



NORWEGIAN MINISTRY  
OF HEALTH AND CARE SERVICES

Strategy

# Together – against cancer

National Cancer Strategy 2013–2017



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## Foreword

### *Together – against cancer*

Cancer challenges us all in various ways. Even though treatment has improved and an increasing number of patients survive cancer, the number of individuals affected is also increasing. Cancer is not one, but many different diseases. One of the greatest challenges faced by cancer care is therefore the development of more targeted and personalised cancer treatment, adapted to the specific type of cancer and the individual patient's qualities, opportunities and needs.

The World Health Organization has estimated that one in three cases of cancer can be prevented. The risk factors are generally the same as for other lifestyle diseases. Efforts against tobacco are particularly important. It is therefore important to inform people about what can increase the risk of cancer, and society must ensure that everyone is able to make healthy choices.

Our ambition is that the National Cancer Strategy 2013-2017 shall form a foundation upon which the high level of quality in Norwegian cancer care can become even better. Compared with other countries, we have good survival statistics for several cancers. At the same time, we know that there are great challenges relating to certain cancer types, and too many individuals still die of cancer.

The cancer strategy is supported by two mutually reinforcing principles:

- To focus on the patient and change the relationship between patient and therapist, so that patients actively participate in decisions regarding their treatment and care: *"No decision about me without me"*.
- To improve the quality of treatment so that this is integrated and effectively coordinated.

When these two principles work together, they will contribute to innovation, improved patient experiences and improved service quality.

An increasing number of patients are surviving cancer, and many are able to live with their illness for a long time. Collaboration between the health and care services and the voluntary sector is important in order to improve cancer patients' quality of life and ability to cope, and this collaboration will become even more important in the times ahead.

For 75 years, the Norwegian Cancer Society has tirelessly promoted awareness of issues relating to cancer and converted this into action – in many important areas. The Norwegian Cancer Society has also played an important role in the development of the strategy. I would like to thank the Norwegian Cancer Society and everyone who has contributed to this work – professionals, users and representatives of the health and care service.



Jonas Gahr Støre  
Minister of Health and Care Services

## Background

In 2012, the Ministry of Health and Care Services decided to develop a new national cancer strategy. The strategy has a duration of five years. The Norwegian Directorate of Health was assigned the task of submitting a foundation document as a basis for the strategy. The Norwegian Cancer Society has been consulted throughout the entire process, and has collaborated with the Norwegian Directorate of Health in finalising the foundation document. A broad range of individuals have been involved in the work, both through a professional working group and an external reference group.

The target groups for the strategy are the general public and the various actors with responsibility for cancer care, such as national health authorities, the health regions, hospitals, local authorities and General Practitioners.

The Norwegian Directorate of Health's foundation document is published as a separate report from the Directorate: *Status, trends and challenges relating to cancer* (IS-2084).

## Previous plans relating to cancer

The main objective of the National Cancer Plan (1999-2003) was to reduce the number of new cancer cases through a long-term prevention strategy, and to improve diagnostics and treatment.

*National strategy for work within cancer care – quality, competence and capacity* was submitted to the Ministry of Health and Care Services in 2004. The report contained over 200 suggestions for measures targeted towards decision-makers and managers at several levels as well as practitioners working with preventive activities, and at all levels within health and social services.

The cancer strategy for 2006-2009, eventually extended to 2011, established national objectives with accompanying measures within 10 areas: prevention, national screening programs, the cancer patient, the health service and society, diagnostics, treatment, alternative treatment, rehabilitation, palliative care, personnel – capacity and competence, and the Cancer Registry of Norway as a national medical quality register and centre for research.

Since 2005, the specialist health service has been strengthened with the allocation of around NOK 12 billion.

## Partnership against cancer

In order to contribute to the coordinated implementation of the objectives and sub-objectives of the National Cancer Strategy 2013-2017, a “partnership against cancer” has been established. The partnership consists of the Norwegian Cancer Society, the Norwegian Association of Local and Regional Authorities (KS), the four regional health trusts, cancer patient organisations, the Norwegian Cancer Registry and the Norwegian Directorate of Health.

By providing a platform for dialogue and collaboration, the partnership will strengthen the work against cancer locally, regionally and nationally.

## Summary of the strategy’s most important objectives

The strategy specifies national objectives and sub-objectives in several important areas:

- More user-oriented cancer care

An important objective is better information, both for the individual patient and the general population. Cancer patients shall always know who they shall contact regarding their own illness, treatment and follow-up. Patients shall be able to actively participate in decisions regarding their treatment. Other important measures are the development of digital self-help tools, the possibility for patients to view their own records, and the opportunity to communicate with the health service. Cancer patients’ experiences must be used actively in order to improve the quality of the service. Patients shall be involved in the work with professional guidelines, research and innovation.

- Norway shall be a leading example of good patient care

Patients shall experience that the services link together effectively without unnecessary delays. The necessary information shall be accessible to everyone who needs it, which requires the further development of information and communications technology (ICT) systems in line with the White Paper *One citizen – one record*. The objective that 80% of cancer patients shall start treatment within 20 working days of the receipt of their referral is ambitious, but important. Cancer coordinators at the hospitals can help to achieve this objective. It must also be ensured that General Practitioners have a central role in the follow-up of patients. Coordinators in the municipalities and in hospitals must collaborate in order to create a coherent service.

Effective systems for fast and precise assessment and diagnosis must be established, such as diagnosis centres for patients with undiagnosed serious conditions and prostate centres.

- Norway shall be a leading example of cancer prevention

The preventive work against tobacco and alcohol shall be continued. The same applies to the implementation of national nutritional advice and the continuation of the work to increase physical activity. Targeted information about sun exposure and risk is necessary, as is strengthening the work to increase support for the HPV vaccination programme and national screening programmes.

- More patients shall survive and live longer with cancer

It is necessary to ensure sufficient capacity and competence to effectively respond to the large increase in the number of cancer cases in the coming years. Adequate, up-to-date equipment for surgery and radiotherapy must be ensured, and Norwegian patients must receive access to new, safe, effective and cost-effective medications. Access to personnel with the necessary skills must also be ensured in both hospitals and municipalities.

Several quality indicators must also be established for cancer care, particularly indicators that provide information about the outcome of treatment and consequences for the patient's function and quality of life. It is also important to increase the number of clinical studies, and increase the number of studies involving children, young people and the elderly.

- The best possible quality of life for cancer patients and their relatives

Rehabilitation must become an integrated part of the treatment process for cancer patients. Peer support groups and voluntary workers must also be able to participate in cancer care. The work with palliative and end of life care shall be strengthened. It is important to increase competence within palliative care. Relatives shall be ensured good follow-up and guidance, and emphasis must be placed on follow-up measures and information for children and young people who are relatives of cancer patients.

## **Implementation of the strategy**

The strategy's various objectives and sub-objectives must be concretised and implemented by the health authorities and health services within their areas of responsibility and financial frameworks. In some areas it may also be necessary to reallocate resources.

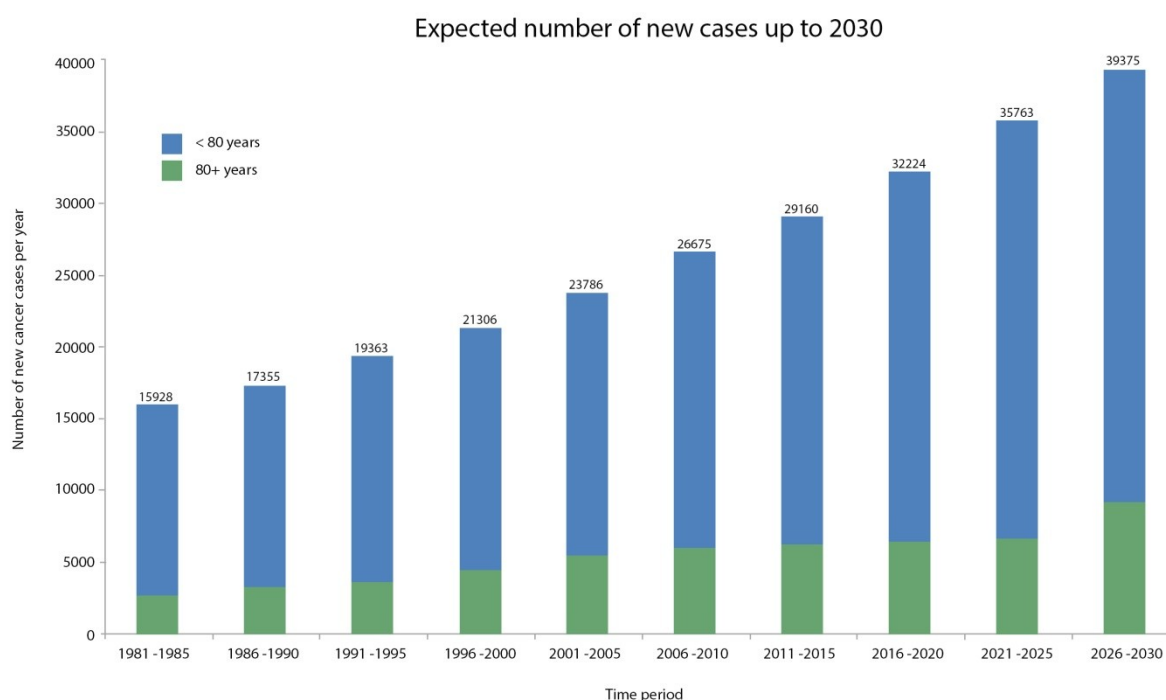
## Status and trends

In 2013, more than 200,000 people living in Norway have or have had cancer. This is around three times as many people as in 1980. Just under 30,000 new cases of cancer are now diagnosed every year, compared with 14,000 in 1980.

