Sundhedsstyrelsen
National Board of Health

NATIONAL CANCER PLAN II • DENMARK

NATIONAL BOARD OF HEALTH RECOMMENDATIONS FOR IMPROVING CANCER HEALTHCARE SERVICES

2005

Sundhedsstyrelsen

National Cancer Plan II • Denmark

National Board of Health recommendations for improving cancer healthcare services

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1 Foreword

At the opening of Parliament on 5 October 2004 the Prime Minister announced that the Government wished to table a new National Cancer Plan aimed at bringing the treatment of cancer in Denmark in line with the highest international standards. At the request of the Ministry of the Interior and Health, the National Board of Health assisted by a number of contributors and advised by the Cancer Steering Committee drew up National Cancer Plan II – The National Board of Health's recommendations for improving cancer healthcare services.

National Cancer Plan II makes a number of recommendations about how improvements can be made throughout the cancer patient pathway. Several of the recommendations will be immediately implementable centrally and locally in the work to improve cancer healthcare services. With some recommendations, a more detailed description is needed of how they can be implemented in practice, and of who should be responsible for their implementation. In some areas, moreover, implementation of the recommendations could have implications that need to be assessed further.

In connection with operationalisation of the medical recommendations the economic consequences of their implementation will have to be assessed in collaboration with the county hospital authorities. A number of the recommendations concern improvements that can be carried out through organisational changes, while others necessitate detailed economic calculations. The National Board of Health believes that once these calculations have been made, it will be possible and appropriate to propose a timetable for prioritisation of the plan's individual recommendations within a given financial framework.

In the view of the National Board of Health, implementation of the recommendations will improve the survival of Danish cancer patients and enhance the overall quality of the healthcare provided. Moreover, the improvement in prevention recommended in National Cancer Plan II should result in many avoided cases of cancer.

The National Board of Health would like to thank the many contributors to the National Cancer Plan who, despite a very short deadline, have made considerable efforts to procure the evidence upon which National Cancer Plan II is founded.

The National Board of Health, June 2005

Jens Kristian Gøtrik
CMO, Director-General

2 Summary

The purpose of National Cancer Plan II is to strengthen cancer prevention efforts and to improve the foundation for providing Danish cancer patients with diagnosis and treatment pathways that are implemented early, are experienced as coherent by the patients, and are of a high international standard. The plan makes medical recommendations in a number of areas where efforts need to be strengthened. The recommendations will subsequently have to be operationalised and implemented by the county hospital authorities adapted to local conditions.

The recommendations made in National Cancer Plan II do not include concrete goals – e.g. that mortality due to intestinal cancer has to be reduced by a certain percentage within five years – because it is rarely possible to formulate such goals on the basis of solid scientific evidence. At the same time, though, one should not wait several years before evaluating whether the efforts have had an effect such as is often proposed in evaluation plans. What is vital is to regularly monitor whether the trend is in the desired direction – e.g. whether mortality from intestinal cancer is decreasing – so that the efforts can be adjusted if necessary. Finally, the possibility to achieve improvements depends on the extent to which the recommendations are implemented.

National Cancer Plan II centres around the patient pathway from prevention to diagnosis and treatment to rehabilitation and palliative care. In addition, the Plan concerns a number of crosscutting areas of significance for the quality of healthcare efforts in the cancer area. For each of these areas the Plan identifies important issues, reviews the current status and makes recommendations for the future efforts.

The main recommendations put forward in National Cancer Plan II are summarised below. The National Board of Health’s assessment is that the main focus in the coming years should be on prevention of smoking, improved organisation of the patient pathways, strengthening of cancer surgery, health technology assessment of cancer drugs and finally, surveillance of the cancer healthcare services.

Epidemiology of cancer (Chapter 5)

The number of new cancer cases in Denmark has been increasing for many years. In 2003, approx. 34,000 cancer cases were diagnosed roughly equally distributed between men and women. An increase in the prevalence of cancer can also be expected in the coming years, primarily because the proportion of elderly persons in the population is growing. The projection for the number of new cancer cases shows that an additional 9,000 cancer cases annually can be expected in 2018–22.

Comparison of cancer patient survival in the Nordic countries shows that with the most widespread types of cancer, the population-based survival is poorer in Denmark than in the other Nordic countries. This is particularly apparent immediately after the diagnosis of cancer. In Denmark, the hospital-based survival during the period 1997–2004 has improved for women with breast cancer, ovarian cancer and lung cancer and for men with rectal cancer.

Patient pathways (Chapter 6)

National Cancer Plan II recommends improved organisation of diagnosis, treatment and follow-up specifically based on patient needs. The majority of patients with suspected cancer have to undergo the same diagnostic investigations and the same treatments, which can therefore be organised in standardised pathways. Experience has shown that it is possible to establish patient pathways based on a number of clearly defined working routines and cooperation structures that without unnecessary delay and concomitantly ensuring appropriate utilisation of resources can provide the individual patient with an uninterrupted treatment pathway from general practice and onwards through the involved hospital departments. It is recommended that hospital administrations and departments should draw inspiration from the organisation of standardised diagnosis and treatment pathways as described in National Cancer Plan II.

An important task for the county hospital authorities is to ensure sufficient capacity to ensure the necessary diagnosis and treatment activity in the patient pathway. Ideally, the necessary activity in the form of investigations and treatments can be estimated on the basis of a knowledge of the prevalence of the individual types of cancer and the relevant clinical guidelines specifying the activities that should be provided in the patient pathway for a given cancer patient. The National Board of Health will therefore ensure the estimation of activity figures with a view to using the data in healthcare planning. National Cancer Plan II does not specify what capacity is needed, e.g. the number of scanners or accelerators, as it is the responsibility of the hospital authorities to organise the work and determine the necessary capacity to achieve an adequate level of activity.

Prevention and early detection (Chapter 7)

More than a third of all cancer cases could be avoided if it was possible to eliminate the lifestyle risk factors presently known. Tobacco is the individual factor that poses the greatest risk, and National Cancer Plan II recommends a number of initiatives having a documented effect on prevention of smoking.

Based on the available evidence for the effect of cancer screening, National Cancer Plan II makes recommendations concerning screening for cervical cancer, breast cancer and intestinal cancer.

Diagnosis of cancer (Chapter 8)

The available data indicate that a number of cancer diagnoses are made at a later stage in Denmark than in Norway and Finland, probably because we in Denmark wait too long before seeing a doctor combined with a delay in referral from general practice to further investigation of suspected cancer. National Cancer Plan II recommends a number of initiatives directed at the public and general practitioners, respectively, aimed at enhancing awareness and action concerning symptoms that might be cancer-related.

All patients with suspected cancer (apart from ordinary skin cancer) should be referred to further examination at the hospital. Here it is vital that the diagnosis is made as rapidly and accurately as possible. National Cancer Plan II recommends strengthening the quality of the diagnostic imaging and the tissue and cell diagnostics and ensuring effective working routines. At the same time, it is pointed out that these specialities should be incorporated in the team effort that should exist around the cancer patients.

Treatment of cancer (Chapter 9)

The key to ensuring high-quality healthcare in the cancer area is that the care is evidence-based and is regularly monitored and adjusted according to needs.

Surgical treatment

With most types of cancer the treatment most likely to lead to a cure is surgery. The quality of cancer surgery is therefore decisive for the treatment result. Analyses of treatment results expressed in terms of survival show that with a number of operable cancers, survival in Denmark is poorer than in the other Nordic countries, especially in the first few months after the diagnosis has been made. One of the conclusions reached by the evaluation of National Cancer Plan I was that cancer surgery in Denmark needs to be optimised. In line with this it is considered that treatment results in Denmark could be improved by strengthening cancer surgery.

A large number of international analyses have shown that several factors are of importance for the success and quality of efforts on the cancer surgery front, including the time of operation relative to the stage of the disease, the number of operations performed by each surgeon and department, whether or not multidisciplinary cooperation has been established, education/continuing education of the surgeon and the whole team, and compliance with clinical guidelines. National Cancer Plan II describes these factors and makes recommendations regarding the future efforts on the cancer surgery front.

Pharmacotherapy

Many new cancer drugs are presently being developed, and it is important that new drugs are integrated in standard treatments based on solid knowledge. At the same time, it is necessary to continually monitor whether the treatment results obtained during drug development are also obtained when the drugs are utilised on a standard basis in routine clinical practice. This is important, both because the drugs often have considerable side effects and because the treatments are often very expensive. National Cancer Plan II therefore recommends the formulation and implementation of national clinical guidelines for standard treatments and the routine registration of treatment efficacy and side effects, and that this documentation should be regularly published and used to adjust treatment practice. A further recommendation is for the establishment of an assessment programme for new cancer drugs that in addition to the traditional assessment of drug quality, safety and side effects should also clarify the health economic, patient-related and organisational consequences of the introduction of a drug as standard treatment.

Radiotherapy

The need for radiotherapy has increased considerably in recent years because the prevalence of cancer is increasing and indications for therapy are being extended at the same time as treatment is becoming more advanced. This trend, which has long been causing problems of compliance with the waiting time guarantee stipulated by law, can be expected to continue. On the basis of several analyses and foreign experience National Cancer Plan II recommends that in view of the expected professional and technological development in the radiotherapy area and the fact that the equipment gradually wears out, replacement and implementation plans should be drawn up at the county/regional level. The National Board of Health is to coordinate the local plans.

Non cancer-specific treatment (Chapter 10)

In addition to the above-mentioned cancer-specific treatments, many cancer patients need other types of treatment and care, for example supportive treatment, rehabilitation and palliative care. Among other things, National Cancer Plan II recommends the formulation of evidence-based clinical guidelines and indicators in order to ensure that patients are also provided with high-quality treatment and care in these areas.

The patient aspect (Chapter 11)

Active participation of patients in the course of their disease and treatment benefits the patients themselves and supports the efforts of the health service. National Cancer Plan II recommends a number of initiatives aimed at enhancing self-care among patients and ensuring that patients with special needs are provided with the necessary guidance and support. Relatives comprise an important resource for many cancer patients, and National Cancer Plan II recommends that departments should ensure the involvement of relatives in treatment and care in accordance with the wishes of the patient.

Personnel and education (Chapter 12)

An important precondition for achieving and maintaining a high international standard of cancer healthcare services is that the treating physicians and other healthcare personnel have the necessary professional qualifications. A special area is cancer surgery, where the necessary qualifications are obtained through such means as systematic mentorship. National Cancer Plan II recommends the formulation of goals for the knowledge and expertise that the individual specialist has to attain during his/her continuing education, and the preparation of an overall plan and establishment of concrete possibilities for improving the continuing medical education and supervision of specialists in the cancer area.

Before the end of 2005, the National Board of Health’s Council for Continuing Nursing Training is expected to submit proposals for a new specialist education for nurses who work with cancer patients. This specialist education will replace the existing one-year continuing education programme.

Research (Chapter 13)

Based on the report “Clinical cancer research in Denmark” published by the Danish Research Agency in February 2005, National Cancer Plan II recommends a number of initiatives aimed at coordinating and enhancing the quality of clinical cancer research in Denmark.

Surveillance (Chapter 14)

National Cancer Plan II recommends that surveillance of the cancer area should be strengthened in accordance with the principles of the Danish Health Care Assessment Programme. Thus the Plan recommends the centralised coordination and presentation of the collected cancer data and the strengthening of the surveillance of healthcare quality and clinical results in the cancer area, including the patient’s assessment of the course of treatment. Furthermore, the Plan recommends the regular preparation of a status report on the quality of cancer treatment to support healthcare planning.

3 Introduction

The purpose of National Cancer Plan II is to put forward recommendations for improvements in the focus areas encompassed by the Plan based on a review of the main issues and current status of the cancer area.

The overall objectives of the cancer healthcare services are to:
- Reduce the number of new cancer cases
- Perform early detection of cancer and the early stages of cancer
- Ensure that persons with symptoms of cancer are correctly diagnosed as soon as possible
- Provide cancer patients with curative treatment
- Provide patients who have incurable cancer with life-prolonging treatment if this is meaningful for the patient
- Provide cancer patients with rehabilitation based on individual needs
- Provide cancer patients who cannot be offered curative or life-prolonging treatment with palliative care
- Provide cancer patients with well-planned coherent care of a high international standard without unnecessary delay
- Include the patient's own assessment and efforts in the course of treatment as an important resource and ensure that the healthcare personnel cooperate with the patient based on respect for the patient's integrity.

National Cancer Plan II centres on the patient pathway, reaching from prevention to diagnosis and treatment to rehabilitation and palliative care. In addition, the Plan concerns a number of organisational aspects of diagnosis and treatment and a number of crosscutting areas of significance for the quality of healthcare in the cancer services. The recommendations made in National Cancer Plan II do not include concrete goals – e.g. that mortality due to intestinal cancer has to be reduced by a certain percentage within five years – because it is rarely possible to formulate such goals on the basis of a solid scientific foundation. What is vital is to regularly monitor whether the trend is in the desired direction – e.g. whether mortality from intestinal cancer is decreasing – so that the efforts can be adjusted if necessary.

National Cancer Plan II has been drawn up on the basis of submissions by a number of different experts (see the Annexes at www.sst.dk. These are only available in Danish). The length of the individual Annexes is not a reflection of the importance accorded to the aspect in question, but rather of the individual author's choice of presentation form. Based partly on these submissions, the National Board of Health has highlighted the main areas where cancer healthcare services need to be strengthened. Thus while each of the contributors are responsible for their own submissions, the National Board of Health is responsible for the text and recommendations in National Cancer Plan II itself.

In connection with the work to implement National Cancer Plan II the National Board of Health will consider how cancer healthcare services should be managed at the central level in future, including incorporation of the haematology area – an area that has not previously been encompassed by the Cancer Steering Committee's work. The future role and composition of the Cancer Steering Committee will also be considered by the Board.

3.1 Background

In February 2000, the National Board of Health published the “National Cancer Plan – Status and proposals for initiatives in relation to cancer treatment”. The National Cancer Plan – hereafter referred to as National Cancer Plan I – was drawn up under the auspices of the advisory Cancer Steering Committee under the National Board of Health. The main purpose was to clarify the possibilities to improve cancer treatment in Denmark in order to reduce cancer mortality. National Cancer Plan I took a holistic approach to the cancer area and thus also included prevention, rehabilitation and palliative care, etc.

In the five years since publication of National Cancer Plan I a large number of important initiatives have been implemented in the cancer area. Prevention has been strengthened throughout the country, especially in relation to smoking, an area where the cancer prevention potential still remains the greatest, however. New initiatives have been taken in the screening area. Diagnosis and treatment of cancer have grown considerably, and greater attention is now accorded to the importance of rehabilitation of cancer patients and to palliative care. Healthcare education now devotes more time to cancer, and specific goals regarding cancer have been set for all specialities in the new specialist education for physicians.

Other important initiatives in the cancer area since 2000 are the introduction in 2001 of the waiting time guarantee for patients with life-threatening cancer and in 2004 of the possibility for experimental treatment abroad. Most recently, in 2004, the decision was made to establish three experimental cancer treatment facilities in Denmark.

A number of other healthcare initiatives are of importance for the cancer area. Thus the Government’s public health programme “Healthy throughout life” identifies cancer as one of eight healthcare areas to be prioritised. The goal is that the number of cancer cases is to be reduced by reducing exposure of the population to risk factors that can cause cancer. Another initiative is the development of the Danish Health Care Assessment Programme. The model is a joint Danish system for systematic and continual quality surveillance and assessment in the whole of the Danish health service.

Despite considerable input of resources to the cancer healthcare services in recent years, compliance with the waiting time guarantee for diagnosis and treatment poses a recurrent problem. Among other things this is attributable to the following factors: The number of cancer cases is increasing due to the increasing proportion of elderly persons in the population and the increasing prevalence of certain forms of cancer; the need for treatment is increasing because new treatments have been developed; and finally, the number of elderly persons being treated is increasing due to the development of milder treatments. This development can be expected to continue, and will have to be taken into account in healthcare planning.

In February 2004, the Danish Centre for Evaluation and Health Technology Assessment under the National Board of Health published an evaluation of National Cancer Plan I. Based on this evaluation, National Cancer Plan II aims to further develop and strengthen the cancer healthcare services.

3.2 Contributors to National Cancer Plan II and members of the Steering Committee on Cancer

The following working groups, institutions and individuals have prepared the contributions that comprise the *Annexes to National Cancer Plan II*. The names of the contributors are shown in the individual annexes. The annexes are only available in Danish at the National Board of Health website www.sst.dk.

