key figures for the total number of people with cancer and for the five selected types of tumours, for 2012 and for the year 2030. These data show, among other things, the difference between the

[17] This appendix is an adaptation from the research report commissioned by the Zorginstituut and drawn up by M.J.J.C. Poos, R. Gijsen, H.H. Hamberg-van Reenen of the Health and Society Centre of the RIVM.

[18] These statistics are based on the broad definition of care expenditure that is used in the so-called 'Care-accounts'. Source: Costs of Illness study.

selected types of tumours: in 2012 skin cancer was the most diagnosed form of cancer, lung cancer had the highest mortality and breast cancer the highest prevalence.

Figure 5: Epidemiological key figures*



*The projections of incidence, mortality and prevalence are based on future changes in risk factors and demographic changes. The statistics for breast cancer show an increasing prevalence and dwindling mortality. These are closely linked to the expected increased duration of survival after breast cancer has been diagnosed.

Incidence

The absolute number of new cases of cancer diagnosed annually during the period 1990-2012 increased by more than 57,000 per year to more than 100,000 per year.

A large proportion of this increase is due to the ageing population and the increase in the size of the population in the Netherlands. In 2030 the absolute number of new cases of cancer in the Netherlands will be 35% higher than in 2012 and will amount to more than 136,000 cases.

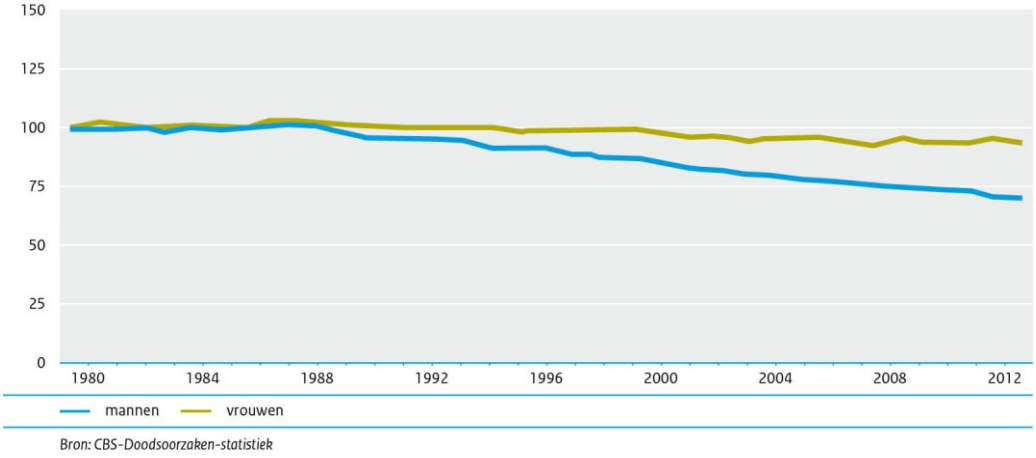
In general, cancer is registered much more frequently in Western Europe, Australia, New Zealand and North America than in less developed regions in the world.[19] The same applies to the five selected types of cancer, although it is noticeable that lung cancer also has a high prevalence in Eastern Asia. Compared with other European countries, the number of new cases of cancer per 1,000 residents is fairly high in the Netherlands.[20]

Mortality

In 2012 there were more than 43,000 mortalities due to cancer, more than 32,000 of which were due to the five selected types of cancer. Mortality due to lung cancer is highest. [21]

In the period 1980-2012 absolute mortalities due to cancer increased from 30,669 to 43,377, a 41% increase. The increase is related to the ageing population and the increase in the size of the population in the Netherlands. If this is corrected, it seems that mortality due to cancer in the period 1990-2012 for men fell by almost 30% and for women by 6% (see figure 6). In fact, therefore, relatively fewer people are dying of cancer. This is probably because treatment has improved.

Figure 6: Cancer mortalities per 100,000 residents per year, according to gender in the period 1980-2012*