The increase in new cases of cancer is due to several factors:

- The population is increasing
- The number of elderly individuals within the population is increasing – and the risk of cancer increases with age
- Improved diagnostics and screening
- Actual increase in certain types of cancer

The number of new cancer cases will continue to increase. The Norwegian Cancer Registry's projections indicate that in 2030 almost 40,000 people will be diagnosed with cancer annually. The most important reason for this increase is the country's ageing population.



More people are surviving cancer. When excluding deaths due to causes other than cancer, almost half of cancer patients lived five years after diagnosis in 1980 (relative survival). This proportion is now more than two thirds. This increase is due to both earlier cancer diagnoses and improved cancer treatment.

But even though many survive, there are still too many patients who die of cancer. More than 10,000 people died of cancer in 2011. Cancer is still the disease which contributes most to premature death. In 2009, 2,636 men and 2,236 women aged



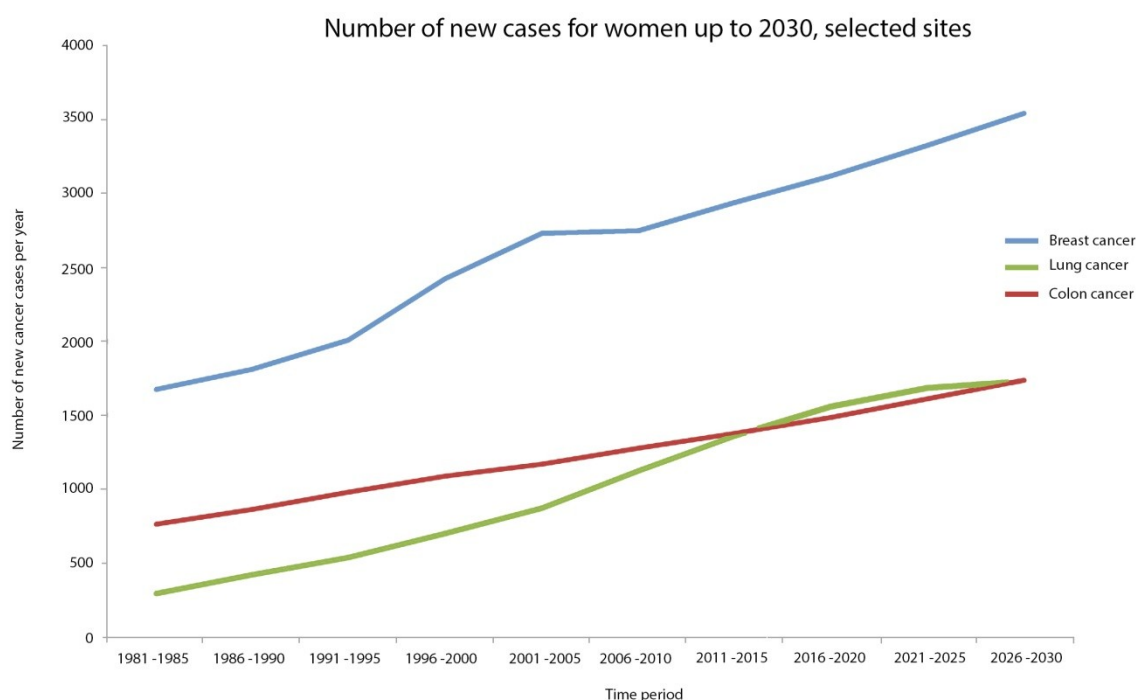
between 35 and 74 died of cancer, 37% and 50% of all deaths in this age group, respectively.

The four most common forms of cancer in Norway are lung cancer, colon cancer, breast cancer and prostate cancer.

### *Breast cancer*

Breast cancer is the most common form of cancer among women in Norway. In 2010, 2,839 women were diagnosed with breast cancer. Women under 40 are affected in less than 5% of cases. The results of breast cancer treatment have improved over many years. Relative survival five years after diagnosis has increased from 76% to 89% in the past 20 years. However, almost 700 women still die of breast cancer each year.

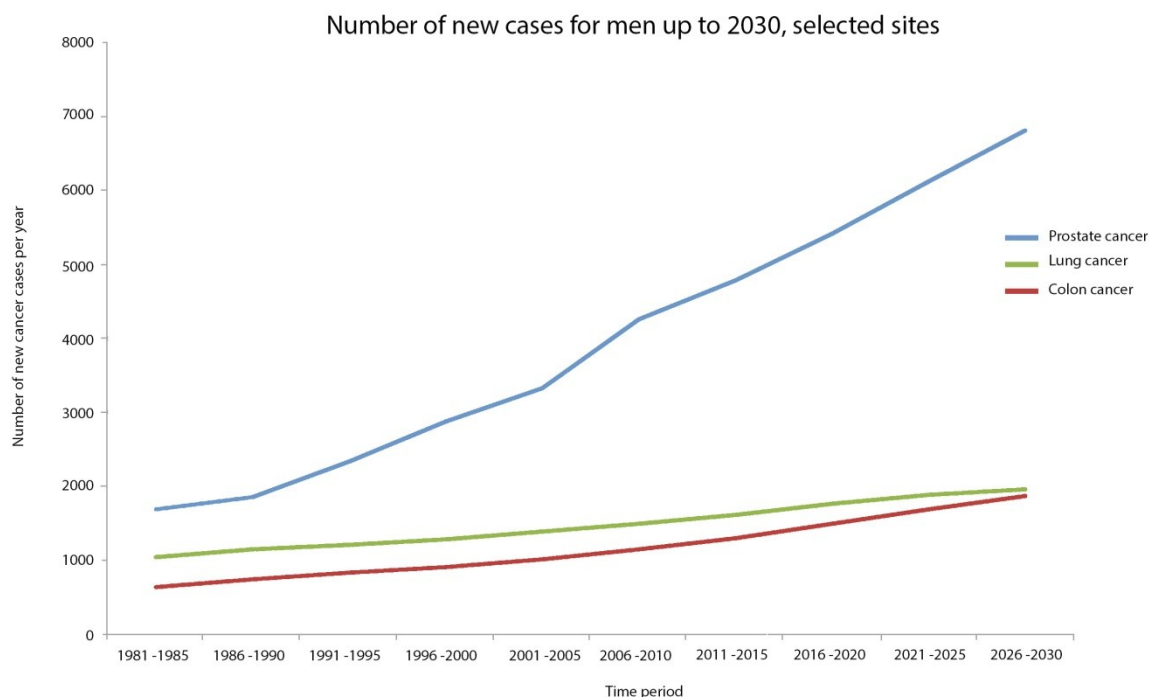
Around half of patients receive breast-conserving surgery. Other patients are offered breast reconstruction, provided that there are no medical reasons which prevent this. Consideration for reconstructive surgery shall be a part of the treatment for patients operated for breast cancer in Norway. Breast reconstruction can be carried out during the primary breast cancer operation, or later if the patient has received chemotherapy/radiotherapy as a part of their primary treatment.



### *Prostate cancer*

Prostate cancer is the most common form of cancer among men in Norway. In 2010, 4,210 men were diagnosed with prostate cancer. 90% of patients diagnosed with prostate cancer are over 60 years of age. Relative survival five years after diagnosis has increased from 60% to 88% in the past 20 years.

Despite national guidelines, reporting and treatment varies considerably. There are several examples of too long a period elapsing between the first suspicion of prostate cancer and clarification of whether treatment is necessary, and if so, what treatment should be provided.



### *Lung cancer*

Lung cancer is the form of cancer which results in the most deaths from cancer in Norway. In 2010, 1,559 men and 1,267 women were diagnosed with lung cancer. Lung cancer is strongly linked to smoking. It is expected that the number of new lung cancer cases will remain stable going forward, and then reduce correspondingly as the number of smokers in Norway decreases.

Five year relative survival for lung cancer in Norway has increased somewhat in recent years, but is still only 16% for women and barely 12% for men. The prognosis is best when the disease is diagnosed when surgery is possible. Today, too many patients are diagnosed too late.

### *Colorectal cancer*

After breast cancer in women and prostate cancer in men, cancer of the colon/rectum is the most common form of cancer among both sexes. In 2012, almost 4,000 people were diagnosed with colon or rectal cancer.

The incidence of colorectal cancer has increased in recent years. This is probably due to changes in diet and lifestyle. Norway has the highest increase in and highest incidence of colorectal cancer in the Nordic region.

Treatment for colorectal cancer has improved significantly. Five year relative survival for colon cancer is now over 60%, somewhat higher for women than for men. For rectal cancer, five year relative survival is around 65%.

#### *Children and young people*

The incidence of cancer among children has remained stable over the past 40 years, with the exception of tumours in the central nervous system, which seem to have increased somewhat. Today, 80% of all children who are diagnosed with cancer live for more than five years following diagnosis. Almost 80% survive past ten years of age. There are around 140-150 new cases of cancer diagnosed in children under the age of 15 in Norway annually.

#### *The elderly*

Around 6,600 patients over the age of 80 are diagnosed with cancer annually. This is a trebling of the figure from 1980. It is expected that the number of cancer patients in this age group will double by 2050.

## Current challenges

Norwegian cancer care is of a high quality. Compared with other countries, for example, Norway has good survival statistics for several types of cancer.

The OECD report “Health at a Glance” from 2011 shows the five year relative survival results for breast cancer, cervical cancer and colorectal cancer in 20 OECD countries. Norway has the best results of all the OECD countries for cervical cancer, and we are also among the best for breast cancer. Our results for colorectal cancer are somewhat above the average for the OECD countries. We have better results than the other Scandinavian countries for all these forms of cancer. This is a significant improvement from the previous OECD report in 2009. Then, Norway was on a level with the average for the OECD countries for all three forms of cancer.