Danish Regions Working Group on Rehabilitation
Danish Cancer Society Working Groups on Symptoms – visit a doctor and Self-care and relatives
National Board of Health Working Group on Cancer Epidemiology
National Board of Health Advisory Group on Palliative Care
National Board of Health National Cancer Plan II Surgery Group
Vejle Hospital, Heads of cancer packages, et al.
Knowledge and Research Centre for Alternative Medicine (ViFAB)

<u>Cancer Steering Committee</u>
Chief Medical Officer, Director-General Jens Kristian Gøtrik (Chairman)
County Director of Health Peter Orebo Hansen, Copenhagen County
County Director of Health Leif Vestergaard Pedersen, Aarhus County
Advisor Lisbeth Andersen, Danish Regions
Professor Søren Laurberg, Danish Surgical Society
Consultant Physician Peter Iversen, Danish Surgical Society
Consultant Physician Ole Hart Hansen, Danish Surgical Society
Consultant Physician Niels Holm, Danish Society for Clinical Oncology
Consultant Physician Gedske Daugaard, Danish Society for Clinical Oncology
General Practitioner Ivar Østergaard, Danish College of General Practitioners
Consultant Physician Jens Karstoft, Danish Society for Diagnostic Radiology
Consultant Physician Beth Bjerregaard, Danish Society for Pathological Anatomy and Cytology
Director Finn Kamper-Jørgensen, National Institute of Public Health
Chief Physician Anne Thomassen, Danish Cancer Society
Head of Department Vagn Nielsen, Ministry of the Interior and Health
Head of Division John Erik Pedersen, Ministry of the Interior and Health
Advisor Hans Lynggaard Jørgensen, Ministry of the Interior and Health
Centre Director Finn Børlum Kristensen, National Board of Health
Head of Division Morten Hjulsager, National Board of Health
Head of Division Eva Hammershøy, National Board of Health

<u>Secretariat: Planning Division, National Board of Health</u>
Senior Medical Officer Ulla Axelsen
Medical Public Health Officer Niels Hermann
Senior Advisor Ulla W. Skott

4 Main recommendations

National Cancer Plan II puts forward recommendations for future work with the issues addressed by the plan. The recommendations concern efforts within planning and implementation at all levels of the health service. It is expected that implementation of the recommendations will considerably strengthen the cancer healthcare services. Each individual section of the National Cancer Plan ends with recommendations for the aspect in question.

The National Board of Health recommends that the main focus of cancer prevention and treatment efforts in the coming years should be on prevention of smoking, improving the organisation of patient pathways, strengthening of cancer surgery, and surveillance of healthcare in the cancer services.

Strengthened smoking prevention

Smoking causes around 5,000 cases of cancer each year in Denmark and is the greatest single risk factor for the development of cancer. National Cancer Plan II recommends a number of initiatives that have all been documented to have a preventative effect on smoking.

Optimisation of patient pathways – organised in packages

The majority of patients with suspected cancer have to undergo the same diagnostic investigations and the same treatments, which can therefore be organised in standardised pathways. Experience has shown that based on a number of clearly defined working routines and cooperation structures it is possible to establish patient pathways that without unnecessary delays can provide the individual patient with an unbroken treatment pathway from general practice and onwards through the involved hospital departments. It is recommended that hospital departments should draw inspiration from the organisation of standardised diagnosis and treatment pathways described in National Cancer Plan II.

Improvement of the quality of cancer surgery

With most types of cancer the treatment most likely to lead to a cure is surgery. The quality of cancer surgery is therefore decisive for the treatment result. Analyses of treatment results expressed in terms of survival show that with a number of operable cancers, survival in Denmark is poorer than in the other Nordic countries, especially in the first months after the diagnosis has been made. A large number of international analyses have shown that several factors are of importance for the success and quality of cancer surgery, including the time of operation relative to the stage of the disease, the number of operations performed by each surgeon and department, whether or not multidisciplinary cooperation has been established, education/continuing medical education of the surgeon and the whole team, and compliance with clinical guidelines. National Cancer Plan II recommends improvements in each of these areas.

Improved basis for the implementation of standard drug treatment

The introduction of new cancer drugs is extremely costly, and several new treatment possibilities have not been uniformly implemented as standard treatments throughout the country. One of the reasons for this is that the documentation available in connection with the marketing permit for new drugs is inadequate for an evaluation of the full consequences of introduction of the drug. Advised by the Danish Medicines Agency, the National Board of Health has drawn up proposals for an HTA-based model for assessing drugs that are expected to be used in standard treatment of cancer. Development of the model should be completed, and the model implemented.

Strengthened surveillance and dissemination of data documenting the quality of the cancer healthcare services

Considerable data collection and analysis take place regularly in the cancer area, but indicators suitable for regular surveillance of treatment quality have only been developed for a few areas. One of the general recommendations in National Cancer Plan II is therefore that indicators should be developed for the individual areas to enable documentation of the quality of the healthcare efforts, and that regular surveillance of them should be established. Moreover, the Plan recommends the establishment of centralised coordination and presentation of the collected cancer data.

5 Epidemiology of cancer

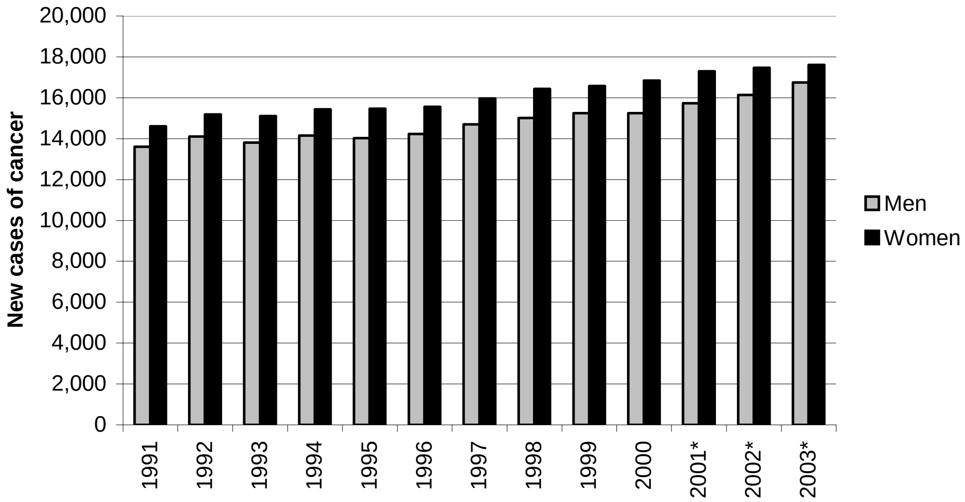
5.1 The trend in cancer in Denmark

At the suggestion of the Cancer Steering Committee, a working group established by the National Board of Health drew up the report “Cancer in Denmark. An updated review of prevalence, mortality and survival” that was published concomitantly with National Cancer Plan II. For more detailed information about the epidemiological aspects of cancer the reader is referred to this report (only available in Danish via the National Board of Health website www.sst.dk).[1]

The report describes the current status of the existing central registers and clinical quality databases and makes recommendations regarding them. In addition, the report describes the trend in cancer in Denmark, and makes comparisons with the other Nordic countries regarding selected forms of cancer.

The number of new cases of cancer has been increasing for many years in Denmark. Over the period 1991–2003, the increase was 17% for men and 16% for women (Figure 1). In 2003, the most frequent forms of cancer were cancer of the gastrointestinal tract, airways and the skin. In women, a large proportion of new cases was accounted for by breast cancer. The largest proportion of new cases of cancer occurs in the elderly. Thus in 2003, 74% and 66%, respectively, of all cases of cancer occurred in men and women over 60 years of age.

Figure 1



Trend in the number of newly diagnosed cases of cancer among men and women over the period 1991–2003. The figures for the years 2001–03 are estimates based on the provisional figures for those years. Source: Danish Cancer Register.

The epidemiology of cancer in Denmark is summarised in Table 1 compared with Finland, Norway and Sweden. Data are shown for the number of new cases per

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[1] Cancer in Denmark. An updated review of prevalence, mortality and survival (only available in Danish)

year, the lifetime risk and the prognosis for eight types of cancer – colon, rectal, lung, breast, uterine, cervical, ovarian and prostate cancer – selected due to their high prevalence and/or poor survival.

Table 1
Key figures for cancer in the Nordic countries (Denmark, Finland, Norway and Sweden) in 2000.

Type of cancer		Denmark		Finland		Norway		Sweden	
		♂	♀	♂	♀	♂	♀	♂	♀
Colon	Incidence (per 100,000)	32	28	21	18	38	33	26	22
	Lifetime risk (%)	2.4	2.1	1.6	1.4	2.9	2.4	1.9	1.7
	5-year survival (%)	48	52	63	59	57	61	59	61
	Additional deaths per 100 PY (3-month)	65	44	46	36	44	32	28	27
Rectal	Incidence (per 100,000)	27	16	17	10	25	17	19	13
	Lifetime risk (%)	2.3	1.3	1.4	0.8	1.9	1.3	1.6	1.0
	5-year survival (%)	49	53	51	57	59	62	56	60
	Additional deaths per 100 PY (3-month)	36	31	47	21	21	21	20	18
Lung	Incidence (per 100,000)	72	45	58	14	53	30	30	21
	Lifetime risk (%)	6.3	4.0	4.6	1.2	4.3	2.7	2.7	1.9
	5-year survival (%)	8	9	10	14	10	15	11	16
	Additional deaths per 100 PY (3-month)	142	133	115	93	129	109	112	96
Breast	Incidence (per 100,000)		114		110		99		107
	Lifetime risk (%)		9.0		8.7		7.8		8.7
	5-year survival (%)		79		84		83		86
	Additional deaths per 100 PY (1st year)		4.6		3.5		2.8		2.3
Cervical	Incidence (per 100,000)		13		5		12		9
	Lifetime risk (%)		1.0		0.4		0.9		0.7
	5-year survival (%)		67		65		70		68
	Additional deaths per 100 PY (3-month)		14.9		15.5		10.9		10.5
Uterine	Incidence (per 100,000)		17		21		21		21
	Lifetime risk (%)		1.5		2.0		1.8		1.9
	5-year survival (%)		82		85		82		84
	Additional deaths per 100 PY (1st year)		6.3		5.5		6.4		4.9
Ovarian	Incidence (per 100,000)		19		14		18		16
	Lifetime risk (%)		1.7		1.2		1.5		1.4
	5-year survival (%)		37		47		45		48
	Additional deaths per 100 PY (3-month)		51		34		40		27
Prostate	Incidence (per 100,000)	63		131		125		132	
	Lifetime risk (%)	4.6		9.8		10.0		10.4	
	5-year survival (%)	49		79		73		76	
	Additional deaths per 100 PY (1st year)	11.2		3.3		4.7		3.5	

Note: The figures for incidence are age-standardised according to a European standard population. The survival figures shown are the 5-year survival relative to the background population and the excess mortality expressed as the number of additional deaths per 100 person-years (PY) in the first 3 months or the first year after diagnosis relative to the background population.

Denmark has the second-highest incidence of **colon cancer** after Norway**.** Thus in 2000, the number of new cases in Denmark was approx. 32 per 100,000 men and 28 per 100,000 women. The lifetime risk of developing colon cancer lies in the range 2–3%. For Danes diagnosed with this type of cancer the 5-year survival is 48% for men and 52% for women. Compared with Finland, Norway and Sweden, the survival of Danish colon cancer patients is poorer. This is particularly apparent immediately after diagnosis for both men and women. Three months after diagnosis the excess mortality is 65 additional deaths per 100 person-years for men and 44 for women, in both cases a figure that is poorer than in the other Nordic countries.

The incidence of **rectal cancer** is greatest in Denmark and Norway. In 2000, the number of new cases in Denmark was approx. 27 per 100,000 for men and 16 per 100,000 for women. The lifetime risk of developing rectal cancer in Denmark lies in the range 1–2%. The 5-year survival for Danish patients is 49% for men and 53% for women, in both cases lower than in the other Nordic countries. The excess mortality for men is 36 additional deaths per 100 person-years, which is poorer than the result obtained in Norway and Sweden. The excess mortality for Danish women is 31 additional deaths per 100 person-years and hence is also poorer than in the other Nordic countries.

The incidence of **lung cancer** has fallen in men in Denmark, Finland, Norway and Sweden but has increased in women. In Denmark the incidence is still higher in men than in women, though, and in 2000, there were 72 and 45 new cases per 100,000, respectively. The 5-year survival in Denmark is 8% in men and 9% in women, which is slightly poorer than that in the other Nordic countries. Correspondingly, the excess mortality was 142 and 133 additional deaths per 100 person-years for men and women, respectively, which is higher than the excess mortality in the other three countries.

The incidence of **breast cancer** in women has been increasing over the past 30 years in all four countries and in 2000 was greatest in Denmark – 114 cases per 100,000 women. The lifetime risk of developing breast cancer is just over 9% for Danish women. The 5-year survival in Denmark is 79% and hence poorer than in Finland, Norway and Sweden. The excess mortality is 4.6 additional deaths per 100 person-years and hence higher than in the other Nordic countries.

The incidence of **cervical cancer** in women has been decreasing over the past 30 years in all countries. In 2000 there were 13 cases per 100,000 women in Denmark, which is thus on par with the level in Norway, but higher than that in Sweden and Finland. Inter-country comparisons need to be interpreted with caution, however, as there might be differences in the way the countries classify cervical cancer versus uterine cancer, as could be indicated by the relatively high incidence of cervical cancer and relatively low incidence of uterine cancer in Denmark (see below). The lifetime risk for developing cervical cancer in Denmark is 1%, and the 5-year survival is 67%, corresponding to that in the other Nordic countries. The excess mortality is 15 additional deaths per 100 person-years, which is higher than in Norway and Sweden.

The incidence of **uterine cancer** in women has been increasing over the past 30 years in Finland, Norway and Sweden. In Denmark the incidence also increased during the first part of the period, but has been falling since approx. 1990. In 2000 there were 17 cases per 100,000 in Denmark, which is lower than in the remaining Nordic countries (see the reservation mentioned in the section about cervical cancer). The lifetime risk is 1.5%, the 5-year survival is 82%, and the excess mortality is 6 additional deaths per 100 person-years, which corresponds to the level in the other three Nordic countries.

The incidence of **ovarian cancer** in women has been stable over the past 30 years in all four countries, although it fell slightly in Sweden at the end of the period. In 2000 the incidence was greatest in Denmark among the Nordic countries – 19 cases per 100,000 women. The lifetime risk is 1.7%. The 5-year survival is 37% for Danish women and hence considerably poorer than for women in the other Nordic countries. This is particularly apparent immediately after diagnosis, when the excess mortality is 51 additional deaths per 100 person-years, which is higher than in the other Nordic countries.

Over the past 30 years there has been a marked increase in the incidence of **prostate cancer** in men in all four Nordic countries. The increase has been least in Denmark, where 63 cases per 100,000 men were diagnosed in 2000. The lifetime risk in Denmark is 4.6%. The higher incidence of diagnosed prostate cancer in the other countries is probably related to the greater use of blood tests for prostate specific antigen – a marker of prostate cancer. The 5-year survival is 49% in Denmark, which is considerably poorer than in the other three countries. The excess mortality is 11 additional deaths per 100 person-years, which is higher than in Finland, Norway and Sweden.

As the Cancer Register is only complete up to and including 2000 the trend in cancer survival in Denmark has instead been calculated for the period 1997–2004 (Table 2) based on hospital submissions to the National Patient Register in order to be able to determine the trend as far forward as possible. The same eight selected forms of cancer have been focussed on in this hospital-based survival as in the Nordic comparison, namely colon, rectal, lung, breast, cervical, uterine, ovarian and prostate cancer.

In general, only relatively small fluctuations are seen in the hospital-based survival over the period 1997–2004. The data for 2004 are preliminary and should be interpreted with caution. It should be noted, though, that survival has improved in women with breast cancer, ovarian cancer and lung cancer and in men with rectal cancer. These improvements are significant for the 1-year survival in the 2003–04 cohort compared with the 1997–98 cohort.

Over the same period there was a tendency towards improved survival in men with lung cancer and in women with rectal cancer.

With the remaining types of cancer, survival is largely unchanged in the 2003–04 cohort compared with the 1997–98 cohort.

Calculations of hospital-based and population-based survival are not comparable.

Table 2
Hospital-based relative 1-year survival (age-adjusted, relative to the background population) in Denmark over the period 1997–2004.

Type of cancer	**Gender**	**Cohort**			
		1997–1998	**1999–2000**	**2001–2002**	**2003–2004**
		Relative 1-year survival (%)			
Colon	♂	67	68	70	68
	♀	71	72	71	72
Rectal	♂	74	77	78	79[1]
	♀	77	79	77	79
Lung	♂	28	28	29	31
	♀	29	31	32	35[1]
Breast	♀	94	95	96	96[1]
Cervical	♀	86	86	86	85
Uterine	♀	92	92	91	91
Ovarian	♀	70	72	73	75[1]
Prostate	♂	85	85	83	86

Note: The survival rates are calculated for four cohorts – hospitalised with newly diagnosed cancer in the following 2-year periods 1) 1997–1998, 2) 1999–2000, 3) 2001–2002 and 4) 2003–2004.

[1] Change in survival between the 1997–98 cohort and the 2003–04 cohort is significant at the 5% level.

6 Patient pathways

6.1 Patient pathways – organised in packages

For a more detailed examination of the topic “Patient pathways in packages” see Annex 6.1, which describes the experience of Vejle Hospital with the development of coherent diagnosis and treatment pathways comprised of small so-called packages. The present account aims to examine the general aspects of the work to improve patient pathways and to put forward recommendations for this work.

