

National Cancer Strategy

2006-2009

Foreword by the Minister of Health and Care Services

Cancer is one of the most prevalent public health diseases of our time. More than 173,000 people in Norway have, or have had, cancer. Every year around 24,000 people are affected by the disease, which results in the deaths of about 10,000 people. The incidence of cancer is increasing and prognoses predict a 25 % increase by 2020. These are facts and figures – what we must not forget is that behind these statistics are ordinary people whose lives suddenly take a new direction when they are given the diagnosis of cancer. Some of these people experience physical pain, depression and angst. Just to do everyday chores can suddenly pose a major challenge. Families are also strongly affected, and for many these can be very difficult times, especially if small children are involved. For society as a whole, the increase in cancer poses serious challenges with respect to the capacity, quality and organisation of the health services that are delivered.

The National Cancer Strategy 2006 – 2009 (Cancer Strategy) is the expression of the Government's desire to meet these future challenges in a driven and holistic manner. The Cancer Strategy therefore defines the national goals and activities for preventative work, screening programmes, diagnostics, treatment, rehabilitation. It also defines goals within the areas of health care professionals, Registers and research activities. The Cancer Strategy will be discussed in the National Health Plan (2007 – 2010).

The central goals of the Cancer Strategy are rooted in the Soria Moria Declaration, and are founded on the following general health policy objectives:

- Social inequality in health shall be addressed through a focus on preventative work
- There shall be equality of access to the health services delivered to the people; that is access shall not depend on economic status, gender, ethnicity or place of domicile.
- The capacity of the services shall meet the needs of the people.
- Improved cooperation between areas of expertise and administrative levels shall be facilitated.

A central, dedicated post will be established in the Directorate for Health and Social Affairs to ensure a cohesive follow-up of the Cancer Strategy. The Directorate will thereby ensure that goals and measures are seen in context to each other. This will be done in part by establishing collaboration and cooperation fora for those stakeholders responsible for implementing the measures. The Directorate will also ensure a good dialogue with the voluntary sector.

The Cancer Strategy is the result of significant contributions from many participants. In particular, I should like to thank the Norwegian Cancer Association for its proactive contributions of expertise and resources.

I wish you all good luck in the continuing work!

Sylvia Brustad

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1. Introduction

1.1. Cancer - the national challenge

At the present time, more than 173,000 people living in Norway have, or have had cancer. Every year, there are around 24,000 new cases of cancer, and this is predicted to rise to 28,000 in 2020. This rise in the incidence of cancer can be related in particular to the higher average age of the population, and to the fact that the risk of developing cancer increases with age.

More and more people are surviving cancer, with around 50% of cancer patients still alive 5 years after diagnosis. This increase in survival rate is primarily due to improved treatment. However, because of the increase in the total number of cancer cases, the number of deaths due to cancer (about 10,000) has not fallen.

The most prevalent cancer diagnosis in men is prostate cancer, and in women is breast cancer. Overall, the most common cancer is cancer of the digestive tract. Cancer in children younger than 15 is very rare (about 150 cases annually), but seems to be increasing, without any obvious explanation.

There is a correlation between socio-economic status (measured by profession, education and income) and the risk for developing cancer, and the survival rate, but the pattern varies for the various cancer diseases. The risk for cancer is slightly higher in cities and densely populated areas than in rural areas; the incidence of cancer is also

slightly higher in the south than in the north¹.

In brief, cancer is and will continue to be a major national challenge, both for the individual who is affected, the family, the preventive programmes, all levels of the health services, and society as a whole.

1.2. Primary goals, target groups and duration

The primary goal of the Cancer Strategy is to meet the cancer challenge in a proactive and holistic manner by facilitating improved quality and competencies, adequate capacity and equality of access, appropriate organisation and better cooperation within and between all areas relating to cancer. With this as the foundation, the Cancer Strategy defines national objectives/steering signals, planned/initiated measures and actions for consideration. These are described in chapters on preventive programmes, national screening programmes, the patient, the health services and society, diagnostics, treatment, rehabilitation, palliative treatment (pain relief), personnel as well as registers and research programmes.

The target groups for the Cancer Strategy are primarily stakeholders with responsibility within the area of cancer, hereunder the regional health authorities, the local authorities, the GPs, the Norwegian Institute of Public

¹ Report from the Cancer Registry of Norway: "Cancer in Norway 2004".

Health and the Cancer Registry of Norway. The Directorate for Health and Social Affairs has been given the responsibility to coordinate follow-up of the Cancer Strategy, cf section 1.3. The timeline of the Cancer Strategy is set from 2006 – 2009. It will be integrated in the National Health Plan.

1.3. Director of the National Cancer Strategy

The Directorate for Health and Social Affairs has been given national responsibility for coordination of the further follow-up of the Cancer Strategy². A dedicated post will be established in the Directorate for Health and Social Affairs with responsibility for this function. The purpose is to sustain comprehensive follow-up, both within the health services and across the health and social services. The actual implementation of measures will follow predefined responsibility structures, but the Directorate is responsible for monitoring that all measures are in line with the goals. The Directorate shall further ensure that collaboration fora are established with relevant parties, and that a good dialogue with the voluntary sector is secured. This collaboration will also provide a better foundation to enable rapid identification of those cancer-related areas where there is a need for programmes to improve follow-up.

1.4. Prioritisation

A key goal of the Cancer Strategy is the correct and high prioritisation of cancer,

² Letter of 13.01.2006 from the Ministry of Health and Care Services to the Directorate for Health and Social Affairs 13.01.2006. State budget 2006 – section 720 Directorate for Health and Social Affairs – allocation of funding - section 6.10.

both by the health services and other sectors responsible for programmes important to this area. The rights of the patient pursuant to the Patients' Rights Act³ and the Prioritisation Directive⁴ are the central instruments for ensuring correct prioritisation. The right to a personal deadline for the latest date by which the patient must have received specialist health services has strengthened the patient's position, and must be deemed to be of particular importance for cancer patients.

Another essential element is that services have the resources necessary for good follow-up of cancer patients. The substantial increases in recent years in budget frameworks for the regional health authorities have created an important foundation from which to achieve this. In addition, the National Cancer Plan (1999 – 2003) contributed with just over NOK 2 billion to a public strengthening of cancer-related areas. Funds have also been allocated to additional prioritised programmes such as the project for development of action programmes for cancer treatment⁵ (NOK 2 million in 2005 and NOK 5 million in 2006) and to co-financing of expensive drugs for hospitals, including cancer treatment⁶ (NOK 18 million in 2005 and NOK 18 million in 2006). The need for additional, extraordinary funding will be assessed continuously in the normal budget processes.

³ Act of 2 July 1999 no. 63 on Patient Rights.

⁴ Directive of 1 December 2000 no. 1208 on Prioritisation of the healthcare services, the right to necessary help from the specialist healthcare services, the right to treatment in a foreign country and on dispensation and the complaints board.

⁵ St.prp. no. 65 (2004-2005) section 720 and St.prp. no. 1 (2005-2006) section 720.

⁶ St.prp. no. 65 (2004-2005) and St.prp. no. 1 (2005-2006) section 732, post 71-75.

2. Background

The Cancer Strategy is the follow-up of the National Cancer Plan (1999 – 2003). This work is based on the recommendations in the report “National strategy for work within cancer care – quality, competence and capacity” (2004) and a nationwide consultation during the autumn of 2004. The central goals of the Cancer Strategy are grounded in the Soria Moria Declaration and other relevant work by the health authorities including follow-up of the White Paper no. 16 (2002 – 2003) *Resept for et sunnere norge / Prescriptions for a healthier Norway* (Public Health Notification) and NOU 2005:3 *Fra stykkevis til helt. En sammenhengende helsetjeneste (From the bricks to the whole. A seamless health service)* (Wisløff committee).

Brief summaries of the main agendas of the National Cancer Plan (1999 – 2003) and the Cancer Report (2004) are presented below.

2.1. National Cancer Plan (1999-2003)

The National Cancer Plan (1999 – 2003) promoted a public strengthening of cancer-related areas by just over NOK 2 billion⁷. The primary goals of the Cancer Plan were to reduce the number of new cases of cancer through a long-term strategy of prevention and to improve the services within diagnostics and treatment.