However, Norway does not fare equally well in all international comparisons. For example, a study published in 2013 shows that the one year survival rates for lung cancer in Norway are poorer than in Sweden, Canada and Australia, but better than in Denmark and the UK. There is therefore room for improvement. Here, tobacco control measures are of great significance.

In 2010, the Norwegian Board of Health Supervision undertook an assessment of the risk picture for Norwegian cancer treatment, and concluded that the level of risk in Norwegian cancer treatment was too high. The four most important risk factors related to late diagnosis, an insufficient flow of information, continuity in the treatment and the monitoring of complications.

In 2009, the Norwegian Knowledge Centre for the Health Services published a report on cancer patients’ hospital experiences. The survey showed that cancer patients had positive experiences with the hospitals in many areas, but that there was potential for improvement. For example, around one in five patients experienced that they had a fixed group of nursing staff or doctor with main responsibility for their care to a little degree or not at all. Between 20% and 30% found the information they received regarding pain and pain relief insufficient, and many felt that they were not sufficiently informed about side effects. The results also indicated that there is a need for improved collaboration and coordination between the hospital and other health care services.

A major challenge for Norwegian cancer care is the significant increase in new cancer cases we will see in the coming years, particularly among the elderly. This increase will place great demands on the capacity and competence in the hospitals and create a need for investments in equipment and infrastructure, but will also be equally challenging for the municipal health and care services.

The municipal health and care services will be responsible for a greater number of more seriously ill cancer patients with complex needs. Far more people are living with cancer, more outpatient treatment is provided, and there are fewer and shorter hospital admissions. In addition, it is an objective that treatment which can be decentralised will

be offered locally, preferably in collaboration with the municipalities. The municipalities shall ensure coordinated thinking which includes prevention, early intervention, early diagnosis, treatment and follow-up, so that comprehensive patient care can be offered to the greatest extent possible within the most effective level of care. This requires capacity, competence and effective coordination within the municipal health care services.

The rapid development of new and improved treatments and of more personalised treatment options also requires more competence and capacity within the health service.

Lifestyle is of importance for the incidence of cancers. Tobacco is the main cause or contributing factor for several forms of cancer. More than 80% of all cases of lung cancer are related to smoking. Alcohol increases the risk of breast cancer and cancers of the digestive system. A high level of consumption of processed meat and red meat increases the risk of colorectal cancer. Insufficient physical activity increases the risk of breast cancer and colon cancer.

Various backgrounds, living conditions, education, income and other social conditions contribute to inequalities in health within the population. There are for example more smokers in low income groups, occupational exposure to hazardous substances is far more usual in manual professions and among employees with shorter educations. In addition, people with low incomes and shorter educations live in areas with relatively high traffic and pollution.

It is an objective that cancer patients in Norway quickly receive access to new treatment methods that are documented as being effective. Often, these methods are new and costly medicines and new technologies which often pose difficult dilemmas for society. What requirements must be set for the effect of new treatment methods if we are to justify the use of collective funds to finance them? How can we ensure that the introduction of new treatments is based upon robust, scientific documentation for the relevant patient groups? How can we ensure that Norwegian patients are able to participate in trials of new treatment methods?

As an increasing number of patients are living longer with cancer, greater attention must be placed on measures to improve the quality of life of those living with cancer. Many patients are able to live good lives even if they suffer late effects following cancer treatment or their cancer has spread, and therefore require life-prolonging treatment, rehabilitation, help with learning and coping, and palliative and general care. This poses special challenges, particularly within the municipal health and care services.

Many patients wish to be at home during the last phase of life. However, less than 15% of Norwegian cancer patients die at home. Measures must therefore be implemented which make it possible for more patients to spend the last phase of their life at home in familiar surroundings with their loved ones.

## National objectives:

**Objective 1: More user-oriented cancer care**

**Objective 2: Norway shall be a leading example of good patient care**

**Objective 3: Norway shall be a leading example within cancer prevention**

**Objective 4: More patients shall survive and live longer with cancer**

**Objective 5: The best possible quality of life for cancer patients and their relatives**

### Objective 1: More user-oriented cancer care

#### National objectives:

- **Cancer patients shall feel cared for, seen and heard**
- **Patients shall always know who they shall contact regarding their own illness, assessment, treatment and follow-up**
- **Patients shall have access to necessary and relevant information about their treatment**
- **Patients shall have good access to information about the disease, treatment methods and consequences**
- **Patients shall be able to participate in decision-making processes**
- **Feedback from cancer patients and their relatives shall be used actively in order to improve the service**
- **User versions of professional guidelines shall be available**

The White Paper on quality and patient safety *God kvalitet – trygge tjenester (Good quality – safe services)* establishes the objective that the services shall be more user-oriented. This means that the needs and expectations of patients, users and relatives shall be the starting point for decisions and measures, and that patients shall receive

information and support so that they can actively participate in the decisions that affect them.

### *A more active patient role*

In the White Paper on quality and patient safety, the government discusses several measures to make the services more user-oriented. In the White Paper on digital services in the health and care sector, *One citizen – one record*, the government has set the objective that online digital services shall make it easier for citizens to interact with the health and care services, and help to ensure that citizens experience the service as accessible and coordinated. Among other measures, the website [www.helsenorge.no](http://www.helsenorge.no) shall be further developed so that information about factors influencing health and illness, and various services and their quality, is more easily accessible.

In addition, self-service solutions shall be developed under the auspices of [helsenorge.no](http://helsenorge.no), which will make it easier for patients to obtain access to information about their health and to contact health care personnel. New research from the Centre for Shared Decision Making and Collaborative Care Research at Oslo University Hospital indicates that cancer patients who receive access to electronic tools that support interaction with health care personnel and provide access to the patient's medical records and self-help tools, experience less pain and discomfort due to their illness and treatment.

Through the project *eBed 2015*, patients in the cancer department at Stavanger University Hospital have the opportunity to participate in and control aspects of their treatment using tablets. The tablets feature functions which include:

- Up-to-date information regarding diagnosis, assessment and treatment
- Control function to ensure that the correct medicine is given to the correct patient at the correct time
- Control function for sample taking
- Copy of patient records

The Norwegian Directorate of Health has been tasked with collaborating with the patient and user organisations in order to develop decision-making support tools to help patients participate in decision-making processes regarding their illness. In 2013, NOK 2 million has been allocated for the development of decision-making support tools for cancer patients.

It is important that services are also available for those who do not wish to or are unable to use electronic solutions.

### *Information and communication*

Feedback from patients and users points to information and communication as important areas for improvement. Good communication between patients and health

care personnel also contributes to improved treatment results and improved health for the patient.

The Cancer Line (Kreftlinjen) is a free telephone service created by the Norwegian Cancer Society. The Cancer Line is a service for everyone who needs answers to questions or information about cancer and cancer related issues. Through the Cancer Line, callers are able to contact professionals such as specialist nurses, lawyers and social workers.

In Norway, 13.1% of the population has an immigrant background. The health challenges within this group, which includes migrant workers, refugees, asylum seekers and reunited families, are complex. Parts of the immigrant population are often assessed at a later stage than the rest of the population, which poses particular challenges for the cancer care. These are primarily linked to delayed diagnosis and language problems. We must strive to provide better information regarding prevention and early diagnosis, and to improve communication with cancer patients where language may be a barrier.

It is an objective that patients shall always know who they shall contact regarding their illness and treatment. In the mission document for the hospitals, the Ministry of Health and Care Services set a requirement that patients who are referred due to suspected cancer shall be appointed a dedicated contact person. The contact person shall ensure that the patient receives the necessary information about what happens when, patient rights and waiting times.

In addition, General Practitioners shall be the fixed medical point of contact for the citizens on their lists.

#### *Patient experiences*

User experience surveys provide useful information about the quality of the service. Hospitals and municipalities should use feedback from cancer patients actively in order to improve the service.

#### **Sub-objectives:**

- Encourage the development of new digital services for cancer patients and their relatives, including decision-making support and self-help tools, quality assured information about health and illness, the possibility to follow one's own treatment plan, access to one's own patient records and communication with the health service
- Ensure that the patient perspective is taken into account in the Norwegian Directorate of Health's work to further develop the national action programmes for cancer



- Prepare good, adapted information about cancer, cancer treatment and patient care for patients and their relatives
- Further develop the national user experience surveys relating to cancer
- Help to ensure effective communication between cancer patients and healthcare personnel, for example through courses or other training
- Further develop the collaboration between the Norwegian Cancer Society, cancer patient organisations, hospitals and municipalities in order to strengthen patient training, preferably under the auspices of the cancer care centres, learning and coping centres and healthy lifestyle centres
- Stimulate increased user participation in cancer research and innovation
- Further develop information about cancer for the population, patients and relatives on helsenorge.no

## **Objective 2: Norway shall be a leading example of good patient care**

### **National objectives:**

- **The treatment offered to cancer patients shall be coordinated as coherently and effectively as possible, without unnecessary delays**
- **80% of all cancer patients shall start treatment within 20 working days of receipt of their referral**
- **Effective systems for the fast and precise assessment and diagnosis of various types of cancer shall be established**
- **Effective interaction, a good flow of information and clear division of responsibilities and tasks shall be established within the specialist health service, between the specialist health service and the municipal health and care services, and within the municipal health and care services**
- **Increased use of individual plans for cancer patients**

### *Improved coordination of services*

When patients require coordinated health and care services from various parts of the specialist health service and in the municipal health and care services, good individual services are not good enough. We must also ensure effective interaction between the services. It must be an objective that patients and users encounter an integrated service that is well coordinated and characterised by continuity, and which features coherent treatment chains and high quality treatment and patient care, regardless of who has responsibility for the individual services.

