



ZINNIGE ZORG ROOM FOR IMPROVEMENT REPORT

In-depth phase neoplasms: care during the
final stage of life of patients with incurable
intestinal or lung cancer

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Zorginstituut Nederland and Zinnige Zorg

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We discuss our findings with health care professionals, patients, health care institutions, health care insurers and other governmental agencies. Together with them, we examine what is needed to improve patients' care and avoid unnecessary costs.

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Summary

Background

The final stage of life is one in which a patient is of an advanced age or has a disease and/or is in a phase of a disease that will be life-threatening within the foreseeable future. In cases of cancer the disease will generally have spread, and this is described as the palliative phase. Current cancer treatment makes it possible to control the cancer and the metastases during months and sometimes even years, while retaining a good quality of life. Nevertheless the patients still have an incurable disease.

People sometimes think that the palliative phase and the final stage of life is the same as the phase of dying. This is emphatically incorrect. The stage of dying is the phase before the end of life. The palliative phase is the phase from the diagnosis of an incurable (metastatic) disease, until death. The final stage of life is the phase of a disease that will become life-threatening within the foreseeable future. The start of the palliative phase is clear: it is upon diagnosis of metastatic disease. The start of the final stage of life (a life-threatening disease within the foreseeable future), however, is more difficult to define, because survival is more variable due to improved treatment possibilities.

In-depth research

In this Room for Improvement Report, *Zorginstituut Nederland* presents the results of its in-depth research into care for patients with lung cancer or cancer of the intestines in the final stage of life. Publications, scientific and secular, have raised the suspicion that treatment is relentless in the final stage of life. This refers to chemotherapy and irradiation. A large-scale study carried out recently in the Netherlands involving the care experience of patients, their families and care givers painted a similar picture.¹ *Zorginstituut Nederland* has carried out research into care given in the final stage of life of people with lung cancer and cancer of the intestines. Specifically we carried out research into treatment given by medical specialists and diagnostics carried out on patients with lung cancer or cancer of the intestines in the final months of their life. We also examined aspects in the care chain that may influence such treatment. In particular the research focussed on communication with patients, (joint) decision-making and communication between the care-providers involved.

We chose lung cancer and cancer of the intestines because in general metastatic lung cancer has a poor prognosis and metastatic cancer of the intestines is a disease that actually has a long period of survival. Having chosen these two types of tumours, the *Zorginstituut* examined whether a difference in course of the disease influenced the care offered in the final stage of life.

Findings

The most important research result is that less use is made of treatment during the final months of life: chemotherapy, radiotherapy, biologicals and operations are less likely to be initiated as the end of life draws near. This differs from the picture of relentless treatment during the final stage of life. However, general care given in the final months of life does increase: patients visit casualty more frequently, are admitted to hospital or to IC more frequently, they receive more surveillance visits and diagnostics. Research shows that this general consumption of care is influenced by the treatment perspective. Patients who receive palliative treatment such as chemotherapy or radiotherapy during the final months of their life have a higher

chance of being admitted to hospital or of dying in hospital than patients who received palliative treatment for their symptoms, while generally, people would prefer to die at home if at all possible. For this reason we see possibilities for improving this care. Specifically in the way in which an appropriate treatment perspective is clarified and discussed, both for patients and for the care-providers involved, along the entire chain of care. We elaborate on this in three recommendations.

The research results paint a picture that applies to both patients with lung cancer and those with cancer of the intestines. We do not preclude the possibility that the results and insights from this study could also be generalised to apply to other types of tumours.

Recommendations

Below we expound on three recommendations for improving care: clarification of palliative care needs, clarification of the treatment perspective and multi-agency harmonisation. The starting point for the improvement recommendations is an appropriate treatment perspective, and the consideration this is given by the patient and the care providers involved. After this, proper harmonisation between care providers is a precondition for ensuring that, in practice, care is actually given from the patient's perspective. For this reason we elaborate on the chain of care and specifically multi-agency harmonisation. If the recommendations are implemented, patients will have more clarity about the possibilities and limitations of disease-oriented palliative treatments such as chemotherapy, radiotherapy or surgery. At the same time patients will get clarity about their options in the event they choose not to undergo disease-oriented treatment. An added effect is that the care providers involved will be more able to deploy care with an appropriate treatment perspective: care that is in keeping with the patient's wants and his or her care needs in view of the imminent end of life.

During consultations, the parties emphasised the great value of a societal debate, with the help of the media. *Zorginstituut Nederland* sees added value for continuing both activities.

Starting to explore palliative care needs upon diagnosis of an incurable disease, irrespective of the recognisable initiation of the final stage of life

To offer care that is in line with a patient's palliative care needs, the patient's personal aims and preferences must be explored at an early stage: at the start of the palliative phase, at the moment when the incurable disease is diagnosed. Afterwards, during the further palliative course of the disease, the care needs should again be explored and where necessary adjusted so that care is deployed with an appropriate treatment perspective. Guidelines, such as those developed by the scientists, can support care givers in entering into timely – and repeated – dialogue with patients about their palliative care needs and the appropriate treatment perspective.

Clarifying the treatment perspective: shedding light on treatment possibilities and impossibilities:

Other possibilities for care still exist if disease-oriented treatment – such as palliative chemotherapy and/or radiotherapy – is no longer possible. Increased transparency in treatment guidelines about treatment possibilities, and possibilities for non-initiation of treatment, provides medical specialists with a basis for informing patients. Providing patients with good information precedes (joint) decision-making. It allows a patient an opportunity to consider the possibilities and impossibilities of disease-oriented treatment when considering which treatment and

care is appropriate.

Improving multi-agency harmonisation and increasing primary care involvement

Improving multi-agency agreements will improve the continuity of care for patients and ensure that care is provided in the most appropriate location that is preferred by the patient. An efficient multi-agency handover is a precondition for ensuring in practice that care is actually given from the patient's perspective. Multi-agency harmonisation could improve with a national multi-agency information standard for handovers between primary and secondary care. The standard for handovers will state what agreements exist on care to be given during the final stage of life and at the end of a life, and how it should be in line with a patient's preferences (also known as advance care planning, hereafter ACP). This recommendation also requires (additional) training for the professional groups concerned, specifically in shared decision-making skills and ACP.

Implementation

Parties have already introduced some good initiatives. During consultations, the parties made concrete suggestions for implementation and ownership in line with initiatives in this field of care. In view of the involvement and accountability of all parties, *Zorginstituut Nederland* expects implementation of the improvement recommendations to go smoothly.

1 1. Introduction

1.1 1.1 Systematic screening

In this Room for Improvement Report *Zorginstituut Nederland* presents in-depth research into care for patients with lung cancer or cancer of the intestines in the final stage of life. The *Zorginstituut* published this report within the context of a systematic assessment of the insured package. It is one of the in-depth studies within the ICD-10 field Neoplasms (C00-D48).

The aim of this Room for Improvement Report is to gain insight into the potential for improving care and how these improvements can be realised. We are establishing this potential for improvement in dialogue with the parties. The improvement measures will be implemented in a follow-up trajectory. Appendix 1 provides detailed information about the working method of *Zinnige Zorg*, the parties involved and the process that resulted in this Room for Improvement Report.

1.2 1.2 Choice for final stage of life in cases of lung cancer and cancer of the intestines

In April 2015 the *Zorginstituut* published the screening report on Neoplasms.² This revealed that cancer patients were almost all being treated or managed by a medical specialist during the last three months of their life. More than half of the patients admitted to hospital in those last months of their life end up in Intensive Care, receive chemotherapy, receive radiotherapy or undergo surgery. There are also signals from professional groups, patients' associations, health insurers and the KNMG report ('Not everything that is possible should be done') that treatment continues even when it has no added value for the patient.

Coalition of hope

Research from the United States shows that circa 70% of patients with metastatic lung cancer and 81% of patients with metastatic cancer of the intestines do not know that treatment for their disease does not have a curative intention. We do not know whether this finding also applies to the Dutch situation. From a large-scale Dutch study among patients, their families and care givers on their experience of care in the final stage of life, we know that talking about the final stage of life, and accepting the end of life, is not common in our society. Doctors prefer not to speak about 'non-initiation' of treatment. At the same time, patients do not want to give up. According to the researchers, this so-called 'Coalition of Hope' is an important mechanism that can contribute to relentless treatment. **Fout! Bladwijzer niet gedefinieerd.**

Cure is no longer possible once cancer has spread. The short-term prognosis for metastatic lung cancer is generally poor. Survival time for metastatic cancer of the intestines is longer. By choosing these two tumour types, we want to examine whether a different course of the disease has any influence on care provided in the final stage of life. If the study results are the same for types of tumour with a different course, we do not preclude the possibility that the results and insights can be generalised to other types of tumour. Parties in the field support the choice of these two types of tumour for in-depth analysis in relation to this topic. ^{2,a}

1.3 1.3 Demarcating the in-depth analysis

To obtain insight into where room for improvement exists, the *Zorginstituut* carried out an analysis that is comprised of various elements. We explain further below.

In-depth study

Zorginstituut Nederland has carried out research into care provided in the final stage of life of people with lung cancer and cancer of the intestines. This so-called snapshot of daily practice is based on external research that was commissioned by the *Zorginstituut* and carried out over the period 2013 to 2015 incl. In addition, during a consultation meeting in September 2015, together with the parties, improvement measures were formulated to demarcate the in-depth analysis. We translated the proposed improvement measures into research questions and then commissioned a number of parties to carry out external research. In translating the research questions, we focussed on general points of departure for the systematic screening: the perspective of the patient and the care he/she needs.³ In particular the research focussed on communication with patients, (joint) decision-making, and communication between the care-providers involved in the health care chain. To summarise, it involved the following research questions:

- (i) which instruments are available to support doctors and patients in the process of (joint) decision-making on treatment decisions in the final stage of life?
- (ii) which palliative care needs exists and how large are they?
- (iii) how does harmonisation take place with primary care and advance care planning: to what degree are GPs involved in harmonisation with patients and other care givers?

A summary of the research tasks and the external research parties is provided in appendix 2.

Elements of good and appropriate care

The *Zorginstituut* describes eight approaches in the form of eight elements of good and appropriate care. These elements are described further in appendix 1. These elements are used to describe current care practice based on, for instance, guideline analyses, analyses of practice data, (cost-)effectiveness analyses and quality data analyses.

^a The parties involved include: Dutch Patients' Federation, Living with cancer, Dutch Association of General Practitioners (NGH), Dutch Association of Surgeons (NVvH), Dutch Association of Doctors for Lung Diseases and Tuberculosis (NVALT), Dutch Association for Radiotherapy and Oncology (NVRO), Dutch Association of Internal Medicine (NIV), Dutch Association for Medical Oncology (NVMO), Dutch Association of Hospitals (NVZ), Collaborating Top-Clinical University Hospitals (STZ), Dutch Federation of University Medical Centres (NFU), Federation of Medical Specialists (FMS), Dutch Association of Health Insurers (ZN)

Kwaliteitscriteria	
Kenbaarheid van zorg	Beschikbaarheid van kwaliteitsstandaarden (zoals richtlijnen), informatiestandaarden, patiëntinformatie/keuzehulpen en meetinstrumenten (PREMs/PROMs).
Toepassing in de praktijk	Implementatiegraad van kwaliteitsstandaarden, patiënten versies/keuzehulpen en meetinstrumenten: analyses praktijkdata, literatuur. <ul style="list-style-type: none"> • Worden aanbevelingen in de praktijk geïmplementeerd? • Hoe is de uitvoering van de zorg?
Uitkomsten van zorg	Is er kwaliteitsinformatie over uitkomsten van zorg beschikbaar en vindbaar?
Pakketcriteria	
Effectiviteit	Is de zorg effectief, wat heeft de patiënt aan de behandeling? <ul style="list-style-type: none"> • Wetenschappelijke onderbouwing van richtlijnen. • Er kunnen signalen zijn die aanleiding geven om (opnieuw) te onderzoeken of de zorg bewezen effectief is en voldoet aan het criterium <i>Stand van de Wetenschap en Praktijk</i> middels een formele beoordeling volgens de GRADE systematiek?
Kosteneffectiviteit	Is de zorg kosteneffectief? <ul style="list-style-type: none"> • Hebben richtlijnen hier iets over geschreven? • Er kunnen signalen zijn die aanleiding geven om (opnieuw) te onderzoeken of de zorg kosteneffectief is.
Noodzakelijkheid	Is het noodzakelijk om de behandeling te verzekeren?
Uitvoerbaarheid	Is voldaan aan de randvoorwaarden en de houdbaarheid van het deel uitmaken van een interventie in het basispakket?
Overall	
Samenhang in de kwaliteitscirkels	Hier kijken we wat de samenhang van de kwaliteitscirkel is en wie zich hiermee bezig houdt.

As the reason for this Room for Improvement Report resulted in clearly demarcated topics, the *Zorginstituut* did not carry out additional systematic reviews of guidelines or onus of proof of Advance Care Planning, shared decision-making and the timely deployment of palliative care. Furthermore, the results of the data analyses do not form a reason for carrying out effectiveness analyses of individual diagnostics or treatment interventions (see appendix 4).

Scope

The scope of this Room for Improvement Report is the care provided by medical specialists in the final stage of life. Home care, care in hospices and after-care for survivors are beyond the scope of this Room for Improvement Report.

1.4

1.4 Structure of this report

In **section 2** we explain concepts frequently used in this Room for Improvement Report. Concepts such as the final stage of life and the various palliative treatments are not always used consistently. In **section 3** we provide general information about incurable lung cancer and cancer of the intestines. Care offered to people with lung cancer and cancer of the intestines in the final stage of life is described in **section 4** based on the study results: the 'snapshot' of daily practice. Using this snapshot, we shed light on the potential for improvement. In **section 5** we refer to changes in care that are needed to realise more appropriate care in the final stage of life: the 'improvement activities'. The improvement activities proposed by the parties, the external research results involved and the analysis of elements of good and appropriate care form the basis to this Room for Improvement Report. **Section 6** discusses the implementation and monitoring of improvement measures.

2 2. What care is involved?

In this section we explain important concepts that are frequently used in this Room for Improvement Report. We do this because such concepts as the final stage of life and the various palliative treatments are not always used consistently. Some attention is also given to the concept of relentless treatment.

The survival of patients with incurable diseases has improved during recent decades due to the arrival of personalised treatment possibilities. As a result, the duration of the final stage of life is more variable, and cannot be estimated with any certainty. According to some publications – scientific and secular –, doctors continue treatment for a long time in the final stage of life. Patients, relatives and care givers are of the same opinion. **Fout! Bladwijzer niet gedefinieerd.**

2.1 2.1 Palliative care

Palliative care is care during the treatment of an incurable disease and care in the phase in which a patient is dying (see figure 1). Palliative care focuses on various dimensions of being ill, e.g., physical, psychosocial and existential dimensions. In principle, such care is provided in a multidisciplinary setting (by several care providers).⁴

The final stage of life is one in which a patient is of an advanced age or has a disease and/or phase of disease that will be life-threatening within the foreseeable future.^b In cases of cancer the disease will generally have spread, and this is described as the palliative phase. Current cancer treatment makes it possible to control the cancer and the metastases during months and sometimes even years, while retaining a good quality of life. Nevertheless the patients still have an incurable disease.

People sometimes think that the palliative phase and the final stage of life of life is the same as sometimes the phase of dying. This is emphatically incorrect. The stage of dying is the phase before the end of life. The start of the palliative phase is clear: it is upon diagnosis of metastatic disease. However, defining the start of the final stage of life (a life-threatening disease within the foreseeable future), is more difficult, because survival is more variable due to improved treatment possibilities.

The focus in the terminal phase is on trying to ensure the best possible quality of death. In the palliative phase, and thus also in the final stage of life, the focus of care is on retaining quality of life. After death, follows a period of after-care for surviving relatives.

Palliative treatment comes in various forms. In all cases, the objective is to retain or improve quality of life. On the one hand by treatment that focusses on the disease and metastases in order to prevent symptoms (disease-oriented treatment), on the other hand by treating symptoms (disease-oriented symptom palliation). If the disease no longer responds to this disease-oriented treatment, it ends and the focus switches to maximum symptom relief and comfort (best supportive care).^c

^b There are several definitions of the final stage of life. This Room for Improvement Report uses the definition described in the report KNMG. Niet alles wat kan, hoeft. 2015. Available via <https://www.knmg.nl/advies-richtlijnen./dossiers/niet-alles-wat-kan-hoeft.htm>

^c For an explanation of the various concepts, we use the definitions of various sources, such as the national

Disease-oriented, potentially life-extending palliation:

The primary objective of disease-oriented palliation is to retain and promote quality of life by inhibiting the disease (the cancer and the metastases), thereby reducing and where possible preventing symptoms. Disease-oriented therapy can potentially be life-extending. Examples of this are palliative chemotherapy, immunotherapy or hormone therapy. These can be used if there are numerous metastases in the patient's body.