The most important measures included:

- Prevention of new cases of cancer through measures that targeted a

⁷ St.prp. no 61 (1997-1998) On the National Cancer Plan for investments in equipment at Norwegian hospitals and institutes. S. no. 226 (1997-1998).

reduction in tobacco consumption, healthier diet, increased physical activity and protection against radiation.

- Expansion of the Breast screening program to a national screening service for all women between the ages of 50 and 69.
- Increasing radiation treatment capacity by 39 operational radiation devices throughout the country.
- Competence building within the specialist health services, particularly targeting palliative treatment, hereditary cancers and gene therapy.
- Increasing accessibility to key personnel including specialist doctors, oncology nurses, radiologists and radiographers.

The National Cancer Plan was evaluated by SINTEF and FaFo in the spring of 2004, cf Report “Iverksetting av Nasjonal kreftplan 1999-2003” (Implementation of the National Cancer Plan 1999-2003). The conclusion was that the Cancer Plan had, in general, been implemented in accordance with the intentions and deployments of the Norwegian Parliament. From 2004, the action points from the plan have been continued, in principle, integrated in ordinary operations, and as part of a new National Cancer Strategy⁸.

2.2. The Cancer Report (2004)

The Ministry of Health and Care Services appointed a Working Group in 2003 with the mandate to draw up a proposal for a strategic follow-up of the

⁸ St.prp. no. 1 (2003-2004) section 732, post 79 Cancer treatment, etc.

National Cancer Plan (1999-2003). The Working Group was led by the Directorate for Health and Social Affairs and comprised representatives from the Ministry of Health and Care Services, the Directorate for Health and Social Affairs, the Southern Regional Health Authority, the Norwegian Employers' Organisation for Locally owned Enterprises, the Cancer Registry of Norway and the Norwegian Cancer Society.

The Cancer Report "Nasjonal strategi for arbeid innenfor canceromsorgen – kvalitet, kompetanse og kapasitet" (National strategy for work within cancer care – quality, competence and capacity) was handed over to the Ministry of Health and Care Services in 2004. The report contains more than 200 proposals for action points targeting decision-takers and managers at all levels, practitioners of preventive work, and all levels in the health and social welfare services.

A brief summary of the working Group's findings:

- Investments in prevention of cancer must continue, hereunder measures targeting smoking cessation, healthy diet, protection against radiation and increased physical activity.
- Increased capacity of treatment programmes must be facilitated to meet the increase in number of cancer cases, especially among the elderly.
- The quality of cancer care should be strengthened through development of the quality registers and increased research,

hereunder improved integration of research in clinical activities.

- There is a need for national standards of diagnostics and treatment, hereunder a scheme for rapid introduction of new (expensive) methods with documented efficacy.
- Processes targeting increased function distribution and regional collaboration should continue when evidence-based data demonstrates that volume is important for quality.
- There is still improvement potential with respect to rehabilitation programmes post-treatment and for palliative treatment of terminally ill patients.
- There is a need for strengthening training, recruitment and staffing within several healthcare professional groups.

In the autumn of 2004, the Cancer Report was sent out for national consultation. The consultative bodies agreed in principle that the Report was thorough and well-grounded. Some criticism was made on the omission of a social perspective of the preventive approach, and that no prioritization had been made of the more than 200 proposed action points.

3. National objectives and measures

3.1. Preventive work

National objectives/steering signals:

- New cases of cancer shall be prevented through measures directed at tobacco use, diet, radiation protection, physical activity and alcohol.
- The cancer preventative work shall contribute to a reduction in social inequalities within health.

Planned/initiated measures:

- National strategy plan to remediate social inequality in health
- National strategy plan for a smoking cessation programme 2006-2010
- Action plan for improved diet in the population – timeframe 2007-2011
- The Ministerial Action Plan for increased physical activity 2005-2009 – “Together for physical activity”
- A system that alerts to high UV levels, and which will reach the entire population
- Escalation plan targeting substance abuse

Measures in preparation:

- Evaluation of measures against radon inside buildings
- Evaluation of schemes for quality improvement in the solarium industry

A general approach

Cancer can affect all people, and a healthy lifestyle is no guarantee that you will not develop the disease. However, there is a proven correlation between lifestyle and some forms of cancer, and preventative work is thus highly important. The main objective of preventative work is to prevent the disease or damage from arising, so that the individual can live many years in good health. Preventative work is based on knowledge of risk factors that affect health in general and which contribute to various health problems and diseases. Smoking cessation work is for example, important in the prevention of cancers and heart and lung disease. This type of general approach is, moreover, important in making transparent that many sectors of society and policy areas

have a significant impact on the health of the nation.

Preventative work in Norway has been considerably strengthened in recent years, primarily as a result of the Public Health

Paper and National Cancer Plan⁹. Several measures have been implemented within smoking cessation, diet, radiation protection, physical activity and substance abuse. The government will continue these efforts in general, and increase focus on illness prevention. Another goal of the Government is to reduce social inequality within health. The Government emphasises collaboration with the voluntary sector, which

⁹ cf. section 2

contributes vital services and support in many areas of preventative work.

Social inequality in health

Significant social inequality has been documented for many health-related criteria in Norway. The differences are considerable, whether expressed using socio-economic status or education, profession, income or any combination of these factors. The social inequalities apply to both sexes and all age groups. This is the background for the Government's work on a National Strategic Plan to remediate social inequality in health. The Strategy will focus on measures targeting vulnerable groups; on actions against structural and underlying causes of health problems; on measures to secure equivalent and good health services, and on wide-based prevention measures.

There is little doubt that the health information campaign has made a major contribution to the changes in the people's health lifestyle. Because lifestyle is not just a personal choice, but reflects a peer phenomenon linked to group identity, it is also important that preventative work focuses on the underlying and structural factors affecting behaviour. There are clear socio-economic differences linked to who is able to stop smoking. However, this is not just a result of having more knowledge on the harmful side-effects of smoking, but is also a result of resources and strength to carry through. Good public health work in this area must therefore apply to facilitating and personalising a change in lifestyle – from unhealthy to healthy habits.

Smoking

Use of tobacco has a highly negative effect on health in general and is also a known risk factor in the development of cancers, in particular lung cancer. A smoking cessation policy must therefore target a reduction in the number of people who smoke every day, limit recruitment of first time smokers and prevent passive smoking. A national target has been set for a 50% reduction in young smokers within 5 years, and the long-term vision is a completely smoke-free generation of young people, cf. the Public Health Paper and its processing by the Norwegian Parliament.

Cancer preventative work has potential to achieve major benefits, if smoking cessation is prioritised both before and after smoking has lead to serious health problems. Currently, several schemes are running for smoking cessation including Røyketelefonen (telephone helpline), stop smoking programmes, educational programmes in schools, and training of course leaders. Work has also been initiated to draw up a national strategy for smoking cessation for the period 2006-2010. Measures for strengthening the health services role and involvement in smoking cessation, training of healthcare personnel within maternity care, the health centres and the school health services have been proposed.

Diet

Positive developments have taken place within the nation's diet in the last decades, but a large proportion of the population continue to eat too much saturated fat, sugar and salt and too little wholemeal bread, vegetables and fruit. Diet has been shown to be

extremely important in the development of several diseases including cancer. A healthy diet can contribute to preventing development of disease in general and cancer in particular. Moreover, cancer treatment itself subjects the body to severe stress, and nutritional considerations before and after treatment are thus extremely important.

The Government will work to raise the awareness of the nation about the relationship between food, diet and health and also make it easier to make the healthy choices. To achieve this goal, an inter-ministerial 5 year action plan for 2007-2011 will be drawn up to improve diet in the nation. Diverse measures will be evaluated including research and monitoring, access to healthy foods, information, communication and attitude-changing, as well as instruments such as taxes and duties and legislation.

Protection from radiation

There is a clear relationship between exposure to UV radiation from the sun/solariums and skin cancer. The prevalence of melanomas has increased in recent decades, particularly amongst young men and women who sunbathe excessively. There is also a known correlation between radon exposure in housing and at the workplace and lung cancer. Recent epidemiological studies estimate that radon is a contributory factor in about 14 % of all new lung cancer cases in Norway.

The National Cancer Plan included many measures for reduction of radon in housing/indoors. The Public Health Paper emphasised dissemination of knowledge about the negative effects of

UV radiation on health. There is, nevertheless, still major potential for cancer preventative work within radiation protection.