Patient pathways in which the individual steps are planned as pre-booked well-defined events as far as concerns timing and content have been called packages. A package contains bookings for the number of new patient pathways found to be necessary at the local level for a given disease. For an ideal patient pathway in a package, all the steps of diagnosis, treatment and follow-up are planned and pre-booked for the whole pathway before a patient starts on day 1. Typically, a set number of new pathways will start on a set day of the week.

6.1.1 The issue

The key to improving patient pathways for cancer patients is to improve organisation of the pathway a patient follows, as well as to improve the quality of the healthcare provided. Many studies have shown that what matters most to the patients is the standard of the healthcare content of the pathways. However, it is very difficult for the patients to obtain information about the clinical quality of healthcare because it is not documented. They are able to obtain information about the waiting time, however, and to take it into account. It is of great importance to cancer patients to avoid unnecessary waiting times, among other reasons because the long waiting times can result in the disease progressing further, thereby reducing the chance of cure.

The aim of improving organisation of patient pathways is firstly to eliminate waiting times, both before the patients start the investigation phase and between one investigation or treatment and another. Bottlenecks sometimes occur (the accumulation of many patients waiting for example for a CT scan), perhaps due to an unexpected influx of additional patients. Acute intervention and elimination of the bottleneck are necessary to prevent the package pathways grinding to a halt. Secondly, the aim is to ensure that the patients always know what and when the next step is. Patients must not get into a situation where they feel lost in the system or are given cause to speculate about whether they have been forgotten, for example because they have not yet been called in for an appointment that they are waiting for.

As mentioned earlier, the quality of the patient pathway is determined both by the medical content and its organisation. It is also determined by the physical conditions at the hospitals, both in the form of sufficient and modern equipment and in the form of adequate and modern facilities. This applies for example to the availability of a sufficient number of outpatient clinics, operating theatres and wards. As regards wards, it is necessary that there is an appropriate balance of multi-bed and single-bed rooms all with modern bathrooms and toilet. It is important that dying patients and their relatives can be offered the possibility to be separate from severely ill patients or patients almost ready for discharge. Likewise, consultation rooms need to be available for patients in multi-bed rooms. The surgical departments need to be able to draw on the services of the intensive care wards to a sufficient extent for newly operated cancer patients, as well as on the so-called intermediate wards (wards providing the possibility of closer monitoring) integrated among ordinary wards.

6.1.2 Status and recommendation

Experience from the work on optimising patient pathways is described below under four main topics: Clinical content, patient aspects, personnel aspects and the organisational planning. A number of examples of practical solutions are mentioned followed by recommendations.

6.1.2.1 Clinical content

The clinical content of a pathway is planned according to national clinical guidelines. Local adaptation of the guidelines ensures coherence and quality in the pathway in the primary sector and onwards at the hospital. The general practitioners and the hospital departments together draw up local guidelines for what investigations should have been performed before the patient is referred to the hospital. The patient pathways are documented using relevant combinations of selected indicators in the patient administration system and clinical quality databases.

Patient pathways – Clinical content
Recommendation

- The clinical content of all pathways is to be planned in accordance with national clinical guidelines adapted to local conditions
- Clinical quality is to be documented using selected indicators in patient administration systems and clinical quality databases

6.1.2.2 Patient aspects

One of the main aims in establishing packages is to ensure a coherent pathway free of unnecessary waiting times. Pre-booking of appointments ensures that planned appointments are always available both for investigations and for the subsequent consultations during which the result is communicated to the patient. An example of an initiative to reduce waiting times is open chest radiography clinics where general practitioners can refer patients directly to a radiograph, for example on suspicion of a lung tumour.

Coherent patient pathways ensure that the patient continually experiences having contact and does not feel abandoned without clear information or appointments. Each patient is assigned a contact person who can be a nurse or a doctor whom the patient can contact if questions arise. This direct assignment of a specific person has proven practical and valuable for the patients. The patient is regularly informed about the investigation results and about where, when and how the next step in the pathway will take place. When pathways are well described (within a package), all the personnel are so familiar with them that everyone can give relevant and identical information about what is going to happen. A message to a patient that he/she will receive further information or be called in for an appointment at another department should not be considered acceptable. In contrast, the patient should always be given a specific appointment. The patient must not hover between different departments. When a patient is discharged from one department, he/she should be unambiguously handed on to the next department, which should immediately assign a contact person to the patient.

Patient pathways – Patient aspects
Recommendation

- Patient pathways should be designed such that the patients avoid unnecessary waiting times
- The patients should be continually informed about what is going to happen next and right from the very beginning should be assigned to a nurse or doctor who can be contacted if questions arise

6.1.2.3 Personnel aspects

The conditions under which the personnel work change with the establishment of patient pathways organised in packages. A package can be run by a multidisciplinary team of specialist physicians from the relevant specialities (radiologists, surgeons, pathologists, oncologists, etc.). The individual team has to be large enough to be able to function properly the whole year round, and the planning horizon for holidays, continuing medical education, etc. has to be appropriately long. All members of the team have necessarily to accept the obligations it entails, and this can mean decisive changes in working conditions depending on local culture and traditions. In order to optimise a pathway it can be appropriate to reassign individual clinical tasks to team members within another specialities. This break with traditional division of responsibility between the specialities necessitates openness and willingness among the specialists to reassign clinical tasks to colleagues in another speciality.

In a multidisciplinary team of specialist physicians responsible for treatment of cancer, the team members can beneficially function as an entity and have to be able to directly refer patients to and book appointments in each other’s departments without going through a middleman. For example, a pulmonary specialist should be able to book the patient in a package appointment for a CT scan after having seen the chest radiograph without the radiologist first having to assess the referral. The team must not be so large that the team spirit and joint responsibility are lost or the expertise is diluted. The mainstay of the team are the specialist physicians with special responsibility for cancer patients. Each team can beneficially have a practical leader, to ensure that the agreements and decisions made regarding supplementary examinations, diagnosis and treatment are implemented.

Patient pathways – Personnel aspects
Recommendation

- Specialists responsible for treating cancer patients should be part of a binding continuous multidisciplinary team cooperation that ensures appropriate pathways

6.1.2.4 Organisation

The development of packages of optimised patient pathways entails several types of challenge, both methodological, logistical and practical. It is vital that the relevant expertise is available in order to be able to meet these challenges. With the increasing complexity of hospital organisation, managements can benefit from new supplementary expertise within logistics and planning. The use of internationally recognised quality development models[2] is appropriate during the transition and to ensure the involvement of the healthcare personnel in the processes. This requires an active, committed management that also understands the importance of allowing room for engaged personnel to take responsibility themselves for the necessary developmental steps towards a pathway package that functions well both for the patients and for the hospital.

Experience shows that the use of information technology in all areas in which information is exchanged increases the speed of patient pathways and facilitates the work routines. For example, paper referrals are often placed in piles for subsequent expedition, whereas electronic referrals are expedited immediately upon being read on screen. All communication between the primary sector and the hospital should therefore be carried out electronically; the same applies to the communication of referrals and test results between hospital departments. Joint electronic access to data on laboratory analyses and radiographs between the primary and hospital sectors facilitates the exchange of information. With digitalised radiographs, for example, the pulmonary specialist can evaluate a radiograph on his PC and react to the findings.

Package models can beneficially contain some degree of excess capacity of pre-booked appointments. Experience shows that the weekly pre-booked capacity should correspond to a level slightly below the highest activity peak, for example measured as the number of referrals in the busiest weeks. At the same time it is important that the pre-booked “package appointments” that remain unused are released at fixed points in time for the use of other referred patients, for example two days beforehand. The whole system of organisation in package pathways ceases to function if the pre-booked appointments are instead occupied by patients who have been waiting for a long time. If an accumulation of patients (bottleneck) arises, for example patients waiting for a scan, extra appointments will have to be rapidly created.

Patient pathways – Organisation
Recommendation

- Patient pathways in packages should be developed and used locally
- Logistical and development expertise can assist the management’s work with organisation of the pathways
- Information technology should be employed everywhere to transmit information and communications between the primary sector and hospital as well as internally in the hospital

6.2 Patient pathways – activity estimations

The question of whether to use capacity calculations or activity calculations is examined briefly in Annex 6.2.

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[2] Eg. The Breakthrough Model, www.ihi.org

6.2.1 The issue

The National Board of Health has considered whether it should continue to advise the Counties and Copenhagen Hospital Corporation regarding what capacity they should have available within certain areas of diagnosis and treatment. Capacity discussions have hitherto chiefly concerned such aspects as *the number* of accelerators or CT scanners, etc., but not the activity in relation to the prevalence of cancer. Calculations are available regarding the expected trend in the prevalence of cancer that could serve as the basis for calculating changes in activity requirements for use in healthcare planning.

6.2.2 Status and recommendation

The National Board of Health considers it appropriate that future guidance can be based on activity viewed in relation to disease prevalence. It appears to be inappropriate that the National Board of Health continues to provide guidance in the form of specific figures indicating how a given capacity problem can be solved, for example what the level of manning should be for a particular piece of equipment or how many accelerators should be purchased if waiting times become too long. Previous experience from the time when advice was provided on very specific capacity dimensioning expressed in terms of the number of apparatuses or personnel indicates that this model is too inflexible to work with.

It is considered that the hospital authorities should themselves be responsible for planning the necessary capacity, the practical design and the implementation in a given area on the basis of an assessment of the required level of activity. It is expected that it will be possible to estimate the level of activity from a calculation based on disease prevalence in combination with recommendations in clinical guidelines concerning what diagnosis and treatment has to be carried out for the disease in question. At the same time, this calculation should be corrected for the previous level of activity within the individual areas of disease. In the case of radiotherapy of cancer patients, for example, there is a correlation between the number of cancer patients in need of radiotherapy, the number of treatment sessions they need (cf. the clinical guidelines) and hence how much accelerator activity is required per patient. Ideally, if the number of patients is known for the individual types of cancer, so too is the total requirement for an activity such as radiotherapy. It should therefore be possible to incorporate the expected future trend in the prevalence of cancer in Denmark in capacity planning. The National Board of Health will investigate whether this form of activity calculation can serve as the basis for future guidance in the area.

Patient pathways – Activity calculation
Recommendation
The National Board of Health will calculate the expected level of activity based on the prevalence of the individual types of cancer and the national clinical guidelines for diagnosis and treatment of the diseases

7 Prevention and early detection of cancer

7.1 Primary prevention

For a more detailed review of cancer prevention, see Annex 7.1.

7.1.1 The issue

Risk factors are known for about half of all types of cancer. In our part of the world, smoking, overweight, alcohol, physical inactivity, ultraviolet radiation and infections are the risk factors for which the cancer prevention potential is greatest. It is estimated that it would be possible to eliminate around 35% of all cases of cancer if these risk factors were eliminated. In addition to these well-documented areas, the diet area also offers considerable cancer prevention potential, but the scientific evidence for this remains incomplete. Smoking, including passive smoking, is the single factor mainly responsible for the current trend in cancer in Denmark, and effective measures to curtail smoking would comprise a particularly significant contribution to cancer prevention. In addition to preventing cancer, prevention of smoking and the other risk factors would also have general health-promoting and preventative effects that would benefit public health. A number of other risk factors for cancer are addressed in Annex 7.1.

The types of cancer for which the prevention potential is greatest are respiratory system cancer (larynx, lungs, pleural membranes), cancer of the upper gastrointestinal tract (mouth and tongue, larynx, oesophagus, stomach), skin cancer (malignant melanoma), cancer of the renal system (kidneys, renal pelvis and bladder) and cervical cancer.

The correlation between known risk factors and health effects, including the development of cancer, is relatively well described, while the evidence for effective prevention methods is sparser. This does not apply to the structural control policy measures, though, whose efficacy and cost-effectiveness are well documented. The beneficial effect of the introduction of health policies at workplaces and in municipal institutions is well documented as regards smoking policy, while no evaluations are yet available regarding policies pertaining to diet, physical activity and alcohol. As regards the effect of general public education and information efforts as stand-alone measures, the results are less clear. Nevertheless, there is no doubt that primary prevention of cancer is far more cost-effective than secondary prevention.

In general, a combination of different prevention methods has the greatest effect, for example health-promoting, framework-setting measures aimed at the general population (e.g. the stipulation of age limits for the purchase of alcohol and tobacco, price policies, marketing policies) coupled with prevention measures more directed at the individual (e.g. smoking cessation schemes, parental agreements concerning alcohol consumption by adolescents, exercise at workplaces).

7.1.2 Status and recommendation

7.1.2.1 Tobacco

Over the past 10 years a number of important initiatives have been implemented in the smoking prevention area in Denmark. Tobacco advertising and sponsorship has been banned, the legislation regarding smoke-free environments has been tightened, and warning texts on cigarette packets have become tougher. During the same period, attention has focused on smoking cessation and all the Counties and some of the larger Municipalities have established smoking cessation programmes for both the general public and patients. The STOP cooperation from 1995–2002, the two initiatives by the Ministry of the Interior and Health and the National Board of Health “National Centre for Smoking Cessation” and the “The Fund for the establishment and implementation of smoking cessation programmes for the population”, the Counties and a number of other actors such as the Danish Cancer Society and the pharmacies have all contributed significantly.

In recent years the Ministry of the Interior and Health, the National Board of Health and the health charities have enhanced efforts to ensure smoke-free environments in society. Danish society is moving in the direction of an increasing number of smoke-free environments, but a large proportion of the population is still involuntarily exposed to passive smoking.

Not all the measures taken in recent years help curtail smoking, however. Thus when the levy on cigarettes was reduced by approx. 15% in 2003 to mitigate the effects of the abolition of the 24-hour regulation regarding cross-frontier shopping, sales of taxed cigarettes increased in 2004 by 5–10%. According to the Ministry of Taxation the increased sales are primarily attributable to a marked decrease in cross-frontier shopping in Germany.

With respect to effective tobacco policy, Denmark ranks 15th out of 28 EU and EFTA countries with 41 points out of 100. Denmark mainly scores low regarding price policy, smoke-free environments in public spaces and at workplaces, and the allocation of funds to tobacco control.

Tobacco
Recommendation

- Completely smoke-free environments should be ensured at workplaces and in public spaces, in particular where children are found, e.g. schools, kindergartens and sports halls
- Publicly financed differentiated smoking cessation programmes for the population, including for special groups, should be expanded. The programmes should be equated with the health service programmes for treatment of alcoholism, etc.
- Broad information campaigns should be conducted among the population and educational programmes at schools and further education establishments
- Tobacco levies should be set as high as possible within the tax policy framework
- Warnings on cigarette packets should be larger and more effective
- Tobacco should be included as a priority area in municipal prevention policy, and goals should be set for smoking prevention

7.1.2.2 Inappropriate nutrition and overweight

The partnership “6 a day” aims to promote the consumption of fruit and vegetables in Denmark through information campaigns and implementation of initiatives to increase their consumption. The partnership, which started in 1999, includes the Danish Nutrition Council, the National Consumer Agency, The National Board of Health, the Danish Heart Foundation, the Danish Cancer Society, the Danish Veterinary and Food Administration and Danish trade and industry represented by the Danish Fruit, Vegetable and Potato Board.

Overweight/obesity needs to be prevented as the success rate for treatment is very low: Five years after a weight loss, 99% of persons have regained or exceeded their initial weight. The National Board of Health’s proposals for a national action plan to combat severe overweight makes 66 specific recommendations as to prevention and treatment initiatives at the private, the local and the central levels.

The National Board of Health has launched a number of initiatives aimed at documenting the effect of measures to combat overweight. In 2004, DKK 7 million was allocated to local projects aimed at prevention and treatment of overweight. The results of these projects will be reported during 2005. The Development Fund for 2005–2008 includes a DKK 73 million appropriation for a municipal programme of initiatives and assessment aimed at prevention/treatment of overweight in children and adolescents. The appropriation is available as grants that the Municipalities can apply for to cover development projects.

Under the auspices of the Nordic Council of Ministers, proposals are being drawn up for a joint Nordic action plan on diet and physical activity that is expected to be completed during 2005. The Government intends to establish an Exercise and Nutrition Council assigned responsibility for drawing up proposals for an action plan on obesity in children and providing evidence-based advice about exercise and nutrition.

The Government’s overall efforts to combat overweight are described in reference 43, Annex 7.1.

Inappropriate nutrition and overweight
Recommendation

- Health policies should be implemented in municipal institutions and at workplaces, including diet and exercise policies
- Increased availability of fruit and vegetables should be ensured in institutions and at workplaces
- Restrictions should be introduced on the marketing of sweets, soft drinks and other fatty and sweet foods

7.1.2.3 Alcohol abuse

Initiatives are being established in Denmark to deal with alcohol abuse, with the focus being on adolescents, parental responsibility, model projects concerning children in abuse families, the introduction of alcohol policies in Municipalities and at workplaces, the education of alcohol therapists and on ensuring treatment possibilities for persons with alcohol problems.