*****Standardised according to the population of the Netherlands in 2010 and indexed (1980 is 100).

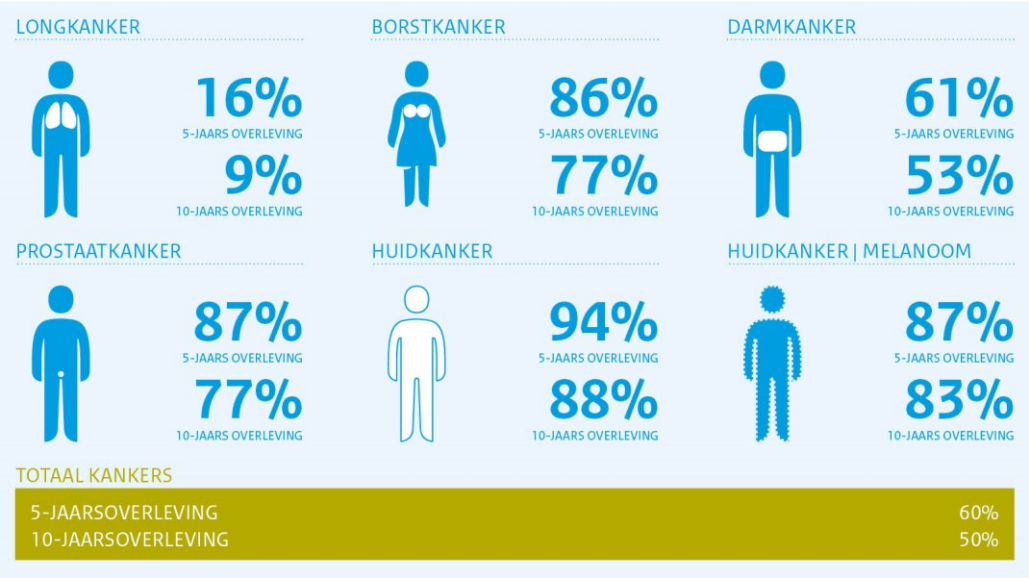
[19] Estimated cancer incidence, mortality and prevalence worldwide in 2012. IARC Cancer Base No. 11. Lyon: International Agency for Research on Cancer, 2013. Website: http://globocan.iarc.fr. Consulted 14 August 2014. Paris: IARC/WHO.

[20] European Cancer Observatory: Cancer incidence, mortality, prevalence and survival in Europe. EUCAN version 4 February 2013. European Network of Cancer Registries, International Agency for Research on Cancer. Website: http://eco.iarc.fr. Consulted 14 August 2014.

[21] The CBS manages the CBS-Mortality Causes Statistics. This registration includes the causes of all deaths of residents in the Netherlands. CBS publishes details of this on CBS-Statline (see http://statline.cbs.nl/statweb/).

Survival
Cancer patients' chance of being cured and their survival chance is closely related to the type of cancer and the degree to which the tumour tissue has grown into the underlying tissue and spread throughout the body. The relative 5-year survival of all patients diagnosed with cancer in the period 2006-2010 is
60%. The relative 10-year survival of all patients diagnosed with cancer in the period 2001-2005 has been fixed at 50%.[22]

Figure 7: Survival for the 5 selected types of cancer



The 5-year survival of patients with cancer increased from 47% in the period 1989-1994 to 60% in the period 2006-2010. The 10-year survival increased from 40% in the period 1989-1994 to 50% in the period 2001-2005 (Source: NKR). The following causes can be cited for the improved survival:
- Cancer is discovered at an earlier stage.
- The treatment of cancer has become more effective.

Burden of disease
The greatest burden of disease of the selected types of cancer among the population is due to lung cancer. The list of diseases with the greatest burden of disease, expressed as DALYs, places lung cancer, breast cancer, intestinal cancer, prostate cancer, and skin cancer respectively on the sixth, seventh, fifteenth, thirteenth and thirty-seventh place. The greatest proportion of burden of disease due to cancer is formed by years lost due to early death (life-years lost).[23]