The knowledge base for implementation of measures against radon in existing housing has now been evaluated¹⁰. This will be used as the foundation for evaluation of measures to reduce exposure of the population to radon.

The Norwegian Radiation Protection Authority (NRPA) has initiated work on alerts of high UV levels that will reach the entire population. This work must be followed up with active information programmes. There is also a need to evaluate schemes to improve the standards of the solarium industry, for example by regular inspection and improved information to the public, the industry and the municipalities that will be responsible for inspection.

Radiation protection is not only important in prevention of cancers. Diagnostic radiology and radiation therapy both involve a certain cancer risk, and it is therefore important to optimise and quality assure use of these types of radiation both for patients and healthcare professionals, cf. discussion in 3.4 and 3.5.

Physical activity

Regular physical activity is extremely important for the welfare and health of the nation. Too little activity, or a sedentary lifestyle, has negative consequences for health and is in itself a

¹⁰ Report "Tiltak mot radon i boliger. Oppsummering av tiltak under Nasjonalkreftplan 1999-2003". ("Measures against radon in housing. Summary of action points in the National Cancer Plan 1999-2003.")

risk factor in the development of disease. In relation to cancer, it has been demonstrated that physical activity reduces the risk of breast cancer and stomach/intestinal cancer.

The activity level of the Norwegian population is generally too low, with clear social differences in exercise habits. Good exercise habits are rooted in early childhood and adolescence. An obvious challenge is therefore to promote physical activity not only in this group, but also in other social groups that are too sedentary.

As part of the follow-up of the Public Health Paper, an action plan for increased physical activity has been drawn up (The Ministerial Action Plan for increased physical activity 2005-2009 – “Together for Physical Activity”). The action plan includes mechanisms and measures within the responsibility areas of eight Ministries. Using wide collaboration across all administration levels, the goal is to contribute to:

- Low threshold activities and good opportunities for physical activity in leisure time locally, and in important arenas such as kindergarten, schools and the workplace.
- Activity-promoting residential areas and local communities which stimulate physical activity and which accommodate access for everybody. This must be included in the planning and facilitation of our physical surroundings.
- Motivation to an active lifestyle – through good advice and follow-up in the health services, public-targeting information and attitude-creating programmes.

In the continuing follow-up of the Action Plan, there will be a particular need for facilitation of locally-based low threshold activities, competence raising measures and achievable information programmes to foster awareness of the importance of physical activity, how little is necessary to make a difference, and what the individual can do to reap health benefits.

Alcohol

Alcohol increases the risk of cancer of the mouth, oesophagus, upper airways, liver and, in women, of the breast. A correlation has also been demonstrated with certain types of cancers of the digestive tract, and with lung cancer, giving an increasing risk in conjunction with smoking.

Internationally, specialists are paying increasing attention to the relationship between alcohol and cancer. This has been discussed in a specialist report prepared for the European commission in connection with an Alcohol Strategic Plan for EU¹¹. It is also anticipated that WHO will address this issue in more detail in their next Alcohol Report.

¹¹ Peter Anderson and Ben Baumberg (2005): “Alcohol in Europe” (A report for the European Commission Institute of Alcohol Studies, England)

3.2. National Screening Programmes

National objectives/steering signals:

- The offer of early diagnosis and follow-up of genetically disposed risk groups shall be continued
- Mass screenings for cancer of the cervix and the mammography program shall be continued
- The Ministry will continuously assess the need for expansion of the existing screening programmes and/or new programmes. The assessments will be based on national experiences and prioritizations, as well as criteria determined by WHO

Planned/initiated measures:

- The mammography program shall be evaluated

Measures in preparation:

- Improved work division and coordination of activities within inherited cancers
- Evidence-based summaries, methods evaluations and research to clarify the effect of systematic breast screening of younger and older patient groups than those included in the Mammography program (50-69 years)
- Relevant follow-up of mammography screening based on evidence-based summaries/evaluation results
- Evaluation of a trial project for expansion of the mammography screening program to include women from 45-49 years
- Evidence-based summaries, methods evaluations and research to clarify the effect of systematic screening of other type of cancer such as colon/rectal cancer, prostate cancer, lung cancer, melanomas (mole cancers) and cancer of the ovaries.
- In addition, changes in the Cancer Registry Directive that will necessitate registration of all mammography

Potentially cancerous conditions are normally identified by individuals who are aware of their own state of health, and/or healthcare personnel with knowledge of indicative symptoms. This will continue to be the most common starting point in the municipalities and specialist health services for initiating diagnostic investigation of potential cancers. As a supplement, a dedicated service has been established for early diagnosis, counselling and follow-up of genetically disposed risk groups. National mass screening programmes

have also been established for cervical cancer and breast cancer.

Early diagnosis, counselling and follow-up of genetically disposed risk groups.

It is estimated that at least 15,000 people in Norway carry genetic material for various types of inherited cancer (in particular breast cancer, ovarian cancer and bowel cancer), and that these cancers affect about 200 people in this risk group every year. What is unique to this group is that each person has a very high risk of developing cancer, the

disease can occur at a very young age and that it can, as a rule, be prevented and/or cured.

The regional centres of excellence for inherited cancers at the regional hospitals conduct research, testing and patient diagnostics as integrated operations, and offer genetic counselling to the patients and their families, cf. National Cancer Plan (1999-2003). This offer of early diagnosis, counselling and follow-up of genetically disposed risk groups shall be continued. There is a need in the follow-up of the Cancer Strategy for a review of the current organisation, with the aim of improved work division and coordination of activities within inherited cancers.

Mass screening for cervical cancer

The primary aim of mass screening for cervical cancer is to reduce its prevalence and mortality rate. The mass screening program encourages all women aged 25-69 to go to their GP or gynaecologist every three years to take a cell sample from the cervix. Women who have abnormal cell samples are followed-up in accordance with recommended guidelines. The mass screening program is managed by the Cancer Registry, in collaboration with the Norwegian Institute of Public Health.

Mass screening for cervical cancer is in line with international recommendations¹², and the offer shall be continued. However, the content of the mass screening, including methods used (for example use of viral tests), testing intervals and follow-up are being continuously assessed using evidence-based review. It is also necessary to

increase the participation of groups at risk that do not attend mass screening.

Incidentally, a vaccine against cervical cancer will be registered in the near future. An assessment is currently underway, under the auspices of the Norwegian Institute of Public Health, on when and how such a vaccine could be implemented in Norway.

Mammography programme

The primary aim of the Mammography programme is to reduce the morbidity and mortality due to breast cancer. This program invites all women aged 50 to 69 to a breast screening examination every two years. The examination takes place at a hospital mammography centre or in a mobile unit (bus).

The Mammography program was established as a pilot project in 1996 in four counties (Akershus, Hordaland, Oslo and Rogaland). It is now a national program (from February 2004) as part of the National Cancer Plan (1999-2003). The Cancer Registry is responsible for all professional aspects and a collaboration has been established with NRPA and the Norwegian Institute of Public Health. The regional health authorities are responsible for running the screening program.

Systematic screening of presumed healthy people is a method that has been much discussed by the specialists. Discussion revolves primarily around the cost-effectiveness of such programs, and problems such as the extent of over diagnosis, false positive findings and false negative findings. Systematic breast cancer screening is nevertheless in line with current international

¹² Cancer Report, cf. discussion in section 2.2.

recommendations¹³, and the Mammography program will be continued. The content of the program, including methods used, testing intervals and follow-up must be continuously assessed using evidence-based audit.

The Mammography program has now been in existence for around 10 years and contains highly interesting individual-based data that will provide new and important information on the efficacy of systematic breast screening. The program will be reviewed in the next few years, including its effect on mortality. The Ministry will ensure that a review is initiated, and that it is objectively implemented.

Many stakeholders have expressed a desire to expand coverage of the Mammography programme (currently 50-69 years) to include younger and/or older age groups. Systematic screening has also been proposed for other types of cancer such as colon/rectal cancer, prostate cancer, lung cancer, melanomas and ovarian cancer. The Ministry will continuously assess the need for expansion of existing screening programmes and/or establishment of new. To secure a relevant screening program, assessments will take as the starting point national experiences and prioritisations and the following criteria determined by WHO:

- The condition shall be common and debilitating.
- The natural progress of the condition must be known.
- There must be an identifiable latent or pre-symptomatic period.