Cancer patients often move through complex patient assessment and treatment processes, in which they are transferred between their General Practitioner, the hospital and other municipal health and care services. Within the specialist health service, they often come into contact with several different treatment centres and departments. This can result in cancer patients experiencing the services as fragmented and uncoordinated, and that they themselves must act as coordinator for the various service providers. Effective patient care requires effective interaction, logistics and communication between the various treatment centres and levels.

Patients who require long-term and coordinated services are entitled to an individual plan. An individual plan can be an important tool in ensuring interaction between the service providers, and in ensuring patient assessment and treatment processes that feature continuity and a clear division of responsibilities.

In the annual letter of instruction to the regional health authorities for 2013, a requirement has been set that a treatment plan shall be prepared for patients who shall undergo extensive assessment and treatment within the specialist health service. The plan shall describe the planned patient assessment and treatment process, with estimated dates for the various parts of the process. The plan shall be a working document for the patient and therapist.

Both the specialist health service and municipality are obligated by law to appoint a coordinator. In accordance with Section 7-2 of the Health Care Act, the municipalities' obligation applies to patients and users requiring "long-term and coordinated services". Section 2-5(a) of the Specialist Health Services Act imposes a duty to appoint a coordinator for patients requiring "complex or long-term and coordinated services". The Specialist Health Services Act states that the coordinator should be a doctor, but other health care personnel may act as a coordinator when this is regarded as appropriate and justifiable. In accordance with both the Specialist Health Services Act and the Health Care Act, the coordinator's tasks include ensuring the necessary follow-up of the individual patient, interaction between the services and progress in the work with the patient's individual plan.

Many hospitals have created cancer coordinator positions. Cancer coordinators in hospitals are not usually doctors, but most often nurses or other health care personnel. In many cases, practical coordination tasks will be an inappropriate use of the doctor's time. There is therefore reason to consider whether changes should be made to the legislation, so that it is no longer a requirement that coordinators within the specialist health service should be doctors.

Telemark Hospital and Stavanger University Hospital are among the hospitals that have created cancer coordinator positions. The coordinators are responsible for coordinating the fastest possible assessment and treatment for patients, ensuring the provision of information about the treatment process for the patient and relatives at an early stage,

and following up the patient until treatment starts. The coordinator also ensures that referrals reach the intended recipient and are quickly assessed.

In the municipalities, cancer nurses, General Practitioners and resource nurses may coordinate the treatment process. The Norwegian Cancer Society provides financial support for 97 cancer coordinator positions in 147 municipalities across the country.

General Practitioners have an important role as medical coordinators and as contributors to the creation of integrated and effective patient care within the municipal health and care services and between the municipal health and care services and the specialist health service. The revised General Practitioners' regulations, which came into effect on 1 January 2012, clarify the General Practitioner's medical coordination responsibility.

The Coordination Reform envisages a greater municipal responsibility for the health and care services. At the same time, the specialist health service shall be reorganised by decentralising services wherever this is possible, placing more focus on mobile organisations which support the municipal services, and centralising highly-specialised functions where this provides the best quality. The reform shall help to ensure an improved and more integrated treatment process for cancer patients. The objective is increased competence within the municipalities for all processes relating to cancer diagnoses. This shall increase the quality of treatment and follow-up. In order to achieve this, an important element is that General Practitioners, to a greater extent than previously, shall be able to utilise other municipal services in order to offer patients the best medical follow-up. This applies during the assessment/referral phase, follow-up after or between treatments in hospital, and where patients require palliative care at the end of life. The revised General Practitioners' regulations clarify the municipal responsibility for General Practitioner services in the municipalities.

A good flow of information is necessary in order to ensure rapid assessment and coherent services. The White Paper on digital services, *One citizen – one record* establishes the objective that health care personnel shall be able to access the necessary patient information quickly and effectively. This applies throughout the entire patient assessment and treatment process, regardless of where the patient becomes ill or receives treatment.

It is critical that the exchange of patient information can occur electronically between hospitals and between hospitals and the municipal health and care services. It is also necessary that information regarding image diagnostics, pathology and blood tests is easily accessible in electronic patient records. The government's main objective is one citizen – one record.

#### *More effective assessment and diagnosis*

The Norwegian Board of Health Supervision's report regarding the risk picture for Norwegian cancer care from 2010 points to late diagnosis as one of the greatest risk

factors in cancer care. Accurate and fast diagnosis and assessment form the basis for good treatment outcomes.

It is important that the general public is aware of the symptoms and danger signs that may be a sign of cancer, and that individuals consult their doctor in time. If cancer is suspected, the General Practitioner must clarify the situation and quickly refer the patient for further diagnosis within the specialist health service.

The hospitals must facilitate efficient assessment, where as many examinations as possible can be carried out and responded to within a short period of time, preferably within the same day. In order to achieve this, systematic work must be undertaken to eliminate bottlenecks. Such bottlenecks may be capacity for image diagnostics, examinations of cell and tissue samples in pathological laboratories, or the possibility for fibre optic examinations of the digestive system.

Patients suspected of having a specific type of cancer are currently referred to the relevant specialist department for assessment in accordance with national guidelines and the specific routines for the individual hospital. Based on the patient's clinical condition and findings, the patient is often assessed by several different professionals within a multidisciplinary team (MDT), preferably in regular meetings where decisions regarding treatment are made in consultation with the patient. Breast cancer diagnosis centres have for a long time undertaken such diagnoses for patients with suspected breast cancer. Connecting the diagnostic centres, which feature radiologists and pathologists, with clinical specialists such as surgeons and oncologists within one centre forms the basis for effective multidisciplinary assessment and decision-making, which ensures patients high quality assessment treatment processes and patient care. In the same way, diagnosis-specific centres can be established for other cancers, such as prostate cancer. Vestfold Hospital has established such a prostate cancer centre in order to facilitate the effective and efficient assessment of patients with prostate cancer. In the revised national budget for 2013, NOK 10 million is allocated for prostate cancer centres within the health regions.

Patients with unclear symptoms or where cancer or another serious illness is suspected may experience being referred between various specialist hospital departments or between the hospital and their General Practitioner, resulting in the assessment process taking too long. Two pilot projects are therefore being established for diagnostic centres for this patient group at the University Hospital of North Norway and Akershus University Hospital.

#### *National action programmes*

National action programmes with guidelines for cancer treatment continue to be an important part of the *Nasjonal strategi for kreftområdet (National cancer strategy) 2006-2009*. As of October 2012, 13 national action programmes exist for various types of cancer. A further seven action programs are currently being developed. The action programmes are prepared through collaboration between the Norwegian Directorate of

Health, the specialist environments, health regions and Norwegian Knowledge Centre for the Health Services. The action programmes shall help to ensure high quality, equal services for patients in different parts of the country.

The national cancer guidelines contain normative cancer assessment and treatment times within the specialist health service. This means that referral shall be considered within five working days, assessment shall have started within 10 days, and treatment started within 20 days. The hospitals follow-up the objective that treatment shall be started within 20 working days for 80% of the patients treated for breast cancer, colon cancer and lung cancer.

#### *Amendments to the Patients' Rights Act*

In the spring of 2013, the Ministry of Health and Care Services suggested amendments to the Patients' Rights Act to Parliament. The new rules state that the hospitals must consider referrals within 10 days and that patients shall quickly be notified when they have an appointment.

The new rules apply to all patient groups, including those who have a serious illness, and are a minimum requirement or safety net to ensure that patients are assured that they will receive an examination and treatment within a reasonable timeframe. However, cancer patients require faster clarification. The recommended assessment and treatment times for cancer patients therefore involve faster clarification of the patient's condition than in both the old and new legislation.

#### *Standardised patient assessment and treatment processes*

The development of standardised patient assessment and treatment processes as a part of the national action programmes will help to improve logistics and interaction, reduce the level of risk and increase patient safety. Standardised patient assessment and treatment processes can also give patients and their families a better overview, predictability and understanding of the various stages of the treatment, and therefore increased assurance.

Effectively organised standardised patient assessment and treatment processes with recommended timeframes shall ensure the patient a fast, predictable and coordinated process through diagnosis, assessment, treatment and follow-up. In terms of content, they will have clear similarities to the Danish model with "package processes" for cancer treatment, adapted to the organisation of the Norwegian health service. Standardised patient assessment and treatment processes are being considered for addition to the action programmes for various cancers. Information and communications technology (ICT) solutions should also support standardised patient assessment and treatment processes.

## **Sub-objectives:**

- Establish functions such as coordinators for patients within the large cancer groups at all hospitals which assess and treat patients for cancer
- Ensure that coordinators in the municipalities and in hospitals collaborate in order to create a coherent service
- Ensure sufficient capacity within pathology, image diagnostics (CT, MR, PET-CT) and endoscopy through recruitment, correct staffing and division of tasks, strengthened specialist competence, the necessary physical infrastructure and up-to-date equipment
- Evaluate pilot projects for diagnosis centres for patients with unclear symptoms
- Establish multidisciplinary outpatient clinics where this is appropriate, including prostate centres, where in a single or a few hospital visits patients can be assessed by various types of specialists involved in assessment and treatment
- Develop models for the organisation and management of well-functioning multidisciplinary teams (MDT)
- Ensure that the General Practitioner has a central role in the follow-up of the patient
- Develop decision-making support tools for General Practitioners regarding assessment for various forms of cancer
- Ensure sufficient cancer competence within the general practice specialist course through the on-going audit of doctors' specialist training
- More General Practitioners shall be specialists within general practice
- Develop guidelines for referral to the specialist health service for General Practitioners, and describe these in the national action programmes
- Establish standard patient assessment and treatment processes, and integrate these in all the action programmes
- Establish ICT solutions which provide health care personnel with fast and efficient access to the necessary patient information and support standard patient assessment and treatment processes
- Further develop the national action programmes in order to cover the entire patient assessment and treatment process

## **Objective 3: Norway shall be a leading example within cancer prevention**

### **National objectives:**

- **Norway shall achieve the WHO's objective of a 25% reduction in premature deaths due to non-communicable diseases (NCD) by 2025**
- **Cancer prevention shall be undertaken in a way that counteracts social inequalities in health**
- **The cancer screening programmes shall have a documented effect on morbidity and mortality and the lowest possible risk of side effects or harm**

The World Health Organisation (WHO) has estimated that one in three cases of cancer can be prevented. It is therefore important to inform people about factors that may increase the risk of cancer, so people are motivated to change their lifestyles. Society must also facilitate healthy choices.