Disease-oriented symptom palliation:

The objective of disease-oriented symptom palliation is to reduce local symptoms and thus realise the best possible quality of life with retention of cognitive functions. The objective of disease-oriented treatment of symptoms is to reduce symptoms quickly or in the not too distant future by treating the tumour. *Treatment does not inhibit the disease, but tackles mainly the symptoms of the disease. Examples are palliative surgery and palliative radiotherapy. The latter can be used as local treatment of local (i.e. at the site of) tumours or metastases that cause symptoms.*

Supportive treatment (best supportive care):

There are two components to supportive treatment: one that focuses on disease-related symptoms and the side effects of the 'active' treatment. This is comprised of treatment with drugs. A second component focuses on the psychosocial and existential dimensions of disease. Best supportive care is often given in addition to other palliative forms of treatment.

Care provided in the final stage of life is comprised of more than the above-mentioned palliative treatments. Care can also include visits to casualty departments, admissions to hospital (in a ward or on Intensive Care), visits to out-patients' departments or day-time treatment and the diagnostics involved. This is described as general care in this Room for Improvement Report.

2.2

2.2 Relentless treatment

There is no unequivocal definition of relentless treatment. In general one speaks of relentless treatment if the treatment has no further added value, or if a patient is suffering unnecessarily. This will be different for each patient, as explained below.

New – more individualised – treatments make it possible to keep a rein on cancer for several months or even several years. In certain cases of advanced disease, treatment can be given with other medicines, making it possible to inhibit the disease for a varying period of time. These are disease-specific treatments that can potentially extend life, though they cannot cure the disease. The question is, when does a treatment still have added value and when can one speak of relentless treatment or overtreatment? In other words: when does a (marginal) increase in life expectancy no longer weigh up against the side effects, burden on the patient and loss of quality of life? Seen in this light, it is important to be able to recognise initiation of the final stage of life. In general, when the estimated life expectancy is short, professionals tend to refrain from deploying disease-oriented treatment in

guidelines 'General principles of palliative care' of the IKNL and the report 'Not everything that is possible should be done'

order to avoid overburdening the patient unnecessarily. However, it is not always easy to recognise and demarcate the final stage of life. Toleration of new, more individualised, treatments is generally better than that of classic chemotherapy. As a result, estimating whether treatment still has added value can become even more complex. In other words, the variability of the duration of the final stage of life makes it difficult to estimate when treatment has become relentless (figure 1).

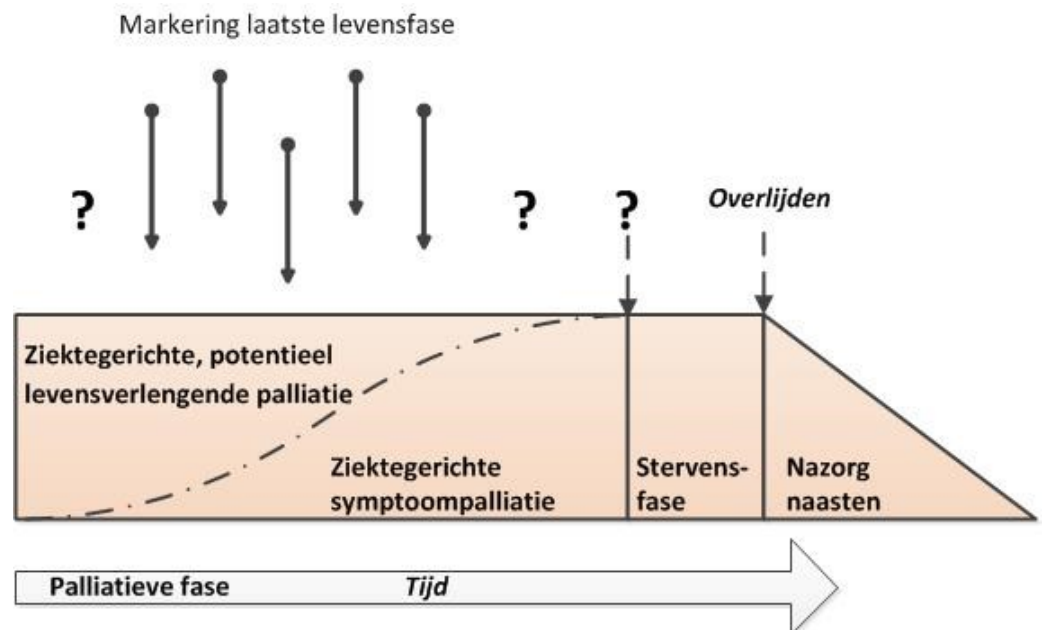


Figure 1. Various phases/stages of the palliative phase

2.3 2.3 Decision-making in the palliative phase

Ideally, the doctor and patient are involved in a joint process of decision-making on the objectives of treatment and care. They do this based on scientific knowledge about the possibilities and limitations of treatment and based on the patient's preferences: does the patient want to live longer or have a better quality of life?^d Communication with the patient and about adjusting his/her life's objectives and treatment perspectives, in view of altering prospects regarding the disease, probably play a bigger role in the final stage of life than in earlier phases of the disease.

Advance Care Planning

"Advance Care Planning (ACP) is a continuous process of discussions about life goals, how care fits in with these and how they can best be adjusted according to the patient's preferences. Treatment decisions about, e.g. resuscitation, and palliative care options will be part of this, as will discussing certain scenarios, e.g. the occurrence of complications and the side effects of treatments."⁶

^d There are different values and norms about initiating a discussion on disease and imminent death. Research has shown that the degree to which patients are willing to participate in decision-making on treatment varies greatly. This is to do with differences in values and norms about patient's autonomy and the right to integral information. Separate from the degree to which patients want to participate, most patients want to be well-informed about the disease and possible treatments

Decision-making will repeatedly weigh up potential health gains in terms of reducing symptoms and extending life against the possible impact of treatment on the patient's quality of life. This impact is not only about possible side effects, but also about the time a patient invests in undergoing treatment and the general care this inevitably involves. Transport to and from hospital and a period of admission can represent both a physical and a mental burden to the patient.

Shared decision-making is an intense process of decision-making and communication that is necessary for preference-sensitive or value-sensitive decisions. Preferred or preference-sensitive decisions are when there is more than one treatment option or where dilemmas exist about the advantages and disadvantages of the intervention.⁷

The quality and quantity of life often seem mutually exclusive where palliative care is concerned. This need not necessarily be the case, as we will illustrate with a case:

Case – Mr Van Zanten.^e

Mr Van Zanten had only been a pensioner for a few months when his lung specialist told him that he was incurably ill. He had been diagnosed with lung cancer or, to give it its full name: non-small cell lung cancer, stage IV. This means that the disease had already spread to other organs, including his liver. Mr Van Zanten learned that he would die from the disease, possibly within a year.

Mr Van Zanten had always lived a full life and was in fact never ill. He enjoyed life to the full and had a Burgundian life-style. Last year his brother-in-law died after a long, dreadful battle against metastatic intestinal cancer. After the funeral, he told his wife and two daughters that he would never choose to battle for so long, as it was not in his nature. During the discussion with the lung specialist, Mr Van Zanten heard that there was in fact only one treatment option and that was chemotherapy. Not to cure him, but possibly to reduce the symptoms and extend his life a little. The drawback to treatment was that it would last three months and result in many side effects. Normally speaking, Mr Van Zanten would have chosen not to undergo this treatment, but fate had decreed that he just heard that one of his daughters was pregnant and he would become a grandfather for the first time. As he desperately wanted to experience this event and he was in relatively good condition, he decided to undergo chemotherapy after all.

In this case the patient opted for a treatment that he would not initially have regarded as adding to his quality of life. By choosing to extend his life, and accepting the inevitable side effects, he hoped he would be able to experience becoming a grandfather. This event was of enormous value to him and would actually contribute to his quality of life.

^e Fictitious case

3 3. The final stage of life in cases of lung cancer and cancer of the intestines

In the previous section we saw that the duration of the final stage of life is variable due to improved treatment possibilities. In this section we discuss the clinical picture and epidemiology of incurable lung cancer and cancer of the intestines.

The care of people with lung cancer or cancer of the intestines is expected to increase. This expected increase is based on the ageing population and improved treatment possibilities, as a result of which more people are surviving after treatment and needing general care or follow-up treatment.

3.1 3.1 Clinical pictures

Incurable lung cancer and cancer of the intestines

Cells can break loose from a malignant tumour. These cancer cells can be transported by the blood to elsewhere in the body and grow into new tumours. This is when the disease has spread; these are called metastases. Initially, metastases remain undetected. Eventually, however, metastases can cause symptoms. Whether they cause symptoms depends on the tumour's activity and its location. Lung cancer spreads mainly into bone, the adrenal glands, the liver and the brain. Intestinal cancer spreads mainly into the liver, the peritoneum or the lungs. Metastases in bones can cause pain or fractures. Extensive metastases in the liver can cause nausea, lack of appetite, a yellowish skin and metastases in the lungs can block the airways, resulting in breathlessness or pneumonia. Cure is no longer possible once metastases have developed in other places than the site of the original tumour.

The course of the disease and the prognosis of patients with cancer that has spread depends largely on the particular characteristics of the tumour, the patient's physical condition and the availability of effective treatment options. Treatment for metastases is generally medicinal and focusses on the whole body, because metastases generally occur in several places in the body. This is known as systemic therapy. The average life expectancy of metastatic lung cancer patients who are not treated is seven months and with treatment (e.g. chemotherapy or biologicals) it is several months longer. The treatment arsenal was recently enlarged with new products for patients with locally advanced and metastatic lung cancer. These are expected to extend the period of survival.⁶ The life expectancy of metastatic intestinal cancer patients who receive treatment is about two and a half years. Survival varies more widely, however, within the stage of metastatic cancer of the intestines. Sometimes curative treatment is still possible in cases with limited metastases in the liver or lungs, possibly with a longer survival. In that case treatment is generally comprised of local treatment of the metastases (mostly surgery) combined with systemic therapy (e.g. chemotherapy).

3.2 3.2 Epidemiology

Annually about 12,000 people are diagnosed with lung cancer in the Netherlands.

⁶ In 2015 the BOM committee issued positive advice on Nivolumab for the treatment of non-small cell lung cancer. Nivolumab is a form of immunotherapy for the treatment of non-small-cell lung cancer for the stages of locally advanced or metastatic disease after prior treatment with chemotherapy for locally advanced or metastatic disease.

Roughly speaking there are two types of lung cancer: non-small cell lung cancer (or NSCLC, 80% of the patients), and small cell lung cancer (or SCLC, 15% of the patients with lung cancer). SCLC can be distinguished from NSCLC by the course of the disease, which is frequently aggressive. For both types of tumour, in more than 80% of cases the disease has already spread to the lymphatic glands or other organs at diagnosis. Cancer of the intestines has the highest incidence in the Netherlands after breast cancer in women and prostate cancer in men and it generally occurs in people older than 60 years. In 2015, 15,549 people were diagnosed with cancer of the intestines. The cancer of almost half of the patients is still limited to the intestines at diagnosis, while the other half already have metastases elsewhere, in the lymphatic glands or other organs.

After being diagnosed, the chance that a patient will still be alive after five years depends very much on the stage of the disease at diagnosis. The chance that a lung cancer patient is still alive five years after being diagnosed is 10% or less. This differs from patients who had no metastases at diagnosis: 75% of these are still alive five years after being diagnosed. In 2015, 12,851 people died of lung cancer. These survival statistics are more favourable for patients with cancer of the intestines. The chance that a patient is still alive five years after being diagnosed with non-metastatic cancer of the intestines is 90% or more. While those whose disease had already spread to other organs at diagnosis have a five-year survival of less than 10% without treatment. In 2014, 4,906 patients died as a result of cancer of the large intestines.

Cost developments

In 2011 the total costs for people with lung cancer or cancer of the intestines were 401 million and 488 million euro respectively. Claim details relating to care during the last three months of the lives of people with cancer show that almost everyone who died during the period studied was under the care or control of a medical specialist. More than half of the patients with lung cancer and cancer of the intestines were admitted to hospital (including admission to IC) or received treatment during the final stage of their life. These costs are expected to have doubled by 2030.² This expected increase is based on the ageing population and improved treatment possibilities, as a result of which more people are surviving after treatment and needing care or follow-up treatment.

3.3 Chain of care for an incurable disease

After an incurable disease has been diagnosed, a choice is made between palliative care and treatment, depending on the patient's condition and the extent of the metastases. Various care providers are usually involved in their care, depending on the patient's care needs. Apart from a medical specialist, other professionals who may be involved are nurses and paramedics, e.g. a social worker, psychologist, spiritual carer or physiotherapist. Palliative care is multidisciplinary care.

When disease-oriented treatment is not possible, care focusses on maximum comfort and alleviating symptoms. This is when patients are generally 'discharged' from hospital and referred back to their GP. The GP often sees the patient for the first time after a longer period of treatment and perhaps follow-up treatments in hospital. Unexpected medical problems can occur after 'discharge' from the hospital. For instance, existing symptoms can suddenly exacerbate, or new symptoms may develop. This may result in a situation in which a patient has to visit casualty for diagnostics, and possibly be admitted for treatment. Assessments in casualty, visits to outpatient clinics and the resulting diagnostic tests and treatments can be very

burdensome, both physically and mentally, for people with far advanced disease and a poor physical condition.

A GP usually cares for a patient in the period when death is imminent. Although dying in one's own home is regarded as the ideal, sometimes care cannot be provided at home. This leaves the possibility of dying in a hospice or another care institution that is equipped for the purpose.

4 4. Care in the final stage of life for people with lung cancer or cancer of the intestines: insights from daily practice

In the previous section we saw how treatment possibilities have improved, also in the palliative phase of the disease. As a result, how long the final stage of life will last varies, and assessing whether treatment has any added value for the patient is complex. In this section we describe care that is provided in the final stage of life of patients with lung cancer or intestinal cancer. We do this using the results of external research commissioned by the *Zorginstituut*. Such research answers the question of whether treatment is becoming relentless. Strictly speaking, to answer this question we need research into the degree of health gains or losses as a consequence of the care given and what added value this has for the patient. We can see where care can be improved by describing it from the patient's perspective. Our conclusion is as follows:

Most people in their final stage of life want as far as possible to receive care at home (or close to it) and to die at home.^{8,9,10} However, in the final stage of life we see an increase in the number of hospital contacts, depending on the objective of the treatment. This is about general care use: visits to emergency care, admissions to hospital and intensive care departments, visits to out-patients clinics and the resulting diagnostic tests. This leads us to surmise that there is room to improve how the treatment perspective is considered and discussed with patients and with care providers involved in the entire chain of care.

4.1 4.1 Diagnostics and treatment interventions in the final stage of life: snapshot of actual practice

The *Zorginstituut* asked an external research group to describe the care based on diagnostics and treatment interventions supplied.^{11, 12} The care supplied was analysed based on the claims of medical specialists registered in the claim information system (DIS).⁷ Patients were selected who had lung cancer or intestinal cancer, who died either in 2013, 2014 or 2015. We operationalised the final stage of life by looking at care interventions during the last six months, three months and one month before death occurred. In this way, our interpretation of the research results took into account that recognising initiation of the final stage of life is not easy. Apart from describing the care given, we also examined the backgrounds to the care given. This took place from the patient's perspective, by assuming that most people want as far as possible to receive care at home (or close by) and to die at home.^{8, 9}

DIS-data reflect registered care. These details do not adequately reflect unnecessary care in the daily practice of health care.

For this reason, the researchers analysed additional data sources. For instance, the SentiMELC and PRADO data provide insight into the characteristics of care and the

⁷ Claim details are registered by hospitals for their claims. These details do not adequately reflect unnecessary care in the daily practice of health care. After all, actual actions in a hospital may not correlate with the administration of actions as recorded in claim registers. Claim registers do indicate precisely provisions for which health insurers were actually invoiced

underlying treatment goals of the care given. The relationship between treatment goal and care outcomes was analysed based on these data.^{8, 9} Using VEKTIS data, the researchers examined the correlation with care given in primary care, e.g., via home care and care in nursing homes. This means they examined whether hospital care was being replaced by primary care.¹⁰ By means of a parallel analysis of several sources, the researchers examined whether the picture painted by the DIS data can be confirmed or explained in more detail. For a full description of the research results, see the underlying external reports. Following an interim consultation with the parties in October 2016, *Zorginstituut Nederland* carried out its own supplementary analyses, e.g. based on registration data on expensive drugs.