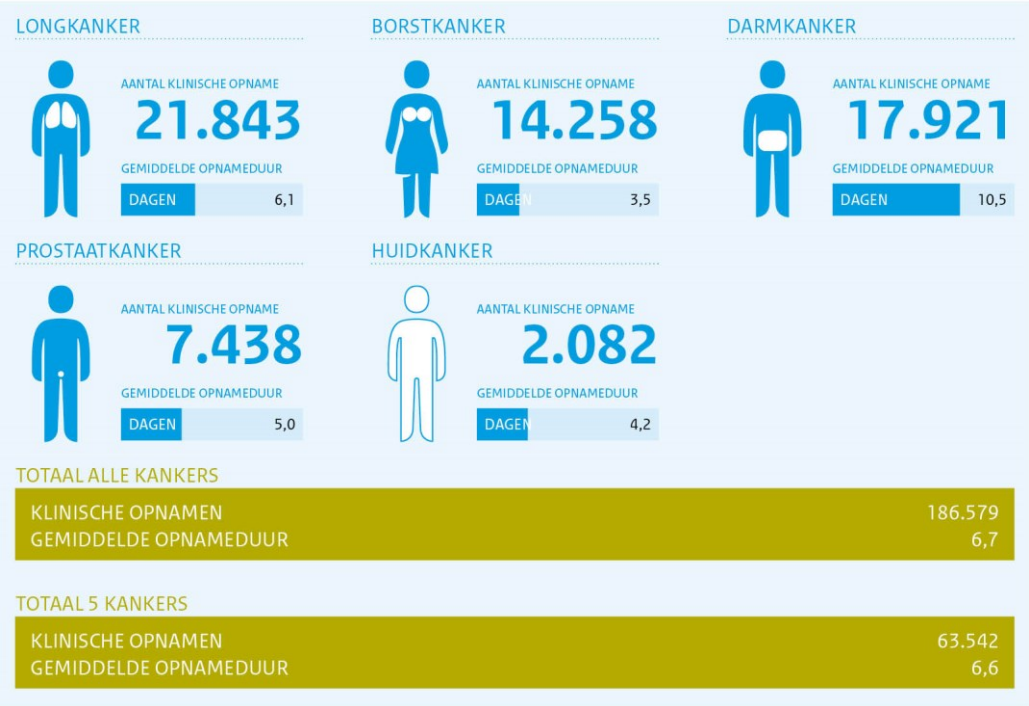
[22] Survival statistics are relative because the survival of patients who have been diagnosed with cancer is related to the survival of persons in the general population (with common age and gender).
[23] DALYs is a frequently used measure for expressing the effect of a disease on public health. The DALY is an aggregate measure for loss of health in the population and is comprised of two components: years lost due to early death and years lived with disease, taking into account the severity of the disease.

Care consumption and costs

Care consumption
In the two years after being diagnosed, cancer patients have on average 11 contacts per year with their GP practice. This includes visits to the practice, telephone contact, consultations and visits by the GP.[24]

In the Netherlands in 2011 there were 186,579 clinical hospital admissions (excluding daytime admissions) for cancer. Admission lasted on average 6.7 days. The total number of clinical hospital admissions for cancer is 9.2% of the total number of clinical hospital admissions. Of the five selected types of cancer, the number of hospital admissions is highest for lung cancer and the average duration of admission is longest for intestinal cancer. The following figure provides an oversight of this.

Figure 8: Clinical admissions and average duration of admission in 2011

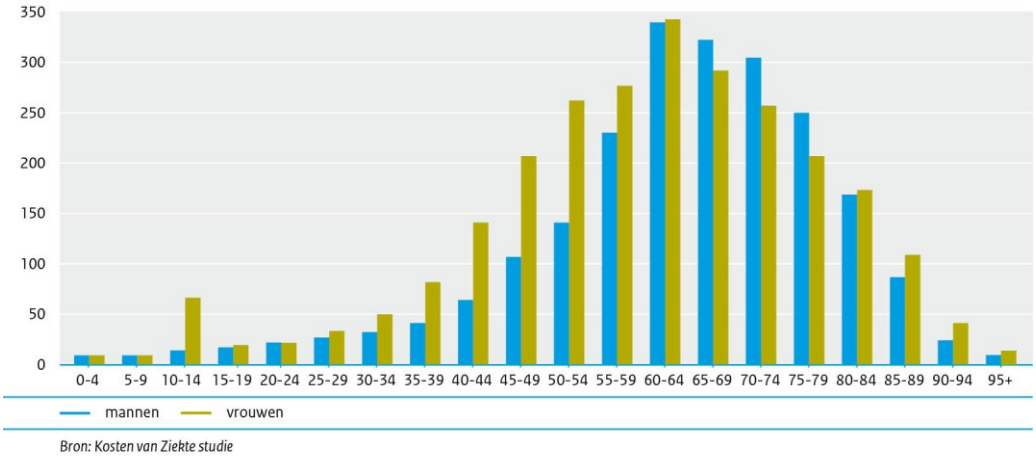


Costs
In 2011 the total costs of care for patients with cancer was 4.8 billion euro. This also includes the costs of care for benign neoplasms. The costs for cancer account for 5.3% of the total costs for Dutch health care (89.4 billion euro). These statistics are based on the broad definition of care expenditure that is used in the so-called 'Care-accounts' (Source: Costs of Diseases Study).
Most of the costs for cancer are incurred in the ages between 55 and 80 years.