The WHO's global objective is a 25% reduction in premature deaths relating to cancer, type II diabetes, cardiovascular diseases and chronic respiratory diseases by 2025. Based on the measures which the WHO defines as effective and cost-effective, suggested measures have been prepared targeted towards four risk factors - the use of tobacco, unhealthy diets, physical inactivity and excessive alcohol consumption. In addition, preventive measures must be targeted towards environmental factors.

In the public health White Paper *Good health – a shared responsibility*, the government has set national public health objectives. The report states that Norway shall be one of the three countries in the world which has the longest life expectancy, a population which experiences more years of good health and well-being and reduced social inequalities in health, and shall create a society which promotes good health across the entire population. The objectives will be achieved by reducing premature deaths and reducing social inequalities in premature mortality. Cancer prevention will be central in achieving these objectives.

In addition to the public health White Paper, the national health authorities have issued several guiding documents that are followed up and which will strengthen the preventive efforts. Among these is the *National strategy to combat harm caused by the consumption of tobacco 2013-2016: A future without tobacco*. The White Paper regarding an integrated substance abuse policy, *Look at me! A holistic substance abuse policy* from 2012 shall be followed up, as shall the strategy to reduce radon exposure from 2009. Public health initiatives and preventive measures to reduce the risk of cancer will often coincide with similar measures to prevent other illnesses, such as cardiovascular diseases. Such measures must be viewed simultaneously and coordinated.

The general public receives information about the links between poor diet, being overweight, insufficient physical activity and excessive alcohol consumption and an increased risk of cancer, but many people do not follow the advice regarding these factors. The quality of the information must be of such a nature that it motivates the target group to take action. General Practitioners have a particular responsibility for identifying at-risk persons on their patient lists, including persons at risk of developing lifestyle-related cancers, and if necessary, ensuring individual guidance and follow-up.

The healthy lifestyle centres offer a structured follow-up system for persons who need to change their lifestyles, primarily with regards to physical activity, diet and quitting smoking. The healthy lifestyle centres can be both for individuals with an increased risk of developing lifestyle-related diseases, including cancer, and for persons who need help to change their lifestyles following cancer treatment.

A strong link has been proven between the HPV virus and cervical cancer. The vaccine against human papillomavirus (HPV) was introduced as part of the childhood immunisation programme for girls in the seventh grade from the school year 2009/2010. The HPV vaccine protects against the types of HPV which are the cause of at least 70% of cases of cervical cancer. The Norwegian Knowledge Centre for the Health Services shall submit a summary of knowledge which analyses the effect, safety and cost-benefit of various immunisation strategies for boys and girls.

### **Sub-objectives:**

- Follow up the tobacco prevention work in line with the National strategy to combat harm caused by the consumption of tobacco 2013-2016, *A future without tobacco*
- Follow-up preventive measures relating to the excessive consumption of alcohol in line with the White Paper on an integrated substance abuse policy, *Look at me!* from 2012
- Continue work with the implementation of national nutrition advice and the “Keyhole label”
- Continue the work to increase physical activity among the population in general and among children and young people in particular, including the implementation of information campaigns about physical activity
- Continue the work to ensure the best possible participation in the HPV vaccination programme for young girls
- Encourage the establishment of healthy lifestyle centres which integrate healthy lifestyle services and learning and coping functions, and which anchor peer support work within the municipalities
- Ensure a good level of competence regarding prevention and lifestyle habits among health care personnel and within the population



- Targeted information about exposure to the sun and the risk of cancer

### *Screening*

The aim of the national cancer screening programmes is to discover precursors to cancer or cancer at an early stage in order to reduce morbidity and mortality.

The methods used must be sensitive and precise, so that they effectively distinguish between ill and healthy individuals, are easy to execute and have a low risk of side effects. In addition, the costs of the screening programmes shall be reasonable in relation to the benefits.

The screening programmes must be continually quality assured and regularly evaluated based on the achieved results.

The results of the majority of patients who are examined through a screening test/examination are seen to be “normal”. However, a small percentage of the screening population receive a positive result. Such findings require further investigation in order to clarify whether disease is actually present. False positive results can cause strains in the form of unnecessary anxiety and worry for the individual, as well as unnecessary follow-up examinations. Screening may also discover cancers that may never develop into symptomatic illnesses. False positive results and overdiagnosis are a challenge in all screening programmes.

Participation in screening programmes is voluntary. The provision of good, balanced information is important so that those who are invited to participate can make an informed choice regarding whether to participate or not. The individual must be informed of the advantages and benefits of participating in a screening programme, and the effects and risks relating to the various screening tests. Those who are invited to participate must also be given information about possible complications in the event of treatment, and the risk of overtreatment.

Two national cancer screening programmes have been established in Norway – the mammography programme and the cervical cancer screening programme.

The cervical cancer screening programme recommends that all women aged between 25 and 69 have a Pap test taken once every three years. Since the programme was established, the incidence of cervical cancer has reduced by 30%. Over half of all cervical cancer cases are diagnosed in the 20% of women who do not participate in the screening programme. In recent years, fewer women have participated in the screening programme, particularly younger women.

The mammography programme invites all women aged between 50 and 69 to a mammography screening every two years. The results from two new analyses of the effect of mammography screening show a 20% and 30% reduction in breast cancer mortality among women invited to participate in the screening programme, respectively. In recent years, there has been increased awareness of the fact that the

mammography programme provides an increased risk of the overdiagnosis of breast cancer, i.e. cancerous tumours are discovered that would not have developed into a serious illness even if they had not been discovered. Critics of the mammography programme have asserted that the effect on mortality does not outweigh the disadvantages of overdiagnosis. The programme is now subject to a research-based evaluation.

Most cases of colorectal cancer develop through benign precursors, so-called polyps, through a process estimated to take 5-15 years. This makes colorectal cancer particularly suitable for screening, where it is possible to identify cancer, and also to remove polyps in order to prevent cancers from developing. A pilot project to screen for colorectal cancer has therefore been initiated at Bærum and Moss hospital. The programme has been set up in such a way that two different screening tests can be compared. The pilot project will therefore be able to identify which of the two tests provides the best results with the least possible negative effects.

The introduction of screening for prostate cancer has been considered. However, the current test, the PSA (prostate-specific antigen) test, is not accurate enough to be used as a screening method in order to establish who has prostate cancer requiring treatment. Screening for prostate cancer is therefore not recommended for the general population.

For lung cancer, the effect of screening with modern computer tomography is still unclear, and can therefore not currently be recommended as a national screening programme.

Screening outside the organised national screening programmes, so-called “wild screening”, makes it difficult to evaluate the effect of the national screening programmes. Screening tests in areas in which it is not recommended to establish national screening programmes in Norway, e.g. PSA screening for prostate cancer, poses a risk of overdiagnosis and unnecessary treatment and follow-up.

There is a need for national screening programmes to be controlled by the authorities. The Norwegian Directorate of Health has therefore been tasked with establishing an overall strategy and management structure for the national screening programmes.

### **Sub-objectives:**

- Ensure sufficient capacity and competence to execute the necessary screening programme examinations
- Work systematically to improve participation in existing screening programmes
- Ensure good, balanced information for those who are invited to participate in the screening programmes

- Assure the quality of all cancer screening programmes in line with European screening guidelines
- Continually assess whether new knowledge of screening may call for new or changed screening programmes
- Measures to avoid “wild screening”:
  - Provide information to General Practitioners and other health care personnel regarding who should be offered screening
  - Provide information to target groups so that they do not request screening unnecessarily
- Consider reporting of mammography screening outside the mammography programme.

## **Objective 4: More patients shall survive and live longer with cancer**

### **National objectives:**

- **Norway shall be among the countries in the world with the highest five year survival rates following cancer diagnosis and the lowest cancer mortality**
- **Cancer patients in Norway shall be offered diagnosis, investigation, treatment, follow-up and rehabilitation at a high international level**
- **Norwegian cancer research shall be undertaken at a high international level**
- **The Norwegian Cancer Registry shall be further developed, and associated national quality registers shall be established for the most common forms of cancer**
- **Good indicators shall be developed in order to measure the quality of the cancer treatment**
- **Norway shall continue to be among the countries in the world which have the best outcomes of cancer treatment for children**
- **Elderly patients with cancer shall receive cancer treatment adapted to their functional level and any other morbidity**
- **The incidence of side effects and late effects relating to cancer treatment shall be reduced**

### *Cancer treatment*

Cancer is currently treated using surgery, radiotherapy and medicines. Cancer treatment will often use a combination of these forms of treatment. Psychosocial follow-up is also a central part of the total treatment for cancer patients and their relatives.

Surgery is central in the treatment of many types of cancer, both to cure the patient and to relieve symptoms. Cancer treatment currently constitutes a significant proportion of the activities of the large surgical specialities. Developments throughout the past 10-20 years have resulted in significant changes in surgery. These changes include the use of keyhole surgery and robot-assisted procedures. An important change over the past 20 years is that cancer surgery is now undertaken within far fewer units, so the individual units and surgeons obtain greater experience. We have seen that this has given good outcomes for rectal cancer, breast cancer and lung cancer, and this trend is expected to continue.