Research results

Lung Cancer

The number of patients who undergo systemic therapy treatment (chemotherapy and biologicals), surgery, radiotherapy and non-conventional radiological tests decreases as the time before death gets shorter. A new care activity is initiated for more than half of the patients during the last six months of their life. This is mainly general care, e.g. visits to casualty, days nursed, days in intensive care, visits to out-patient clinics and conventional diagnostics and laboratory tests (blood tests). This general care consumption per person increases during the final month of life. The duration of admission increases on average from 1.2 days per month in the final six months of life to an average of 9 days in the last month of life. Days spent in IC increase from 1 day per month in the final six months of life to six IC days in the last month of life. The average number of visits to casualty six months before death is 0.2 per month. This is 1.2 contacts per month in the last month. On average, patients underwent 0.3 CT-scans per month in the final six months of life. This was 1.6 CT-scans in the last month.

Intestinal cancer

The picture for patients with intestinal cancer also shows that as the date of their death approaches there is a fall in the number of patients who undergo several days of treatment, system therapy treatment, radiotherapy fractions, operations and non-conventional radiological tests. However, here too we see that the average volume of general care consumed increased in the last month of life for more than half of the patients. The average duration of hospital admission during the final six months of life is 1.8 days, while it increases to 8.8 days in the last month of life. For IC-days, these figures are 1 day per month in the final six months of life, increasing to five IC-days in the last month of life. The average number of visits to casualty six months before death is 0.2 per month. This is 1.2 contacts per month in the last month. On average, patients underwent 0.3 CT-scans per month in the final six months of life. In the last months this was 1.6 CT-scans.

The *Zorginstituut's* own analyses based on DIS and registration data on expensive drugs confirm the picture described above. The intensity of general care

⁸ SentiMELC data (NIVEL) were used to support and explain the picture that emerges from the snapshot of actual practice. Since 20015, within the framework of the SentiMELC study (Monitoring End of Life Care based on a Sentinel network of GPs) all sorts of data are being collected on care during the final stage of life. They are registered by GPs who are affiliated with 'GP reference stations'. Registrations via these reference stations are organised by NIVEL, under the name 'end of life' by the EMGO Institute

⁹ Consultation on palliative care is recorded in PRADO (IKNL). PRADO is a web-based electronic registration and administration programme for consultants in palliative care affiliated with the IKNL and for local consultation teams who work with IKNL

¹⁰ VEKTIS data are used to reflect care consumption at intervention level in primary care and for a better understanding of regional differences. This is reflected separately for AWBZ, GP care and the transport of patients during the last one, three and six months prior to death

consumption increases where number of hospital contacts is concerned: i.e. number of days admitted, IC-days, visits to outpatients clinics.¹¹ This is not the case for treatment interventions such as classical chemotherapy or radiotherapy. From these analyses we conclude that there is a relatively small and dwindling number of patients for whom treatment intensity increases: 15 to 25% of patients who receive disease-specific treatment during the final six months of their life will still receive disease-specific treatment in the last month of their life (see appendix 3). The SentiMELC and PRADO data support the picture of the dwindling deployment of disease-specific treatment. During the last three months of life, 20-30% of the patients receive treatment that focusses primarily on symptom reduction. For the remaining patients, care and treatment focus primarily on the disease and the intention is curative or life-extending. As patients near the end of their life, the intention of treatment shifts and in the last month of life 70-80% of the patients receive palliative care that focusses primarily on symptom reduction. The research results do not differ significantly for patients with lung cancer and those with intestinal cancer. The same applies to patients selected in the years 2014 and 2015.

The researchers also examined the correlation with care given in primary care. The hypothesis is that if care facilities are available and used in primary care, then less care will be consumed in hospitals. According to this hypothesis, a low number of days spent being nursed in hospital is expected if the number of days being nursed and cared for at home is high, and vice versa. This was analysed based on Vektis data. The analysis shows that no substitution (shift) takes place from hospital care to primary care: in regions with a high number of hours of care and nursing given at home, the number of days of nursing in hospital could be either high or low. Conversely, in regions where the number of hours of care and nursing at home is low, the number of days of nursing in hospital could be either high or low.

What is the background to the picture that emerges from these results?

The SentiMELC data suggest that a significant proportion of chemotherapy treatments are mainly palliative forms of chemotherapy. The researchers also found a relationship between a treatment goal with the intention of extending life and the amount of general care consumed in hospital. It seems that when the palliative objective is to extend life, the chance of death in hospital is greater than when treatment focusses on symptom reduction. This relationship was seen for both lung cancer patients and patients with intestinal cancer. Patients with lung cancer or intestinal cancer who received treatment with a curative or life-extending objective had a three-fold increased risk of being admitted in the 2nd or 3rd month before their death in comparison with patients who received treatment whose primary goal was symptom reduction. The risk for patients with intestinal cancer was almost four-fold.

Another noticeable finding is the high volume of diagnostics. In general, it is generally agreed in the Netherlands that diagnostics should be limited as far as possible in the final stage of life. Diagnostics are only used if they have consequences for treatment policy. However, the available data did not provide insight into the backgrounds of the high volume of diagnostics. The dilemma is due caused by the complexity of identifying a patient in the final stage of his/her life.

4.2

4.2 Observations

Based on the above, we conclude that general care consumption in hospital

¹¹ Care intensity is the average number of care activities that took place per patient, per month (for patients with ≥ 1 care activity)

increases, depending on the treatment objective.

In the final months of their life, most people want as far as possible to receive care at home and to die at home. The location of care and death is therefore generally regarded as an important indicator of the quality of palliative care.¹⁰ However, this indicator should not be seen separately from other possible influencing aspects of the chain of care. Specifically in the final stage of life it is important that the care provided is in keeping with the patient's preferences and changing care needs. The question is how to consider and discuss this treatment objective and the treatment perspective with the patient and with other care providers. To this end, we carried out additional external research based on improvement areas proposed by the parties (see Introduction). The description of these research findings resulted in recommendations for improvements and are part of the next section.

5 5. Room for Improvement Report

In this section we describe recommendations for improving care that is provided in the final stage of life of people with lung cancer or intestinal cancer. *Zorginstituut Nederland* arrived at the following recommendations based on in-depth research into areas for improvement that were suggested by the parties and based on an analysis of the elements of good and appropriate care. These can be found, respectively, in the underlying external reports and in appendices 3 and 4.

Points of departure for this in-depth analysis are the patient's perspective and the care that is needed in view of the imminent end of life. We focussed in particular on communication in consultation rooms, where decision-making takes place and communication and the harmonisation of care between care professionals in the entire chain of care. These points of departure were an integral part of the analyses and resulted in the improvement possibilities described below.

5.1 5.1 Improvement possibilities

We have identified three improvement possibilities: clarification of palliative care needs and wants and patient's preferences, clarification of the treatment perspective and multi-agency harmonisation. Below we describe these improvement possibilities and discuss the underlying reasoning in more detail. Good coordination between care givers, particularly where multi-agency care is concerned, is a precondition to actually allowing providing care from the patient's perspective. For this reason we shed light on the chain of care, and specifically, multi-agency harmonisation.

Timely exploration of palliative care needs when an incurable disease is diagnosed, irrespective of a recognisable initiation of the final stage of life

To offer care that is in line with a patient's palliative care needs, the patient's personal aims and preferences must be explored at an early stage: at the start of the palliative phase, i.e. at the moment when the incurable disease is diagnosed. Personal objectives and preferences change continually during the course of the disease. For this reason, during the further palliative course of the disease, the care needs should be explored again and where necessary adjusted so that care can be adjusted accordingly.

Reasoning

The impression given by both scientific and secular publications is that, in general, thoughts only shift to the deployment of palliative care at a 'late' stage, often in acute situations, or if it is clear that the patient doesn't have long to live (death is imminent). As a consequence, the patient and his family may have insufficient opportunity to prepare themselves for the imminent decease. However, pinpointing the initiation of the final stage of life is difficult. We asked an external research group to estimate the volume of palliative care needs of patients with lung cancer and intestinal cancer.¹³ This insight is important for harmonising care effectively.

What does the study show?

The study shows that, depending on the diagnostic instrument used, 8-54% of the patients need palliative care. Due to the lack of good, scientifically proven diagnostic instruments, this is no more than an indication of the actual care needs. Existing diagnostic instruments make use of medically defined criteria, mostly physical signs or symptoms, that are estimated by the doctor and not by patients

themselves. The researchers therefore refer to the presumed palliative needs of patients. Supplementary qualitative research was done by means of interviews with individuals and focus-groups, involving patients from all phases of the palliative course of the disease, as well as regular care providers and those trained in palliative care. The researchers then used a Delphi procedure to reach agreement on developing guidelines for supporting care professionals in the timely deployment of palliative care. It seems that palliative care needs vary considerably. Care needs are not limited to only physical problems and philosophical matters surrounding the imminent death or the process of dying. Care needs can also include questions about treatment decisions or shifting the treatment perspective during the early palliative phase, before the phase of dying. Furthermore, situations were identified that 'predict' in which situations patients' need of palliative care may develop or change. In short, these are moments at which new evolutions occur in the disease or in the patient. At such moments dialogue should take place with a patient so that care can be adjusted accordingly. Guidelines can support care professionals in starting the dialogue with patients in good time.¹³

Improvement activities:

- The main recommended improvement is bringing into practice the timely recognition of palliative care needs; namely, from the moment that the incurable disease is diagnosed, and irrespective of a recognisable initiation of the final stage of life. Guidelines such as those developed by the researchers can lend a hand here,¹³ so these should be developed further.
- Recognising the need of a timely discussion from the moment that an incurable disease is diagnosed, and recognising initiation of the final stage of life should be highlighted for both doctors and patients. The website recently developed by the NFK is along these lines.¹⁴ Another possibility is raising awareness among care professionals by including the recommendation in the national treatment guidelines for medical specialists and GPs.

Clarifying the treatment perspective

Other possibilities for care still exist if active palliative treatment, such as chemotherapy and/or radiotherapy, is no longer possible. Increased transparency in treatment guidelines about treatment possibilities, and possibilities for non-initiation of treatment, provide medical specialists with a basis for informing patients. Providing patients with good information precedes (joint) decision-making.

Reasoning

High quality evidence is essential to provide patients with 'evidence-based' information about appropriate treatment choices. To gain insight into which instruments are available to support the process of providing information and joint decision-making, we commissioned in-depth research into what is known in scientific literature about decision-making instruments for patients (decision aids) and for doctors (decision support systems).^{15, 16}

What does the study show?

Scientific literature shows that decision aids for patients and decision support systems for doctors have been insufficiently validated (externally) according to the most recent treatment insights. Scientific developments are rapid. This makes developing good decision-supporting instruments complex. Developing decision aids and decision supports systems in the short term is unrealistic due to methodological, organisational and financial aspects.

The *Zorginstituut* concludes, based on the in-depth research, that an 'evidence-gap' exists.¹⁶ On the one hand, a solution can be found in carrying out randomised research that focusses on direct (head-to-head) comparisons of the various

palliative care and treatment options. However, in view of the rapidly evolving treatment landscape, this is not realistic. On the other hand it would be valuable to examine the extent to which the relative effectiveness of the various palliative treatment options can be determined based on existing evidence. For a patient-oriented estimation of the relative effectiveness, it is important that effectiveness analyses are accompanied by information about outcome parameters that are important for patients. After all, it is important that patients know what effect a given treatment choice has on quality of life. The *Zorginstituut* also feels that special attention should be given to patient selection: this is important when using treatments that can potentially be burdensome for patients with a variable, but overwhelmingly short, life expectation.

Improvement activities

- Increasing transparency regarding treatment possibilities and limitations in the national guidelines for medical specialists will improve the information provided for doctors and patients. Various initiatives exist in this field. An example is the Onco-guide currently being developed, which shows decision trees for diagnostics and treatment based on data on the patient and the disease. The decision trees are based on guidelines and expert protocols. The IKNL is developing the Onco-guide in collaboration with care professionals.¹⁷
- When good decision-supporting instruments are lacking (e.g. decision aids or DSS), an easy option is a more practical shared decision-making solution that makes use of the campaign '3 good questions'. This is an initiative of the Dutch Patients' Federation and the Federation of Medical Specialists.¹⁸ It allows patients and doctors to ask: "what are my possibilities?", "what are the advantages and disadvantages of my possibilities?" and "what does this mean in my situation?"
- The recommendations mentioned in this report demand (extra) training of the professional groups involved, specifically in skills relating to shared decision-making.

Improving multi-agency harmonisation: increasing primary care's involvement in making ACP agreements (ACP = advanced care planning)

Multi-agency agreements will improve the continuity of care for patients, and care will be provided in the most appropriate location that is preferred by the patient. Multi-agency harmonisation could improve with a national multi-agency information standard for handovers between primary and secondary care. The standard for handovers states what agreements exist on care given during the final stage of life and at the end of a life, and how these are in line with a patient's preferences. Patients' preferences about care in the final stage of life and the imminent end of their life are recorded during the ACP.^{6, 12} Improved ACP documentation will make these agreements clear to care providers involved. As a result care will be provided for patients in the most appropriate location.

Reasoning

External research based on claim data shows that most people in the Netherlands die at home.^{12,10} At the same time, in the previous section we saw that general care consumption in the final months of life increases and that hospital care is not being replaced by primary care, irrespective of the presence or absence of institutions

¹² "Advance Care Planning (ACP) is a continual process of discussions about a patient's life goals, how care fits in and how it can best be adjusted in keeping with the patient's preferences. Treatment decisions about, e.g. resuscitation, and palliative care options will be part of this. As will discussing certain scenarios, e.g. the occurrence of complications and the side effects of treatments and whether there is a representative who can make these decisions."

where people can receive care in the final months of their life.^{10,13} In view of people's desire to die at home if possible, the question is whether good quality care is actually being provided. This leads to the question of how care is harmonised between care providers in the final stage of life, specifically multi-agency harmonisation and communication. External research was commissioned for this.¹⁹ The researchers examined communication between GPs and their patients. The reason for this is that the GP's role as gatekeeper in health care is in keeping with their role as guide and coordinator of care in a phase in which care and treatment decisions can be complex.

What does the study show?

The picture presented by data from GP patient files suggests that, in the final year of life, most correspondence is from medical specialists to GPs. This relates to medical matters such as the diagnostic trajectory and treatment. ACP agreements are hardly ever documented. One exception to this is documentation on ACP agreements regarding resuscitation policy and IC policy: this was almost always present, in a standard format, in the letter from the medical specialist. In the final month of life, GP documentation is mainly about terminal care agreements, e.g. agreements on sedation or euthanasia. This does not imply that GPs do not discuss other ACP matters with their patients prior to the terminal phase. On the contrary, patients have many contact moments with their GP in the last year of their life. Patient files suggest that discussions took place with patients about the final stage of life and the imminence of death. The lack of documentation about ACP agreements that have been made provides other care providers with little insight into how they could organise the care they provide accordingly.

Improvement activities:

- Increasing harmonisation and involving GPs in making ACP agreements will require a joint format, preferably a national, multi-agency information standard, documenting ACP agreements, that the patient understands the diagnosis and prognosis, and his/her wants and preferences. Preferably, documentation on ACP agreements will be a fixed part of the patient file.
- An international product is the ICHOM outcome indicator for measuring quality of death. This uses location of death and number of days in hospital during the last 30 days prior to death. The quality of death should preferably be evaluated consistently, using an indicator for multi-agency ACP documentation and an outcome indicator for measuring care continuity. Continuity of care emphatically does not mean that the patient has a single care provider as point of contact. Within this context, continuity of care means that the right care provider gives care that is appropriate for the patient at the right moment and in an appropriate location.

¹³ Possibilities for offering a form of home care, though immensely important, were beyond the scope of this in-depth analysis

5.2 5.2 Elements of good and appropriate care

We describe current care practice based on eight elements of good and appropriate care. The basis for this is the analysis framework for these elements, as described in appendix 1. During the systematic assessment, we focus on the patient's perspective and the care he/she needs.³ Conditions for allowing care to actually take place from the patient's perspective are good communication with the patient, including ACP, (shared) decision-making and good communication along the entire chain of care. The *Zorginstituut* did not carry out any additional systematic reviews of guidelines or onus of proof regarding ACP, shared decision-making and the timely deployment of palliative care. Furthermore, the results of the data analyses do not form a reason for carrying out effectiveness analyses of individual diagnostics or treatment interventions (appendix 3).