The Danish alcohol control policy is liberal relative to that of the other Nordic countries. In Denmark it is mainly alcohol availability that is subject to fewer restrictions than in other comparable countries, but alcohol prices and taxes are also relatively lower in Denmark than in the other Nordic countries.

Alcohol abuse
Recommendation

- Levies on alcoholic products should be set as high as possible within the tax policy framework
- The minimum age for purchasing alcohol should be raised
- Priority should be accorded to systematic, evidence-based alcohol treatment that covers all relevant alcohol problems from alcohol abuse to actual alcoholism

7.1.2.4 Physical inactivity

Focus on the preventative and health-promoting effects of physical activity has increased over the past 15 year. The initiatives have included campaign activities, the launching of model projects in the counties in relation to the National Board of Health's "Exercise on doctor's orders" (exercise given on prescription) campaign, documentation and strategic studies, including health economics analyses of the costs associated with physical inactivity.

Physical inactivity
Recommendation

- Exercise policies should be introduced at workplaces and in educational institutions
- A National action plan should be developed for physical activity

7.1.2.5 Ultraviolet radiation

The prevention efforts in this area, which aim to change the population's sun exposure habits, are the joint responsibility of the Danish Environmental Protection Agency, the Danish Cancer Society and the National Board of Health. Hitherto they have consisted of informing the public in general as well as specific groups such as adolescents, parents of small children, travellers and kindergarten personnel. Recommendations concerning the use of solaria and wishes regarding the standardisation of solaria have been issued jointly by the Nordic governments.

Ultraviolet radiation
Recommendation

- Education and continuing education of public health nurses and the other municipal health care workers regarding healthy sun habits
- Intensified information to the public concerning healthy sun habits, including special focus on information for younger women

7.2 Screening for cancer

For a more detailed examination of mass screening for cancer see Annex 7.2.

7.2.1 The issue

Three screening methods are presently sufficiently well documented that the international and national literature recommends the establishment of screening programmes: 1) Cervical cancer screening (cytological tests for cell changes in the cervix), 2) Breast cancer screening (mammography) in women, 3) Intestinal cancer screening (examination for faecal blood) in men and women. Research projects are currently examining the effect of screening for lung cancer and prostate cancer.

In Denmark the justification for breast cancer screening has been the subject of some discussion. The National Board of Health has followed the discussion and the published studies in the area and continues to recommend that breast cancer screening should be offered every second year to women aged 50–69 years.

It is important to follow the effect of screening programmes through the surveillance of both short-term objectives, e.g. participation rate, detection rate, false positives and false negatives, and long-term objectives such as a reduction in prevalence and mortality in the case of screening for cervical cancer and a reduction in mortality in the case of screening for breast cancer and intestinal cancer.

Screening of high-risk groups comprises a special problem in the cancer area. With certain cancers there is a well-defined hereditary syndrome (e.g. familial colon polyposis). When diagnosing such cases there can be reasons to assess whether there is familial accumulation, to obtain genetic advice and to register the families in relevant registers for the individual disease.

7.2.2 Status and recommendation

Cervical cancer screening of the recommended target groups has been introduced and is provided by nearly all Counties. Mammography screening has been introduced by Copenhagen Hospital Corporation and three Counties. No Counties have yet introduced screening for intestinal cancer. Based on the recommendations in National Cancer Plan I and a Danish health technology assessment, the Government has allocated funds for feasibility studies of intestinal cancer screening in two counties. The studies are expected to be initiated in 2005.

Cancer screening is not monitored at the national level in Denmark.

Mass screening
Recommendation

- Cervical cancer screening should be offered every third year to women aged 23–59 years
- As soon as possible, all Counties/Regions should introduce mammography screening every second year to women aged 50–69 years
- When the results of the planned feasibility studies of intestinal cancer screening become available a decision should be made as to whether intestinal cancer screening should be provided to men and women aged 50–74 years

continued

cont.

- A working group should be established to draw up proposals for a national programme for central surveillance of implemented screening programmes in accordance with EU recommendations

8 Diagnosis of cancer

Early diagnosis of cancer is important. Delayed diagnosis can have consequences for both treatment and the prognosis. There are many possibilities for delays in the pathway from the time a person acknowledges the presence of symptoms necessitating a visit to a doctor, and onwards to when a diagnosis has been made and a course of treatment can be initiated. The patient can hesitate too long in visiting a general practitioner, and the general practitioner can perhaps dismiss the symptoms and fail to initiate relevant tests. Delays can also be due to long waiting times for diagnostic tests, e.g. for diagnostic imaging at the hospital. Delays can arise in each of the three phases independently and in the links between them. These delays are termed *patient's delay, doctor's delay* and *system delay.* The latter two types of delay are discussed in sections 8.2 and 8.3. The delay problem in general is discussed in Annex 8.1.

8.1 Symptoms – see a doctor

8.1.1 The issue

The duration of the period from the time a patient first experiences symptoms of cancer to the time he visits a doctor can influence the possibilities for providing milder/less extensive treatment and for the chances of surviving the disease.

8.1.2 Status and recommendation

The available data indicate that a number of cancer diagnoses are made at a later stage in Denmark than in Norway and Finland judged from the stage of the disease at the time of diagnosis (Annex 6) (As Sweden only started to include registration of disease stage in its cancer register a few years ago, it is not included in the present comparison). Compared with Norway and Finland, 10–15% of Danish breast cancer cases are at a more advanced stage at the time of diagnosis, and it is known that a delay of 2–3 months influences survival. Based on the stage distribution at the time of diagnosis, the diagnosis is made later in Denmark than in Norway and Finland in 10–20% of rectal cancer patients and 5–30% of colon cancer patients. Studies of the significance of delays for the prognosis for these types of cancer point in different directions, and the question thus remains unresolved. Based on the existing data it is not possible to say with any certainty whether the reason is a delay in seeing a doctor (patient's delay), a delayed diagnostic investigation (doctor's/system delay) or a combination thereof.

International research indicates that the delay in visiting a doctor contributes to the diagnosis being made relatively late, but little is known about the reasons why cancer patients put off seeing a doctor.

There have been numerous public information campaigns about cancer and the importance of seeing a doctor early. These campaigns are considered to have had an effect. New campaigns and various forms of initiatives have been considered in an effort to get people to see a doctor earlier.

Symptoms – See a doctor
Recommendation

- Development of a coherent public information strategy about symptoms that should lead the patient to see a doctor and about treatment possibilities. The strategy should encompass a combination of media and communication methods and should also encompass information to healthcare professionals so that they can support the strategy
- Compulsory education about health/disease in older school classes to provide general knowledge about the body and about normal/abnormal body reactions
- Research into patient behaviour in the face of symptoms and into the reasons for cancer patients’ delay in seeing a doctor, including the significance of such factors as gender, age, social class, social network and the doctor-patient relationship

8.2 Initial diagnosis in the primary sector

Delayed diagnostic investigation in general practice – doctor’s delay – is discussed in greater detail in Annex 8.1.

8.2.1 The issue

Persons who see a doctor about a symptom have not necessarily thought that the symptom could be a sign of cancer. The doctor will seek a cause of the symptom, perhaps without specifically looking for cancer. If the possibility of cancer is not considered, the examinations that the doctor initiates will not be accorded special priority. Consequently, suspicion of cancer may not arise until later when one or more test results become available. If the results – for example a radiograph – show that there is no sign of cancer, the patient and doctor will often be satisfied with that. If the symptoms continue, it is important for the doctor to assess whether renewed tests are relevant, especially taking into consideration that the test result could be a false negative.

Among the many patients with a symptom complex that raises suspicion of cancer, general practitioners need to be able to identify the few who should be investigated further. It is important to find an appropriate balance that ensures that the “right” patients are referred to further investigation as rapidly as possible, while concomitantly ensuring that the hospitals are not overburdened with patients who do not need diagnosing at the hospital. If the symptoms are unclear it can be justifiable to wait and see what happens provided a clear agreement is made with the patient about how and when to follow-up on them. The term “watchful waiting” has been designated for procedures that ensure that a symptom is not forgotten.

8.2.2 Status and recommendation

Misjudgements in the early phase of an investigation can enhance the patient’s total waiting time for the relevant cancer treatment. An important tool that can help ensure that doctors correctly diagnose and refer the patients is local clinical guidelines based on national guidelines for the diseases, i.e. guidelines describing which symptoms should raise suspicion of cancer and what tests should be initiated in general practice or specialist practice. Regular continuing medical education of general practitioners and specialists will support implementation of the clinical guidelines in routine practice.

The evaluation of National Cancer Plan I encompassed intestinal cancer, breast cancer and lung cancer and revealed that local clinical guidelines have not yet been drawn up in many places and that most of the local guidelines that do exist do not correspond to the national guidelines. The evaluation also found that only a small proportion of general practitioners followed national guidelines when referring patients (lung cancer and intestinal cancer). The patient pathways in general and specialist practice are not documented in the same way as they are in the hospital sector – in clinical quality databases or in patient administration systems. It could therefore be a good idea to agree upon a common documentation practice for milestones, e.g. the time the first symptom was noted, the time of the first consultation at the general practitioner and the time of referral to hospital. Through this documentation it would be possible to obtain knowledge of the patient pathways and identify possibilities for improvements.

At the same time the evaluation of National Cancer Plan I showed that overall responsibility for the continuing medical education of general practitioners has not been assigned formally, and that possibilities for continuing medical education differ considerably at the local level. Some Counties have implemented specific continuing medical education programmes for general practitioners on the major forms of cancer, for example Funen County, which arranges a series of courses aimed at regularly updating the knowledge of general practitioners (see also Section 12.2 Continuing medical education of physicians in the cancer area).

Initial diagnosis in the primary sector

Recommendation

- Together with relevant hospital departments, physicians in the primary sector should draw up local guidelines for clinical diagnostics in the primary sector based on national clinical guidelines
- It should be possible for the hospital investigation to build directly on the initial diagnostics performed in the primary sector
- Continuing medical education of general practitioners about cancer should be ensured
- Indicators and common documentation should be developed to enable quality development of the patient pathway in the primary sector

8.3 Diagnostic investigation at the hospital

For a more detailed review of diagnostic imaging and tissue and cell diagnostics, see Annex 8.3 A and 8.3 B.

8.3.1 The issue

Waiting times for diagnostic investigation at the hospitals (system delay) regularly give rise to discussions about the extent to which the necessary capacity is available. The primary diagnostic investigation will often include diagnostic imaging as patients are referred to diagnostic imaging when cancer is suspected. The proportion of these patients that actually have cancer varies from one type of cancer to another. With most types of cancer, the prevalence of cancer among referred patients is estimated to range from about 1:50 to 1:100. Capacity in the diagnostic imaging area is under pressure due to the increasing number of cancer patients. At the same time, the introduction of a number of new treatments has particularly increased pressure on scanners used to plan and monitor the treatments.

A large number of the new treatments will place greater demands on diagnosis, especially in relation to pathology, where attention needs to be focussed on the molecular biology techniques in connection with “tailor-made” treatments for the individual patient. As these treatments are very expensive and often entail side effects, it is vital to identify the patients who will benefit from the treatment.

The quality of diagnostics is based among other things on a well-established cooperation with the clinical specialities, the so-called multidisciplinary teams discussed in Sections 6.1 and 9.1.

Radiology and pathology need to be involved not only in the diagnostic process, but also in connection with planning and monitoring the course of treatment.

8.3.2 Status and recommendation

Experience from diagnostic imaging departments indicates that it is possible to optimise department operation and thereby enhance effectiveness and reduce waiting times by critically reviewing the procedures in connection with the individual radiological investigations. The number of scanners in the diagnostic imaging centres will now be augmented as the Ministry of the Interior and Health has established a DKK 300 million loan fund for CT and MR scanners in April 2005.

In accordance with a central regulation, all radiology departments have drawn up quality manuals focusing on radiation hygiene and working routines. The medical quality of the actual radiological examination and associated description of the images is also of key importance. Various quality development methods have been implemented to a varying extent to ensure this quality. An important means of quality control is comparison of the diagnostic imaging findings with the subsequent surgical findings via close cooperation between the involved specialities in the multidisciplinary teams. Another important means of quality control is parallel assessment of images and comparison of the two assessors’ findings.

A special type of scanning is PET (positron emission tomography), which can be used for primary diagnosis, stage differentiation, relapse diagnosis and monitoring of treatment efficacy with a number of types of cancer. Currently, and probably to a greater extent in the future, PET scanning is and will be used in combination with CT and MRI, with the images being merged in a so-called fused image providing both anatomical (CT and MR) and functional (PET) information. The diagnostic value of such fused images is very high, and it is expected that this combined approach will radically change treatment monitoring with a number of types of cancer.

In 2002, a Working Group established by the National Board of Health published the report “PET – recommendations for expansion of PET and FDG production”. The Working Group recommended focussing on so-called dedicated PET, and that during the establishment phase the dedicated PET facilities should be concentrated geographically around the oncology centres and in university hospital environments. The aim was to ensure optimal utilisation within the oncology area, high utilisation of the scanners within other highly specialised areas and close interdisciplinary cooperation with regard to quality development, research and teaching. The Working Group also concluded that in the long term it might be possible to spread PET scanning outside the above-mentioned environments if the patient population warrants and if conditions are suitable regarding the available medical expertise, staff, technical facilities and cooperation. PET scanners are currently only available in a few departments. The demand for PET scans has increased, and it must be expected that the pressure on the existing PET scanners will increase markedly.

If the primary diagnosis indicates that a patient has cancer, a final diagnosis has to be made, and the type of cancer and its extent have to be determined. This is done by taking cell and/or tissue samples to be analysed at the pathology departments. Each day the departments submit cancer diagnoses to the Cancer Register electronically via the nationwide Pathology Databank. The Pathology Databank is thus an important tool for surveillance of pathoanatomy quality.

A few Counties have some experience in ensuring effective working routines in the pathology departments. Response deadlines thus have to be agreed upon with the involved clinical departments so that they can rapidly plan the next steps in consultation with the patient. Among other means, quality control is performed by comparing the results of the primary diagnostic sample with the subsequent surgical sample.

Diagnostic investigation at the hospital
Recommendation

- The diagnostic imaging departments should ensure effective work routines, assessment of the possibilities for assigning tasks to personnel groups with shorter education, optimisation of equipment utilisation and regular assessment of the need for replacement and new purchases
- The medical quality of diagnostic imaging examinations and the associated descriptions should be ensured and documented
- It should be ensured that data from the Pathology Databank can be used for quality surveillance
- The multidisciplinary teams should ensure the necessary feedback between diagnostic image assessors, pathologists and surgeons, etc. in order to enhance the quality of cancer diagnostics
- The molecular diagnostics area should be strengthened in the pathology departments cooperating with the oncology centres
- The National Board of Health should consider whether the 2002 report “PET – recommendations for expansion of PET and FDG production” needs to be updated

9 Treatment of cancer

9.1 Surgical treatment

With the majority of cancer patients, surgical treatment is a decisive determinant of the overall treatment result. It has been pointed out that Danish cancer surgery as a whole needs to be improved. In 2003, the Cancer Steering Committee initiated a review of intestinal cancer surgery in order to identify where improvements could be made (http://www.sst.dk/publ/Publ2004/ treatment _tarmkraeft_DK.pdf). The plan was to subsequently perform corresponding reviews of the other major cancer surgery areas; this was superseded by the work with the present National Cancer Plan II.

Surgical cancer treatment is examined in Annex 9.1A-L. The annex contains a chapter on each of the following 11 areas of cancer surgery: breast cancer, gynaecological cancer, head/neck cancer, skin cancer, lung cancer, neurosurgical forms of cancer, sarcomas, intestinal cancer, urinary tract cancer, cancer of the upper gastrointestinal tract and cancer of the eye. The individual chapters of the annex have been prepared by surgeons from the respective areas. Each area is reviewed following the same systematics, specific issues are identified, and recommendations are made in cases where the authors considered that improvements are needed.

This chapter presents the issues identified and describes the current status of these issues in the cancer surgery area in general. Thereafter recommendations are made regarding future surgical treatment of cancer. The presentation is subdivided into the following themes: Clinical quality and patient pathways, organisation and quality of surgery, surgical training and finally, surgical clinical research.

9.1.1 Clinical quality and patient pathways

9.1.1.1 The issue

The purpose of clinical guidelines is to ensure that patients are given the best evidence-based treatment. The guidelines describe the individual steps of the investigation, treatment and follow-up process and serve as a concrete tool for ensuring the quality of cancer treatment. In most surgical areas, guidelines have been prepared for the various preoperative, operative and postoperative phases. The content of the guidelines can be clinically very concrete, for example describing which diagnostic investigations should be performed or what treatment should be used. They can also contain a description of the pathway, for example that the cancer patients have to be treated and monitored in an intensive care ward in the postoperative phase after extensive surgery. If this is not possible (e.g. due to lack of space in that ward), the clinical guidelines are infringed. The implementation of clinical guidelines and consequently the assurance of adequate treatment quality is a primary management responsibility. The example illustrates that implementation is not just a management responsibility at department level, but at several managerial levels because it concerns not only the individual departments involved but also the function of the hospital as a whole. It also illustrates that a comparison of actual practice with the guidelines can be used to identify quality deficiencies and assign responsibility for these.