- The screening test must be reliable, valid and reproducible.
- The screening test shall be acceptable, risk-free and easy to conduct.
- The screening test shall have a high positive predictive value.
- The screening test shall be sensitive and specific.
- The screening programme shall be cost-effective with respect to the advantages of early diagnosis.
- Effective and available treatment shall exist.
- The health services shall have the capacity to treat those cases identified through the screening program.
- Agreement must be reached on who shall be offered treatment.

The need for evidence-based summaries, method evaluations, and research to increase the evidence-basis on the efficacy in relation to certain age groups and types of cancer shall be assessed in the follow-up to the Cancer Strategy.

Private breast screening

Private breast screening is conducted on patients not included in the Mammography program. The Cancer Registry of Norway Directive¹⁴ § 2-1 states that there is a registration obligation only if medical aid is given in a case of cancer. If the findings are negative, the only notification obligation applies to people who have participated in a screening program for early detection. This lack of registration obligation means that we do not capture information on the contribution made by private screening, even though it is

¹³ Cancer Report, cf. discussion in section 2.2.

¹⁴ Directive of 21 Dec. 2001 no. 1477 on Collection and treatment of health information in the Cancer Registry of Norway.

publicly financed through the reimbursement system. The Ministry will therefore evaluate whether there is a need for changes to the Cancer

Registry Directive that will ensure that all mammography is registered.

3.3. The cancer patient, the health services and society

National objectives/steering signals:

- A good meeting between the cancer patient and the health services lays the foundation essential for the quality of cancer care
- There must be better compliance with the regulations that are intended to contribute to good cooperation, communication and continuity in the patient's meeting with the health services, including within cancer care
- Improved cooperation between services and administration levels must be facilitated so that the patient receives a best possible holistic service.
- Good cooperation between the cancer patient's support network, including family and the voluntary sector, must be facilitated.
- The cancer patients must be provided with better assistance to map their non-medical needs, with information on their rights and with help to exert their rights, including in non-medical areas

Planned/initiated measures:

- New work and welfare administration (NAV reform) from 01.07.2006
- Action plan to strengthen specialist health services for the elderly
- White Paper on the delivery of care services of the future

3.3.1. ***The meeting between the cancer patient and the health services***

The personal attributes of the healthcare professionals

Cancer can be accompanied by physical pain, mental stress and practical challenges. In other words, the cancer patient is in a highly vulnerable situation. This makes it extremely important that their meeting with the health services takes place in a reassuring way. In addition to exercising high levels of professionalism, healthcare personnel must also have necessary personal attributes. Such skills often encompass understanding, kindness, respect, being

there, empathy and an ability to communicate. The cancer patient must also make a significant contribution, for example by attending appointments for treatment and checkups, or by following advice on the best possible lifestyle. A good meeting between the cancer patient and the health services lays the foundation essential for the quality of the cancer care.

Supportive regulations

Several rights and obligations have been introduced in recent years to underpin good cooperation, communication and continuity in the meeting between patients and the health services. It is important that these also apply in cancer care.

For example, the hospital must appoint a *doctor responsible for the patient* as soon as possible after admission or outpatient pre-examination, unless this is clearly unnecessary, cf. Directive on doctor as contact for patient¹⁵ § 3, cf. Act on Specialist Healthcare Services¹⁶ § 3-7. The doctor shall be the patient's permanent medical contact during their stay in hospital, cf. Directive § 4. In a follow-up, measures to improve the contact doctor scheme will be assessed further by the committee that has assessed measures to improve cooperation (NOU 2005:3).

The hospitals are obligated to *educate* patients and carer/family, cf. Act on Specialist Healthcare Services § 3-8 no. 4. Good information is a prerequisite to providing the patient with the security necessary to tackle the disease, and the situation as a patient, in the best possible way. Patient education occurs through normal contact with healthcare personnel and through the hospitals' Training and empowering centres (cf. section. 3.7).

If they so desire, cancer patients requiring long-term and coordinated social and health services are entitled to preparation of an *individual care plan*, cf. Act on Patient Rights § 2-5, Act on Social Services¹⁷ § 4-3a, Act on Municipal Health Services¹⁸ § 6-2a, Act on Specialist Healthcare services § 2-5 and

the Directive on individual care plans¹⁹ § 4. The individual care plan shall contribute to providing the patient with a comprehensive, coordinated and individually tailored service. The patient has the right to participate in the work with their plan, and this must be accommodated.

The patient also has the right to *involvement* in their treatment, including the right to be involved in the choice and implementation of available and appropriate examinations and treatment methods, cf. Act on Patient Rights § 3-1. Real user involvement is conditional on the patient being perceived as a premise provider to the process of achieving good treatment, and that they are given adequate and appropriate information about the disease and treatment.

Cancer among the elderly increasing
The elderly with complex health problems comprise an increasing proportion of the health services patients. In Norway, 7.8 percent of the population are over 75, while this group comprises 11 percent of the total number of admissions to Norwegian hospitals. In the future, the group of sick elderly will have a different composition and disease profile than today, and the burden on the health services by the population group older than 75 will increase dramatically. Prognoses for 2030 predict a growth of 40 to 60 % for disease types such as cancer²⁰.

¹⁵ Directive of 1 December 2000 no. 1218 on Doctor as contact for patient, etc.

¹⁶ Act of 2 July 1999 no. 61 on Specialist Healthcare Services, etc.

¹⁷ Act of 13 December 1991 on Social Services, etc.

¹⁸ Act of 19 November 1982 no. 66 on Healthcare services in the municipalities

¹⁹ Directive of 23 December 2004 no. 1837 on Individual care plan in accordance with health legislation and Act on social Services

²⁰ Also applies to dementia, high blood pressure, stroke, cardiac infarct, arthritis, femur fracture and hip replacements (Scenario 2030)

In order to meet these challenges, work has been initiated on an action plan designed to strengthen the specialist health services for the elderly. The action plan will assess the role the local hospitals will have in health services for the elderly, propose measures to strengthen competence and increase recruitment of healthcare personnel and will also evaluate financial funding to secure prioritization of elderly patients with complex diseases. The objective is outward-oriented specialist healthcare that contributes to effective patient progression from the hospital bed to home.

The government will also invest heavily in strengthening nursing and care services, and a White Paper on future care services is planned for submission in spring 2006. One important objective is the securing of 10,000 additional man-years, and to achieve this, dedicated action plans will be drawn up for recruitment and education of key personnel.

Cooperation

During the progress of the disease, the cancer patient has to meet several services and administration levels. A cohesive healthcare service demands good cooperation between the various services and administration levels. Schemes such as coordinators and palliative teams (cf. discussion in section 3.8) are intended to help realise this. Rights such as the right to an individual care plan have also been introduced (cf. discussion above). In spite of this, achieving good cooperation is still a major challenge, also in cancer care.

The Government will continue to work for improved cooperation in the health services in general. Please refer to NOU 2005:3 *Fra stykkevis til helt – En sammenhengende helsetjeneste (From the bricks to the whole - A seamless health service)*, which is now being followed-up by the Ministry.

3.3.2. Carer/family and the voluntary sector

The situation of the carer/family

The carer/family of the cancer patient, whether they be spouse, partners, parents, brothers and sisters, children or close friends can be a significant resource both with respect to care and practical aspects. It is important that the carer/family is able to provide these support functions.

However, the carer/family can also constitute a vulnerable group. Young children in a family affected by cancer must be given the utmost consideration when mother, father, or sibling become ill or die. An increasing number of cancer patients live alone with no close relatives. The situation of the carer/family, or of those who have no carer/family, must therefore be mapped and used as the basis for provision of help by public bodies.

Voluntary sector

The voluntary sector is a significant resource both for the cancer patient and their carer/family. The Norwegian Cancer Society, with its more than 140,000 members and permanent donors is one of the country's largest voluntary organizations. Together with cooperating patient associations, the society contributes useful information,

good advice, practical help and support. The government's general attitude is that the voluntary sector is in many areas an important contributor and a desired supplement to the public services. The government will therefore continue to provide the voluntary sector with good conditions to deliver non-commercial services, including to cancer.