As part of the follow-up of the National Cancer Plan (1999-2003), radiation capacity was increased to 39 radiation devices (linear accelerators) on a national basis. This has considerably improved the treatment offered to patients, and the use of radiotherapy has increased. However, the use of radiotherapy is still too low within certain areas, particularly palliative radiotherapy.

Radiotherapy is becoming increasingly individualised and tailored to the individual patient's needs through the use of CT, MR and PET in the planning. The purpose of this is to increase the effect of the therapy and minimise side effects, and we see good results from this today. Rapid technological developments in equipment provide further opportunities in this area, requiring new investments for the replacement of outdated equipment.

Treatment with protons as an alternative to ordinary radiotherapy with photons makes it possible to administer higher doses of radiation to deep tumour tissues and correspondingly lower doses to less deep, normal tissues. Proton therapy is not currently offered in Norway, but a small group of patients, particularly children and young people, receive treatment involving proton therapy abroad. The regional health authorities under the leadership of the Western Norway Regional Health Authority, are now investigating possibilities to establish a proton therapy centre in Norway.

Medicines used in cancer treatment include traditional cytotoxic medicines (chemotherapy), newer targeted medicines that influence the immune system and various hormones. The medicines can be used to cure cancer or to extend the patient's life, as well as in palliative care, and several medicines are often administered in combination.

The use of medicines in cancer treatment has significantly increased over the past 10 to 15 years because several new, effective treatment regimes have become available. This has resulted in more patients surviving cancer and living longer, fewer patients relapsing, and more patients experiencing improved quality of life, and this trend is expected to continue. Many of the new medicines are costly, which significantly challenges the health service. Various financing solutions can influence the objective to use medicines correctly, both medically and economically. A trend within medicines is that an increasing number of expensive medicines for specialist treatment are

becoming available. In some areas, medicines are available that must be taken in hospital, while others can be taken at home. Regardless, the aim is that medicines shall be used correctly, both medically and economically.

Large areas of cancer treatment require medical expertise. For a number of forms of cancer there is a documented link between the treatment outcome and the number of patients who are treated, including in terms of survival, complications and relapse. It is therefore necessary to centralise a number of services in an appropriate number of centres in order to ensure a robust treatment environment with the necessary medical expertise and experience. At the same time, it is necessary to develop good local competence for services that can be provided closer to the patient.

The increasing number of cancer cases that is expected to be seen in the coming years will require the development of capacity for surgery, radiotherapy and medicinal treatment.

All forms of treatment are in continual development:

- New minimally invasive surgical techniques
- Personalised precise radiotherapy, both with traditional photon treatment and with proton treatment in order to avoid serious late effects
- Medicines for use in cancer treatment are continually being developed based on new biological knowledge, and can to an increasing extent be tailored to the individual patient's needs based on risk factors, markers and gene profiles

It will therefore be necessary to frequently update the national action programmes in order to ensure that they are in line with new knowledge. The rapid developments in cancer treatment also make it necessary to adapt how the services are organised. New and advanced surgical techniques require changes in the organisation and infrastructure of hospitals.

Decisions regarding the individual patient's treatment are most often made by a multidisciplinary team (MDT) at regular meetings. MDTs are composed of various types of specialists so that they are adapted to the various types of cancer. These are most often different types of surgeons, oncologists, radiologists, pathologists and other professionals. Most often, the patient meets one or two of the specialists on the team, but patient meetings with the entire team can also be held so that the patient is able to meet with several specialists at the hospital during the same appointment. It is important to facilitate active participation for patients and their relatives.

#### *New system for the introduction of new methods*

A new, national system for the evaluation of the methods used within the specialist health service is currently being introduced through a collaboration between the hospitals, the Norwegian Directorate of Health, the Norwegian Knowledge Centre for the Health Services and the Norwegian Medicines Agency. The new system shall

ensure that available knowledge regarding new treatment methods and medicines can be utilised more quickly.

The system shall cover medicines, medical equipment, procedures and diagnostic methods, and be used in prevention, assessment, diagnosis, treatment, follow-up and rehabilitation. The system will be an important tool for quality and priority-setting, and shall be used during both the introduction of new methods and the phasing out of old ones. All new methods shall be evaluated in accordance with the system prior to being taken into use. This will increase patient safety and provide health care personnel with the knowledge that all utilised methods are documented as being safe and effective. The evaluation of methods may be undertaken locally, regionally or at national level. Decisions regarding the introduction of new medicines shall always be made through national processes.

New technologies are also being introduced in the municipalities, influencing and challenging their economies, organisation and competence. At the same time, it is important to recognise that the use of welfare technologies in the municipal health and care services creates many opportunities. For example, this enables more patients to live longer in their own homes, despite reduced functional abilities and serious illnesses. This is a desired development..

#### *Nutritional treatment*

Cancer patients are particularly at risk of malnutrition prior to diagnosis, during treatment, and as the disease progresses. Weight loss results in decreased tolerance of the treatment, reduced treatment efficacy and reduced survival. In order to achieve the best possible result of the cancer treatment, it is important to treat nutritional problems and weight loss in parallel with the cancer treatment.

#### *Dental health*

Cancer treatment affects patients' dental health. Patients treated for cancers of the head, neck and throat are most affected, but complications in the teeth/oral cavity also occur in around 40% of patients with cancer in other parts of the body.

Dental health problems can be reduced through effective prevention and oral health follow-up routines. Health care personnel who shall guide and inform patients must therefore have good knowledge of how cancer treatment may affect dental health, as well as the financial support schemes for dental treatment for cancer patients.

#### **Sub-objectives:**

- Ensure sufficient capacity and competence within surgical and oncological treatment through increased training and recruitment and the effective staffing and division of tasks,
- Develop expertise, and ensure the necessary treatment premises and equipment

- Establish national quality and robustness requirements for hospitals offering cancer treatment
- Review the status of cancer surgery in Norway by 2014
- Ensure that Norway has modern radiotherapy equipment
- Consider the establishment of a Norwegian proton therapy facility
- Establish agreements for proton therapy abroad for Norwegian patients pending the establishment of a Norwegian facility
- Ensure that Norwegian patients receive access to new, safe, effective and cost-effective medicinal treatments
- Update the national action programmes in line with new knowledge
- Endeavour to hold multidisciplinary patient meetings for certain types of cancer
- Follow-up and evaluate the system for the introduction of new methods within the specialist health service
- Ensure that patients receiving cancer treatment receive relevant information about oral and dental health issues relating to cancer and treatment
- Develop dental health services at hospitals, particularly those which cover dental health examinations and the treatment of patients in cancer departments

#### *Late effects following cancer treatment*

New forms of treatment and more intensive cancer treatment have resulted in an increase in the number of cancer patients who are cured. However, many patients develop new health problems as a result of their illness and/or treatment. Such health problems are known as late effects. Late effects may be persistent symptoms, functional limitations and illnesses that appear during or a short time after cancer treatment, or which debut months to many years after completing cancer treatment.

The number of individuals who have had cancer and undergone cancer treatment will continue to increase, which will result in an increase in the number of persons with late effects or who are at risk of developing late effects.

Patients must receive information about the risk of late effects so that they can help to prevent late effects through lifestyle choices and seek timely help in the event of symptoms.

Approximately 75% of those who survive cancer have little risk of developing late effects, and can be followed up by their General Practitioner. Those with moderate or high risk may have varying needs for follow-up by the specialist health service.

It is necessary to ensure good competence about late effects in all parts of the health service.

Regional competence about late effects should also be developed, with personnel who can provide advice about the diagnosis and treatment of late effects to General Practitioners, and accept patients with complicated late effects for assessment and treatment.

The national competence service for late effects following cancer treatment was established at Oslo University Hospital in 2005 in order to research and disseminate knowledge about the somatic and psychosocial late effects of cancer to the health service, authorities and patients.

### **Sub-objectives:**

- Ensure good competence about late effects at all levels within the health service
- Ensure the follow-up and treatment of patients with late effects. Establish routines to provide patients with individualised information about preventive measures and the risk of late effects
- Further develop the national action programmes in order to cover late effects

### *Children and young people*

Norway currently has regionalised, network-based services for childhood cancer, based on international guidelines. All children are offered the same treatment.

The main challenge in childhood cancer care is the many small diagnosis groups with varying treatment needs.

Assessment, diagnosis and the starting of treatment are centralised in childhood cancer centres at the university hospitals. Further treatment is undertaken through close collaboration between the university hospitals and the local paediatric departments.

Many children and young people between the ages of 15 and 18 are treated for cancer in adult departments at the hospitals. In order to ensure optimal follow-up during and after treatment, children must be monitored in children's oncology centres until they are 18 years old. This patient group must be ensured treatment in children and young people's departments when this is appropriate based on the department's competence and experience in treating the relevant form of cancer, the clinical picture and the expected treatment processes, as well as the individual patient's wishes. In many cases, young people between the ages of 16 and 26 are better served by treatment or protocols that are identical or very similar to those used in childhood, and this must be taken into consideration.



Children and young people can live with the late effects of cancer for a long time. Adolescence is a vulnerable time for many, and being diagnosed with cancer involves significant additional strain. Young people also need special follow-up in terms of their education, employment and social lives. Health clinics, school health services and General Practitioners can help to ensure that children and young people with late effects of cancer receive the follow-up they need both somatically and mentally, and are able to move through their adolescence and into adulthood in the best possible way.

Children and young people may react to medicines differently than adults, and are often under-represented in clinical studies.

The Norwegian Directorate of Health is currently working with national professional guidelines for palliative care for children and young people, which shall be published during 2013.