Determining improvement measures per element of good and appropriate care is relevant for follow-up phases in the cycle of improvement of the systematic assessment, e.g. the implementation phase and the monitoring phase. In the next section (section 6 Implementation and monitoring) we provide a summary of elements of good and appropriate care that are relevant to the improvement measures. See appendix 4 for an extensive description of our analyses.

5.3 5.3 Effects and outcomes of more appropriate care

Effects and outcomes for patients:

If the recommendations are implemented, patients will be clear about the possibilities and limitations of disease-oriented treatments such as chemotherapy, radiotherapy and surgery. At the same time patients will be clear about their options should they refuse to undergo disease-oriented and potentially life-extending treatment. Discussing this in time will allow the patient and his/her family an opportunity to consider in good time care and/or treatment with an appropriate treatment perspective.

Effects and outcomes for care providers:

An additional effect is greater transparency about palliative care needs and ACP agreements for doctors and other care providers. Care providers involved will be better able to provide care with an appropriate treatment perspective.

5.4 5.4 Cost Consequences

The Room for Improvement Report focusses primarily on improving care in the final stage of life of people with lung cancer or intestinal cancer. Naturally, introducing the improvement measures will also have consequences for care. These are included in the Budget Impact Analysis (BIA). Current data do not permit an exact calculation of the cost effects of implementing the improvement activities. For this we had to make assumptions and use information from research in other European countries. The BIA is described below.

Assumptions:

Current situation

- Each year 10,766 patients die of lung cancer or intestinal cancer.
Source: Research carried out by IQ Healthcare, commissioned by *Zorginstituut Nederland*.^{11,12,10}

- Of these, 38% were admitted to hospital once or more frequently during the last 3 months of their life. Source: Research carried out by IQ Healthcare, commissioned by *Zorginstituut Nederland*.^{11,12},
- Patients admitted to hospital once or more frequently during the last 3 months of their life were nursed for in total 10.1 days per patient. Source: Research carried out by IQ Healthcare, commissioned by *Zorginstituut Nederland*.^{11,12},
- A day being nursed (in hospital), including diagnostics and treatment, costs about €1,125.²¹
- Substitution (re-location) from hospital care to a primary care institution involves costs. These costs take into account patients who need relatively intensive care: a day being nursed in a hospice costs about €425.^{38,21}
- Costs relating to palliative care given by GPs, doctors and/or home care remain the same. These costs were therefore not included in the equation.

Potential substitution of care

- If patients receive timely ACP discussions and ambulant, specialist palliative care, the number of patients with one or more hospital admissions in the final 3 months of life will fall by 21%.²⁰
The costs of ambulant palliative care and the mix of disciplines this requires is estimated at €966 per patient in the Netherlands.²¹ This is based on the composition of specialised palliative teams comprised of 0.12 FTE GPs, 2 FTE nurses and 0.4 FTE administrative assistant per 100 patients.²² Care provided by a nurse can partly be replaced by other care providers, e.g. paramedics and spiritual guidance.²³
- If patients receive timely ACP discussions and specialist palliative care in hospital, the admission duration of patients admitted to hospital on one or more occasions in the final 3 months of their life will fall by 33%.^{24,25} Palliative care in hospital costs about €927 per patient.²¹ To calculate the costs of this team, we made the same assumptions as in the IKNL's business case.²¹ Calculations were made based on Dutch published data in combination with recommendations on palliative care in hospital by the Dutch Federation of University Medical Centres.^{21,23} A specialist palliative team is comprised of 1.5 FTE medical specialists (made up of several disciplines) and 2 FTE specialist nurses and costs €927 per admitted patient.²¹

Calculating the budget impact

Budget impact is the outcome of savings and investments. The 10,766 patients per year with lung cancer or intestinal cancer can be divided into four groups:

- **Group A** – These are patients who currently had no hospital admission during the last 3 months of their life. This is a total of 6,675 patients (= 10,766 * (1 – 38%)).
- **Group B** – These are patients who are currently admitted to hospital once in the last 3 months of their life, for whom 21% of admissions could be avoided with timely palliative care. This is a total of 859 patients (= 10,776 * 38% * 21%).
- **Group C-zkh** – These are patients who are currently admitted to hospital at least once in the last 3 months of their life, excluding the group of 21% whose admission could have been avoided with timely palliative care. This is a total of 3,232 patients (= 10,776 * 38% * 79%).

Probably half of group C will probably still be admitted to hospital despite ACP

discussions and extra ambulant palliative care. According to Tanke, a 33% reduction in admission duration can be realised for this group. This is the C-zkh group, and amounts to 1,616 patients (= 50% * 3,232).

- **Group C-hp** – The other half of group C will choose for a hospice instead of a hospital after ACP discussions and extra ambulant palliative care. This is the C-hp group, and also amounts to 1,616 patients. As patients in the death phase are the target group of hospice care, we do not apply the 33% reduction in hospital admission to this group.

The following table shows which changes in care we propose:

Group	Number of patients	Current care	Future care
A	6,675	-	Ambulant=specialised palliative guidance
B	859	10.1 days nursed	Ambulant-specialised palliative guidance
C-zkh	1,616	10.1 days nursed	Ambulant=specialised palliative guidance 6.8 days nursed Hospital-specialised palliative guidance
C-hp	1,616	10.1 days nursed	Ambulant-specialised palliative guidance 10.1 days nursed in hospice

Revenues

Reduction in Group B hospital admissions (number of patients * duration of admission * costs of a day nursed = 859 * 10.1 * €1,125)	€ 9,761,828
Reduction in group C-hp hospital admissions (number of patients * duration of admission * costs of a day nursed = 1,616 * 10.1 * €1,125)	€18,361,534
Reduction in group C-zkh admissions (number of patients * reduction in duration of admission * costs of a day nursed = 1,616 * 3.3 * €1,125)	€6,059,306
Total savings	€ 34,182,669

Investments

Each patient receives ambulant specialised palliative care and ACP (number of patients * costs of ambulant palliative care = 10,766 * €966)	€ 10,399,956
High care days admitted for group C-hp, as substitution for days nursed (number of patients * duration of admission * costs of hospice = 1,616 * 20 day * €425)	€13,736,000
Hospital specialist palliative care for group C-zkh (number of patients * costs of hospital palliative care)	€1,498,010

= 1,616 * €927)

Total investments

€25,633,988

Introducing timely ACP discussions and specialist palliative care (ambulant and in hospital) could result in estimated savings of:

€34.2 million - € 25.6 million (savings – investments) per year =

€8,547,594

Conclusion

Costs at the expense of the care budgetary framework (BKZ) could be reduced by €8.5 million per year for the final stage of life of patients with lung cancer or intestinal cancer. Realising this will take a shift in costs to primary care of €10.5 million per year (for ambulant specialist palliative care) and to hospices of €10.5 million per year (for the care of a category of patients needing relatively intensive care). This is a conservative estimate because the palliative care supplied via primary care and hospices was not included in the calculations; after all, this care is already part of the current situation.

Limitations

To calculate the cost effects we used public sources and studies from other European countries (including Spain and Italy), in addition to statistics from Dutch daily practice.^{20,25} Comparable similarities were found on this topic with the care field in the Dutch situation.^{21,23,24} The estimated cost effects are therefore an indication of the potential cost effects.

6 6. Implementation and monitoring

6.1 6.1 Implementation

Implementing these improvements is the task of parties in health care, based on their respective accountabilities within the health care system. During consultations, the parties made concrete suggestions regarding implementation and ownership in line with initiatives in this field of care. Parties have already introduced some good initiatives. During the implementation phase, where necessary, further collaboration will be sought with other parties.

The following schedule summarises, per field, which activities are needed. Where appropriate, we specified improvement measures based on the suggestions of parties during the written consultation.

Element van care <ul style="list-style-type: none">• Improvement activities
Knowledge about good care <p><i>The timely recognition and discussion of palliative care needs during the entire palliative course of the disease, irrespective of recognising initiation of the final stage of life: upon diagnosis of an incurable disease and then, if appropriate, during the further palliative course of the disease.</i></p> <ul style="list-style-type: none">• During consultation the parties emphatically stated that societal debate, with the help of the media, is extremely valuable for increasing awareness of the matter. The website recently developed by the NFK http://www.uitbehandeldmaarnietuitgepraat.nl/ is along these lines.
<p><i>Clarifying the treatment perspective.</i></p> <ul style="list-style-type: none">• Care professionals' awareness can be increased by increasing the clarity of existing treatment guidelines about treatment possibilities, and about care possibilities when patients reject treatment. Furthermore, awareness among patients can be increased by developing a patients' version of the treatment guidelines. <p><i>The Zorginstituut sees added value for continuing both activities.</i></p>
Application in practice <p><i>Clarifying the treatment perspective.</i></p> <ul style="list-style-type: none">• When good decision-supporting instruments are lacking (e.g. decision aids or DSS), a simpler more practical solution is possible with the aid of the '3 good questions' campaign. This is an initiative of the Dutch Patients' Federation and the Federation of Medical Specialists.• The recommendations mentioned in this report demand (extra) training of the professional group concerned, specifically in the field of skills relating to shared decision-making.
<p><i>Promoting the timely deployment of palliative care by care professionals.</i></p> <ul style="list-style-type: none">• Further work should go into developing the instrument designed by the researchers.¹³
<p><i>Improving (multi-agency) harmonisation between care professionals.</i></p> <ul style="list-style-type: none">• Develop a national information standard for handing over ACP agreements, in particular harmonisation and handovers between GPs and second line care professionals.

Care outcomes

Develop indicators for monitoring and documenting ACP agreements on care and/or treatment in the final stage of life and multi-agency harmonisation in relation to this.

- in particular attention will be given to whether multi-agency documentation on ACP agreements (incl. communicating these to the patient) has taken place.
- develop an outcome indicator for measuring the quality of death and care in the last 30 days of life. There is an international ICHOM outcome indicator for measuring the quality of death. This uses location of death and number of days in hospital during the last 30 days prior to death.¹⁰ Preferably this outcome indicator should be used in combination with a care continuity indicator. Within this context, continuity of care refers to providing the patient with the right care at the right time, by the right care providers, and in an appropriate location.

Effectiveness

Proof of high quality of appropriate treatment choices is essential to ensure that patients are provided with 'evidence-based' information and to eventually determine an appropriate treatment perspective. Based on in-depth research, the *Zorginstituut* feels that an 'evidence-gap' exists here.³¹ For a patient-oriented estimation of relative effectiveness, it is important that effectiveness analyses are accompanied by information about outcome parameters that are important to patients. Although there is no concrete improvement activity in relation to this, *Zorginstituut Nederland* wants to remain in dialogue with the parties about where the highest possible scientific evidence is needed, especially regarding awareness of good care in treatment guidelines for medical specialists.

Feasibility

Agreements need to be made on the contents of a handover standard that reflects ACP dynamics. In addition, during consultation, the parties indicated which preconditions are needed for an effective handover, such as ownership and technical ICT support.

6.2**6.2 Monitoring**

The *Zorginstituut* will monitor the improvement activities:

- Monitoring annually whether there is any progress in the various improvement activities. Both qualitative and quantitative reports on progress will be sent to the Minister of VWS;
- At the request of the parties, *Zorginstituut Nederland* will organise follow-up meetings in order to promote collaboration, discuss progress and resolve any signs of stagnation;
- The *Zorginstituut* will facilitate in shaping national agreements about the organisation of care;
- Three years after publishing this Room for Improvement report, the *Zorginstituut* will write an evaluation report.

In view of the involvement and accountability of all parties, *Zorginstituut Nederland* expects successful implementation of the promised improvements in the guidelines and in the provision of care, and does not feel that statutory instruments will be necessary.

Appendix 1: Accountability

Zinnige Zorg's working method for the systematic assessment programme

Points of Departure

The *Zorginstituut* designed a systematic working method for the *Zinnige Zorg* Programme for examining the use that is made of care in the insured package. The key is to identify and reduce ineffective and/or unnecessary care in order to improve the quality of care for patients, increase health gains and avoid unnecessary costs. We carry out a systematic assessment for a field of disorders as defined in the ICD-10 classification system. A systematic assessment is carried out based on a number of points of departure:

Central role for patients

When assessing care, a central role is given to patients and the care pathway they follow. The underlying question is always how much does a patient benefit from the care given? Is he receiving care that is appropriate to his situation, or is he perhaps receiving too little care (under-treatment) or too much care (over-treatment)?

Shared decision-making

Care must be in keeping with patients' personal circumstances. In addition to the diagnosis, patient-related matters play a role in the choice of treatment, such as a patient's expectations, his/her professional situation, impact on social functioning, pain perception, motivation, etc. For some diagnoses it is clear which treatment options should be deployed. Often, however, various treatment options exist, each with their pros and cons, and opting for a given treatment will depend more on the preferences of the patient and his carer. Shared decision-making is a way of arriving at an optimum treatment pathway together with a patient. Various instruments exist that can support the shared decision-making of doctors and patients effectively – such as decision aids, option grids and patients' versions of guidelines – and which increase the quality of the decision-making process.

Stepped care

We assume that courses of treatment start based on the stepped care principle. According to this principle, care is offered based on a step-by-step plan: the least burdensome effective treatment is used first, and only when this gives insufficient results are more complex or more invasive interventions offered. Stepped care is a general point of departure, not a mandatory requirement. The 'start moment' is not necessarily step 1, as steps may be skipped, according to the symptoms with which a patient presents.

Parties in health care are involved throughout the entire process

The *Zorginstituut* wants to realise active agreement with the parties in health care. This will benefit the quality of the analyses and the basis of support for improvement measures. We involve the parties who bear responsibility in all phases of the systematic assessment.

The parties are invited to attend various consultations via umbrella arrangements. They are also given an opportunity to participate in supervising the research of external research bureaus. Lastly, we ask parties for comments on draft versions of reports.

Phases of systematic assessment

In order to promote good care, we carry out a systematic assessment according to a quality circle, or improvement circle, as illustrated in the following figure. This circle is comprised of four sequential phases:

1. Screening phase
2. In-Depth Analysis Phase
3. Implementation phase
4. Evaluation phase

Methodology

Circle of improvement for Appropriate Care



Figure 1: Zinnige Zorg's circle of improvement

Zinnige Zorg's circle of improvement starts with a screening phase, in which we analyse how care is currently being given ('snapshot'). Based on this, a number of topics are chosen for in-depth analysis. In the second phase, the in-depth phase, we determine the potential for improvement, per topic. In the third phase (implementation) it is mainly up to the parties in health care to implement the agreed improvement measures. Lastly, in the evaluation phase we examine the extent to which goals that were set have been achieved and whether a new circle of improvement should start, possibly using different instruments for improvement. Where necessary, if insufficient results are realised, the *Zorginstituut* can make use of its statutory instruments (e.g., clarification, advising on inclusion – or exclusion from – the package, power to overrule within the framework of the Multi-Year Agenda). Below we describe the four phases of the circle of improvement in more detail.

Screening phase

The objective of the screening phase is to select a number of topics for in-depth analysis with a possible potential for improving the quality and effectiveness of care by using care more appropriately. These topics are recorded in a report that is sent, together with the underlying analysis, to the parties in health care and to the Minister of Health Welfare and Sport.

Figure 2 shows how we obtain establish in-depth topics by consulting various sources in a systematic analysis. Sources include quality standards (guidelines, care

standards and care modules), scientific literature, claim data and other data, and the parties in health care. This involves not only collecting and analysing all the detailed information, but also searching for signals from daily practice in order to obtain the clearest possible picture of care provided in the current situation. We look at the care path followed by a patient from the perspective (the “spectacles”) of the *Zorginstituut*, with elements that the *Zorginstituut* defines as good and appropriate care (see explanation below).