3.3.3. Societal framework conditions

Mapping the cancer patient's non-medical requirements

Severe and long-term cancer illness will often have consequences for the financial situation of the patient and their ability to carry out practical tasks. Information about available economic and practical help can be perceived as difficult to obtain for somebody who is vulnerable with an illness. It is therefore important that the cancer patient receives help to define their non-medical needs. Relevant measures shall be evaluated to this end in the follow-up to the Cancer Strategy. Mapping could cover personalised information on the consequences for work and education, social security supplements and support benefits, and an evaluation of help with practical aspects and the situation of the carer/family.

The NAV reform: simplifying being a user of public departments

The government is working to simplify being a user of public departments and a new cohesive and effective work and welfare administration (the NAV reform) is to be established. As the first step in the reform, the Norwegian

unemployment office and social securities are being dismantled and replaced by a new department from 01.07.2006. As the next step, a work and welfare office will be established in each municipality. In addition to being responsible for the government schemes mentioned, the office shall assume municipal responsibility for economic social help and any other social services. The process shall be completed by 2010.

3.4. Diagnostics

National objectives/steering signals:

- Sufficient knowledge must be secured within the municipal healthcare services (in particular within general practitioners/non-specialists) to enable satisfactory identification and follow-up of indicative symptoms.
- Diagnosis of potential cancer diseases in the specialist healthcare services must take place within reasonable timeframes, must be suitably organized, must be of high standards and must be equally accessible.

Planned/initiated measures:

- National action programmes for cancer treatment including investigation and diagnosis will be drawn up.

Measures in preparation:

- Measures for improved logistics and more appropriate organisation of hospital diagnostic services
- Measures for improved quality assurance of diagnoses

Non-specialists/GPs role

For most cancers, early diagnosis is the best safeguard against lower morbidity and mortality. Early diagnosis is reliant on patients going to doctors early in the course of the illness. The doctor (normally the GP) must have sufficient knowledge to be able to rapidly identify the symptoms of a cancer, conduct necessary/recommended investigations and refer to a competent body in the specialist healthcare services. The referral must contain exhaustive information in which any suspicion of cancer is clearly apparent so that unnecessary waiting for further examination and diagnosis by the specialist health care services is avoided. Identification of relevant cancer symptoms is a major challenge for the GP whose patients normally present with a wide range of symptoms, most of which are not indicative of a serious illness.

Timeframes

Patients referred to a hospital or specialist outpatients clinic, have the right to receive an evaluation of their health within 30 working days after the referral has been received, cf. Act on Patient Rights § 2-2 first subsection. In cases of suspected serious or life-threatening conditions, the patient has the right to an even speedier evaluation. This applies to most patients with a suspected cancer. Recommended timeframes for initiation of diagnostic evaluation of the simple cancers will be presented in the coming national action programmes for cancer treatment, cf. discussion below.

Appropriate organisation of the services

A cancer diagnosis often requires several types of investigation. Some must take place in a certain sequence and involve several specialist groups and laboratories. The diagnostic procedure can sometimes take an unnecessarily long time. This can result in great mental stress for the patient,

and in delays with implementation of necessary treatment.

Much indicates that there is potential for improved logistics and organization of the diagnostic services, including work division between clinics and laboratories, and between the laboratories. Improved logistics and organisation will in turn enable improvement of the diagnostic capacity. Necessary measures will therefore be evaluated in the follow-up of the Cancer Strategy.

Quality and equality of access: National action programmes

Much work has been laid down by many professional groups within cancer care to reach consensus-based recommendations on diagnostic examinations that patients with a possible cancer diagnosis should undergo.

The recommendations of these professional groups have until now lacked official status but have, nevertheless, provided the fundament on which the hospital diagnostic services are based.

As part of the national Cancer Strategy, work was instigated in 2005 to develop these groups' recommendations further to become national action plans for cancer treatment. This work is led by the Directorate for Health and Social Affairs in collaboration with specialists and the Norwegian Knowledge Centre for the Health Services. NOK 5 million have been allocated for this purpose in 2006²¹.

The action programmes will contain standards for the entire treatment

period for the various types of cancers; from suspicion of cancer to exploration, diagnostics, treatment and medical rehabilitation. A proposal will also be drawn up for a scheme for continuous updating of the action programmes, including early alerts to new technology and methods. In addition, a dedicated subject library is planned as part of the Health library. Use of PET will be evaluated separately.

Work with the national action programmes will provide a solid basis enabling correct directives on prioritisation in cancer to be given to management of the health services. Please refer to further discussion in section 3.5.

Quality assurance of diagnosis

Correct treatment is conditional on correct diagnosis, and quality assurance of diagnosis is therefore of the utmost importance. Follow-up of the cancer strategy will necessarily include evaluation of relevant measures to improve quality assurance, for example, requirement for double control of samples and a higher autopsy frequency. Formalisation of inter-disciplinary collaboration equivalent to that of the KVIST group (cf. discussion in section 3.5), will also be considered.

²¹ St.Prp. no. 1 (2005-2006) section 720.

3.5. Treatment

National objectives/steering signals:

- Treatment of cancer patients shall take place within personalised and reasonable timeframes, shall be appropriately organized, shall be of high standards and shall be equally accessible.
- Processes targeting function division and multi-regional collaboration shall continue, both within cancer surgery and other areas in which the evidence base has demonstrated a correlation between volume and quality.
- Radiation therapy capacity shall be expanded as planned

Planned/initiated measures:

- National action programmes for cancer treatment will be drawn up
- Quality assurance work carried out by the KVIST group shall be continued and expanded

Measures in preparation:

- The correlation between the treatment modalities of surgery, radiation therapy and medication, including consequences for capacity and organization will be evaluated

Timeframes

The patient has a statutory right (cf. Act on Patient Rights § 2-1 and Directive on Prioritisation § 2) to necessary health care from healthcare specialists when he/she

- has a prognosis of shortened life span or not inconsiderable reduction in quality of life if the health care is postponed,
- can expect to benefit from the health care, and when
- the costs are reasonable with respect to benefit gained from the health care.

The so-called "entitled patient" shall be given a personal deadline for the latest medically defensible date by which the specialist healthcare services must have delivered medical services. The regional health authorities for the region in which the patient lives is responsible for

ensuring that the necessary health care is delivered to the patient within the set deadline. If the deadline is not met, the patient can apply directly to the National Office for Social Insurance which shall immediately procure such a service from public service providers, from private service providers in the country (if necessary), or from a foreign country (if necessary). If the patient's condition worsens, then as a consequence of the requirement for defensibility, the health care must be delivered at a time earlier than the deadline. Recommended deadlines from demonstration of cancer to initiation of necessary treatment by the specialist healthcare services will be presented in the national action programmes for treatment of cancers, which are under preparation, cf, discussion in section 3.4 and below.

Treatment in a foreign country

If an entitled patient cannot be offered the necessary health care in Norway because adequate medical facilities do not exist in Norway, the patient has the right to necessary health care in a foreign country cf. Act on Patient Rights § 2-1 subsection five and Directive on Prioritisation § 3. The right to treatment in a foreign country is conditional on there being no defensible, equivalent treatment in Norway using an accepted method. The rule of thumb is that if treatment is offered in Norway this shall be used, even if more advanced treatment may be offered in a foreign country. This applies even if the patient wishes treatment at a foreign institution or using a method that is not used in Norway. A further condition is that the treatment provided in a foreign country is an accepted method, and is not experimental or a trial study. In exceptional cases, however, the patient may receive experimental treatment or participate in trial studies in a foreign country.

Freedom to choose which hospital

A patient has a right to choose which hospital they wish to be treated at, cf. Act on Patient Rights § 2-4. This right to choose includes all public hospitals and any private hospitals that have an agreement with a regional health authority about the freedom to choose hospital. The right to choose hospital does not mean a right to choose more specialised treatment than that for which the patient has been referred. The patient cannot choose the level of treatment. The right to choose applies throughout the entire course of treatment. This means that the patient can choose both where evaluation shall take place and where treatment shall be

delivered. The patient can also use the right to choose while treatment is ongoing, and thus has the right to change hospitals. This is, of course, dependent on the changeover being medically defensible. The right to choose does not apply to emergency admissions.

Appropriate organization of the service

Cancer treatment by specialist health care services is conducted partly in the specialist departments of the regional hospitals and partly in the specialist departments and outpatients of non-regional hospitals. The regional health authorities are responsible for organisation of the specialist health care services in their regions, cf. Act on Specialist Health Care Services § 2-1a.