### **Sub-objectives:**

- Ensure that children and young people under 18 years of age can be treated at children's oncology centres where this is appropriate and the patient desires it
- Cancer patients between the ages of 16 and 26 requiring psychosocial follow-up shall receive services adapted to adolescents and young adults
- Establish coordinator functions for the treatment and follow-up of children and young people at the regional childhood cancer centres
- The Norwegian Directorate of Health shall develop a guide for health care personnel specifically targeted towards the follow-up of young people in line with the action plan for children and young people

### *Elderly patients with cancer*

The number of elderly patients diagnosed with cancer is increasing, and is expected to rise from the current 6,600 persons per year to around 13,000 persons per year by 2050. Being able to offer this older patient group effective cancer treatment and care is a professional and capacity-related challenge. Elderly patients will often have other illnesses in addition to cancer, which can be challenging in terms of assessment and treatment. Many elderly patients with cancer will require extensive help and close follow-up in their daily lives.

Elderly patients may also metabolise medicines and react to medicines differently than younger patients. Elderly cancer patients are strongly under-represented in clinical studies. Decision-making processes and treatment choices are therefore often based on the results for healthier and younger patient groups and the individual therapist's judgement. This results in a risk of both over and under treatment. Without more

research which also includes the oldest cancer patients, there will continue to be insufficient knowledge of what is necessary to create effective treatment and care services for this group.

**Sub-objectives:**

- Good competence regarding the elderly and cancer in the specialist health service and the municipal health and care services
- Prepare guidelines for the treatment of elderly cancer patients in the action programmes
- Encourage research on elderly patients with cancer and the development of treatment plans tailored to the needs of older cancer patients

*Personnel and competence*

Sufficient personnel with the necessary competence is the most important prerequisite for good quality and equality in the cancer care services. Projections from Statistics Norway (SSB) in 2012 show an increasing shortage of health care personnel towards 2035.

Within many medical specialties relating to cancer there is currently a shortage of specialists, or is expected to be a shortage within the next few years. The Norwegian Directorate of Health is reviewing the specialty structure for doctors in order to ensure that it is in line with future needs for specialist competence.

There is a need to increase the availability of nurses with further education in cancer and palliative care, both within the specialist health service and in the municipal health and care services.

Norway can cover some of its competence and personnel needs by allowing tasks previously linked to a particular profession to also be carried out by other professional groups in order to improve the utilisation of the nation's overall competence and resources.

**Sub-objectives:**

- Ensure access to specialists within relevant professional areas (oncology – including specialist areas, surgical organ specialties, medical organ specialties, gynaecology, pathology, radiology, general practice) through targeted education, recruitment and a sufficient number of positions

- Ensure a sufficient number of nurses and other health care personnel with cancer treatment competence within the specialist health service and the municipal care services
- Ensure the education and recruitment of radiation therapists and medical physicists
- Consider a certification scheme for medical physicists within image diagnostics and radiotherapy
- Establish schemes so that nurses and health workers in the municipal health and care services can undertake practical training within the specialist health service
- Establish a learning network for nursing home physicians

### *The Cancer Registry*

Norway has a good overview of the population and a unique national Cancer Registry. We also have many good central health registries in various areas, such as the Norwegian Patient Registry and Cause of Death Registry. Norway therefore has an excellent basis for research into causes of cancer and the quality improvement of cancer care through the use of registry data.

The Cancer Registry consists of a basis registry, the Incidence Registry, which collects data about new instances of cancer. The data is used to map the incidence, survival and mortality rates of cancer in Norway, and for research into the causes of cancer.

The Incidence Registry has eight associated registries which are national quality registries. The cancer quality registries contain data about diagnostic assessments and treatments – and the consequences of these – throughout the course of the disease. The long-term effects on those who are cured are also studied. The data shall be used for quality improvement and research.

The work to establish and operate national quality registries for cancer is founded on the Cancer Registry Regulations, which state that the Cancer Registry shall: “undertake, promote and provide a basis for research in order to develop new knowledge of the causes of cancers, their natural course and the effect of treatments in order to promote and develop the quality of preventive measures and health care that is offered or provided to combat cancer, including the follow-up of individual patients and patient groups”. The establishment of quality registers is therefore a natural expansion of the Cancer Registry’s activities from the mapping of the incidence, survival and mortality rates of cancers to documenting the effect of the assessment and treatment of cancer in the specialist health service.

It is a challenge that the Cancer Registry currently has around a 1.5 year lag in the registration and publication of data. This makes it more difficult to actively use the

registry in the quality improvement work within the health service. Pending a future electronic registration solution integrated with the hospitals' electronic patient records, the Cancer Registry has developed a separate simple registration solution (the Cancer Registry's Electronic Notification System (KREMT)) for quality registries across the Norwegian health network.

The establishment and operation of cancer quality registers is being undertaken in close collaboration with the clinical environments for the various forms of cancer through reference groups based on various professional environments relating to cancer.

### **Sub-objectives:**

- Actively use the cancer quality registries to follow up the extent to which the cancer action programs are followed
- Ensure up-to-date data in the Cancer Registry and underlying quality registries
- Ensure the quality registries are firmly rooted within the professional environments
- Investigate solutions for electronic notification routines to the Cancer Registry as an integrated part of electronic patient records

### *Quality indicators*

Knowledge of quality within the service is a necessary prerequisite for all quality improvement.

A quality indicator is an indirect objective, a pointer, which says something about the quality of the area being studied. Structural indicators provide information about limits and resources, competence and available equipment. Process indicators provide information about activities within the patient assessment and treatment process, for example diagnostics and treatment. Outcome indicators provide information about what the service achieves with regard to survival, health benefits, satisfaction etc. Patient-reported outcomes measure the result of treatment on patients' function and quality of life, seen from the patients' perspective.

We currently have the following national quality indicators for cancer:

The proportion of patients with breast cancer, colon cancer and lung cancer who receive treatment within 20 working days of their referral being received at the hospital (process indicator), and five-year survival for patients with breast cancer, colorectal cancer, lung cancer and prostate cancer (outcome indicator).

More quality indicators for cancer should be developed, particularly outcome indicators and patient-reported outcomes. Process indicators are also important, since they provide an indication of patients' experiences of quality, for example waiting and treatment times for cancer treatment.

Patient experience surveys also provide important information about the quality of the service and must be part of an integrated set of quality indicators.

The Norwegian Directorate of Health has a statutory responsibility for the development, dissemination and operation of national quality indicators in the health service. The work to develop quality indicators for cancer shall be undertaken in collaboration with the oncological occupational groups and user representatives.

### **Sub-objectives:**

- Establish more quality indicators for cancer, particularly outcome indicators, and make these available on [www.helsenorge.no](http://www.helsenorge.no)
- Develop patient-reported outcomes relating to cancer

### *Research and innovation*

There is a high level of Norwegian cancer research. However, further efforts are needed. Effective collaboration between the clinical environments, basic research environments and the epidemiological environments, as well as with industry and commerce, is a prerequisite for increasing knowledge about the underlying mechanisms which lead to cancer and the development of more precise diagnostic methods and new, targeted and effective cancer treatments.

A national cancer research network has been established under the auspices of the National collaborative group for health research, in which the universities, university college and health trusts are represented, see [www.helseforsk.no](http://www.helseforsk.no). There is a need to establish further research networks relating to cancer.

One of the greatest challenges faced by cancer care is the development and implementation of more targeted cancer treatment, adapted to the characteristics of various tumours and individual patients. The genetic changes that occur in the body when an individual gets cancer vary for the different types of cancer and from person to person. This means that the effect of traditional cancer treatments, such as chemotherapy and radiotherapy, varies from patient to patient. Researchers are now testing new methods that utilise the molecular changes in each individual tumour in order to develop improved and more targeted treatments.

Individualised medicine is a new way of classifying, understanding, preventing and treating disease, in which various factors are identified and utilised in order to improve and adapt prevention and treatment to the individual person. Key drivers of the approach are the development of so-called deep sequencing technology, increased access to genetic tests, and knowledge of the link between genes and the development of disease or the potential to prevent it. The approach will hopefully be able to contribute to more precise treatment and limit side effects. The approach is based on a strong user perspective in which individuals, through increased knowledge and in accordance with their own wishes, can take a more active role in and responsibility for their own health and well-being and choice of treatment. In the spring of 2013, the regional health trusts, under the leadership of the Southern and Eastern Norway Regional Health Authority, were assigned the task of undertaking a national investigation of individualised medicine within the health service, with a deadline of 1 June 2014.

Increased user participation in research is desirable, including in cancer research. The White Paper on quality and patient safety *Good quality – safe services* emphasises the importance of involving patients and users in the entire research process. This will ensure that the research reflects users' needs and viewpoints to a greater extent on important research points (including quality of life) and that research results are used within the health and care services.

After several years with a decline in the number of clinical studies undertaken in Norway, the figures for 2012 show an increase. The increase is particularly large for studies relating to cancer. A network for clinical studies between the clinical trial units at the university hospitals in Norway has been established – the Norwegian Clinical Research Infrastructure Network (NorCRIN). NorCRIN also participates in the equivalent European network, ECRIN.

Because the patient base in each of the Nordic countries is small, Norway has been a driving force behind the implementation of a three-year project (2013-2015) for clinical multi-centre studies at Nordic level – the Nordic Trial Alliance. This may have contributed to the increase in the number of clinical studies, including those relating to cancer.

It is an objective that more cancer patients shall have the opportunity to participate in clinical studies. Many cancer patients wish to take part, but it can be difficult to find an overview of current clinical studies, and to identify which ones are relevant to the individual patient. In 2012, the health regions were tasked with establishing a national database for the registration of clinical intervention studies undertaken in the hospitals. This will give patients, relatives and other interested parties information about current clinical intervention studies through [www.helsenorge.no](http://www.helsenorge.no).