Among other things, the evaluation of National Cancer Plan I showed that some locations lack functioning clinical guidelines for referral from the primary sector to the hospital departments.

For surgical specialities it is vital that they have the possibility to work closely together with associated surgical specialities on cancer surgery tasks. Surgical cooperation between gynaecological and gastrointestinal surgery can be relevant for example for patients with gynaecological cancer.

The specific surgical efforts do not stand alone but are based on broad, well-functioning cooperation with a large number of ancillary and supporting functions at the hospital, which is one of the preconditions for a good overall result. These include inter-departmental cooperation as well as concrete cooperation between specialist physicians in a multidisciplinary team that holds regular clinical joint conferences about investigation and treatment decisions.

9.1.1.2 Status and recommendation

It has been documented that the use of clinical guidelines helps maintain and enhance quality provided that they are implemented, complied with and actively updated.

Progress on the development and implementation of clinical guidelines and associated indicators varies considerably within the different surgical specialities. With several specialities the extent to which the national clinical guidelines are fully implemented and monitored in clinical databases with suitable indicators is only limited. This restricts the possibility to specifically assess where quality should be improved. Several surgical specialities state, for example, that descriptions of the surgical procedures and methods for precise determination of stage are not yet fully encompassed by the guidelines, as is also the case for the other aspects of surgical treatment and follow-up.

The specialities find that there is a particular need to promote the work on the use of guidelines and the definition of indicators. Goals need to be set for operationalisation of the indicators and how monitoring of indicators should be organised and applied. This applies both to indicators that are reported to the National Patient Register (NPR) via the patient administration systems and to those monitored through clinical quality databases (see Section 14.1 and associated annex for more about monitoring). The work with data, i.e. the processing of both incoming and outgoing data, needs to be acknowledged as a decisive precondition for the maintenance and development of clinical quality and hence should be accorded higher priority by management.

Considerable experience has been gained with the use of clinical databases and associated indicators, especially within breast cancer, lung cancer and intestinal cancer and through the work of the National Indicator Project. To a large extent this experience can be usefully disseminated to the remaining cancer surgery areas in order to promote the process.

Multidisciplinary teams consisting of surgeons, radiologists, pathologists and oncologists, etc. have been established in several locations and have proven very valuable in cancer treatment (see Section 6.1 and Annex).

It has been shown that surgical cooperation among surgical specialities can also be made to work in cases where the specialities are not located in the same building. In such cases the cooperation can be based on explicit agreements and guidelines specifying how acute and planned cooperation situations are to be handled.

Clinical quality and patient pathways for surgical cancer patients

Recommendation

- The quality of surgical treatment of cancer should be ensured through updating and implementing national clinical guidelines for all areas
- Correspondingly, indicators should be developed that should be suitably documented in patient administration systems, central registers and clinical databases
- The surveillance findings should be utilised in the continuing quality improvement, and the work should be promoted in order to rapidly optimise clinical quality
- Surgical departments should engage in multidisciplinary team cooperation on the treatment of cancer patients
- Efforts should be made to ensure that the departments that perform cancer surgery have modern facilities and equipment so that the framework for implementing the clinical guidelines is present
- Assurance of adequate clinical quality and optimised patient pathways is a management responsibility at several levels

9.1.2 Organisation of surgery and surgical quality

9.1.2.1 The issue

The evaluation of National Cancer Plan I emphasises the necessity of centralising cancer surgery at fewer centres in order to optimise clinical quality. The number of the individual surgical procedures performed per department and per surgeon is considered to be inadequate. Annexes 9.1A–L, which review the 11 cancer surgery areas, also address the relationship between volume and quality in terms of the number of patients who need to be operated at each department and by each surgeon in order to ensure satisfactory clinical results. Expressed more precisely this is the number of times a given surgical procedure has to be performed per month or year by both the individual surgeon and by the surgical department as a whole in order to maintain sufficient routine and expertise to ensure satisfactory clinical quality.

The question of volume and quality thus also applies in relation to the maintenance of a qualified surgical nursing care and correspondingly for the anaesthesia and intensive care department physicians and nurses and the staff of the other supporting departments.

9.1.2.2 Status and recommendation

Since publication of National Cancer Plan I in 2000, surgical expertise has been centralised within a few areas. This development is far from complete, however. Annexes 9.1A–L provide surgical volumes (number of operations per surgeon/department per year) for the individual cancer surgery areas as a basis for ensuring quality. The international literature contains a number of studies on the relationship between surgical volume and treatment quality expressed as different outcome measures, e.g. survival rate. The studies examine the significance of volume for both the individual surgeon and the surgical department. Such studies can help serve as the basis for a recommendation on how many patients a department should treat and a surgeon operate in order to ensure sufficient routine and satisfactory clinical quality. In a few areas there is evidence for allowing minimum figures to be set for both the individual surgeon and the individual department.

In order to be able to determine whether measured surgical quality just reflects random variation or really expresses a surgeon's or department's surgical quality the level of activity has to be high enough to enable statistical evaluation of the results. An operating volume of 100–120 operations per year of a given type is just sufficient to allow such statistical evaluation and is concomitantly the number shown by experience to be sufficient to ensure maintenance of good routine. Surgical departments that treat cancer patients also treat patients with benign diseases for which the surgical procedures can be closely related. This factor can be taken into account when assessing the number of operations necessary to ensure maintenance of adequate routine at department and surgeon level.

Overall department surgical quality reflects the average of the results obtained by the individual surgeons. It is therefore important that this internal variation is also assessed in detail. The number of operations of a given type performed by the individual cancer surgeon per unit of time is decisive as regards maintenance of expertise. Together with the results obtained, regular documentation of the individual surgeon's surgical activity can reveal whether expertise is maintained to a sufficient extent. It will be possible to determine this activity via the patient administration systems.

The division of tasks in Danish cancer surgery has hitherto been partly based on the National Board of Health's guideline concerning planning of the specialities (2001) drawn up and decided upon together with the county hospital authorities. The guideline stipulates which hospitals are to deal with the various diagnosis groups. One of the important reasons for the guideline has been to ensure a sufficiently high volume of treatment of the individual diseases to ensure maintenance of adequate quality, routine and expertise and to enable development. The guideline also describes how the volume/quality issues with regard to division of tasks can be organised in various ways, for example through inter-county cooperation or through centre-satellite agreements, etc.

The guideline does not stipulate specific figures for the necessary minimum volume for the individual diagnosis groups. Checks of several specialities show that the guideline is often not complied with in that cancer surgery is also performed at departments other than those agreed upon by the National Board of Health and the county hospital authorities. The figures also show that with several types of procedure the number of operations performed at many departments is inadequate to enable statistical evaluation of clinical quality.

Organisation of surgery and surgical quality
Recommendation

- The future surgical treatment of cancer should be centralised in departments having a sufficient volume of operations for the individual types of cancer to ensure satisfactory treatment quality and to enable this to be assessed in a statistically reliable manner

continued

cont.

- The individual surgeon should document relevant continuing medical education and perform an adequate number of cancer operations of a given type to ensure satisfactory quality and to enable this to be assessed in a statistically reliable manner
- At the same time as ensuring an adequate number of operations per surgeon, efforts should be made to ensure organisational robustness so that the necessary surgical expertise is always available in the department
- The individual departments' and surgeons' volume and treatment results with different types of operation should be continually monitored in order to enable adjustment and optimisation of treatment quality; ensuring the quality of cancer treatment should be seen as a management responsibility at several levels
- Within each cancer surgery area, a concrete assessment should be made based on the surgical volume and associated disease prevalence in order to determine the minimum population that a department should serve

9.1.3 Surgical training

9.1.3.1 The issue

The performance of cancer surgery necessitates that the surgeon has undergone special training after completion of the specialist education. The special needs for surgical training in order to be able to perform specific surgical procedures and techniques is to some extent met through participation in and supervised performance of operations. Departments that perform cancer surgery need to have a sufficiently great volume if there is to be room for supervised operations both for younger specialist physicians undergoing training in cancer surgery and for refining and maintaining the expertise of senior surgeons. This professional training and maintenance of expertise is only presently visible as a management responsibility to a minor degree at both department and hospital management level.

9.1.3.2 Status and recommendation

Expertise requirements for specialists treating cancer patients have been described in a few areas of cancer surgery. In some cases, moreover, the requirements for and content of continuing medical education for these surgeons have also been described. Consideration is currently being given to whether certification for the individual types of operation would provide a means of ensuring the surgeon's expertise. The safeguarding of a high professional standard among cancer surgeons is considered to be achieved through such means as intercollegial refinement, including detailed systematic assurance that the correct surgical methods are applied. Nurses and physiotherapists/ergotherapists involved in the cancer surgery units also have to be able to participate in relevant national continuing education programmes.

Surgical training
Recommendation

- Levels of competence for specialists who perform surgical treatment of cancer patients should be specified for each type of cancer

continued

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- The content of continuing medical education should be specified, including specific goals for all cancer surgery areas
- Cancer surgeons under training should participate in operations to an extent sufficient to ensure their training; the necessary extent should be specified for each cancer surgery area
- Cancer surgeons should be provided with and should document relevant continuing medical education in accordance with guidelines for the amount and content of such education stipulated by the relevant professional organisations and health authorities
- Nursing and therapist expertise in cancer surgery units should be described and ensured
- It is a management responsibility at several levels to ensure sufficient surgical training and expertise

9.1.4 Surgical clinical research

9.1.4.1 The issue

The development of cancer surgery and the attainment of a high international level of quality require active surgical research. Integration of clinical research in the work with clinical databases and associated indicators will promote both research and clinical quality as both draw upon the same data material. International research cooperation requires a high standard of clinical quality and can therefore help provide an incentive to ensure the development and quality of Danish cancer surgery.

9.1.4.2 Status and recommendation

The research efforts within the various cancer surgery areas appear to differ considerably and are often associated with young surgeons undergoing training. The research structure should be assessed with a view to optimising the research (see Section 13.1 and Annex). In this connection it would be useful to accord higher priority to national cooperation on clinical indicators and databases. The considerable experience gained from the nationwide clinical databases and the National Indicator Project could benefit the remaining cancer surgery areas. Research cooperation with the best international research environments necessitates high clinical quality, and such cooperation therefore helps to set the standard for clinical quality and encourage it to be maintained.

Surgical clinical research
Recommendation

- Areas where clinical research efforts need to be strengthened in order to enhance the quality of surgical treatment of cancer should be identified
- Research should be an important obligation for surgical departments involved in the treatment of cancer and should be integrated in the routine clinical work, including the work with clinical databases and indicators, where the experience gained should be widely applied
- Cooperation should be established with the best international research environments in order to ensure clinical quality of the highest international standard

9.2 Pharmacotherapy, including the introduction of new drugs

9.2.1 The issue

The first step in the introduction of new drugs for use in the treatment of cancer is to perform so-called protocol studies. The clinical part of the protocol study tests the new drug's quality, efficacy and safety. A selected group of patients is offered participation in a study in which a large amount of data is collected, including data on the drug's effect, for example on survival, and its side effects. If the results of the study are positive and a number of conditions are met, the drug can be approved by the drug regulatory authorities. The professional environments may then recommend that the drug be included in the standard treatment of relevant types of cancer. The established standard treatments should thereafter be provided on the basis of specific clinical guidelines, and compliance with the guidelines should be monitored, as should the efficacy of the treatment.

The development of new drugs for cancer patients has progressed very rapidly in recent years and in the case of some types of cancer this means that cure is now possible. With a number of types of cancer, new drugs enable survival to be prolonged to some extent. Activity in this area can be expected to increase further in the form of the development of new drugs, clinical research on new combinations of known drugs and individualised treatments based on molecular genetic profiles.

The introduction of new drugs in the cancer area entails considerable expense. In the period 1999–2004, spending on cancer drugs in the hospital sector increased from DKK 346 million to 1,198 million per year.

9.2.2 Status and recommendation

9.2.2.1 Guidelines for standard treatments of cancer

National clinical guidelines for standard treatments have been prepared for several types of cancer. In addition, the SKA (Confederation of cancer departments in eastern Denmark) has collated information on the standard treatment regimens provided at departments of oncology and medicine. From this it is apparent that there are a number of differences in the standard treatments provided at the different departments without the grounds for the necessity of the differences being apparent. Compliance with the guidelines is not monitored.

Guidelines for standard treatments of cancer
Recommendation

- National clinical guidelines for pharmacotherapy (standard treatments) should be prepared for all types of cancer; the guidelines should be regularly updated

9.2.2.2 Monitoring of standard treatments

When a treatment progresses from being part of a protocol study to an established treatment, the systematic collection of data will usually cease. The problem with this is that the studies that lead to registration of a drug always involve a selected patient group, e.g. persons below the age of 75 years who do not have other types of cancer, cardiovascular disease or diabetes. In contrast, the patients who are subsequently offered the treatment are not selected according to the same narrow criteria, and the results that are obtained under controlled conditions will not necessarily be reproducible in daily clinical practice. Without monitoring of treatment efficacy and side effects, reliable knowledge will not be available on how the drug works in a broader patient population. There is therefore a need to monitor the results obtained with standard treatments using cancer drugs, not least given that the treatments often have severe side effects where it is vital that the advantages of the treatment outweigh the disadvantages. Systematic registration of treatment results is not presently carried out.

A simple model should be used for reporting a few key data such that the submission of the data is practicable in clinical practice. Clinical databases can be expanded and used in conjunction with data submitted to the National Patient Register. In this case the databases should be required to and have the necessary resources to process and disseminate the collected information. The objective is to document the quality of cancer treatment and to provide feedback to enable adjustment of the clinical guidelines in relation to the results obtained.

An example of monitoring of the effect of standard treatments in the Protocol Patient Administration System (PPAS) used at Rigshospitalet. In connection with the initiation of cytostatic treatment the physician records a series of information about the patient and the treatment in the PPAS. The PPAS can subsequently be cross-referenced with the Green System, a patient administration system containing information on date of death, etc. It is thereby possible to monitor survival subdivided by diagnosis and treatment. The PPAS is described further in Annex 9.2A.

Since 1 January 2004 the National Patient Register has contained specified subcodes for cytostatic treatment, including codes for combination treatments. These data should be used actively in the monitoring and improvement of standard treatments. Work is needed to develop the interface between documentation for clinical databases and for the National Patient Register, partly to optimise the documentation and partly to ensure that duplicate registration is avoided and optimise resource use in the area.

Monitoring of standard treatments

Recommendation

- The standard treatments should be documented through continual registration of their efficacy and side effects in order to enable continual optimisation of the treatments

9.2.2.3 Implementation of standard treatments

As mentioned above, the introduction of new drugs in the cancer area entails considerable expense, and several of the new treatments have not been uniformly implemented throughout the country. One of the reasons for this is that the documentation available in connection with the marketing authorisation for new drugs is inadequate for assessing the full consequences of introduction of the drug. A need therefore exits to establish an improved basis for evaluation and prioritisation in connection with the introduction of new drug treatments. Programmes for overall evaluation of new drugs already exist in such countries as Sweden, Norway, Finland, Canada and Australia.

With the advice of the Danish Medicines Agency the National Board of Health has drawn up proposals for an HTA-based model for evaluating drugs that are expected to be used in standard treatment of cancer. Depending on needs the evaluation should encompass the drug's quality, safety and side effects, as well as the health economic, patient-related and organisational consequences of the implementation of a treatment. In addition, the evaluation should consider how the treatment supplements/replaces the existing treatments. The proposed model for HTA-based evaluation of drugs is described in detail in Annex 9.2B.

Implementation of standard treatments
Recommendation

- Development of the described HTA-based model for evaluating drugs being considered for use as standard treatment of cancer should be completed and the model implemented

9.3 Radiotherapy

For a more detailed review of the radiotherapy area see Annexes 9.3A and 9.3B. In addition, the reader is referred to: 1) "The Accelerator Report 2004", prepared by the Accelerator Committee under the Danish Society for Clinical Oncology and 2) "Model-based analysis of future capacity needs in the radiotherapy area" published by DSI Danish Institute for Health Services Research. The latter report can be obtained from the Danish Centre for Evaluation and Health Technology Assessment under the National Board of Health.

9.3.1 The issue

The need for radiotherapy has increased considerably in recent years due to the increasing incidence of cancer. New treatment recommendations encompass more and often more complicated treatments, and radiotherapy is used in a curative, adjuvant and palliative manner.

At the same time, regular replacement of accelerators has been inadequate at several of the Danish radiotherapy departments with the result that their equipment is technologically outdated. This means that it is not always possible to follow the new treatment recommendations when using these accelerators or that the treatment become time-consuming.

As a consequence, the waiting time for radiotherapy has increased, and several of the centres have not been able to comply with the 4-week waiting time guarantee.

The trend towards more complicated and technologically demanding radiotherapy is expected to continue, thereby imposing requirements for technologically updated equipment in the individual oncology departments as well as to the number of personnel and their training.