Research has demonstrated a close correlation between quality and treatment volume, particularly for surgical intervention in cancer. The Ministry has therefore imposed on the regional health authorities the need to submit evidence-based data to support the organization of the services²². As a result, all regional health authorities have pooled resources and divided treatment within surgical intervention according to function (in particular breast cancer, lung cancer, ovarian cancer and colon cancer). These processes will continue, and also be extended to other sections of the treatment services in which a correlation has been shown between volume and quality.

Concomitant with the centralisation of advanced surgical intervention, the provision of simpler cancer treatment,

²² Steering document 2004 and Remit document 2005.

follow-up, rehabilitation and palliative treatment has been decentralised. Radiation therapy capacity, for example, has been expanded with 37 operational radiation devices located throughout the country as a consequence of the National Cancer Plan (1999-2003). The revised goal of 39 operational radiation devices will be achieved according to plan in 2007. In 2006, the regional health authorities were required to develop decentralised services at local hospitals for those patients that need a service locally²³.

One element of the follow-up of the Cancer Strategy will be evaluation of the treatment modalities surgery, radiation therapy and medication, including the consequences for capacity and organisation.

Quality and equality of access: National action programmes

Under the direction of the Directorate for Health and Social Affairs, work was initiated in the autumn of 2005 to define national action programmes for cancer treatment, cf. discussion in section 3.4. The starting point is specialist recommendations from relevant groups, which are quality assured and expanded/updated using evidence-based summaries.

The work with defining the national action programmes has been allocated to working groups within the following specialist areas:

- Breast cancer
- Cancer of the female reproductive system
- Cancer of the male urinary tract/prostate
- Lung cancer

²³ Remit document 2006.

- Gastrointestinal cancer, including colorectal
- Head/throat cancer
- Inherited cancers
- Paediatric oncology (solid tumours, CNS tumours and leukaemia/blood disorders)
- Haematologic cancers
- Sarcomas/soft tissue cancers
- Melanomas and other skin cancers
- Lymphomas
- Endocrine oncology
- Neuroendocrine surgery
- Neuro oncology
- Palliative treatment
- Radiation therapy²⁴

The national action programmes will foster Norwegian cancer treatment services of a high standard. The action programmes will also contribute to a common understanding of which services the Norwegian healthcare providers shall deliver through a national standardized service, and will also secure equality of access to treatments for the patients regardless of where they live in the country.

Quality assurance of radiation therapy

The purpose of radiation therapy is to kill the cancer cells; but the same radiation can also kill healthy cells. In order to improve the quality assurance of radiation therapy, the KVIST group (KValitetssikring I STråleterapi - Quality Assurance in Radiation Therapy) was established as part of the National cancer plan (1999-2003). The KVIST group is led by NRPA, and through

²⁴ Work initiated under the auspices of Norwegian Radiation Protection Authority (NRPA) in collaboration with the KVIST group and which will be included in the action programmes.

systematic and interdisciplinary work has generated positive attitudes to quality assurance in general, and has strengthened the cooperation between various specialist groups and departments, in particular. This has

resulted in the development of a common system for error reporting. The work of the KVIST group shall be continued and developed, and a similar method is under consideration for diagnostics, cf. section 3.4.

3.6. Alternative treatment

National objectives/steering signals:

- Alternative treatment of cancer patients shall take place in line with current legislation
- It is necessary to strengthen the evidence-base on the effect of alternative cancer treatments, including combination with other more conventional treatment
- Access to information about alternative treatment forms and whether these have documented effect must be facilitated for cancer patients and their carers/families

Planned/initiated measures:

- A National Research Centre within Complementary and Alternative Medicine (NAFKAM) has been established at the University of Tromsø
- A contact forum between consumer organisations, alternative practitioner organisations and the health authorities has been established
- A National Information Centre on Alternative Treatment (NIFAB) will be established affiliated to the University of Tromsø and NAFKAM

Increasing numbers of cancer patients are looking to alternative treatments, including products from the health food sectors, a service that is extensive both in Norway and abroad. Treatment of cancer is primarily the preserve of healthcare personnel, cf. Act on Alternative Treatment of Illness²⁵ § 7. Practitioners of alternative treatment can nevertheless deliver services to cancer patients if the treatment is intended only to alleviate or reduce symptoms of the disease, consequences of the disease or side-effects of conventional treatment. The same applies if the treatment is intended to strengthen the body's immune

system or capacity for self-healing, cf. § 7 second subsection. Under certain circumstances, practitioners of alternative treatment also have opportunity to treat the cancer itself if this is done in collaboration or consultation with the patient's doctor, or if the healthcare service cannot offer curative or palliative treatment, cf. § 7 third subsection.

It is necessary to consolidate the evidence-base on the efficacy of the various alternative methods, and also combination with other more conventional treatments. An effect of this will be to obviate

²⁵ Act of 27 June 2003 on Alternative Treatment of Illness, etc.

subjection of patients to (expensive) unnecessary and/or harmful treatment.

Public investment in alternative treatment has increased substantially in recent years, partly through the building up of a national research centre within complementary and alternative medicine (NAFKAM) at the University of Tromsø (established in 2000), and partly through grants to diverse research projects under the auspices of

the Research Council of Norway. NAFKAM is developing a program for training in alternative treatments for healthcare personnel and students at university colleges and universities. A contact forum has also been established between alternative practitioner organisations and the health authorities. Further, a national information centre on alternative treatment (NIFAB) is in the process of being established in Tromsø.

3.7. Rehabilitation

National objectives/steering signals:

- Rehabilitation shall be strengthened in general and for cancer patients
- Cooperation between specialist environments, services and administration levels shall be facilitated
- The evidence-base on prevention and treatment of sequela of cancer disease and/or treatment shall be expanded
- The healthcare service shall have a necessary focus on the mental health of the cancer patient during the entire treatment and rehabilitation period

Planned/initiated measures:

- In 2006, the regional health authorities have been required to prioritise rehabilitation in general
- Standards for medical rehabilitation after various cancer diseases will be drawn up as part of the national action programmes for cancers
- Develop the operations of the Norwegian Knowledge Centre for the Health Services to include studies of long-term effects after treatment of cancer at the Norwegian Radium Hospital (established in 2005)
- Implement the Plan for Strengthening the Psychiatric Health Care Services 1999-2008

Measures in preparation:

- Expansion of programmes for cancer patients at the training and empowering centres
- National plan for rehabilitation
- Actions for improved cooperation, for example establishing/developing rehabilitation teams

Coping, quality of life and rehabilitation
At present there are around 173,000 people in Norway who have or have had cancer. Increasing numbers recover

completely from the disease, and many of these need help to enable them to return to as normal a life as possible. Empowering the patient to cope

optimally with the disease and also experience best possible quality of life during the course of the disease, are highly important elements of this process.

Rehabilitation can be defined as “*time restricted, planned processes with clearly defined objectives and means, in which several players cooperate on providing assistance necessary to complement the users own efforts to achieve best possible function and coping abilities, independence and participation socially and in society*”²⁶. In other words, rehabilitation covers training of physical functionality and skills, psychological coping and social adaptation (for example with respect to schooling and working life).

Responsibility for rehabilitation within the healthcare services is shared between municipal services and specialist healthcare services, cf. Act on Municipal Healthcare Services § 1-3 first subsection and Act on Specialist Healthcare Services § 2-1a, cf. Directive on habilitation and rehabilitation²⁷ §§ 7 and 12. The municipalities must ensure that everybody who lives or stays in the municipality with a need for rehabilitation is offered necessary investigation and follow-up, cf. Directive § 7 second subsection. As one of their four primary tasks, the hospitals are responsible for training of patients and carer/family, cf. Act on Specialist Healthcare Services § 3-8 no. 4. This type of training is provided for example at the hospitals’ training and

²⁶ White Paper no. 21 (1998-1999) Responsibility and coping. Towards a cohesive rehabilitation policy.

²⁷ Directive of 28 June 2001 no. 765 on habilitation and rehabilitation

empowering centres, whose importance as a resource is increasing, and not only for cancer patients and their families.

The challenges within rehabilitation are common for many patient groups, and the services for cancer patients are normally integrated into the general rehabilitation offered by the municipalities and the specialist healthcare services. However, for cancer patients and their families there is also a dedicated provision at the Montebello Centre. This centre is run as a foundation established by the Norwegian Ministry of Health and Care Services grounded in the Rikshospitalet-Radiumhospitalet Medical Centre (University Hospital and Radium Hospital Medical Centre).