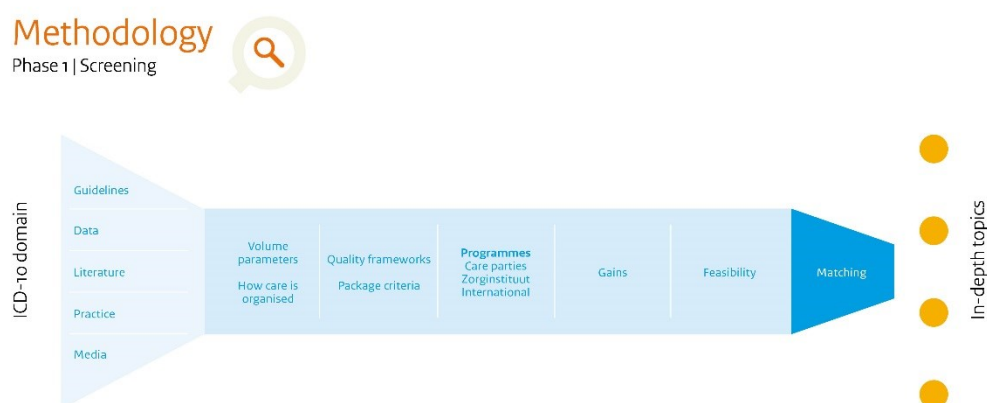


Figure 2: From sources to in-depth topics in the screening phase

The choice of in-depth topics is based on the systematic analysis (based on the elements of good and appropriate care), the size of the topic (number of patients, burden of disease, budget impact), possible improvements and what the parties in health care feel is important.

In-Depth Analysis Phase

The screening phase is followed by the in-depth phase. The objective of this phase is to make the method for achieving potential improvements in the selected topics as concrete as possible.

Per topic, based once again on the elements of good and appropriate care, we carry out an in-depth study and supplement any knowledge that is missing by means of extra data-analyses, scientific reviews, studies of daily practice and/or literature studies.

The final results are recorded in a so-called Room for Improvement Report. This states which improvements in care and in health the *Zorginstituut* feels are possible, in respect of both content and amount, and provides an estimate of the total sum of costs involved (budget impact). We try to ensure that agreements with the parties on improvement measures are as concrete as possible. The Room for Improvement Report is also sent to the parties in health care and to the Minister of VWS.

Implementation phase

The implementation phase is primarily a task for the parties in health care: patients, care professionals, institutions and health insurers. It takes place based on agreements made in the in-depth phase. In the implementation phase the *Zorginstituut* can play a supportive and facilitating role, for instance, by organising

meetings, providing data and feedback, and by carrying out additional research. In order to guarantee compliance with agreements, both in respect of content and time, the *Zorginstituut* can place action points from the Room for Improvement Report that relate to quality standards and measuring instruments on the Multi-Year Agenda.

Periodically, the *Zorginstituut* reports on progress booked to the accountable parties and to the Minister of VWS.

Evaluation phase

During the evaluation phase, the *Zorginstituut* examines, together with the parties involved, whether the results mentioned in the Improvement Report have been achieved. Based on this, we determine whether a new circle of improvement should start, possibly using different instruments for improvement. During this phase we also examine whether all necessary information is structurally available.

Elements of good and appropriate care

We carry out an analysis of care in both the screening phase and the in-depth phase. To do this, we use the "elements of good and appropriate care". Together, these give an idea of what the *Zorginstituut* regards as good and appropriate care. They are also consistent with our quality and package management tasks. The following analysis scheme is used:

1. Knowledge about good care

A description of what we know about the availability of national and international quality standards (such as guidelines), measuring instruments (questionnaires and indicators) and information standards.²⁶ We see whether these can be found in, e.g., the *Zorginstituut*'s Register. Their inclusion in the Register shows that they fulfil the procedural criteria of the Assessment Framework²⁶. We try to ensure that everything that can be found is included in *Zorginzicht.nl*.

Does patients' information exist, such as a patients' version of guidelines, or information about diagnosis and treatment on the website of a patients' association or on *KiesBeter* or *thuisarts.nl*?

Are there decision aids, option grids or outcome indicators which are relevant to patients, such as measures of quality of life, PROMs²⁷ and PREMs²⁸? On which websites (public database and public information) can they be found?

In addition to procedural matters, we also look at the content of standards and guidelines: what recommendations are made that are relevant to our topic and is there sufficient scientific evidence for (recommendations in the) guidelines? Lastly, we look at concordance between guidelines for first and second line treatment.

2. Application in practice

We use various sources (such as claim data, publications, formal and informal consultations) to look at how care takes place in practice (including concordance between primary and secondary care) and what the experts think about it. We compare this to what we found in practice on recommendations in quality standards.

3. Care outcomes

Do patients benefit from the treatment? Is information available about quality of care and care outcomes, and can it be found by care providers, patients and citizens? For instance, is there a complication register, statistics on post-surgery mortality, experiences of patients with outcomes or experiences (measured with PROMs and PREMs)? And where can we find this information, e.g. on websites such

as ZorginZicht.nl (public database), Kiesbeter.nl or Zorgkaartnederland.nl?

4. Effectiveness

Is the care effective? If we feel that the scientific evidence in the guidelines (as assessed under element 1, Knowledge about good care) is of sufficient quality, we use the recommendations from the guidelines as point of departure for good care. If the guidelines are of insufficient quality, or dated, then we can let the parties know that the guidelines need to be updated. A formal assessment based on the criteria established by the *Zorginstituut*, including a systematic review based on the GRADE system²⁹, only takes place if this is dictated by bottlenecks and there are no recommendations in the guidelines or there seems to be insufficient scientific evidence.

An important part of an assessment of effectiveness are the primary questions, as described in the so-called *PICOT*: Patient – Intervention – Comparator Outcome – Time. For which group of patients is the care intended and is that the group for which research is available? Which treatment or care is being offered and has this care been studied? With which control treatment (regular care, standard therapy) was the care compared and what is the added value of the recommended care? And which outcomes relevant to patients were examined in order to determine whether the care was effective and for how long?

5. Cost-effectiveness³⁰

Cost-effectiveness shows whether the (added) costs of treatment are in reasonable proportion to the added effectiveness. We look at whether the guidelines have anything to say about cost-effectiveness, we look at the (scientific) literature and, if necessary, we carry out our own cost-effectiveness study.

6. Necessity³¹

This is where we examine whether a form of care should be part of the basic health insurance or whether it involves costs that people could pay for themselves. Weighing this up involves two different aspects: severity of the disease (burden of disease) and the societal necessity of actually insuring the treatment concerned. With burden of disease the emphasis is on medical necessity, while with 'necessity to insure' the emphasis is on whether insurance is actually necessary.

7. Feasibility³¹

Care that is not feasible cannot be supplied. The feasibility element indicates whether the preconditions have been fulfilled and how sustainable including an intervention in the basic package is. Relevant to this are, e.g., basis of support, how care is organised (indications and administration), funding, jurisdiction and ethics. This also involves, for instance, whether a funding formula (intervention description) exists for an intervention that should be included in the basic package.

8. Consistency in quality circles

This is where we look at whether quality circles are used that focus on improving care, who uses them, and the interdependence that exists between quality circles.

Difference in the screening phase and the in-depth phase

The spectacles with which we examine care are, in principle, the same for all phases of the assessment, based on the eight elements mentioned above. Sometimes the nature and intensity of the systematic analysis differs in the screening phase and in the in-depth phase. The terminology itself shows that the first involves a global inventory, at the level of a disorder (ICD-10), and that the selected topics are

examined in more detail during the in-depth phase. This phase often also combines various data sources.

Use of data in the analysis

The *Zinnige Zorg* programme makes regular use of quantitative data. Using these data meticulously is particularly important for the quality of the analysis, acceptance of the findings and to protect privacy. The *Zorginstituut* explicitly recognises the importance of this and takes all necessary measures for processing the available data meticulously. The following is an explanation of key elements of how we process quantitative data.

Based on care-related questions, the *Zorginstituut* carries out data research into how care from the basic package is used in daily practice. To do this we collect information from many sources: from discussions with interested parties to scientific publications, from RIVM statistics to claim data.

These are in part quantitative data, often claim data such as those of the Declaration Information System (DIS), Care Interventions and Claims (ZPD), and the Medicines and Medical Device Information Project (GIP). When using data, the *Zorginstituut* has various measures for ensuring that security and privacy are guaranteed optimally. For example, the *Zorginstituut* uses pseudonymised personal data over several years and from various sources, which can be combined to answer a specific problem.

We use claim data to get an idea of daily practice in health care. Claim data reflect registration practices and not necessarily the care actually provided. Nevertheless, these data do form an important source of information, sometimes the only one, and can provide valuable signals relating to care quality. An in-depth exploration of the possibility of using other data sources is currently taking place, in collaboration with VWS and other parties in health care.

Safeguarding privacy is of paramount importance. Personal data used are therefore pseudonymised and cannot be traced back to individuals. Nevertheless, they are regarded as sensitive personal data, so we are very meticulous in carrying out analyses and always comply with current legislation. The data are only used for research goals/analyses defined in advance, they are not made available/used for other objectives and they are not disseminated. The results of the analyses are published at a level that precludes any tracing back to the level of individual persons, patients, insurers or care providers.

This systematic analysis was approved in agreement with care professionals, patients, institutions, health care insurers and the government.

Patients' associations
Dutch Patients' Federation
Intestinal Cancer the Netherlands
Lung Cancer the Netherlands
Professional associations/Scientific associations
Dutch College of General Practitioners (NHG)
Dutch Association of Doctors for Lung Diseases and Tuberculosis (NVALT)
Dutch Association for Gastrointestinal Surgery (NVGIC)
Dutch College of Surgeons (NVDH)
Netherlands Association for Internists (NIV)
Association for Gastrointestinal-Hepatology Doctors (NVMDL)

Dutch Association for Medical Oncology (NVMO)
Netherlands Association for Radiotherapy and Oncology (NVMO)
Dutch Association for Oncology Nurses (V&VN)
Dutch Association for Thoracic Surgery (NVT)
Care providers
Federation of Medical Specialists (FMS)
Top Clinical Hospitals Association (STZ)
Dutch Federation of University Medical Centres (NFU)
Dutch Association of Hospitals (NVZ)
Health Insurers
Association of Dutch Healthcare Insurers (ZN)

Systematic analysis timepath: Final stage of life in cases of lung cancer and cancer of the intestines.

<u>16 April 2015:</u>	Report on the screening phase "Systematic Analysis of neoplasms"
<u>15 September 2015:</u>	Initial meeting "Final stage of life in cases of lung cancer and cancer of the intestines.
<u>Sept./Oct. 2015</u>	Elaboration of research questions.
<u>October 2015:</u>	Commissioning of research by the <i>Zorginstituut</i> .
<u>1st quarter 2016:</u>	Start of external studies
<u>3rd quarter 2016:</u>	Studies completed
<u>22 September 2016:</u>	Symposium with research parties "Appropriate care in the final stage of life of patients with lung cancer and intestinal cancer"
<u>06 October 2016:</u>	Follow-up meeting with stakeholders about external research results.
<u>21 April- 2 June 2017:</u>	Written consultation
<u>June-July 2017:</u>	<u>ZIN incorporates written consultation responses</u>

Appendix 2: Third-party studies commissioned by *Zorginstituut Nederland*

Disclaimer

The study reports found on our website are the underlying study reports used by the *Zorginstituut* in realising this report.

Responsibility for the data and conclusions in the underlying study reports rests entirely on the research institutions that drew up the reports. The *Zorginstituut* did not always adopt those data and conclusions in its own reports.

The following summary of sources used by the *Zorginstituut* is by no means complete.

Below is a summary of the underlying study reports on which this Room for Improvement Report is based. These reports can be accessed via the links in the e-mail that was sent to the executive boards and affiliated representatives. The most important findings are summarised in the previous sections.

Research task	Implementing party/ contribution to the research problem
<p>Research into care provided in hospital to patients with lung cancer or intestinal cancer in the last months of their life: Research into the snapshot of daily practice: diagnostics and treatment interventions •Backgrounds to the care given</p>	<p>IQ Healthcare, Radboud UMC in collaboration with Dept. of Social Medicine, EMGO+, Expertise Centre of Palliative care, VU UMC and Netherlands Integral Cancer Centre (IKNL)</p>
<p>Research into harmonisation of care between GPs and specialists, communication about care between GPs and patients, including agreements surrounding ACP.</p>	<p>Radboud UMC First Line Medicine in collaboration with Radboud UMC, IQ Healthcare and Radboud UMC, Pain and palliative care</p>
<p>Inventory of the extent of demand for palliative care</p>	<p>Radboud UMC, Anaesthesiology, Pain, Palliative Medicine in collaboration with Netherlands Integral Cancer Centre (IKNL) and LUMC, expertise centre for palliative care</p>
<p>Inventory of instruments that support patients in the (joint) decision-making process on treatment decisions in the final stage of life</p>	<p>Dutch Institute for Research into Health Care (Nivel)</p>
<p>Inventory of instruments that estimate life expectation and treatment options for patients with lung cancer or intestinal cancer for whom cure is not an option.</p>	<p>VU Medical Centre, Department of Clinical Epidemiology and Clinimetrics and Mathematical modelling</p>

Appendix 3: The *Zorginstituut*'s own analyses

In-depth analysis of the topic 'Care consumption in the final 3 months of life of patients with lung cancer or colonic cancer'

In response to the 'Snapshot of daily practice in the final stage of life' provided by IQ Health Care, we looked more closely at the use of radiotherapy and chemotherapy, days admitted and visits to casualty during the final stage of life. According to the 'snapshot of daily practice', treatment intensity increases in the final months of life.

We also looked at care consumption in the presence of disease-oriented treatment and care consumption in the absence of disease-oriented treatment. The idea is that this form of treatment is associated with more intensive care consumption.

Radiotherapy during the final stage of life

Table 1 shows that patients with lung cancer regularly receive radiotherapy during the last 3 months of their life, though this is rarely the case for patients with colonic cancer. For this reason we limited ourselves to patients with lung cancer.

Table 1: Use of radiotherapy during the last 3 months of life

	Number of patients with lung cancer	Number of patients with colonic cancer	Number of patients with both lung cancer and intestinal cancer
Number of patients who died in in 2012 up to and including 2015	36,625 (= 9,156 per year) (IKNL 2014: mortalities 10,346 per year)	25,058 (= 6,265 per year) (IKNL 2014: mortalities 4,906 per year)	1,147 (= 287 per year)
Number of patients with radiotherapy in the last 3 months of life (excl. brachytherapy)	6,910 (= 19%)	1,637 (= 7%)	168 (= 15%)

Some forms of radiotherapy in the palliative phase take effect within 4-6 weeks (e.g. radiation of painful vertebral metastases). With other forms, the time to radiation effect is longer, e.g. for radiation of the skull. We focussed on radiation of the skull because the short estimated life expectation means there is a chance that patients will not benefit from the radiation and will die prematurely.

There is no claim-type or care activity specifically for radiation of the skull. However, 5 sequential radiotherapy fractions in combination with brain diagnostics (CT-scan or MRI of the brain, PET-'whole body' (WB) suggests radiation of the skull. We looked at how often this combination occurred in the final stage of life.^{xiv}

^{xiv} A series of 5 sequential radiotherapy sessions can be interrupted by a weekend. For example: radiation on Thursday -> Friday -> Monday -> Tuesday -> Wednesday, counts as a series of 5 sequential fractions. The

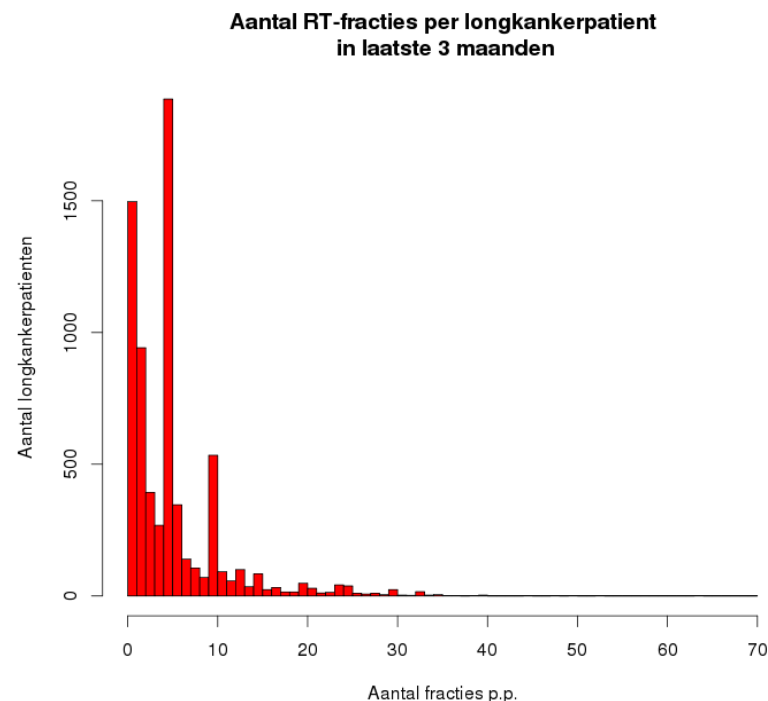
Table 2 shows how many patients may have undergone skull radiation in the last 3 months of their life over the 4 years studied.