In May 2004, the Accelerator Committee under the Danish Society for Clinical Oncology published the "Accelerator Report 2004". The report showed that there is a need to replace existing equipment and, in view of the above-mentioned factors, to procure additional equipment. Among other things the Committee concluded that radiotherapy needs would grow by 40% between 2002 and 2007, and that if the increase in demand was not met by a corresponding increase in capacity the consequence would be unacceptable waiting times for radiotherapy throughout the country.

In September 2004, a benchmarking was published that compared two Danish radiotherapy centres with a radiotherapy centre at the Dutch hospital NKI-AVL. The analysis generated discussion about whether productivity at the Danish radiotherapy centres was sufficiently high as that at NKI-AVL was higher than at the two Danish radiotherapy centres.

When planning and performing radiotherapy a number of logistical functions have to be managed. These relate both to patient aspects and personnel aspects. Higher priority needs to be accorded to these logistical functions in order to ensure optimal planning of the work and utilisation of the equipment (see the recommendation in Section 6.1.2.4).

The personnel resources – expressed in terms of both number and qualifications – are a key factor in both the planning and performance of radiotherapy. The professional groups involved in radiotherapy for which personnel shortages already exist or can be expected are the oncologists, the physicists and the radiographers.

9.3.2 Status and recommendation

The 2005 Budget Act allocated DKK 300 million to a loan fund for the purchase of accelerators. This loan fund was opened in March 2005, thereby providing a “shot in the arm” to the Danish radiotherapy centres. The necessary capacity also has to be ensured in the future, however. The investments will have to be based on strategic planning in which account is taken of the trend in treatment needs, the wearing out of equipment and technological development in the area. The strategic planning should also encompass the personnel and in this respect take into account that future planning and performance of radiotherapy entail considerable changes as a result of new treatment forms and procedures.

As a result of the 2004 benchmarking two delegations subsequently visited the NKI-AVL. Most recently a delegation was in Holland in March 2005. The delegation represented the majority of radiotherapy centres, politicians, heads of hospital authorities, the Ministry of the Interior and Health and the National Board of Health. At the same time a closer review of the figures from NKI-AVL has shown that the difference in productivity is not as great as first believed. There is still potential for improvement at the Danish radiotherapy centres, however. When reporting the visit the delegation made a number of proposals within the areas apparatus/equipment, physical framework, administration and production management, work planning and education and research. It is considered that the proposals will be able to develop and improve current Danish practice in the radiotherapy area through enhanced productivity, improved quality, coherent patient pathways and improved working climate.

The 2005 Budget Act allocated a DKK 100 million appropriation to an effectiveness fund to which the county hospital authorities can apply for support to enhance the effectiveness of cancer treatment, including radiotherapy. No effect of the appropriation is likely to be detectable before 2006 at the earliest.

It is expected that expansion of radiotherapy capacity will entail problems with manning the physician positions. There are already vacant physician positions in some oncology departments. As some of the new more specialised radiotherapy techniques require greater involvement of physicians than the current techniques, it is predicted that the coming years will see a shortage of oncologists with expertise in more advanced radiotherapy.

The assessment is that there already is and will continue to be a shortage of educated physicists as only a limited number of training positions are being established. If the staffing needs for physicists are to be met, training capacity will have to be expanded. In order to be able to concomitantly maintain the necessary technical (continuing) education of the treatment staff, research environments should be established in the area. More specifically, this could be achieved by establishing a university education for medical physicists, as has been done in other countries.

The Netherlands has a paramedical personnel group specially trained in radiotherapy – “radiation technologists”. Given the more technically oriented profile of such an education, the recruiting population is expected to differ from that for a typical nursing education.

Capacity in the radiographer education is being increased from under 50 per year in 2005 to triple that in 2007. The use of radiographers in radiotherapy is rather limited, however, in part because of the relatively small role radiotherapy plays in their education.

Radiotherapy
Recommendation

- In view of the trend in treatment needs, the wearing out of radiotherapy equipment and technological development in the area, each County/region should draw up replacement and implementation plans. The National Board of Health ensures coordination of the local plans
- A national classification system for radiotherapy should be introduced
- Consideration should be given to whether centralisation of selected radiotherapy treatments could enhance productivity
- Overall short-term and long-term plans should be drawn up for all personnel needs and associated educational and recruiting initiatives
- The international network of radiotherapy departments should be expanded to facilitate regular exchange of experience regarding development and operation

9.4 Experimental treatment

For a more detailed account of experimental treatment see Annex 9.4.

9.4.1 The issue

The philosophy behind cancer treatment in Denmark is that as much of the treatment as possible should be evidence-based, i.e. founded on scientifically documented results. The evidence-based standard treatments are developed on the basis of research, and some patients are offered treatment as part of research projects, so-called protocol studies.

With the most seriously ill cancer patients, however, the desire can arise to provide further treatment as a last resort when the possibilities for standard treatments and treatments that are part of research projects are exhausted. Such a treatment could be of an experimental nature. The designation experimental treatment is used in this context to designate treatments that are not standard treatments or treatments that are not part of research projects.

In *principle,* experimental treatments are treatments given in the earliest phases of the development of new treatment technologies where knowledge is still insufficient to allow randomised controlled trials, and where it is consequently not yet relevant to consider whether the treatment should be offered as a standard treatment. In *practice,* it has sometimes proven difficult to differentiate the treatments that should be encompassed by the special financing scheme for experimental treatment.

9.4.2 Status and recommendation

The financing of oncological treatment in Denmark is the responsibility of the hospital authorities, i.e. the Counties and Copenhagen Hospital Corporation. An exception, though, is experimental treatment, which is financed by the State, with state funds having been allocated for the financing of experimental treatments abroad and at private hospitals in Denmark (the second opinion scheme) since 1 January 2003. Through the special financing scheme for experimental treatment the politicians have demonstrated a desire for special treatment possibilities for patients with life-threatening cancer or other life-threatening disease for whom no further treatment is available at public hospitals in Denmark or who cannot be offered treatment in accordance with the rules about highly specialised or research-related treatment abroad.

I 2004, 440 patients were referred to evaluation under the second opinion scheme, which is a marked increase relative to the 310 patients referred in 2003. The patients involved differ widely in age and represent a wide range of cancer diagnoses.

In autumn 2004, the Ministry of Interior and Health initiated an evaluation of the second opinion scheme. The evaluation is expected to be completed in mid 2005 and among other things encompasses a patient satisfaction survey, an assessment of the extent to which the Second Opinion Panel’s advice is followed at the treating departments and an evaluation of the scheme’s administrative procedures.

In 2005, the initiative was taken to establish three experimental cancer treatment units in Denmark located in northern, southern and eastern Denmark. It has been decided that part of the annual sum allocated for experimental treatment can be used for treatment of patients at these units instead of abroad.

The units will be located in connection with the referral oncology departments: In order to ensure inter-unit coordination, a national coordination committee has been established consisting of representatives of the oncology departments, the Danish Medicines Agency, the National Board of Health and the Second Opinion Panel. The Danish units for experimental treatment will systematically collect and collate treatment results for all patients treated at the units.

The aim of establishing the experimental treatment units is to enable Danish cancer patients for whom the remaining treatment possibilities are exhausted and for whom experimental treatment is a possibility to receive such treatment in Denmark.

The establishment of Danish experimental cancer treatment units thus improves the possibility to provide Danish cancer patients with the treatments that are given in connection with the first phases of drug development. However, it must be expected that the number of patients desiring treatment within the framework provided by the current design of the second opinion scheme will increase considerably.

Experimental treatment
Recommendation

- Once the results of the second opinion scheme evaluation become available, the possible consequences should be discussed by the Cancer Steering Committee
- The Cancer Steering Committee should await the initial experience with the Danish experimental treatment units and should follow the area
- An analysis should be performed of the problem of differentiating between standard treatment, research-related treatment and experimental treatment in order to clarify which patient groups should be encompassed by the scheme for experimental treatment

10 Non cancer-specific treatment

10.1 Supportive treatment

For a more detailed review of supportive treatment see Annex 10.1A. The annex is based on the situation pertaining for oncology and radiotherapy, but corresponding problems apply to cancer patients undergoing surgery.

10.1.1 The issue

Supportive treatment concerns the prevention and treatment of cancer-related symptoms and complications and the side effects of cancer treatment during the whole course of the patient’s disease. Or to put it another way: Everything that does not relate to treatment of the specific cancer. Palliative care and rehabilitation are major independent areas that are often considered to be part of supportive treatment (see Sections 10.2 and 10.3). Virtually all cancer patients need supportive treatment adapted to the severity of their disease and treatment complications. Healthcare personnel thus need to be well educated in order to be able to also manage this part of cancer treatment.

10.1.2 Status and recommendation

A very large number of supportive treatments are carried out at considerable cost and the development of new supportive treatments is expected to increase. In most cases there are no national recommendations or clinical guidelines and indicators for supportive treatment. The various oncology centres and surgical units each have their own practice. Thus broad, coordinated gathering of documentation and experience based on common indicators is not performed. Experience gathering is only performed in a few areas in the form of patient diaries. Continuing education of healthcare personnel regarding supportive treatment is incorporated into the education of oncologists and courses for oncological nurses.

Supportive treatment
Recommendation

- National evidence-based clinical guidelines with associated indicators should be developed for all supportive treatment under both the surgical and non-surgical parts of the patient pathway
- The treatment results should be monitored using the developed indicators. The work should be coordinated with corresponding initiatives within palliative care and rehabilitation
- The continuing education of specialist physicians regarding supportive treatment should be ensured

10.1.3 Scalp cooling – the issue

For a more detailed review of scalp cooling see Annex 10.1B.

The use of scalp cooling in conjunction with chemotherapy is considered to be a supportive treatment. In connection with the 2005 Budget Act it was agreed that “when drawing up National Cancer Plan II the Cancer Steering Committee should collect information on experience with the use of scalp cooling in cancer treatment and assess the advantages and disadvantages with a view to reaching a decision on the use of this treatment in the hospital service ”.

The aim of scalp cooling is to preserve the hair in patients receiving chemotherapy. The principle of scalp cooling is to cool the patient’s scalp during short-lasting intravenous infusion of chemotherapeutic agents. This reduces exposure of the hair follicles to the chemotherapeutic agents, thereby avoiding or reducing chemotherapy-induced hair loss. From the point of view of the individual patient, scalp cooling is a supportive treatment that potentially reduces the cosmetic side effects of chemotherapy.

10.1.4 Scalp cooling – status and recommendation

The National Board of Health has previously informed the hospital authorities that in principle, scalp cooling should only be provided at the oncology departments as part of controlled trials so as to enable systematic collection of data. At the same time the National Board of Health has pointed out to the hospital authorities that the departments in question should make sure that the provision of scalp cooling to certain patients does not have negative consequences for other patients, for example in the form of longer waiting times or a shortage of capacity for introducing new documented evidence-based oncological treatments

A poll of the county hospital authorities shows that only one County has initiated a controlled trial, and this is to be evaluated in the second half of 2005. Some Counties provide scalp cooling on a limited basis to a specific group of patients undergoing chemotherapy. Their experience is based on a small number of patients and differs from County to County. The remaining Counties do not provide scalp cooling due to the inadequate documentation and lack of capacity.

Although the loss of their hair is a very traumatic experience for some patients, the benefits of scalp cooling have not yet been convincingly documented. Finally, the treatment entails a theoretical enhanced risk for the subsequent occurrence of metastases in the scalp. As far as concerns Danish oncological treatment capacity, the introduction of scalp cooling will reduce the overall treatment capacity at the oncology departments, among other reasons because the duration of treatment is prolonged for the individual patient.

Scalp cooling
Recommendation

- Based on the available knowledge the National Board of Health cannot recommend the introduction of scalp cooling on a general basis for patients undergoing chemotherapy
- The National Board of Health still considers that if scalp cooling is provided, it should be given as part of a controlled trial aimed at systematic accumulation of knowledge

10.2 Rehabilitation

For a more detailed review of cancer rehabilitation see Annex 10.2.

10.2.1 The issue

In step with the improved treatment possibilities, an increasing number of patients are being cured of their cancer. The average 5-year survival after the diagnosis has been made is now 45% for men and 56% for women. These figures hide considerable variation from one type of cancer to another. In 2005, there are approx. 250,000 Danes who have undergone or are undergoing treatment for cancer, of which approx. one third are of working age. Many cancer patients have sequelae from the disease and treatment in the form of fatigue, weight loss, pains, reduced vitality, etc. The health service thus faces a major challenge: While it is now possible to enable an increasing number of patients to survive for an increasing length of time, nothing is being done to specifically and systematically deal with the physical and psychological problems that a large proportion of these patients experience during or after treatment. The number of cancer patients in need of rehabilitation is not known exactly.

In general, rehabilitation of cancer patients shares a number of common features with the rehabilitation efforts needed in respect of other patient groups, although rehabilitation of certain groups of cancer patients is considerably more complex. Experience has shown that with many cancer patients, relatively simple rehabilitation measures are sufficient to improve the rehabilitation process if rehabilitation is initiated as early as possible in the patient pathway. With other cancer patients, rehabilitation might be needed at various stages along the whole pathway.

10.2.2 Status and recommendation

At a very rough estimate, no more than 70% of newly diagnosed cancer patients potentially need rehabilitation. In the international literature the consensus is that one third of all cancer patients do not need rehabilitation, one third need short-lasting, often less comprehensive rehabilitation, and one third need comprehensive long-term rehabilitation.

The rehabilitation needs of cancer patients differ markedly, thereby imposing very great demands on the healthcare professionals’ knowledge. The introduction of referral parameters is expected to ease the problem and help ensure that patient needs are met appropriately. From the socioeconomic point of view it is best to focus rehabilitation efforts as effectively as possible in order to ensure the best possible utilisation of both personnel and financial resources. In 2005, a practical and cursory identification tool intended to provide an overview of the individual cancer patient’s situation and recommend possible treatment and intervention is being tested in Denmark and Norway.

The need to provide cancer patients with more coherent care in the health service is receiving increasing attention. The central authorities have taken a number of initiatives to promote the pathway concept, among other means through agreements on contact person schemes and better planning of pathways in close cooperation with the cancer patients, but this only takes place in a few places. At present, the only persons continuously involved in the whole rehabilitation process are the cancer patient and possibly the patient’s relatives. In practice the different healthcare professionals are normally only responsible for the part of the process involving themselves, the consequence being that it becomes unclear who is responsible for the coherence of the pathway, which should comprise a continuum focussing on common objectives.

Cooperation between specialists at the cancer departments and personnel in the primary sector can strengthen the quality and coherence of the long-term rehabilitation efforts. When responsibilities are assigned to the Municipalities and the new Danish administrative regions in connection with the local government reform it is important to ensure the greatest possible coherence for the patient through the use of the right personnel resources. An important tool for maintaining this coherence could be the development of patient pathway descriptions for the whole pathway in both sectors. The establishment of rehabilitation units associated with the cancer department outpatient clinics would also strengthen rehabilitation efforts.

Numerous different rehabilitation measures are utilised in Denmark at different levels, but experience with them is not gathered, and no structure has been established for disseminating the experience gained in the primary sector or from research projects. The first efforts to collate nationwide experience with rehabilitation will be initiated by the cancer rehabilitation centre Dallund in 2005.

Actual outcome measures have not yet been developed for rehabilitation efforts. No indicators exist that show when cancer patients have completed their course of rehabilitation. Individual goals should be set for each cancer patient specifying the desired result and the rehabilitation efforts and progress made should be regularly documented. The data should encompass relevant variables/indicators documenting the results and quality of rehabilitation and should be used to continually assess and develop rehabilitation efforts in Denmark.

No organised coherent structure of research environments has been established to investigate the comprehensive area of healthcare comprised by rehabilitation. Knowledge of which forms of intervention affect psychological and social functioning among people affected by cancer is still lacking and there is consequently a need to establish coordinated research programmes aimed at developing rehabilitation methods and procuring evidence for the effects of rehabilitation.

The establishment of centres of expertise (cf. the Danish Medical Research Council's Committee on the National Cancer Plan and Research) associated with each of the three university regions would contribute to the development of concrete rehabilitation measures aimed at dissemination of knowledge and experience, initiation of research and development and education and training of personnel. The activities of the three centres should be coordinated nationally.

Rehabilitation
Recommendation

- The rehabilitation needs of individual cancer patients should be carefully determined in order to facilitate goal-oriented rehabilitation efforts early during the course of the disease
- Clinical guidelines and patient pathway descriptions (cross-sectorial) and associated indicators should be developed to ensure and monitor the quality of rehabilitation efforts

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- Relevant personnel should receive education and training in rehabilitation
- Coordinated research programmes should be established aimed at developing rehabilitation methods and procuring evidence for the effects of rehabilitation

10.3 Palliative care

For a more detailed review of palliative care see Annex 10.3.

10.3.1 The issue

Palliative care has been developing in Denmark over the past 10–15 years. Knowledge and information about the possibilities that exist in the palliative care area are insufficiently widespread among healthcare personnel and hence are not adequately disseminated among patients and relatives. In order to ensure high-quality palliative care it is vital that the field be adequately covered in both the basic and continuing education of healthcare personnel.