Due to the general need to strengthen rehabilitation services, the Ministry has placed demands on the regional health authorities to prioritise this area²⁸ in 2006. Improving the rehabilitation services shall be effectuated in accordance with these directives and expert recommendations using a series of dedicated measures and action plans. Further, evaluation of the need for a rehabilitation plan which will focus in particular on children will be made by the end of 2006. Moreover, standards will be set for medical rehabilitation after cancer illnesses as part of the national action programmes for cancer treatment, cf. discussion in sections 3.4 and 3.5.

Cooperation

Rehabilitation shall be a comprehensive process in which the various activities are seen in relation to each other. Individual care plans (cf. discussion in

²⁸ Remit document 2006

section 3.3) and inter-disciplinary rehabilitation teams are examples of such instruments that can contribute to cohesive measures and good cooperation between experts, services and administrative levels. Further development of measures to improve cooperation shall be evaluated in the follow-up to the cancer strategy plan.

Sequela

Successful rehabilitation of cancer patients presupposes good knowledge by the healthcare services on the prevention and treatment of sequela of cancers and/or treatment. Sequela cover long-term effects, long-term side-effects and late-onset damage, ranging from bothersome to crippling, and temporary to permanent. In 2005, the Ministry approved the Norwegian Knowledge Centre for the Health Services for studies on long-term impact of cancer treatment at the Radium Hospital. The Norwegian Knowledge Centre for the Health Services has been given a particular responsibility to secure national competence raising and dissemination within its specified specialist areas²⁹.

Mental health

Having cancer is a severe mental strain. For some patients, this can develop into depression or angst and a need for treatment that requires its own measures, either from the service providers in the municipality or specialist healthcare services (psychiatric health care services). Good

and holistic cancer care must focus on the patient's mental health throughout the entire treatment and rehabilitation period, and not just when terminally ill. It is essential that the somatic service providers expand their competence on psychiatric problems, and that the psychiatric health care services improve competence on the stresses and needs particular to cancer patients. Equally important is collaboration between the professional fields, both at system level and with the individual patient. The Government has, in general, prioritised to strengthen the services within psychiatric health care, through the implementation of the Plan for Strengthening the Psychiatric Health Care Services 1999-2008.

²⁹ Government Circular I-19/2003 on highly specialised services – nationwide functions and national centres of medical excellence.

3.8. Palliative treatment

National objectives/steering signals:

- Expertise on palliative treatment of cancer patients shall be strengthened, also within the municipal healthcare services
- Improved collaboration and cooperation between services and administrative levels shall be facilitated

Planned/initiated measures:

- The Directorate for Health and Social Affairs has in 2006 been asked to take the initiative necessary to strengthen the inter-disciplinary expertise in municipal healthcare services with respect to pain treatment and palliative treatment, for example, by preparation of dedicated guidelines
- Standards for palliative treatment will be drawn up as part of the National action programmes for cancer treatment

Measures in preparation:

- Measures to improve cooperation, for example the establishment/development of palliative teams, coordinators and programmes for competence transfer

In the final stages of life

Palliative treatment can be defined as “*active treatment, nursing and care for patients with incurable illness and expected short lifetime. Alleviation of the patient's physical pain and other troublesome symptoms are core elements together with measures targeting psychological, social and spiritual/existential problems. The objective of treatment, nursing and care is the best possible quality of life for the patient and their carer/family. Palliative treatment and care neither accelerates death nor prolongs the actual process of dying, but perceives death as an integral part of life.*”³⁰ This definition limits palliative treatment to patients with an incurable illness and who are in the final stages of life.

Palliative treatment is independent of diagnosis, but cancer patients, with an estimated annual need of 20,000, comprise the dominant group. Responsibility for the medical services lies with both municipal and specialist health care services. Treatment takes place primarily in nursing homes and hospitals, often in hospice wards which are separated from other medical activities. Many patients wish to spend as much of their remaining time as possible at home, in which case follow-up and nursing after a stay in hospital becomes the responsibility of the GP and municipal home nursing and care services.

Competence within palliative treatment by specialist healthcare services has been strengthened in recent years, partly as a consequence of the establishment of regional centres of treatment expertise at the country's regional hospitals, cf. National Cancer Plan. A separate state funding scheme

³⁰ “Norwegian association for Palliative medicine - Standards in Palliation” (Norwegian Medical Association. 2004).

has led to the establishment of palliative services in many municipalities³¹. Grants have also been given to professional development and competence raising measures at training nursing care homes in each health authority through the Recruitment Plan for Health and Social Care (2003-2006)³². Moreover, each specialisation area has prepared a "Standard for palliation", which is considered to be a useful tool in the organization of this area. Voluntary organisations make essential contributions, in particular with respect to network building between hospitals and the municipal healthcare services throughout the country.

Nevertheless, there is still a need to invest even more in competence building within this area, not least within the municipalities. The Directorate for Health and Social Affairs has therefore requested in 2006 that necessary initiatives be taken to strengthen the inter-disciplinary competence in the municipal healthcare services with regard to pain and palliative treatment, for example by the preparation of professional guidelines³³. The state grant scheme for establishing palliative services outside the specialist health care services shall also be assessed and considered in relation to the program for training nursing care homes³⁴.

³¹ St.prp. no. 1 (2005- 2006) section 761, post 67.

³² St.prp. no. 1 (2005- 2006) section 761, post 67.

³³ Letter from the Ministry of Health and Care Services to the Directorate for Health and Social Affairs of 13.01.2006. State budget 2006 – section 720 Directorate for Health and Social Affairs – allocation of funding - section 6.10.

³⁴ St.prp. no. 1 (2005- 2006) section 761 post 67.

Cooperation

Patients who receive palliative treatment travel frequently between hospital, nursing home and/or their home. Palliative teams have been established in many areas in order to ease these transitions and to improve cooperation between services and administrative levels. The palliative teams are inter-disciplinary, comprising doctors and nurses, with assistance from physiotherapists, ergonomists, social workers, psychologists/psychiatrists and priests (e.g. the "Telemark model"). The palliative teams are based at the hospital and collaborate with municipal healthcare services, for example through common consultations. If needed, the palliative teams visit the patient in their home. Establishment and/or development of palliative teams is one example of coordination measures that will be evaluated in the follow-up to the cancer strategy. Other coordination measures could be provision of coordinator positions (for example contact nurses) for follow-up of the individual after a stay in hospital, and programmes for competence transfer (e.g. practice at the hospitals).

Right to refuse life-prolonging treatment

In accordance with the Act on Patient Rights § 4-9 second subsection, the dying patient has, in certain circumstances, the right to refuse life-prolonging treatment. The patient has the right to refuse to accept treatment if there is no prognosis of improvement or recovery, but only a certain life-prolongation that in reality is a prolongation of the dying process. Healthcare professionals are obligated to respect the patient's wishes concerning refusal of treatment if the patient is dying. This applies even if the

patient experiences pain that can be alleviated with medication or similar. Refusal can only apply to treatment, not nursing or care. If a dying patient is not capable of communicating their treatment wishes, the healthcare professional must respect a request from the carer/family to refrain from giving treatment, if, after an independent assessment, the healthcare professional also finds this to be the patient's wish, and that this wish should clearly be respected. Evaluation of

whether the wish should clearly be respected should take into consideration whether the family member who has submitted the request has had close contact with the patient over a longer period of time; whether there is disagreement between the carer/family; whether the family's motives could be guided by considerations other than those of the patient's wishes.

3.9. Personnel – capacity and competence

National objectives/steering signals:

- Development of applicable systems for dimensioning and content of basis education, houseman placements, further education and post-education shall contribute to securing sufficient capacity and adequate competence of healthcare professionals at all levels of cancer care.

Planned/initiated measures:

- In 2006, requirements have been imposed on the regional health authorities to ensure, on a general basis, a correct quantitative and high qualitative provision of education and competence building for healthcare professionals who have the regional health authorities as practice arenas and/or place of work. More specifically, demand has been made to maintain and establish an appropriate number of educational positions for doctors in specialisation. The situation for cancer-related specialisations such as oncology, pathology and radiology shall be evaluated separately.
- In 2006, requirements have been imposed on the regional health authorities to plan follow-on education of personnel to meet current and future challenges.
- The regional health authorities assumed financing responsibility in 2005 for five consultant positions within paediatric oncology, which previously was financed by the Norwegian Cancer Society.