The largest proportion of care costs for cancer (73%) in 2011 were funded from the basic insurance (Zvw: 3.5 billion) and 9% via the AWBZ (0.4 billion euro). In 2011 the government funded 13% of the costs via its budget. Due to the existence of population screenings for breast cancer and intestinal cancer, more AWBZ/WLZ funds cover the costs of these diseases.

[24] Korevaar J, Heins M, Donker G, Rijken M, Schellevis F. Oncology in GP practices. General Practitioners Act 2013;56(1):6-10.

Figure 9: Costs of cancer in the Netherlands in 2011 according to age and gender



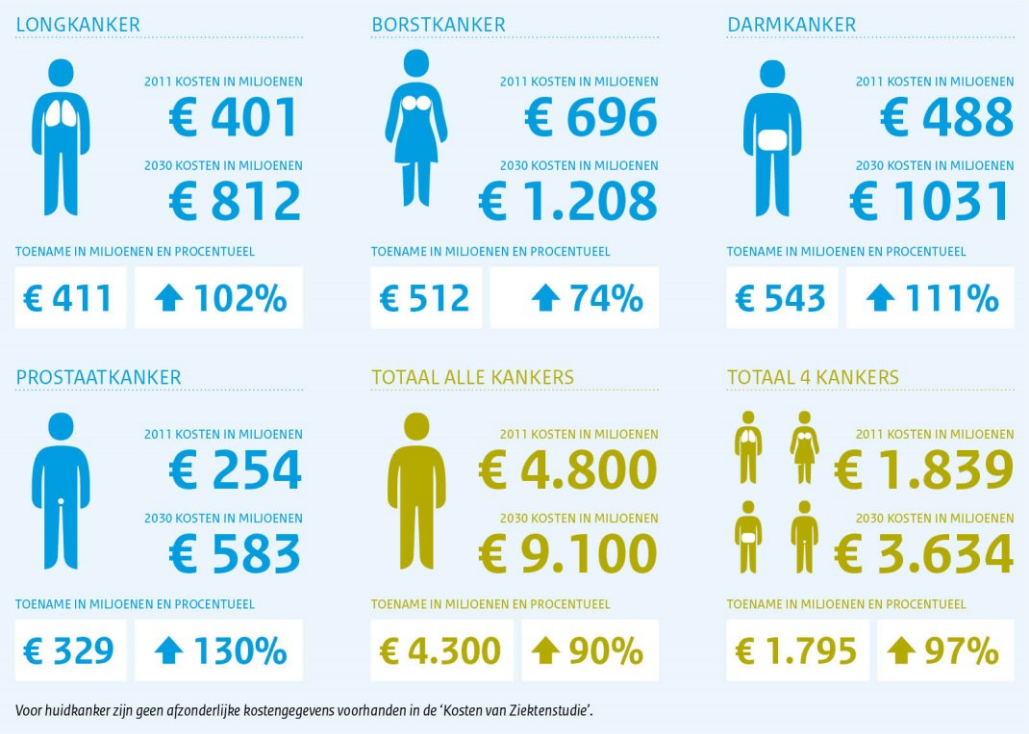
N.B.: The vaccination programme against cervical cancer caused the peak in costs for females aged 10 to 15 years.

The total care costs for cancer are estimated, according to the Budgetary Care Framework (BKZ), at 4.0 billion euro. According to the BKZ, costs are a ministerial accountability and are, mainly, costs of care under the Zvw, the AWBZ and the Wmo.[25] Costs for supplementary insurances, personal payments and a few welfare items were not included (though they are included in the 'Care Accounts').

Care expenditure on cancer is expected to almost double up until 2030; this will rise to 9.1 billion euro in 2030. For the five selected cancers, an increase up to 3.6 billion euro is expected for that year. Figure 9 reflects the combined costs for all cancers and for the five selected cancers. Data on costs are available for skin cancer. Expenditure for breast cancer was highest in 2011; and the expected growth will be lowest for 2030. This is despite the expectation that the costs of other types of tumours will more than double in 2030.

[25] The combined WMO expenditure on all types of cancer amounted in 2011 to an estimated 71 million euro. Wmo costs include the costs of family household help and medical devices.

Figure 9: Care costs in 2011 and 2030 *



* Absolute and percentage growth, at the level of Care Accounts.
*For this calculation, changes in expenditure in the various care sectors were analysed over the the period 2007-2011 and used to make a future projection (without taking inflation into account); demographic projections were also included.
** No individual cost data are available for skin cancer in the 'Costs of Diseases Study'.