Even though society has become more open, care of seriously ill and dying patients is still a taboo area. In 2001, 55% of cancer patients died in hospital, and 26% in their own home. Since 1993 the percentage of cancer patients dying in hospital has decreased slightly, and the percentage of patients dying in their own home, in a nursing home or sheltered accommodation or in a hospice has consequently increased. 627 patients died in a hospice in 2004 as compared with 498 patients in 2003.

Palliative care at the basic level encompasses the care provided in general hospital departments and in the home. Palliative care in hospitals is the responsibility of the department personnel, while that of home-based patients is the responsibility of the district nurses and general practitioners. Palliative care at expert level is directed at patients with a complex symptomatology requiring specialist and/or multidisciplinary care and is provided in hospital palliative care units, hospices and/or via palliative care teams by specially trained personnel who are solely occupied with palliative care. With certain professional groups, however, the expert function is provided on a consultant basis.

Care for relatives, which is also part of palliative care, is discussed in Section 11.2. Further detail is to be found in Annexes 10.3 (Palliative care), 11.1 (Self-care) and 11.2 (Relatives).

10.3.2 Status and recommendation

In 2004, the Danish College of General Practitioners issued a clinical guideline on palliative care in the primary sector for general practitioners and district nurses aimed at improving the treatment and support provided to severely ill and dying patients in their own home.

Hospital departments are organised around performing acute and planned treatment and care. Palliative care requires knowledge, insight, the necessary facilities and personnel and especially the necessary time and peace for the task. The individual hospital department therefore has to be able to change its focus, which can be a difficult task in view of current general efficiency requirements.

The results of an as yet unpublished health technology assessment show that coordination and cooperation between the county and municipal areas of responsibility for healthcare, including cooperation with general practitioners is a difficult and complex task.

There are currently six hospices in Denmark with a total capacity of 70 beds. An additional three hospices with a total capacity of 32 beds are currently being established and are expected to be able to admit patients in 2006. The 2005 Budget Act allocated funds for the establishment of new hospices so as to ensure nationwide hospice capacity corresponding to a minimum of 12 beds in each County. By the end of 2004, palliative care teams had been established by virtually all the Counties and Copenhagen Hospital Corporation.

No clear and unambiguous objectives and guidelines have been established for the education of personnel responsible for palliative care, neither as regards basic care nor expert care. In 2001, the Danish Society for Palliative Medicine took the initiative to establish a joint Nordic educational programme on palliative medicine for physicians. Efforts are currently being made to develop a basic module and thematic specialist modules on palliative care for other healthcare personnel.

No system has yet been established for the electronic documentation of palliative care so that the efforts can be monitored in order to enable quality to be improved and to meet patient and relative needs for information to enable them to make a choice.

Palliative care
Recommendation

- Cross-sectorial patient pathways should be coordinated and follow locally adapted national clinical guidelines; the efforts should be monitored using common indicators integrated into the existing documentation systems
- The education of specialists, nurses and other health care professionals in palliative care should be supported
- Implementation of clinical guidelines for palliative care in the primary sector should be supported through joint courses for district nurses and general practitioners
- Efforts should be made to establish a knowledge and research centre for palliative care

11 The patient aspect

11.1 Self-care

For a more detailed review of self-care see Annex 11.1.

11.1.1 The issue

Cancer patients are better able to deal with their disease if they have control over their own lives and believe that they will also be able to control their lives in the future. In practice this can mean that they participate actively in their own treatment and care, for example by seeking knowledge, participating in health-related activities (diet, exercise, etc.), being aware of and informing about symptoms, administering their own medicine, being aware of their own psychological reactions and seeking support, contributing to good cooperation with the healthcare personnel, etc. Many cancer patients have the resources for this, but as they are placed in a new and unfamiliar situation they may need help to cope.

It is to the benefit of both the patients themselves and the health service that patients participate actively in the course of their illness and treatment. It is therefore in the interests of both the patient and the health service that the patients have sufficient confidence, knowledge and capacity to be able to cooperate with the healthcare personnel to achieve the best possible result.

There is widespread and increasing interest in understanding the overall needs of the patients and involving their own resources in caring for and treating their cancer. Knowledge of patient needs during the various stages of the pathway is limited and fragmented, however.

One should distinguish between activities that should be offered to *all* cancer patients, and those that should be offered to *selected* cancer patients with special needs. A “screening tool” is needed to enable identification of those with special needs, but one should be aware that the patients themselves know what special needs they have.

11.1.2 Status and recommendation

The spontaneous and individual support that healthcare personnel provide to cancer patients regarding self-care is of considerable importance, but has not been systematised. Some departments accord priority to ensuring that the patients have a personal physician and contact nurse, thereby improving the possibility for providing individually adapted support. Psychologists employed in oncology departments primarily provide teaching and supervision to the personnel. To a lesser extent communication training has been provided for healthcare personnel and patient education for cancer patients (and relatives).

Information about disease and treatment together with platforms for exchange of experience and mutual support among Danish cancer patients can be found on the Internet – e.g. www. cancer.dk, www.netdoktor.dk and www.sundhed.dk. The Danish Cancer Society provides cancer counselling in all counties (usually supported by the Counties) as well as a telephone counselling service, “The Cancer Line”. In addition, a number of patient associations and alternative/complementary treatments exist that cancer patients make great use of.

Communication between the healthcare personnel and the patient has proven to be of importance for patient self-care. When communication is good (empathic, in dialogue form, respectful, individually adapted information, etc.) the patient is better able to master, understand and remember the information, thereby reducing uncertainty and anxiety, increasing satisfaction and enhancing treatment compliance. A Danish study has shown that "enhanced, cancer-related self-efficacy after the consultation was associated with 1) the experience of a higher degree of control (measured before and after the consultation) and 2) the experience that the doctor listened and took the patient's thoughts and questions into account."

Patient involvement is important with respect to patient self-care. Studies have shown that patients who are involved in clinical decisions are more satisfied, exhibit better treatment compliance and experience better treatment results than patients that have not been involved. The experience of having influence can serve as an important shock absorber that protects against negative psychological and physical reactions when facing stress and negative events, just like faith in one's own ability to deal with stress, disease, discomfort and pain has proven to influence biological processes such as the immune system and experience of pain, as well as health behaviour.

A number of studies have also shown that patient education, which aims at helping the patient acquire knowledge and competence and obtain support, has a positive effect on patient self-care.

Many hospital departments that treat cancer patients have good experience with goal-oriented efforts to strengthen patient self-care. Among other means this can be done by incorporating procedures for involving patients, ensuring that patients are well-informed about waiting times and the possibilities to turn "waiting time" into "preparation time", training of healthcare personnel in communication skills and the introduction of contact nurses and personal physicians. Patient education as an integral part of a patient pathway is a concrete possibility to strengthen patient self-care.

Professional counselling should be offered to patients with special needs. Studies have shown that approximately half of all cancer patients have moderate or severe psychological problems. Many of these patients will benefit from professional counselling as early in the process as possible, among other reasons to prevent and treat anxiety and depression disorders. These more serious psychological sequelae of cancer can have consequences for social and health service resources, for example in the form of enhanced needs for treatment.

Having the same contact persons among the healthcare personnel promotes patient involvement, overview, peace of mind and confidence. Departments that have introduced personal physicians and contact nurse schemes report good experience with this. In a few parts of Denmark a model has been tested in which a healthcare contact person follows the patient throughout the whole patient pathway, i.e. also from department to department.

Regular studies should be undertaken of patient needs for involvement and communication, assessment of treatment pathways, etc. The results of the studies should be used actively to change the health service practice (see recommendation in Section 14.2.2).

Self-care
Recommendation

- Referral guidelines should be developed regarding psychosocial problems and needs among cancer patients in order to be able to provide demand-based and practicable solutions
- Hospital departments that treat cancer patients should make concerted efforts to strengthen patient self-care
- Patients with special needs should be individually assessed and thereafter offered psychological and social counselling, physiotherapy and dietary guidance

11.2 Relatives

For a more detailed review of the role and needs of relatives in connection with cancer see Annex 11.2.

11.2.1 The issue

For a large proportion of cancer patients, relatives play an important and active part in the patient pathway. It is an important task for the healthcare personnel to regularly discuss with the patient to what extent he/she wants his/her relatives to be informed and involved. The relatives could include not just the patient's family, but also close members of the patient's network made known to the healthcare personnel.

Relatives should be considered by the healthcare personnel to represent both a patient resource and persons who are themselves in need of information and support during what is often a long process. The relatives need relevant information about cancer and about treatment, care and rehabilitation plans. Special attention should be accorded to children and adolescents whose parents have cancer.

11.2.2 Status and recommendation

Patients currently want and do play a more active and responsible role in relation to their own course of disease and treatment combined with greater rights regarding information and self-determination. This development towards more independent and self-determining patients makes great demands on both patients and their relatives.

The very complex patient pathways also entail that patients have contact with different hospitals and/or departments. Unfortunately the relatives often serve as coordinator between the many links in the pathway.

Treatment strategies have changed and there is now more emphasis on short-lasting admissions and outpatient treatment. As a consequence, cancer patients are discharged at a time where there might be a need for relatives to take responsibility for care and nursing tasks that were previously performed by healthcare personnel. It is thus important that the treatment pathway should as far as possible be planned beforehand so that both patients and relatives can oversee the whole pathway and thence also the need for information and help.

Relatives

Recommendation

- At the start of the patient pathway the healthcare personnel should find out who the patient's relatives are and whether the patient wants the relatives to be kept informed. The healthcare personnel must ensure that the relatives that the patient wants involved know which member of the personnel is primarily responsible for the patient
- The department should prepare guidelines for conversations with the relatives and for involving the relatives in the patient's illness and treatment

11.3 Alternative medicine

For a more detailed review of alternative medicine see Annex 11.3.

11.3.1 The issue

Cancer patients use alternative medicine for a number of reasons. The majority choose alternative medicine as a supplement to conventional treatment and only a few on the grounds that they do not have confidence in conventional treatment.

11.3.2 Status and recommendation

There are no recent Danish studies indicating the percentage of cancer patients employing alternative medicine. The results of interviews with selected groups of cancer patients indicate that between 45% and 75% of Danish cancer patients use alternative medicine. Even though opinion as to what constitutes alternative medicine changes during the course of time, the studies nevertheless indicate that the number of patients using alternative medicine in the sense of complementary treatment is increasing.

Some cancer patients want to use alternative medicine during hospital admission. The National Board of Health therefore encourages hospital departments to wherever possible accept patient wishes regarding the use of alternative medicine during admission. In a communication to Danish hospitals in 2000 the National Board of Health recommended that hospital department guidelines concerning alternative medicine should be incorporated into the department instructions.

In view of the growing interest in alternative medicine among the Danish population a number of initiatives have been taken at central level over the past 20 years, e.g. the establishment of the National Board of Health's Council on Alternative Medicine in 1985 and establishment of the Knowledge and Research Center for Alternative Medicine in 1999. Among other things, the aim has been to disseminate information about alternative medicine to the established health service and general public, to promote dialogue between the established health service and alternative therapists and to promote and develop research in the field.

Conventional and alternative therapists disagree as to how the effect of alternative medicine can be documented. The conventional treatment system usually requires randomised controlled trials before the effect of a treatment is considered to be documented. In principle, the same method can be used in the case of alternative medicines or dietary supplements. A lack of financing and research training can render this difficult, however. In addition, many alternative therapists do not work with the same concept of disease as conventional therapists, but rather with the individual person’s energies or resources, and the treatment is specially compiled for each individual person.

Together with the Danish Cancer Society, the patients association Cancer Society The Thistles and Buen Information Centre, the Knowledge and Research Center for Alternative Medicine has initiated a project aimed at describing the effects of the most frequently used forms of alternative cancer treatment and alternative medicines. The project encompasses the preparation of Cochrane reviews and systematic reviews. For more information about the progress of the project see the Annex 11.3.

Alternative medicine
Recommendation

- The National Board of Health’s November 2000 recommendation to Danish hospitals that they should generally refrain from opposing patient desires to use alternative medicine during admission still applies. The existing knowledge on alternative medicine could beneficially be disseminated to the established health service in order to support dialogue between patients and healthcare professionals
- Hospital department guidelines concerning alternative medicine should be incorporated into the department instructions
- Greater knowledge needs to be acquired about the effect of alternative medicine through both quantitative and qualitative studies encompassing a range of outcome measures (clinical, psychological, health economic)

12 Personnel and education

12.1 Personnel

12.1.1 The issue

It has been pointed out that there are personnel shortages in several areas of cancer diagnosis and treatment, but the current and expected coming overall personnel shortages have not been determined.

The National Board of Health prepares labour market forecasts for physicians. The latest physician forecast for 2000–2025 made in 2003 predicts that the number of specialists will decrease in the coming years, but that the total number of physicians will concomitantly increase due to increased output of newly educated physicians from the universities. At the present there are vacant internships and specialist positions within several of the specialities involved in the diagnosis and treatment of cancer. This trend is expected to continue in the coming years. No recent analysis of demand is available.

There are also personnel shortages within other professional groups. The National Board of Health does not have concrete information about which professional groups are affected and the extent of the personnel shortage.

The National Board of Health is responsible for dimensioning educational capacity for specialists, while the Counties/Copenhagen Hospital Corporation are responsible for dimensioning educational capacity for all other professional groups.

12.1.2 Status and recommendation

A number of measures can increase the supply of or reduce demand for personnel during personnel shortages. The supply can be increased by providing incentives to keep elderly personnel working and by actively recruiting foreign healthcare personnel, as well as by increasing undergraduate and postgraduate educational capacity. The demand can be reduced by structural changes, through improving working efficiency and in the case of physicians, by changing the duty structure and by reassignment of tasks both within the physicians' group and from the physicians to other professional groups, e.g. nurses and technicians.

Experience with reassignment of tasks has been made in several parts of the country. Examples are radiographers who have been trained to interpret certain radiographs, and nurses who have been trained to perform ultrasound scans or certain types of fibroscopy. Other countries have experience in letting technical personnel take over tasks within the planning of radiotherapy that were previously the domain of physicians and physicists. The personnel assigned these new tasks are typically radiographers and technicians (medical dosimetrists).

Personnel
Recommendation

- Active efforts should be made both locally and nationally to enhance the supply of and/or reduce demand for healthcare personnel within the areas where there are personnel shortages

continued

cont.

- Given disease trends and treatment needs in the cancer area, consideration should be given to whether or not the educational capacity dimensioning and labour market forecasting work regarding physicians and other healthcare personnel should be improved

12.2 Continuing medical education of physicians in the cancer area

For a more detailed review of continuing medical education of physicians in the cancer area see Annex 12.2.

12.2.1 The issue

The reform of postgraduate education for specialists that entered into effect in 2004 entails a relatively short and focussed education in the majority of specialities. This necessitates increased focus on continuing medical education in order to meet the need for special expertise in the cancer area and to allow individual specialists to shape their professional profile. The postgraduate education of specialists is closely regulated, whereas continuing medical education is largely the responsibility of the individual specialist, both as regards the content of their education and its completion.

Appropriate continuing medical education is of decisive importance for specialist physicians who work with the diagnosis and treatment of cancer patients. This group encompasses specialists within most diagnostic and clinical specialities. The aim of continuing medical education is to ensure that the specialists' knowledge and expertise is regularly updated so as to ensure high-quality diagnosis and treatment. At the same time, it is necessary that they maintain and develop knowledge in accordance with national clinical guidelines for prevention, diagnosis and treatment. The scientific societies have provided part of the continuing education and to a varying extent have financed it. The issue can be summarised as follows:

- It is up to the individual specialist to ensure his continuing medical education
- There is no overall organisational structure for continuing medical education programmes
- Continuing medical education programmes are not subject to any systematic quality assurance.

12.2.2 Status and recommendation

Analysis of the educational area for healthcare personnel carried out following publication of National Cancer Plan I led to recommendations concerning the undergraduate and postgraduate medical education. Since then, changes have been made in both the undergraduate medical education and the postgraduate education of specialists (see Annex 12.2). Greater emphasis is now placed on broad expertise within pathoanatomy, diagnostics and clinical skills, communication and health promotion measures. This has helped improve the basis for enhancing the quality of the overall course for cancer patients.

Methods for diagnosing and treating cancer have developed considerably in recent years. This means that it is vital that the individual physician regularly updates his knowledge and expertise, and that there is an increasing need for specialists to profile themselves in particular aspects of the patient pathway via continuing medical education. The need for systematically planned continuing medical education is growing as the coming generation of specialists has undergone a short and focussed education and knowledge and to a greater extent expertise within cancer consequently has to be maintained and enhanced after certification as a specialist. With few exceptions, no goals and plans have been stipulated for the education and expertise that specialists should acquire through continuing medical education.