Table 2, number of lung cancer patients with radiotherapy indicative of skull radiation during the last 3 months of their life

Topic	Number of patients	Share	Average number per year
Number of lung cancer patients who died between 2012 and 2015 incl.	36,625	100%	9,156
Subset with radiotherapy in the last 3 months of life (excl. brachytherapy)	6,910	19%	1,728
Subset with 5 sequential RT fractions in the last 3 months of life	1,870	5%	468
Subset with brain scan (brain CT/MRI/PET-WB) in the last 4 months of life, in addition to '5 sequential fractions' ^{xv}	1,110	3%	228

Figure 1 shows how many fractions were received in the last 3 months of life of patients who received at least 1 fraction. Patients without a brain CT, a brain MRI or PET-WB were not excluded from the figures. Most patients undergo one or two fractions, or 5 fractions. This pattern probably suggests that these were palliative radiation therapies.

Figure 1, number of radiotherapy fractions per lung cancer patient in the last 3 months of life



This analysis was repeated for lung cancer patients who received a series of 5 sequential radiotherapy fractions in the *final month of their life*, in

combination '5 sequential fractions plus brain diagnostics' is not proof of skull radiation, because 'PET-WB plus 5 fractions' is also used for the radiation of a lung tumour. What's more, carrying out a brain MRI/CT does not mean that the outcome was positive

^{xv} Normally there will be 0-3 weeks between the brain scan and the start of skull radiation. To be able to classify all radiations in the last 3 months of life properly, we included the brain scans from the last 4 months of life

combination with brain diagnostics in the last 2 months of their life. This was a total of 186 patients, meaning 46 patients a year.

Conclusion regarding radiotherapy

The increased care intensity is given as radiotherapy care interventions, the objective of which may be palliative. One form of radiotherapy, which may have no effect in the final stage of life due to lack of life expectation, is skull radiation. This involves a small proportion of lung cancer patients.

Chemotherapy in the final stage of life

Table 3 reflects the use of chemotherapy add-ons in the final stage of life of patients with lung cancer or colonic cancer. Concentration is evident among patients with colonic cancer (almost 20 add-ons per patient), so we focussed on this.

Table 3, add-on chemotherapy use of patients with lung cancer or colonic cancer in the final 3 months of life

	Number of patients with lung cancer	Number of patients with colonic cancer	Number of patients with both lung cancer and intestinal cancer
Number of patients who died in in 2012 up to and including 2015	36,625 (= 9,156 per year) (IKNL 2014: mortalities 10,346 per year)	25,058 (= 6,265 per year) (IKNL 2014: mortalities 4,906 per year)	1,147 (= 287 per year)
Number of patients with add-on chemotherapy in the final 3 months	4,005 (= 11%)	94 (= 0%)	82 (= 7%)
Number of add-ons in the final 3 months	7,978 (= 2.0 pp.)	1,838 (= 19.6 pp.)	146 (= 1.8 pp.)

Below we illustrate the use of add-ons, per product, for patients with colonic cancer.

Table 4, Number of administrations of add-ons in the last 3 months of patients with colonic cancer who died between 2012 and 2015 incl.

Description	number of administrations
Irinotecan	1877
Oxaliplatine	1983
Bevacizumab	1500
Panitumumab	1306
Cetuximab	329
Paclitaxel	148
Gemcitabine	143
Docetaxel	31
Pemetrexed	15
Gefitinib	1

- We suspect that capecitabine was used, though it could not be found in the data.

Conclusion regarding classic chemotherapy

The increased care intensity is given as chemotherapy care interventions, possibly with a palliative objective in view of the type of drugs given. The volume of add-on use for patients with lung cancer or intestinal cancer in the final 3 months of life is small: less than one per cent receive an add-on for intestinal cancer and 11% receive an add-on for lung cancer, whereby the average use is 2 administrations.

Days being nursed in the final 3 months of life

The 'snapshot of daily practice' shows that patients with lung cancer or colonic cancer spent a relatively large number of days being nursed in the last 3 months of their life. The number of days being nursed was higher for lung cancer than for intestinal cancer. Below are data on the specialisms and the diagnoses to which days being nursed relate. To avoid cluttering the tables, we only show items requiring more than 100 days of nursing. The diagnosis descriptions were taken from the NZa's "Electronic list of types".

Table 5, days lung cancer patients were nursed, classified according to specialism

DOT^{xvi} diagnosis that includes a day being nursed	days being nursed
Pulmonary diseases	178841
Internal Medicine	24592
Neurology	22402
Surgery	7963
Cardiology	7244
Gastroenterology and liver diseases	3813
Orthopaedics	2268
Clinical Geriatrics	2231
Neurosurgery	1417
Urology	1262
ENT	722
Rehabilitation medicine	655
Cardiopulmonary surgery	652
Anaesthesiology	403
Rheumatology	102

^{xvi} DOT = Increasing the transparency of DBCs.

Table 6, days lung cancer patients were nursed, classified according to diagnosis
 Cut-off point = at least 1000 days being nursed

specialism	diagnosis	Number of days nursed
lung diseases	Pneumonia	15096
lung diseases	COPD	7034
neurology	Neoplasm, intracerebral	6071
lung diseases	Pleural disorders	5873
internal medicine	Malign	4266
neurology	Sec time neopl. intracerebral	3548
neurology	Non-haemorrhagic stroke	2897
internal medicine	Malignancy nno	2385
lung diseases	Other	2058
cardiology	Acute heart failure	1842
lung diseases	Lung embolism	1800
internal medicine	Malign	1754
0335	Poli/setting NA (zt 12 13)	1682
neurology	botulin toxin-treatm policlinic	1544
lung diseases	Pneumothorax	1122
internal medicine	without antiviral treatment	1093
lung diseases	Dyspnoea	1073
cardiology	Chronic heart failure	1046

Conclusion

In general, days being nursed relate to serious diagnoses.

Table 7, days lung cancer patients were nursed, classified according to specialism

DOT diagnosis that includes a day being nursed	days being nursed
Internal Medicine	75838
Surgery	43312
Gastroenterology and liver diseases	11649
Neurology	6340
Cardiology	5525
Pulmonology	5337
Clinical Geriatrics	2673
Urology	2233
Orthopaedics	1001
Gynaecology	711
Rehabilitation	409
Neurosurgery	346
Anaesthesiology	301
ENT	189
Cardiopulmonary surgery	110
Plastic surgery	104

Table 8, days intestinal cancer patients were nursed, classified according to diagnosis
 Cut-off point = at least 1000 days being nursed

specialism	diagnosis	number of days being nursed
internal medicine	Colorectal malignancy	47180
gen. surgery	Malign colonic neoplasm	17431
gen. surgery	Malign rectal neoplasm	7880
MDL	Colorectal malignancy	6682
gen. surgery	Malign recto-sigmoid neoplasm	4815
internal medicine	Bacteraemia/sepsis	2626
gen. surgery	Ileus: paralytic	2173
internal medicine	without antiviral treatment	2056
0335	Poli/setting NA (zt 12 13)	2024
neurology	Non-haemorrhagic stroke	1768
cardiology	Acute heart failure	1644
lung diseases	COPD	1428
internal medicine	Malignancy nno	1389
lung diseases	Pneumonia	1353
cardiology	Chronic heart failure	1271
internal medicine	Ac renal insufficiency and dialysis	1204
gen. surgery	Other non-malign GI disorder	1143
internal medicine	Other malignancy dig. tract	1120
gen. surgery	Peritonitis carcinoma (HIPEC)	1065
neurology	Neoplasm, intracerebral	1046
internal medicine	Ileus/volvulus	1030

Conclusion

In general, days being nursed relate to serious diagnoses for admission. Underlying reasons for admission may relate to symptoms in keeping with the disease and/or in keeping with patients with (multi-) comorbidity.

Visits to casualty in last months of life

The 'snapshot of daily practice' shows that patients with lung cancer or colonic cancer visited casualty relatively often in the last 3 months of their life. The next two tables show for which specialism and for which diagnosis patients visited casualty. There were more visits to casualty for lung cancer than for intestinal cancer. The diagnosis descriptions were taken from the NZa's "Electronic list of types".

Table 9, visits to casualty by lung cancer patients, per specialism, in the last 3 months of life

DOT specialism that includes a visit to casualty	Number of visits to casualty
Pulmonary diseases	16870
Internal Medicine	4043
Neurology	3588
Surgery	2238
Cardiology	2053
Gastroenterology and liver diseases	569
Orthopaedics	409
Urology	257
Clinical Geriatrics	149
ENT	139
Neurosurgery	59
Anaesthesiology	45
Ophthalmology	27
Consultative Psychiatry	14
Rheumatology	10
Dermatology	10
Plastic surgery	5
Gynaecology	3
Cardiopulmonary surgery	2
Radiology	1
Paediatrics/Neonatology	1

Table 10, visits to casualty by lung cancer patients, per diagnosis, in the last 3 months of life

Only diagnoses with more than 100 visits to casualty are shown.

DOT diagnosis that includes a visit to casualty	Number of visits to casualty
NSCLC tumours	10291
SCLC tumours	1969
Pneumonia	1598
COPD	768
Pleural disorders	485
Atrium fibrillation/flutter	454
Non-haemorrhagic stroke	384
Malign	374
Other	283
Malignancy nno	257
Other general diagnoses	251
Lung embolism	241
Thoracic complaints eci	225
Other trauma/casualty diagnoses	210
Chronic heart failure	206
without antiviral treatment	191

Other disorders	185
Dyspnoea	185
Malign	166
Other (stomach)complaints, general	165
Acute heart failure	154
Femur	145
regular treatm./not a policlinical treatm.	134
Bacteraemia/sepsis	123
Haemoptysis	117
Deep venous thrombosis, extreme	115
Cerebral Commotio/contusio	110
Poli/setting NA (zt 12 13)	107
Chest pain	106

Conclusion

In general, visits to casualty by patients with lung cancer relate to serious diagnoses. The underlying reasons for admission may relate to symptoms in keeping with the disease and/or in keeping with patients with (multi-) comorbidity.

Table 11, visits to casualty by patients with intestinal cancer, per specialism, in the last 3 months of life

DOT specialism that includes a visit to casualty	Number of visits to casualty
Internal Medicine	8152
Surgery	3328
Neurology	1101
Gastroenterology and liver diseases	1063
Cardiology	847
Pulmonary diseases	774
Urology	372
Orthopaedics	197
Clinical Geriatrics	166
ENT	43
Anaesthesiology	31
Gynaecology	25
Neurosurgery	17
Plastic surgery	9
Ophthalmology	8
Dermatology	6
Paediatrics/Neonatology	4
Consultative Psychiatry	3
Rheumatology	2
Radiology	1
Cardiopulmonary surgery	1

Table 12, visits to casualty by patients with intestinal cancer, per diagnosis, in the last 3 months of life

Only diagnoses with more than 100 visits to casualty are shown.

DOT diagnosis that includes a visit to casualty	Number of visits to casualty
Colorectal malignancy	4594
Malign colonic neoplasm	834
Colorectal malignancy	566
Malign rectal neoplasm	365
Bacteraemia/sepsis	308
Ileus: paralytic	268
Malign recto-sigmoid neoplasm	267
Other (stomach)complaints, general	247
without antiviral treatment	200
Non-haemorrhagic stroke	196
Pneumonia	184
COPD	166
Ileus/volvulus	156
Acute renal insufficiency and dialysis	150
Acute heart failure	134
Malignancy nno	129
Other non-malign GI disorder	121
UWI (excl. urosepsis)	120
Pleural disorders	118
Intracerebral haemorrhage	115
Poli/setting NA (zt 12 13)	115
Chronic heart failure	108
Other general diagnoses	107
Atrium fibrillation/flutter	102

Conclusion

In general visits to casualty by patients with colonic cancer relate to serious diagnoses.

Care consumption in cases of disease-oriented treatment

Lastly, we looked at the relationship between disease-oriented treatment and care consumption. We operationalised disease-oriented treatments as "use of chemotherapy". Chemotherapy is almost always given to extend life, not to relieve symptoms. The effectiveness of chemotherapy is always assessed based on survival gains, not on improving quality of life. This does not apply to radiotherapy, so this cannot be operationalised as 'disease-oriented'.

We divided the patients into a group that received chemotherapy in the last 3 months of life, and a group that did not. We focussed first on days spent being nursed and then on visits to casualty. Days being nursed are relevant due to the costs, visits to casualty because it is often an undesired panic situation.

Table 13: Chance of one or more days being nursed, in the event of receiving/not receiving chemotherapy

disease	chemotherapy user	received a day's nursing	number of patients
intestinal cancer	no	no	11925
intestinal cancer	no	yes	9613
intestinal cancer	yes	no	852
intestinal cancer	yes	yes	2668
lung cancer	no	no	15418
lung cancer	no	yes	15355
lung cancer	yes	no	940
lung cancer	yes	yes	4912

We can summarise this table as follows:

Chance of one or more days being nursed for

- Intestinal cancer patients without chemotherapy: 45%
- Intestinal cancer patients with chemotherapy: 76%
- Lung cancer patients without chemotherapy: 50%
- Lung cancer patients with chemotherapy: 84%.

Table 14: Average number of days being nursed of those with chemotherapy and those without

disease	chemotherapy recipient	Average number of days nursed
intestinal cancer	No	5.6
intestinal cancer	Yes	10.4
lung cancer	No	6.0
lung cancer	Yes	11.9

Table 15: Chance of one or more visits to casualty by those who did receive chemotherapy/those who did not

disease	chemotherapy recipient	visited casualty	number of patients
intestinal cancer	No	no	13819
intestinal cancer	No	yes	7719
intestinal cancer	Yes	no	1375
intestinal cancer	Yes	yes	2145
lung cancer	No	no	17676
lung cancer	No	yes	13097
lung cancer	Yes	no	1869
lung cancer	Yes	yes	3983

We can summarise this table as follows:

Chance of one or more visits to casualty of

- Intestinal cancer patients without chemotherapy: 36%
- Intestinal cancer patients with chemotherapy: 61%
- Lung cancer patients without chemotherapy: 43%
- Lung cancer patients with chemotherapy: 68%.

Table 16: Average number of visits to casualty of patients who received chemotherapy and those who did not

disease	chemotherapy recipient	Average number of visits to casualty
intestinal cancer	no	0.6
intestinal cancer	yes	1.1
lung cancer	no	0.7
lung cancer	yes	1.4

Conclusion:

Patients who received disease-oriented treatment towards the end have almost twice as many days being nursed and visits to casualty in the last 3 months of their life. This is remarkable because patients who receive chemotherapy are often physically stronger than those who do not (or no longer) receive chemotherapy, so less care consumption would be expected.

Appendix 4: Elements of good and appropriate care

Knowledge about good care

Knowledge about care is about the availability of publicly accessible documents describing good care. These are quality standards such as guidelines and care standards, instruments of measurement and patient information.

Quality Standards

We examined which recommendations in national and international quality standards have been adopted on care in the final stage of life. For the sake of clarity, we discuss our findings below in the same sequence as the improvement possibilities, i.e.: (multi-agency) harmonisation on ACP agreements, timely discussion of preferences and patients' palliative care needs and shared decision-making on palliative care and treatment.

Harmonisation with primary care about ACP agreements

We examined which recommendations have been adopted in national quality standards on (multi-agency) harmonisation of ACP agreements.

We conclude:

The Dutch quality standards are not fully harmonised with primary care. Unlike the SONCOS-norm and the IKNL's non-tumour-specific guidelines on General Principles of Palliative Care, the NHG viewpoint on Oncological Care in General Practice gives GPs an active role in starting the palliative phase.

Explanation based on the findings

The report on multidisciplinary norms for oncological care (SONCOS norm report)³² contains a norm for harmonising and referring back after ending tumour-oriented treatment. This is the moment for agreeing which professional will coordinate the next trajectory and, if necessary, the patient is handed over. The IKNL guidelines on general principles of palliative care recommend that when a patient is no longer receiving symptom-related and/or disease-related treatment, the GP should be involved in discussions and decision-making. This is the moment for considering handing over to primary care and this should be discussed with the patient. GPs have a central role in the terminal phase. The non-tumour specific guidelines refer to tumour-specific multi-agency care pathways. Care pathways describe how the GP should be informed about every step of a care pathway: diagnosis, treatment and after-care trajectory. Care pathways pay attention to recognising the transition from disease-oriented palliative treatment to symptom palliation.