Measures in preparation:

- Review of the staffing, recruiting and/or competence situation for several relevant personnel groups, both in the municipal health and social welfare services and the specialist healthcare services.

Healthcare personnel are the healthcare services most important resource, and many personnel groups carry out essential tasks in cancer care. As a

consequence of the National Cancer Plan (1999-2003), access to key personnel within cancer care has increased substantially, in particular

access to specialist doctors (pathologists, oncologists, radiologists), radiographers, radiologists and oncology nurses (cf. section 2.1).

The primary objective is, and will continue to be, to secure sufficient capacity and adequate competence of relevant healthcare professionals at all levels in the cancer care services. In addition to specialised cancer professionals, this also applies to doctors, nurses, ward auxiliaries, health care workers, physiotherapists and social workers. This presupposes good systems for dimensioning and content of basis education, house officer placements, further education and post-education.

The rapid developments within medicine and technology impose a continuous need to update competence so that the quality and practice of the profession is at all times defensible. This responsibility rests with all bodies that deliver services within specialist and municipal healthcare, and it is also the responsibility of the individual healthcare professional, whether working privately or employed by the healthcare services, cf Act on Specialist Healthcare Services §§ 2-2 and 3-10, Act on Municipal Healthcare Services §§ 1-1, 2-1 and 6-3 and the Act on Healthcare Professionals §§ 4 and 16.

In 2006, requirements have been imposed on the regional health authorities to ensure, on a general basis, a correct quantitative and high qualitative provision of education and competence building for healthcare professionals who have the regional health authorities as practice arena

and/or place of work³⁵. More specifically, demand has been made to maintain and establish an appropriate number of educational positions for doctors in specialisation. The situation for cancer-related specialisations such as oncology, pathology and radiology shall be evaluated separately.

Requirements have been imposed on the regional health authorities to plan follow-on education of personnel to meet current and future challenges, which also includes follow-on education within the cancer care sector.

Incidentally, the National Committee for Specialist Education of Doctors and Placement of Doctors is responsible for following developments in this area, one aspect of which is to provide advice to the Ministry on the need for creation of education positions and consultant positions within the various specializations in each health region, cf. Directive on Specialisation Approval for Healthcare Professionals § 5, cf. Act on Specialist Healthcare Services § 4-2.

Furthermore, regional health authorities assumed financing responsibility in 2005 for five consultant positions within paediatric oncology, which previously has been financed by the Norwegian Cancer Society³⁶. The positions are located at Ullevål University Hospital HA, Rikshospitalet-Radiumhospitalet HA, St. Olav Hospital HA, University Hospital of Northern Norway HA and Haukeland University Hospital HA.

³⁵ Remit document 2006

³⁶ St.prp. no. 65 (2004-2005) Supplementary funding and reprioritisations of the State budget including national insurance 2005 section 732, post 71-75 (RNB 2005)

The follow-up to the Cancer Strategy will require audit of the staffing, recruiting and/or competence situation for several relevant personnel groups,

both in the municipal health and social welfare services and in the specialist healthcare services.

3.10. The Cancer Registry of Norway, the National Medical Quality Registers and Research

National objectives/steering signals:

- The specialized operations of the Cancer Registry of Norway shall be continued
- National Medical Quality Registers shall be established within all important specialist areas, including cancer
- Cancer research shall continue to receive good framework conditions through the established research funding systems

Planned/initiated measures:

- Directorate for Health and Social Affairs has been allocated the task of acting as an advisory body and to secure national coordination of and prioritisation between the National Medical Quality Registers hereunder the quality register for cancer
- There is ongoing strategic investment in cancer research under the auspices of the Research Council of Norway

Measures in preparation:

- Evaluation of measures to secure improved access to and use of data from the National Medical Quality Registers
- Research on selected patient groups (e.g. elderly) and cancer, prevention and treatment of sequela, organization of services for patients with cancer, comparative efficacy studies of various treatment regimens, etc.

The Cancer Registry of Norway and National Medical Quality Registers within cancer

The Cancer Registry of Norway has been created as a personally identifiable register without consent. Operations cover registration, research, advice and information, cf. the Directive on the Cancer Registry of Norway § 1-3. The Cancer Registry is the largest diseases register that contains information on the health and diseases for all persons in the country who have been diagnosed with cancer.

Altogether, nine National Medical Quality Registers have been established for the cancer sector. A Medical Quality Register contains a structured collection of medical information about diagnosis and treatment of patients, which provides an indication of how certain processes function and if certain results have been achieved. Five of the National Medical Quality Registers (specialised registers) are run by the Cancer Registry of Norway: rectum cancer, polyposis, prostate and ovarian cancers, and radiation therapy. The remaining four National Medical Quality Registers; head-throat, acute leukaemias and

lymphoblastic lymphomas, radical prostatectomies and breast cancers are grounded in and run by the regional health authorities. The registers are essential to underpin the data needed as an evidence-base for treatment results, quality development of the services provided and as a basis for medical and healthcare research.

The Cancer Registry records are under continual development, and the objective is to be the first country in the world to hold complete, population-based data on disease progression, treatment intention and outcome. The further development of the quality registers within the cancer sector must be seen in conjunction with the general work that is being done with respect to establishing National Medical Quality Registers. The Directorate for Health and Social Affairs has been allocated the tasks of drawing up a comprehensive plan for prioritisation of the quality registers, to act as an advisory body and to secure national coordination on the establishment of National Medical Quality Registers. A future personally identifiable national patient register (NPR) would support development of the national health and quality registers.

In Norway, registration work in the cancer sector is well advanced, a result not least of the operations of the Cancer Registry. A precondition for good application of the Registry data in quality development and research, are good systems for access and close collaboration with the specialists.

Research

Research is an essential tool in the progression of evidence-based healthcare, and a prerequisite for

medical progress. There is an overriding goal to strengthen research both within preventative and general medicine, and specialist health care services.

Establishing regional health authorities and formal collaboration bodies between the regional health authorities, universities and university colleges, has facilitated a more coordinated and structured research activity by the healthcare authorities. A results-based grant has been established for research activities in the healthcare regions. A national system measuring research in the regional healthcare authorities has shown increased research activities. With regard to general medical research, the Directorate for Health and Social Affairs was given the task by the Ministry³⁷ to study how research and professional development within general medicine can be organised and funded. Proposals include establishing four new practice-proximal research units affiliated to the general medicine institutions/departments at the medical faculties. The proposals are now being reviewed by the Ministry.

An evaluation of Norwegian clinical research under the auspices of the Research Council of Norway in 2004³⁸, revealed that there are several research sectors in Norway that are important contributors to international cancer research. This applies both for research that increases knowledge on the causes of cancers, and research that improves diagnostics and treatment of cancers. The Institute for Cancer Research,

³⁷ Budget-innst. S. no. 11 (2004-2005).

³⁸ The Report "Evaluation of clinical, epidemiological, public health, health-related and psychological research in Norway" (2004).

located at the Radium Hospital of Norway, holds a central position within cancer research based on close collaboration between research and clinics. Other important specialist environments are to be found at the University hospitals and the Cancer Registry of Norway.

Public funding for research, hereunder cancer research, is channelled from various ministries to universities, subsidiary bodies, regional health authorities and the Research Council of Norway. In addition, the National Cancer Plan (1999-2003) allocated dedicated funds to cancer research of NOK 100 million over five years. This funding has been continued through a strategic focus on cancer research under the auspices of the Research Council of Norway (around NOK 21 million per year shared between several projects until 2007). In the voluntary sector, the Norwegian Cancer Society is

a major contributor to cancer research (around NOK 110 million annually). The pharmaceutical industry is also a centre of research, primarily within clinical trials.

One goal is that cancer research shall continue to receive good framework conditions through the established research funding systems. In future there will be particular need for research on selected patient groups (e.g. elderly) and cancer, prevention and treatment of sequela, comparative efficacy studies of various treatment regimens, and organization of services for patients with cancer. Ensuring good implementation and integration of evidence-based healthcare research in medical practice (translation research) is a particularly demanding challenge, and one that it is absolutely essential to meet if we are to ensure high quality in future cancer care.