Research and innovation are closely related. The objective must be that cancer research results shall benefit the individual patient and be able to be used to serve society as a

whole. The research results shall help to solve health challenges, be the basis for new products and services, and contribute to knowledge-based industry and commerce.

### **Sub-objectives:**

- Support Norwegian, Nordic and international collaboration regarding clinically-controlled studies and cohort studies relating to cancer
- Increase the number of clinical studies relating to cancer and increase the number of studies with the participation of children, young people and the elderly
- Increase the share of cancer patients who are offered the chance to participate in clinical studies
- Increased user participation in cancer research
- Increased efforts within translational research aimed at using knowledge of malignant tumour characteristics in diagnosis and treatment
- Increase efforts within national and Nordic multi-centre studies within cancer research through NorCRIN and the Nordic Trial Alliance

## **Objective 5: The best possible quality of life for cancer patients and their relatives**

### **National objectives**

- **Cancer patients shall receive strengthened rehabilitation services**
- **Palliative care shall be strengthened and be in line with the WHO's objective of "the relief of pain and other physical symptoms, together with measures targeted towards psychosocial and spiritual/existential issues".**

### *Living with cancer*

Cancer patients often have long-term contact with the health service. It is necessary to establish treatment, rehabilitation and follow-up processes that are adapted to the increasing number of cancer patients.

Many cancer patients will require psychosocial support. Municipal services such as cancer coordinators, local self-help groups, coping courses and peer support services such as cancer care centres, can be good, low-threshold services. Others will need help from a psychologist or psychiatrist in order to cope with their illness. The General Practitioner knows the patient and plays an important role as coordinator for the

medical treatment. As such, the General Practitioner is in a key position to be able to help the patient to cope with his/her illness.

Vardesenters have been established at Oslo University Hospital, both at the Norwegian Radium Hospital and Ullevål University Hospital, the University Hospital of North Norway and St. Olav's Hospital, and several more are currently being established. The centres have been established through a collaboration between the hospitals and the Norwegian Cancer Society. The Vardessenters shall be arenas and meeting places for those affected by cancer, their relatives and health care personnel with activities which promote quality of life, well-being and coping. Individuals affected by cancer shall be able to receive information, support and guidance, take part in activities, meet others in the same situation, or simply have a place to rest/find peace. The aim is to help individuals affected by cancer to cope as well as possible in their everyday lives, either with their illness or after completing cancer treatment. The Vardesenters are a supplement to the medical treatment and an arena for peer support work.

### *Rehabilitation*

Cancer treatment can place a great strain on the individual and affect his/her physical and mental health. Rehabilitation measures which take the patient's physical and psychosocial needs into account should be planned and integrated as a part of the treatment to the greatest extent possible.

For most users, services will be centralised within the municipality, and for a smaller group, within the specialist health service. The challenges include establishing structures and schemes that make it possible to adapt the services to the individual user's needs.

In the coming years, the municipalities must establish the necessary services in order to execute their new tasks. Short-term placements in nursing homes have a central function, and can be used for rehabilitation or relief.

In 2012, the Norwegian Directorate of Health issued the report *Rehabilitation services for cancer patients: Mapping and recommendations*.

Interest in the use of physical activity in the rehabilitation of cancer patients has increased in recent years. Physical activity plays an important role both during and after cancer treatment. It is well-documented that physical activity improves physical function and quality of life, improves fatigue, and enables patients to better tolerate the treatment.

*Pusterom (Breathing Space)* has been established at several hospitals in collaboration with the *Aktiv mot kreft (Active against cancer)* foundation, and represents a low-threshold training and activity centre where cancer patients receive expert guidance regarding how to get started with physical activity, individual training as well as training in groups, and a "breathing space" away from everyday life as a cancer patient.



### *Relatives*

When an individual is diagnosed with cancer, their family is also involved and affected. Once a cancer diagnosis is made, the adaptation requirements are exceptionally great, including for the patient's relatives. It is often the patient's relatives who attend to large parts of the patient's care, as well as taking care of a range of other tasks. They also ensure contact with the health service and public services, either because they have direct responsibility for the patient or because they provide extensive support and follow-up. This means that many relatives are exposed to great practical, financial and emotional strain. Many seriously ill cancer patients wish to be at home as much as possible. With good collaboration between the patient, relatives, and municipal and specialist health services, it is possible to achieve this. Relatives who receive good training, support and follow-up can be useful aides and contribute to a good treatment process.

The children of patients with serious health problems are particularly vulnerable. Health care personnel are obligated to ensure that the necessary information is provided and that minor children are followed up, so that both children and parents are able to cope with the situation.

Relatives themselves may also require help and support from the health service. This particularly applies to the children of patients, and the partners and close relatives of patients with children. The health service shall ensure that young children who are relatives of patients with serious somatic illnesses receive the necessary information and follow-up. Families must also receive assistance with practical, financial and emotional issues, and the municipality must take responsibility for coordinating this. In 2010, the Norwegian Directorate of Health issued a guide for health care personnel who are obligated to assist minor children who are relatives of cancer patients.

### *Palliative care*

Patients who have terminal cancer can live much longer today than they did just a few years ago. Short hospital admissions and an increasing amount of outpatient treatment in the specialist health service means that the municipal health and care services must care for an increasing number of more seriously ill cancer patients than previously. A larger proportion of care in the last phase of life will be provided in the patient's home or in adapted units/institutions in the municipal health and care services. In addition, many cancer patients will need early palliative care in order to manage side effects and complications, and to avoid overtreatment. Research indicates that early palliative intervention both improves the patient's quality of life and extends the patient's life.

In recent years, specialised palliative care services have been expanded on a national basis. Almost all health trusts have a palliative team. Around 90% of the patients treated by these teams are cancer patients.

All health regions have established competence networks with resource nurses within cancer and palliative care. The regional competence centres for palliative care play an

important role in the coordination of the clinical services, as well as in teaching, research and development. At municipal level, palliative units and palliative beds in nursing homes have been established, and competence-increasing projects have been initiated in many municipalities.

Various studies show that the majority of dying patients wish to die at home. However, Norway is one of the countries in which the fewest patients die in their own homes. A survey shows that the municipalities that are focused on enabling more patients to die at home have also actively focused on the provision of home-based care. Employees in these municipalities are also most satisfied with the collaboration between General Practitioners, patients and relatives. A prerequisite for achieving a planned home death is assured relatives who have support from a good, professional network based around the patient's General Practitioner and the home care service. Both the General Practitioner and home nurses must be available for the patient's relatives in order to provide the necessary assurance. For patients with terminal cancer, palliative care should be administered in and near the home wherever possible, through close collaboration between the General Practitioner, municipal home care nurse and local hospital. Patients who require highly specialised symptom relief must be given quick access to this at the nearest palliative care centre.

The General Practitioner should also coordinate parts of the palliative care for cancer patients together with the care service, and possibly with the cancer coordinator in the municipalities where such a coordinator is established, and involve the palliative team at the local hospital as necessary. A challenge and prerequisite for good patient treatment processes and greater responsibility being allocated to the municipality and General Practitioner is a good collaboration between the General Practitioners and the hospitals.

A national action programme for palliative cancer care has been prepared. The action programme provides recommendations regarding palliative treatment and care within the specialist health service and in the municipal health and care services, as well as recommendations regarding the organisation of the services.

*Competence-increasing measures by 2015* includes a focus on competence-increasing measures for palliative care and care at the end of life. The aim is to strengthen the care services and contribute to competence development within the country's municipalities.

#### *Communication with those facing death*

Communication with patients and relatives experiencing a life crisis is difficult, but important. In work where so much of our own personality, verbal expression and body language are exposed, there is no clearly defined template, but it is important that patients and relatives experience that employees are present and empathetic.

Both the dying individual and his/her close relatives go through processes of loss which have significant consequences for the individual. Most require extensive support

to work through their anxiety and grief. Good palliative care shall include support for relatives during the grieving process, both before and after the patient's death. Children who are relatives must be given extra attention.

Working with dying individuals involves facing existential questions, and space and time must be set aside to work through and confront one's own feelings and reactions. Norwegian Association of Local and Regional Authorities (KS) holds learning seminars for managers and employees in the home care service and nursing homes to strengthen their skills in communicating with patients and relatives about death. Through further work with the project *Samarbeid om etisk kompetanseheving (Collaboration on ethical competence-increasing measures)* employees shall be given space to work through and reflect upon ethical challenges relating to death and end of life care.

Professionals, relatives and other voluntary caregivers participate in end of life care. Voluntary visitation services and grief and discussion groups can be of great importance for both patients and relatives. As part of a national volunteering strategy that shall be prepared through the follow up of the White Paper *Future care*, a system for the recruitment and follow-up of volunteers shall be developed through networking and community work. An important task will be to follow up, support and guide voluntary caregivers in this area.

#### **Sub-objectives:**

- Ensure that rehabilitation is integrated in the treatment process for cancer patients, both within the specialist health service and in the municipalities
- Enable volunteers and peer support groups to participate in cancer care
- Continue to strengthen the work with palliative treatment and care at the end of life through competence-increasing measures, preferably as inter-municipal solutions
- Ensure that palliative medicine is covered in mandatory courses in the specialist training of doctors within oncology, surgery, gynaecology, internal medicine, general practice and other relevant specialties.
- Establish good routines for follow-up measures and information for children and young people who are relatives of cancer patients
- Promote work with relatives by preparing national guides regarding collaboration with relatives
- Ensure relatives receive good follow-up and guidance
- Prepare a summarised version of the action programme for palliative care adapted to the municipal health and care services

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