The viewpoint on oncology care in GP practices describes a role for GPs in the process of joint decision-making at the start of the palliative phase. In this phase patients attach more importance to personal attention and support. Furthermore, they want their GP to be accessible and available and that he/she explains things properly, e.g. about the course of the disease, symptoms that can be expected and treatment possibilities. Discussing the best and worst case scenarios helps patients to experience the palliative phase in a state of full awareness. The viewpoint recommends that in the palliative phase the GP maintains contact with the patient and with the specialist in charge. Together with the patient, his/her immediate family/voluntary carers and professional care providers, the GP draws up the care plan, focussing on the palliative and terminal phase.

Timely discussion of preferences and palliative care needs

We examined which recommendations have been adopted in national and international quality standards on the timely initiation of palliative care.

We conclude:

Various quality standards refer to the importance of good communication and shared decision-making in the palliative phase. Non-tumour-specific guidelines on palliative care refer to the importance of timely initiation of palliative care. However, tumour-specific treatment guidelines lack concrete aids for a timely discussion of the patient's preferences and his/her care needs in a broader sense. Recommendations in current guidelines are limited to the signalling of psychosocial care needs.

Explanation based on the findings

Foreign guidelines pay little attention to signalling, joint decision-making and palliative care. Only American and Scottish guidelines include recommendations along these lines. In November 2016 ASCO published an update of its guidelines, recommending the integration of palliative care and oncological care during disease-oriented treatment. Low-threshold palliative support is an important aspect of this, preferably when initiating the palliative phase.

The SONCOS-norm on the palliative team came into effect as of 1 January 2017, under which hospitals that treat oncology patients must have a multidisciplinary palliative care team that works according to the palliative care guidelines and makes use of an instrument to inventorise palliative care needs.

The national treatment guidelines on lung cancer (non-small cell and small cell) and intestinal cancer (colonic and rectal intestinal cancer) include a paragraph on communication and decision-making. The 2014 guidelines on Colorectal Cancer specifically cover the importance of shared decision-making. They also refer to the importance of informing and treating pro-actively. These guidelines refer to the Medical Treatment Contracts Act (WBG0) that offers a relevant statutory framework. The WBG0 states that a patient's permission is required for interventions that are carried out in fulfilment of a treatment contract. Another provision is that if a patient has indicated not wanting to receive information, then none will be provided. Both sets of guidelines and the tumour-specific care pathways recommend the *Lastmeter* (burden meter) for detecting psycho-social care needs.

The palliative care model³³ and the IKNL general guidelines for daily practice provides instructions for deploying the 'surprise question'. This is a generic instrument that help care providers to establish the final stage of life and to determine palliative care needs. The surprise question refers to a care provider who asks himself whether he would be surprised if his patient were to die within a year. The guidelines on general practice provide recommendations on guidance for a patient in a more disease-oriented than symptom-oriented palliation phase, discussing scenarios and attention to physical, mental, social and spiritual functioning.

Overview of relevant quality standards

Quality standard	Organisation	Year	Recommendation
Guidelines on colorectal cancer ⁴²	IKNL	2014	The guidelines refer to the tumour-specific multi-agency care pathways for

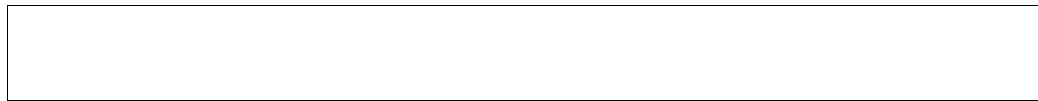
Quality standard	Organisation	Year	Recommendation
			recommendations on exploring the patient's own wants and preferences, ACP, defining the palliative phase.
Guidelines on non-small cell lung cancer ⁴³	NVALT	2015	The guidelines refer to tumour-specific multi-agency care pathways for recommendations on exploring the patient's own wants and preferences, ACP, defining the palliative phase.
Colorectal cancer: diagnosis and management. Clinical guidelines ³⁴	NICE	2011	None
Lung Cancer: diagnosis and management. Clinical guidelines ³⁵	NICE	2011	None
Consensus 1 st , 2 nd and further lines in advanced NSCLC ³⁶	ESMO	2014	None
Clinical practical guidelines on palliative care: ACP ³⁷	ESMO	2014	
Systemic Therapy for Stage IV NSCLC: Clinical Practice Guideline Update ³⁸	ASCO	2015	The multidisciplinary team must have good communication skills.
Integration of palliative care in standard oncology care ³⁹	ASCO	2016	Patients with metastatic disease must receive specialised palliative care early during disease-oriented treatment.
Management of lung cancer ⁴⁰	SIGN	2014	Lung cancer patients must have access to a palliative team.
Palliative and end-of-life care in lung cancer ⁴¹	ACCP	2013	Patients with stage IV and/or many symptoms must be offered palliative care in an early stage of treatment. Discuss for every patient the prognosis and treatment goals at diagnosis and during the entire course of the disease. In cases of incurable lung cancer, start discussions of treatment goals, advantages and disadvantages of life-extending treatment and ACP.

Clarification of treatment perspective in guidelines for medical specialists

Research was carried out into which recommendations are included in national quality standards on (care) possibilities once disease-oriented treatment with a life-extending objective is no longer possible.

We conclude:

Tumour-specific treatment guidelines for medical specialists pay insufficient attention to the importance of caution in carrying out diagnostics and treatments in the palliative phase: there is insufficient clarity about treatment possibilities and care possibilities once treatment has been rejected. The 2015 treatment guidelines on paraplegia, specifically the paragraph on patient selection and indication and the decision tree for diagnostics and therapy selection, can serve as an example of providing clarity about treatment possibilities in guidelines.³³



Explanation based on the findings

As this Room for Improvement Report was prompted by explicitly defined questions, the *Zorginstituut* did not carry out additional systematic reviews or guideline assessments. High quality evidence is essential to provide patients with 'evidence-based' information on appropriate treatment choices. The *Zorginstituut* also feels that special attention should be given to patient selection: this is important when using treatments that can potentially be burdensome for patients with a variable, but overwhelmingly short, life expectation. The Dutch treatment guidelines on Paraplegia and Vertebral Metastases contain a decision tree for estimating life expectancy, and functional status is weighed up when making a treatment choice or when caution is warranted.

Various initiatives exist in this field. An example is the Onco-guide currently under development. The Onco-guide shows decision trees for diagnostics and treatment based on patient data and disease data. The decision trees are based on guidelines and expert protocols. The IKNL is developing the Onco-guide in collaboration with care professionals.¹⁷

Overview of quality standards

The following table shows quality standards relevant to care in the palliative phase. Recommendations on palliative treatments per type of tumour, such as chemotherapy, palliative radiotherapy, are part of tumour-specific treatment guidelines for medical specialists. Alongside these tumour-specific guidelines, there are non-tumour specific guidelines for palliative care with recommendations on general principles in practice and the most recent insights into diagnostics and treatment of symptoms in the palliative phase. The care module on palliative care describes what good palliative care is. In 2015 *Palliactief* and the IKNL started developing a Dutch Palliative Care Quality Framework. Expectations are that the quality framework will have been completed by mid-2018.^{xvii}

Quality standard	Organisatio n	Year	Register xviii	Patient' s version	Measuring instruments	Informatio n standard
Guidelines on colorectal cancer ⁴²	IKNL	2014	no	no	DSCA registration relates only to surgery	no
Guidelines on non-small cell lung cancer ⁴³	NVALT	2015	no	no	DLSA registration relates only to lung surgery	no

^{xvii} The Dutch palliative care quality framework is the initiative of *Palliactief* and the IKNL. The Ministry of Health Welfare and Sport (VWS) has set as target that as of 2020, every citizen will be certain of receiving good palliative care in the right place at the right time and from the right care providers. Since 2015 the IKNL and *Palliactief* have worked together on establishing national unequivocal policy to improve palliative care. The quality framework is being developed by a working group with members mandated by the Dutch Patients' Federation, the NHG, *Verenso*, FMS, V&VN, NVPO and VGZ

^{xviii} An entry in the Register shows that the standard fulfils the procedural criteria of the Assessment Framework of *Zorginstituut Nederland*. Assessment Framework for quality standards, information standards & measuring instruments 2015. Diemen, 2015. (Version 2.0)

Quality standard	Organisation	Year	Register xviii	Patients' version	Measuring instruments	Information standard
Care module on Palliative Care 2013 ⁴⁴	CBO	2013	no	yes	yes, CQ index on <i>Zorginzicht.nl</i>	no
Guide to "Discussing end-of-life in good time" ⁴⁵	KNMG	2012	no	yes	no	no
General principles of palliative care: guidelines for daily practice. ⁴	IKNL	2016	no	no	no	no
Outcome of assessment on oncological care in GP practices ⁴⁶	NHG	2014	no	no	no	no
Qualitative framework on palliative care ^{xvii}	IKNL	2018	expected	2018	no	no
National first line guidelines on palliative care ⁴⁷	NHG	2006	no	no	no	no
ACP toolkit for GPs ⁴⁸	LAEGO	2014	no	no	no	no

National patients' information

We researched what patients' information exists, such as a patients' version of guidelines, or information about diagnosis and treatment on the website of a patients' association, or on *KiesBeter* or *thisarts.nl*.

We conclude:

The website '*Uitbehandeld maar niet uitgepraat*' [treatment has ended but discussion is still wanted] specifically discusses the importance of timely dialogue when cure is no longer possible: what (treatment) possibilities are left for the patient to get through what remains of his/her life as well as possible?

Explanation based on the findings

National patients' information is available for initiating an end-of-life dialogue. The KNMG provides a patients' version on end-of-life, including a check-list with points for discussion. It gives patients a guide on discussing their wants and expectations for the final stage of life with their doctor in the period before severe symptoms develop. A patients' version of the Care Module on Palliative care has also been drawn up⁴⁹.

Information based on this can be found on the website *thisarts.nl/levenseinde* of the NHG. *Zorginstituut Nederland's* website, *Kiesbeter.nl*, has a palliative care dossier. Various other websites also describe care in the palliative phase. Hospitals also offer information, such as the patients' folder 'Incurably ill, planning your care

in good time, published by the Amphia hospital.⁵⁰

The recently developed website of the Dutch Federation of Cancer Patients (NFK) '*Uitbehandeld maar niet uitgepraat*' [treatment has ended but discussion is still wanted] prioritises the timely discussion of end-of-life and the final stage of life.¹⁴ This website emphasises how important it is that patients, their families and care givers have a timely discussion with one another and inform and support one another properly when making choices once cure is no longer possible and the focus is on combating complaints and symptoms. The website informs patients about how long the palliative phase will last and that it can differ per person: varying from weeks to months, even as long as 10 years. This website also provides care professionals with information about good examples of palliative care and about bringing GPs and patients together to discuss the final stage of life. This initiative of the NFK is fully in line with this Room for Improvement Report.

Application in practice

Application in practice is about the level of implementation of quality standards, patients' versions and decision aids. In particular, we discuss in-depth research into support for the decisions of patients and doctors. We commissioned two external research groups for this research.

Two studies inventorised which instruments are available to support doctors and patients in making treatment decisions during the final stage of life. There are various instruments that can effectively support the shared decision-making of doctors and patients, and which increase the quality of the decision-making process. Decision aids inform patients about treatment options and the risks and opportunities involved. Decision-supporting instruments, also known as decision support systems (DSS), are instruments that can support doctors in weighing up the pros and cons of various treatment options. Such instruments give an estimate of survival chances and the burden of various treatment options.

Each of the external studies involved a 'quantitative' part and a 'qualitative' part. The objective of the quantitative part was to analyse daily practice. The 'quantitative' part was carried out using, e.g., data-analyses of data from patients' files, the systematic assessment of scientific literature or a cross-sectional study of Dutch hospitals. The 'qualitative' part was comprised of focus groups and interviews (conducted nationally). The objective of the qualitative part was to supplement or explain in greater depth the picture obtained from daily practice. Below is a summary of the qualitative part of the in-depth studies. In particular we described insights into potential bottlenecks and (pre-) conditions to improving care that are relevant to this Room for Improvement Report. For a full description of the in-depth studies and the outcomes, see the underlying external reports.^{15,16}

We conclude:

When good decision-supporting instruments are lacking (e.g. decision aids or DSS), a simpler more practical solution is possible with the aid of the '3 good questions' campaign. This is an initiative of the Dutch Patients' Federation and the Federation of Medical Specialists.¹⁸

Explanation based on the findings

We conclude that no good decision aids are available for patients, nor DSS for doctors. Most decision aids and DSS that were identified in the scientific literature are under development, insufficiently validated or insufficiently updated in

accordance with the most recent treatment insights. For care professionals these are important reasons for not using such decision-supporting instruments in the decision-making process. However, as a result of methodological, organisational and financial aspects, developing accurate choice-supporting instruments in the short term would be unrealistic.

Various decision aids and DSS instruments were found in scientific literature (see the underlying reports mentioned earlier) for both lung cancer and intestinal cancer. As the stage of death is not within the scope of this in-depth report, instruments for the stage of death were disregarded. Roughly speaking, DSS can be divided into two categories, depending on their proposed objective. One DSS category supports decision-making on therapy-selection, based on an estimate of the tumour's sensitivity to targeted treatment (mostly disease-oriented palliative treatment). Another DSS category marks the transition from disease-oriented to symptom-oriented palliative treatment. Medical specialists attach importance to the development of instruments for therapy selection (the first category) based on molecular-genetic tumour characteristics, alongside general patient characteristics. Consultants in palliative care point out the importance of instruments that, in addition to therapy selection, also estimate life expectancy and the patient's functional condition (the 'second' category). Regular care providers state that they mainly use information on therapy selection to make their own well-considered choice, possibly for discussion within the MDO (Multidisciplinary consultation with other medical specialists), but less for informing the patient.

Extensive support exists among care professionals for shared decision-making. At the same time, they state that in practice there is an almost complete lack of important conditions for shared decision-making. High quality evidence is essential to provide patients with 'evidence-based' information. Another important precondition is involving patients and their families in the process of joint decision-making. In practice, it seems that this will take time. Time in the sense of entering into 'timely' dialogue about patients' own values and preferences, and giving them an opportunity to fully realise that their own values and preferences are important in weighing up the choice of care and treatment. Care professionals state that, without a suitable decision-supporting instrument, a simple practical way to realise good decision-making is with the help of the '3 good questions' campaign'.¹⁸ Increasing awareness of this campaign will encourage patients and doctors to make well-informed choices based on these three questions.

Outcomes

When examining care outcomes, we look at whether quality information on health care outcomes is available and findable.

We conclude:

There are various initiatives in the field of developing outcome parameters or quality information. The *Zorginstituut* is of the opinion that the outcome parameters should be described in conjunction with one another. Preferably, an outcome indicator for location of death will be assessed in conjunction with an outcome indicator for communication with the patient on preferences and palliative care needs, e.g. in the form of ACP agreements and an outcome indicator for continuity of care.

Explanation based on the findings

A palliative care CQ index has been developed that is currently used to evaluate the national Palliative Care Improvement Programme.⁵¹ This index also collects

information on location of death. Attention was also paid to self-management by patients and their families, the proper harmonisation of care, whether care is in accordance with their specific wants, needs and values, and attention is given to the physical, psychosocial and spiritual care needs of patients. These CQ index questionnaires with corresponding work instructions can be found on *ZorginZicht.nl*.

IKNL, NIVEL and the Palliative Care Centre of Expertise studied the feasibility and costs of a Minimum Dataset on Palliative Care in University Medical Centres.⁵² This can be developed further once the Qualitative Framework on Palliative Care has been approved, thus providing a well-supported definition of palliative care quality.

Quality indicators for which hospitals are responsible, by supplying data for the *Zorginstituut*'s Register, relate to indicators collected via the DSCA (lung cancer) and DLSA (intestinal cancer) registers. These indicators are about the volume of surgery, radiotherapy, mortality, chance of survival and completeness of the registers. No indicators are collected for the palliative phase.

An international product is the ICHOM outcome indicator for measuring quality of death. This uses location of death and number of days in hospital during the last 30 days prior to death.¹⁰

When evaluating the multi-agency care pathway for lung cancer and colorectal cancer, the percentage of patients is measured who received palliative chemotherapy or systemic therapy during 30 days prior to death.