Continuing medical education of physicians in the cancer area
Recommendation

- Goals should be stipulated for the knowledge and expertise that specialists should acquire through their continuing medical education while concomitantly enabling individual specialists to shape their own professional profile
- Specialists should be required to document that their continuing medical education is in accordance with the stipulated goals
- An overall plan should be drawn up for the organisation of continuing medical education for specialists in the cancer area in cooperation with the National Board of Health, the hospital authorities, the Danish Medical Association and the scientific societies stipulating who is responsible for its provision, financing and quality assurance

12.3.1 The issue

Nursing education – which is one of the medium-length educations – is a general education. In certain areas of the health service, including the cancer area, further education is required.

12.3.2 Status and recommendation

Since 1980 a one-year continuing nursing education programme has existed for oncological nurses. The programme admits 20–30 nurses per year and encompasses theoretical teaching and clinical training, and closes with a dissertation and written exam.

In continuation of the “Europe against cancer” programme (1987–89), a basic curriculum for the continuing education of oncological nurses in Europe was drawn up in 1990. The work was organised by the European Oncology Nursing Society (EONS) based on recommendations by the EU Advisory Committee on Nursing Training. The educational programme was updated and revised in 1999. The recommendations have been incorporated in the Danish nursing education. Furthermore, Nordic cooperation in this area has been established.

In autumn 2004, the National Board of Health’s council on specialist nursing training decided to establish a working group to draw up proposals for a new specialist education for nurses working with cancer patients. This educational programme is to replace the present one-year continuing education programme and will be specifically designed to meet the needs of nurses working with cancer patients. A proposal for the new specialist nursing education is expected to be ready before the end of 2005.

In 2004, in order to promote and ensure more uniform education of nurses working in the cancer area, head nurses at the oncology and haematology centres and departments drew up “A national model for development of expertise among oncological nurses in Denmark”. It is expected that the model will be incorporated in the work on developing the new specialist education.

Nursing education in the cancer area

Recommendation

- When the proposal for the specialist education for nurses working with cancer patients is issued at the end of 2005 it should be processed rapidly by the parties involved so that the specialist education can be implemented in autumn 2006
- Knowledge of the model for development of expertise within the oncology/haematology area drawn up by the hospital authorities should be widened, and the model should be supplemented with specific expertise within nursing of surgical cancer patients

13 Infrastructure for clinical cancer research

For a more detailed review of clinical cancer research see Annex 13.

13.1.1 The issue

In order to be able to provide future modern treatment that meets the highest international quality standards it is necessary to conduct research in all relevant aspects of the cancer area. Wherever relevant, research is included as an independent topic in the individual chapters of National Cancer Plan II dealing with the various parts of the patient pathway.

13.1.2 Status and recommendation

National Cancer Plan I recommended initiating an analysis of clinical cancer research, in particular focussing on assessing whether the necessary research resources are available so that the activities proposed in the Plan can be implemented as best possible.

On this background, the National Board of Health called on the Danish Medical Research Council to set up a committee to select focus areas with the aim of coordinating and enhancing the quality of Danish clinical cancer research.

The Danish Medical Research Council set up the Committee on the National Cancer Plan and Research upon the recommendation of the three regional research councils, the Ministry of the Interior and Health, the National Board of Health and the Danish Cancer Society.

In February 2005, the Danish Research Agency published the Committee on the National Cancer Plan and Research's report "Clinical Cancer Research in Denmark – Concrete initiatives to support National Cancer Plan I". The report, which was prepared in dialogue with relevant stakeholders involved in clinical cancer research in Denmark, makes proposals for considerably strengthening the framework for clinical cancer research. The main initiatives are the establishment of a regional infrastructure for clinical cancer research, strengthening of the researcher networks that coordinate research efforts on the individual types of cancer, and coordination at the national level.

Infrastructure for clinical research

Recommendation

- Following application to the Ministry of the Interior and Health, the three regional medical research councils should – without the involvement of the Danish Medical Research Council, as was otherwise originally proposed by the Committee on the National Cancer Plan and Research – be given responsibility for implementing the funds allocated for strengthening clinical cancer research through the establishment of the regional infrastructure for clinical cancer research. This would concomitantly ensure that the coordinating function of the three regional research councils is maintained when establishing the new regional infrastructure
- The implementation of the funds should take place within a framework established jointly by the State and the hospital authorities
- In connection with implementation, funds should be allocated to both clinical research units and centres of expertise that can support cancer-related health service research
- A working group should be established with representatives of the Counties, the clinical cancer groups and the National Board of Health to draw up a model for the organisation and financing of the Danish Multidisciplinary Cancer Groups (DMCG) within the framework of the existing guidelines for clinical databases
- As a supplement to the regional infrastructure for clinical cancer research and the DMCG a forum entitled the *Council for Danish Clinical Cancer Research* should be established to ensure that the work in DMCG takes place in accordance with uniform guidelines, and to coordinate the activities in the regional infrastructure for clinical cancer research
- Organisationally the new council should be placed under the Executives' Forum for Health Research. In this connection it should be noted that the council operating costs are expected to be minimal

14 Surveillance

14.1 Surveillance in the cancer area

For a more detailed review of surveillance in the cancer area see Annex 14.1.

14.1.1 The issue

The purpose of surveillance in the cancer area is to obtain data that can be used to monitor disease prevalence and survival and to document the quality of treatment efforts in order to be able to take preventative measures and make improvements. Survival data are important when monitoring the final effect of cancer treatment. In a few areas, indicators have been developed and implemented that reflect the quality of the health care efforts in the cancer area. Patient pathway performance is documented to a limited extent through waiting period analyses.

Considerable amounts of data are continually being gathered and processed in the cancer area, for example by university departments, the Danish Cancer Society, the National Board of Health, the three regional expert centres for clinical databases and the clinical departments. The National Board of Health regularly publishes cancer statistics based on the registers, the Danish Cancer Society publishes statistical analyses, and several of the clinical databases publish annual reports. The many different types of data are not being published in a coordinated and combined manner. As a consequence, no one single site exists that can provide an overall picture of the quality and effect of the cancer healthcare services.

Coordinated surveillance therefore needs to be introduced in order to:

- Monitor the occurrence and trend in population health habits and lifestyle factors of significance for the development of cancer (smoking, diet, exercise and alcohol) with a view to prevention
- Document disease prevalence and treatment results in the cancer area based on both register-based documentation and data from the clinical quality databases
- Monitor the quality and impact of the cancer healthcare services by gathering data on the whole patient pathway in both the primary and secondary sectors to use the data for improvements
- Ensure that up-to-date data are available and disseminated to healthcare planners, clinicians, researchers, patients and others who need to use them.

14.1.2 Status and recommendation

The extent of the present surveillance within the above-mentioned aspects varies, as does division of responsibility and dissemination of the content of the surveillance. In order to make this section more clear, it is subdivided accordingly.

14.1.2.1 Existing and lacking data in the cancer area

Denmark has several nationwide population-based registers that are utilised in the surveillance of the prevalence and treatment of cancer, in particular the Cancer Register, the National Patient Register, the Cause of Death Register and the Pathology Register. From an international viewpoint these registers are unique, and Denmark has a quite special basis for combining epidemiological data on the trend in cancer. Efforts are continually being made to improve the quality of the central registers, and a special initiative has been implemented to update the Cancer Register and the Cause of Death Register. The National Board of Health has prepared electronic submission of data to the central registers, while hospital authorities are responsible for technical and systematic implementation locally.

Data on diagnosis-specific survival in the cancer area can be obtained by cross-referencing the Cancer Register with the Cause of Death Register. There is presently some delay, though, as the Cancer Register for year-groups after 2000 has not been fully updated due to a delay in the work on the Cause of Death Register. The Cancer Register and the Cause of Death Register are cross-referenced in order to obtain data on cancer deaths that have not been reported directly to the Cancer Register. This is an important means of assuring the quality of the data.

A joint development project by the hospital authorities in Nordjylland, Viborg and Aarhus Counties concluded that it is also possible to use the data from the hospital information systems (Patient Administration Systems) combined with the Civil Registration System to determine survival. According to the researchers behind the study the survival estimates can be performed with much less delay and an acceptable margin of error, thus enabling survival data to be utilised more rapidly to adjust treatment efforts on the basis of the results obtained. In cooperation with the local cancer group in Aarhus County and the Danish Cancer Society, the National Board of Health has started work on the use of survival figures based on hospital data for continual prospective surveillance.

In addition to the above-mentioned central registers, several nationwide clinical databases relating to the cancer area can contribute data on the clinical quality. The databases are financially supported (provided they publish annual reports) by a joint fund for databases established by the hospital authorities. The database secretariat at Danish Regions evaluates the applications in accordance with a number of basic medical, organisational and technical requirements, among others that the databases are able to demonstrate that they aim at quality development and that they are expected to publish department-specific quality data. In 2005, six databases have applied for support from the fund. These cover the areas bladder cancer, gynaecological cancer, colon cancer and rectal cancer, lung cancer, lymphatic and myeloid cancer, and stomach and oesophageal cancer.

In the case of breast cancer a research database run by the Danish Breast Cancer Cooperative Group (DBCG) exists that is separately funded by a sum per included patient. The DBCG is working on supplementing the database with a set of indicators so that it can also be used for quality surveillance purposes. With many forms of cancer, clinical databases and associated indicators for documenting quality remain to be developed. There have been both technical and resource-related problems in operationalisation of the clinical databases, and complete implementation of the databases has not yet taken place. The existing clinical databases contain very different data sets, and only the minority encompass the whole patient pathway. Work on their development thus needs to continue. In a few areas of cancer indicators have been developed for the clinical pathway that is registered in the clinical databases. In many areas, however, indicators for clinical quality surveillance will have to be established in connection with implementation of clinical guidelines.

In order to support the continued development and operation of the clinical databases, three regional expert centres have been established.

Apart from those mentioned above, there are a number of other data sources that can provide information on health care efforts in the cancer area, e.g. the annual status report by Danish Regions, the Danish Medicines Agency, the Danish National Survey of Patient Experience (LUP), the National Indicator Project (NIP), The Good Medical Department (a Danish quality improvement programme), the Danish Veterinary and Food Administration and Statistics Denmark.

Existing and lacking data in the cancer area

Recommendation

- Efforts should be made to ensure that the national registers, patient administration systems and clinical databases cover the whole cancer area
- The development and use of indicators should be accelerated
- Electronic data submission to the central registers should be implemented centrally and locally

14.1.2.2 Collection and dissemination of cancer-related data

In 2002, the WHO published a report on national action programmes in the cancer area. The report recommends the designation of a central unit to coordinate the surveillance activities and to draw up an overall surveillance report at regular intervals. At the same time, the report recommends that this central unit should establish cooperation with all the parties who provide cancer data so that planning of the surveillance activities and analysis of the data are coordinated. The importance of joint evaluation of the selected surveillance model in order to enable it to be regularly adjusted is also stressed. The evaluation of Denmark’s first National Cancer Plan also revealed a need for development work aimed at coordinated surveillance of the cancer area. Responsibility for establishing such coordinated surveillance could be placed centrally.

Data are only collected about part of the cancer patient pathway, mainly the part within the hospital service. There is less tradition for using indicators and gathering data for the part of the pathway located in the primary sector. Special efforts therefore need to be made to develop indicators for this area.

In connection with the forthcoming local government reform (January 2007), responsibility for prevention and much of the responsibility for rehabilitation are being transferred to the municipal authorities. In order for cancer data to be comparable throughout the country it is important that in future work a common data set is defined for use in surveillance and improvement of efforts in the cancer area.

The central registers have a long tradition for regular publications. Not all the clinical databases have yet established the necessary routine annual publication of their results. Continued development of the use of the patient administration systems in surveillance will help ensure achievement of a more complete picture of the treatment efforts and the results. Together with other data sources mentioned above that contribute information on healthcare in the cancer area, these data sources will be incorporated in the coordinated surveillance of the cancer area.

A number of user groups are interested in the cancer data available in the registers, e.g. clinicians wanting to monitor the quality of their treatment efforts, healthcare planners wanting to clarify questions relating to prevention or planning tasks, and researchers needing data for research projects. Journalists may also want available key figures about cancer and patients. Efforts should be made to ensure that the user groups in need of information about healthcare efforts in the cancer area have access to these data and the latter are provided in an understandable and usable form.

Collection and dissemination of cancer-related data
Recommendation

- Surveillance of healthcare in the cancer area should be coordinated and strengthened so as to enable the trend in disease and treatment quality to be regularly and coherently monitored
- The coordination should encompass development work encompassing patient administration systems, databases and central registers to ensure coherent surveillance in the cancer area as regards disease prevalence, treatment results and quality. This coordination should be the responsibility of the National Board of Health
- The dissemination of cancer data should be coordinated and improved so as to meet the needs of the different user groups, for example through the regular publication of documentation

14.2 Patient assessment of cancer treatment

14.2.1 The issue

The process that cancer patients undergo is physically and psychologically demanding. Receiving the cancer diagnosis causes anxiety and uncertainty about the future, not only in relation to having a possibly life-threatening disease, but also in relation to the thought of having to face a period of demanding and possibly long-lasting treatment and care. Patients and relatives will have expectations about quality of the treatment and care provided by the healthcare professionals.

It order to be able to develop and improve the quality of the patient pathways it is necessary to know the patients’ expectations and their actual assessments of the pathway they are in or have been through. It is necessary to know their expectations and assessments of both minor parts or phases of the pathway as well as of the pathway as a whole. Obtaining the assessments is only the first step – the real purpose is to use the patients’ assessments in the continual quality improvement work.

14.2.2 Status and recommendation

The Danish Quality Model for the Health Service requires patient perspectives and assessments to be incorporated in the basis for improvements in the health service. Many hospital departments that treat cancer patients have carried out patient satisfaction surveys. They have used locally formulated questions designed for use in solving local problems. Few such studies have been carried out in the primary sector.

In Denmark, a nationwide survey of patient experience is carried out every second year. The survey compares patient experiences and assessments throughout the 54 somatic hospitals in Denmark, but does not specifically focus on cancer patients, who are just included in the patient material alongside other types of patient. The survey encompasses generic questions of relevance for several specialities and encompasses discharged patients from the four major specialities – internal medicine, general surgery, orthopaedic surgery and gynaecology/obstetrics. The nationwide surveys have enabled the identification of areas in need of improvement, but also where more in-depth surveys need to be carried out locally. The surveys have not been designed to specifically determine the expectations and assessments of cancer patients, but it will be possible to design them to also determine these. Through repeated nationwide speciality-specific surveys in the cancer area it will be possible to gather information on the experiences and assessments of cancer patients regarding areas of special significance for cancer patients. Using that information it will be possible to perform comparisons and subsequently exchange experience with the hospitals and departments that achieved the best results. By learning from the departments that achieved good results, and by determining where one's own department can do better, it is possible to make improvements.

Questionnaire surveys are only one of several possible methods for gathering information about the patients' perspective and assessments. Qualitative methods such as focus groups or user panels should also be employed in order to obtain an as qualified a basis as possible for making improvements for the patients.

Patient assessment of cancer treatment
Recommendation

- Wherever cancer patients are treated in the health service – in the primary sector, the hospitals and the individual departments – regular surveys should be performed of patient expectations and assessments of both the individual elements and the treatment pathway as a whole
- The surveys should be carried out both locally and in a coordinated manner at the national level and should be regularly developed
- The survey results should be followed up upon, among other means through comparison of results and through initiatives aimed at ensuring learning and improvement

15 Annexes

(only available in Danish: www.sst.dk)

Annex 6.1 Patient pathway organised in packages

Annex 6.2 Patient pathway activity estimations

Annex 7.1 Primary prevention

Annex 7.2 Screening for cancer

Annex 8.1 Symptoms – see a doctor

Annex 8.3 A Diagnostic examination at hospital – radiology

Annex 8.3 B Diagnostic examination at hospital – pathology

Annex 9.1 A Introduction of cancer surgery

Annex 9.1 B Breast cancer

Annex 9.1 C Lung cancer

Annex 9.1 D Intenstinal cancer

Annex 9.1 E Gynaecological cancer

Annex 9.1 F Urinary tract cancer

Annex 9.1 G Upper gastrointestinal tract cancer

Annex 9.1 H Skin cancer

Annex 9.1 I Head/neck cancer

Annex 9.1 J Neurosurgical forms of cancer

Annex 9.1 K Sarcoma

Annex 9.1 L Cancer of the eye

Annex 9.2 A Pharmacotherapy

Annex 9.2 B PPAS Protocol Patient Administration System

Annex 9.3 A Radiotherapy – DACEHTA

Annex 9.3 B Radiotherapy – Copenhagen County

Annex 9.4 Experimental treatment

Annex 10.1 A Supportive treatment

Annex 10.1 B Scalp cooling

Annex 10.2 Rehabilitation

Annex 10.3 Palliative care

Annex 11.1 Self-care

Annex 11.2 Relatives

Annex 11.3 Alternative medicine

Annex 12.2 Continuing education of physicians in the cancer area

Annex 13 Research

Annex 14.1 Surveillance in the cancer area

Annex 14.2 Patient assessment of cancer treatment

See also:
Cancer in Denmark. An updated review of prevalence, mortality and survival
(only available in Danish)