Effectiveness

In relation to the effectiveness of care, we look at whether care is effective, how does a patient benefit from treatment?

We conclude:

High quality evidence is essential to provide patients with 'evidence-based' information on making appropriate treatment choices. Obtaining insight into several treatment options that permits a comparison of the estimated outcomes of each treatment with one another requires far-reaching demand-driven assessment. In particular, of the various palliative treatment possibilities and how they relate to one another on a level that makes them important outcome parameters for patients. After all, for patients it is the impact a certain treatment choice has on quality of life that is important. Based on our research, the *Zorginstituut* concludes that there is an 'evidence-gap'.

Explanation based on the findings

The amount of evidence on ACP and joint decision-making in RCTs is variable. The problem is choosing the right outcome parameters, the complexity and types of patients and communication.⁵³ In practice, good communication with the patient, and communication between care providers in the care chain are conditions for allowing care to actually take place from the patient's perspective. The *Zorginstituut* did not carry out any additional systematic reviews of guidelines or onus of proof regarding ACP, shared decision-making and the timely deployment of palliative care. The results of the data-analyses do not form a reason for carrying out effectiveness analyses of individual diagnostics or treatment interventions (appendix 3). The Minister wrote in a letter to parliament about Joint Decision-Making (October 2015): 'Our ambition is clear: we want patients to be able, together with their doctor, to make optimum decisions on treatment that is in keeping with their situation. All parties in health care subscribe to this and are working hard to make it possible'.⁵⁴

High quality evidence on appropriate treatment choices is essential to provide patients with 'evidence-based' information. The *Zorginstituut* concludes, based on the in-depth research, that there is an 'evidence-gap' in this field.¹⁶ On the one hand, a solution can be found in carrying out randomised research that focusses on direct (head-to-head) comparisons of the various palliative treatment options. However, in view of the rapidly evolving treatment landscape, this is not realistic. On the other hand it would be valuable to examine the extent to which the relative effectiveness of the various palliative treatment options can be determined based on existing evidence. There are various initiatives of parties that focus on developing such decision-making support for doctors. For a patient-oriented estimation of relative effectiveness, it is important that effectiveness analyses are accompanied by information about outcome parameters that are important for patients. After all, for patients it is important to know what effect a given treatment choice has on quality of life.

Cost-effectiveness

This is where we assess whether care is cost-effective.

A separate analysis of cost-effectiveness is not relevant within the framework of the research questions. This report is not about (cost-effective) interventions, but about a dignified end-of-life and a dignified death and care that is in keeping with this. The assistance this involves is not suited to an financial economic model of cost-effectiveness analyses.

Necessity

Burden of disease within the framework of a systematic analysis is a perspective for depicting the severity of a disease, with the aim of obtaining insight into the medical necessity of treating the disease.

Clearly this question is not relevant for patients with lung cancer and intestinal cancer: the need to offer these patients palliative care is self-evident. Questions can be asked about whether appropriate use is being made of some palliative treatment and general care in hospital during the final stage of life.

Feasibility

We use the criterion feasibility to examine whether there are factors that hinder the successful implementation of care. These could include, e.g. basis of support, budget impact or the organisation of health care on a macro level. These are preconditions for successful application.

During a systematic assessment, we focus on the patient's perspective and the care he/she needs.³ In practice, conditions for allowing care to actually take place from a patient's perspective are good communication in all settings of the care chain. This may play an even larger role in the final stage of life than in earlier phases.

We conclude:

There are various initiatives whose objective is to enable parties to reach agreement in order to realise good palliative care in practice. The *Zorginstituut* feels that an important precondition is the exchange of information between the first line and hospitals about ACP agreements. This will require the development of a multi-agency information standard

The biggest improvement of this Room for Improvement Report lies in ensuring the timely deployment of

palliative care. This requires training and the development of skills that focus on using the new techniques for providing good information and shared decision-making.

Explanation based on the findings

Preconditions for the successful use of multi-agency harmonisation and the timely deployment of palliative care are described in various documents.

Multi-agency harmonisation:

The objective of the 'Quality framework on palliative care in the Netherlands' is to connect national organisations involved in palliative care with scientific organisations and umbrella organisations, care insurers and the government, in order to reach agreement on an unequivocally accepted, multi-agency quality framework on palliative care with appropriate funding. Publication of this quality framework is expected in May 2017. Alongside the quality frameworks, the IKNL also developed care pathway formats for multi-agency care pathways for lung cancer and intestinal cancer.⁵⁵ These formats are models for hospitals to be able to implement the quality framework in teams and to agree on what is expected in patient care, by whom, and when. These care pathway formats pay attention to: shared decision-making, care that is in line with the patient's values and preferences, defining the palliative phase and ACP.

Timely harmonisation with patients' wants and preferences and their palliative care needs: the timely deployment of palliative care:

The palliative team SONCOS-norm came into effect as of 1 January 2017, under which hospitals that treat oncology patients must have a multidisciplinary palliative care team that works according to the palliative care guidelines and makes use of an instrument to inventorise palliative care needs. This team will include at least two medical specialists and a nurse with specific expertise in palliative care. At least one medical specialist on the multidisciplinary team must have completed specific training in the field of palliative care. Patients can at all times consult an internist-oncologist, anaesthesiologist, neurologist, lung specialist, MDL specialist, radiotherapist, pharmacist, psychologist, spiritual carer and social worker, all with expertise in palliative care. The palliative team meets at least weekly and must ensure timely multi-agency consultations and handovers to ensure optimum palliative care is provided at home. It should also be available for consults about patients who have been discharged and are receiving palliative care at home under the supervision of a GP.⁵⁵

Consistency in quality circles

A lot of attention is being paid to improving the quality of care in the palliative phase. There are many initiatives in this field (including the ZonMW *Palliance* Programme). A quality framework for palliative care is being developed that includes all parties in the field. There is a multi-annual programme for the large-scale revision and implementation of palliative guidelines. Intestinal cancer and lung cancer are also on the quality and appropriateness agenda of partners in the Outline Agreement.

The *Zorginstituut* is able and willing to contribute to this quality improvement by providing knowledge, data and research, and by its combined tasks in the field of package management and quality improvement. They participate in the Ministry of VWS's Steering Group on Palliative Care.

Appendix 5: overview of parties' reactions

On 6 October 2016 *Zorginstituut Nederland* organised a meeting at which the parties discussed the analyses of the in-depth studies. During this meeting, the parties had an opportunity to make comments and suggestions about the contents and interpretations of the analyses. The parties' responses contributed additional nuances and clarification of our analysis. This represents a substantial input on their part to realising this Room for Improvement Report. The report of the meeting can be found in appendix 5. In addition to this contribution, the parties were also invited to send a written response to the draft Room for Improvement Report. We invited the parties to respond to the individual improvement measures. We also asked them for suggestions about which parties are relevant for implementing the improvement measures. In their general response, a number of parties, such as the Dutch Association for Radiotherapy and Oncology, and health insurer CZ, declared their support for the Room for Improvement Report. The following is an overview of the parties' comments in more detail. The responses are given per improvement possibility and corresponding improvement measure.

Improvement possibility:

Increase the awareness of patients and care givers about discussing palliative care needs in good time: when the incurable disease is diagnosed and subsequently, if necessary, during the further palliative course of the disease.

NFK's response

According to the NFK, it is important to increase awareness that rejecting (further) treatment is also an option. In its comments, the NFK proposes challenging other stakeholders about such slogans as 'giving up is not an option!' The NFK proposes thinking 'outside the box' in order to reach the public at large. Relevant parties in favour of implementation are: NVALT (lung cancer) and NVMO (solid tumours, including colorectal tumours) and HOVON.

NVMO's response

The NVMO feels that a lot of energy should go into national campaigns. Attention should be given to the fact that 'health care does not have an infinite shelf-life'. Advertising campaigns and slogans that imply that every disease is curable do not contribute to public awareness of the fact that life can sometimes be finite. They emphasise the disease-transcending nature of the importance of promoting awareness by means of media attention. The NVMO proposes involving the following parties: VWS, FMS, NHG and V&VN, and the relevant scientific associations (possibly via guideline committees).

ZIN's responses

We are pleased that the patients' association NFK and the NVMO approve of the improvement activity of increasing awareness among patients and care professionals about the timely and repeated discussion and exploration of palliative care needs.

This Room for Improvement Report specifically relates to people with incurable lung cancer and cancer of the intestines. We do not preclude the possibility that specific experience gained with these

tumour indications will also apply to other fields of indication. We will involve relevant parties as far as possible in the implementation phase. The patients' association suggested HOVON, but this is not a relevant stakeholder in view of the scope of this Room for Improvement Report.

Improvement activity:
Increasing care professionals' awareness by including a recommendation about timely dialogue in the national treatment guidelines for medical specialists and GPs.

NFK's response

The NFK is sceptical about the influence of altering the national guidelines on timely dialogue about palliative care needs. The TFK expects more of the Dutch Qualitative Framework on palliative care, the Care Module and the (SONCOS) obligation regarding palliative teams in all Dutch hospitals. The NFK also emphasised the importance of media attention for timely dialogue.

NVMO's response

The NVMO agrees with the proposed improvement activity, as long as a lot of energy goes into national campaigns about health care not being infinite. Another condition is extra financial room, so that carrying out timely ACP discussions and the repeated updating of ACP agreements can be implemented in practice. Suggested relevant parties for implementation: VWS, FMS, NHG and V&VN and the scientific associations involved (possibly via guideline committees).

ZIN's responses

We note that the objectives of the NFK, the NVMO and the Zorginstituut are largely the same. We see analogy in their interest in increasing awareness among patients and professionals about discussing palliative care needs in good time and the personal wants and goals of patients in relation to care and palliative treatment. We regret that our proposal about a recommendation in the national treatment guidelines for medical specialists cannot count on the NFK's support. We upgraded our Room for Improvement Report partly as a result of the NFK's response. We see that the NVMO also emphasises the value of a social debate with the media's help, and that it is a condition for inclusion in guidelines. The Zorginstituut sees added value for continuing both improvement measures.

Improvement activity:
Facilitate continued development of a guide on the timely deployment of palliative care, whether or not with the support of a palliative consultation team.

NFK's response

The NFK says that it will implement guidelines once they are available. The NFK also mentions not doing work twice.

NVMO's response

The NVMO said it was unable to find the information on guidelines. The NVMO is in agreement as long it involves the concept of early palliative care. As a condition, the NVMO stipulates the crucial conditions mentioned (see previous comments). The NVMO also emphasised the importance of ensuring multi-agency continuity.

**ZIN's
responses**

We conclude that the intended objectives of the NFK, the NVMO and ZIN are largely the same: we see agreement in the importance attached to supporting the timely deployment of palliative care. The guidelines developed by external researchers is an initial step.

**Improvement possibility:
Increase the transparency in treatment guidelines of
treatment (im-)possibilities and limitations, and develop a
patient's version.**

**NFK's
response**

The NFK feels that an instrument for weighing up the advantages and disadvantages of various options will be out-of-date before it is ready for general use (particularly if it has to be validated and tested for cost-effectiveness), e.g. in guidelines. The NFK is more interested in developing a generic instrument, for example, one capable of identifying a patient's underlying wishes.

**NVMO's
response**

In relation to using, for example, the paraplegia guidelines or the Onco-guide, in the opinion of the NVMO it is as yet too early to make a choice. Insight will first have to be obtained in all available possibilities. In other words, they do not agree to the two examples that were specifically named.

**ZIN's
responses**

We note that the methodological objections mentioned by the parties are along the same lines as objections we mentioned in the Room for Improvement Report. Nevertheless, Zorginstituut Nederland is of the opinion that it is possible to create transparency about treatment possibilities and limitations in the form of a decision tree or algorithm that can support doctors in determining treatment policy and in discussing it with their patients. We regret that increasing transparency about this in treatment guidelines cannot count on the support of the NFK and the NVMO. The guidelines that were developed by the external researchers can be an initial step towards a generic instrument for detecting patients' palliative needs and wishes.

Improvement possibility

Develop an information standard for the multi-agency handover of ACP agreements.

NFK's response

The NFK supports the importance of effective handover procedures. To avoid doing work twice, the NFK suggested initiatives in the care field that could focus on optimising handovers and communication between care providers. For instance, as a spin-off within the framework of the current Dutch Palliative Care Qualitative Framework, ZonMw's *Palliantie* programme or the PaTz method for collaborating and transfers surrounding palliative care at home ^{xvii,s,t}, the NFK would like to see the IKNL involved in developments surrounding the Dutch Palliative Care Quality Framework.

NVMO's response

The NVMO agrees with the proposed improvement activity, as long as ACP dynamics are taken into account (once-only documentation is insufficient for chronic incurable diseases and elderly patients). The NVMO is of the opinion that handovers should be ICT-steered and that access should also be available to many other care providers and voluntary carers who are involved. A problem-owner should be designated during implementation. The NVMO advises involving the FMS, an umbrella organisation. The reason for this is ACP's non-disease specific nature and the acknowledged need for ACP and the multi-agency handover of these agreements in other specialist fields.

ZIN's responses

Zorginstituut Nederland sees consensus with the importance that the NFK and NVMO attach to efficient handover procedures that reflect ACP dynamics. The parties emphasize the non-tumour specific and non-disease specific nature of ACP. This Room for Improvement Report specifically relates to people with incurable lung cancer and cancer of the intestines.

These patient groups were selected during the screening phase of the systematic assessment of the ICD-10 field of neoplasms.² We do not preclude the possibility that specific experience gained with these tumour indications will also apply to other fields of indication.

We agree with the NFK that carrying out existing activities twice in the care field must be avoided. We will involve the proposed parties as far as possible in the implementation phase.

Improvement activities:

- **Develop an indicator for monitoring multi-agency documentation of ACP agreements on care and/or treatment during the final stage of life**
- **Develop an outcome indicator (PROMS) for measuring continuity of care**
- **Develop an outcome indicator for measuring quality of death in the last 30 days of life; there is an international ICHOM outcome indicator for measuring quality of death. This uses location of death and number of days in hospital during the last 30 days prior to death.**

NFK's response

Within the framework of monitoring care during the final stage of life, the NFK asks how we define the final stage of life: "is it about the start of palliative care (can be 2 years prior to death) or only the phase of death?" The NFK would like to see the IKNL involved in developments surrounding the Dutch Palliative Care Quality Framework.

NVMO's

In its comments, the NVMO says that implementation will involve

⁵ ZonMw's *Palliantie* programme. The objective of 'More than care' is to noticeably improve palliative care for patients and their families. Subsidy is allocated annually up until 2020. Organisations in the field of research, education and care can submit projects in response to an invitation on ZonMw's website. The programme encourages improvements in palliative care in four fields: awareness and culture, organisation and continuity of care, quality and care innovations, patient participation and support

^t PaTz stands for palliative home care; its objective is to promote collaboration between GPs and (district) nurses and

response

enormous costs for the personnel needed to realise a watertight multi-agency ICT system that guarantees privacy issues. A viable supplementary budget will also have to be made available (in addition to the present budget) with funding for ACP dialogues, organising shared decision-making, continuity of multi-agency care and all the other improvement activities mentioned in the report.

The NVMO feels that indicators should only be chosen if they correctly monitor what took place. A quality death does not automatically mean dying at home, so this indicator cannot be used. The right indicator is that the desired location of death, as indicated during the most recent ACP update, must agree with actual practice (and thus, the ultimate location of death). PROMs are already being used widely. We must take care that in this difficult time patients and voluntary carers are not unnecessarily and extensively burdened with PROMs.

ZIN's responses

The Room for Improvement Report defines the final stage of life within the framework of exploring palliative care needs and ACP irrespective of the recognisable initiation of the final stage of life (see section 5.1), i.e., from the moment of diagnosing an incurable disease, and subsequently at important moments during the course of a patient's disease.

We do not regard care intensity or location of death as indicators of quality of care in themselves. This impression may have been created in this report due to the description of individual external studies in this report. On the contrary, our report actually concludes that, ideally, an indicator for location of death can only be assessed in conjunction with an indicator for (multi-agency) consistency and ACP agreements. Only in this way will we gain insight into whether communication took place with patients about their preferences regarding care (see section 5.1).

to increase their expertise. The PaTz method involves GPs and district nurses meeting one another every two months to identify patients in the palliative phase, to discuss them and include them in a palliative care register. Together they draw up a care plan that focusses on the wants of the patient and those around him/her. All is going well in the field of coordinated and expert home care. Palliative Home Care as Good Example was implemented 16 times via ZonMw's Palliative Care Improvement Programme

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