

A National Cancer Strategy for the Future

– *Summary*

*Report of the Commission of Inquiry on
A National Cancer Strategy*

Stockholm 2009



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To the Minister and Head of the Ministry of Health and Social Affairs

The Government decided on 5 July 2007 to establish a Commission of Inquiry with a remit to present proposals for a national cancer strategy (Terms of Reference 2007:110). Kerstin Wigzell, Director General, was appointed Chair of the Inquiry from 1 August 2007.

Experts appointed to the inquiry with effect from 30 October 2007 were Professor Mats Brommels, Ingrid Kössler, Chairman, Bo Lindblom, Head of Department (until 31 July 2008), Sören Olofsson, Regional Director, Carsten Rose, Head of Clinic, Måns Rosén, Director, Kerstin Sandelin, Associate Professor, Kerstin Sjöberg, Administrator, Ann-Christin Tauberman, Director General, and Professor Bengt Westermark. Charlotte Hall, Senior Adviser (until 25 May 2008) and Åsa Schedin, Desk Officer (until 15 August 2008) were appointed as advisers to the Inquiry. Christina Kärvinge, Director, was appointed expert from 1 August 2008. Maria Wästfelt, Desk Officer, was appointed as adviser to the Inquiry from 26 May 2008 and Mats Nilsson, Senior Adviser, from 1 September 2008.

The Inquiry adopted the name A National Cancer Strategy (S 2007:10). Cecilia Halle, Deputy Director, was appointed Principal Secretary of the Inquiry from 1 September 2007. Johanna Hållén, Information Officer, was appointed Secretary from 8 October 2007. Pia Maria Jonsson, Health Systems Researcher, was appointed as Secretary from 28 July 2008, Professor Bo Lindblom as Secretary from 1 August 2008 and Michael Högberg, Health Economist, as Secretary from 4 August 2008. With effect from 1 October 2008 Elisabeth Franzén, Administrative Officer, has been assistant to the Inquiry with responsibility for text editing and layout of the report.

The Commission of Inquiry hereby presents its report A National Cancer Strategy for the Future (SOU 2009:11) and in so doing has fulfilled its remit.

Stockholm, February 2009

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Summary

The remit and how the work was conducted

On 5 July 2007, the Government decided to appoint a Chair of Inquiry tasked with submitting proposals for a national cancer strategy for the future. The remit has been fulfilled with the publication of this report.

The Government notes in its terms of reference that an increase in the number of people developing and living with cancer can be expected over the next 10-15 years. There is therefore reason to investigate what can be done to prevent cancer morbidity and mortality as far as possible and to improve quality in the management of cancer patients. The national cancer strategy, according to the Government, is to focus on future needs and challenges. It is to adopt a comprehensive perspective and cover primary prevention, early detection, diagnostics, treatment, palliative care and knowledge creation and dissemination. Particular attention is to be paid to the patient perspective.

Information and views have also been gathered from a number of parties involved in the field of cancer during the course of the inquiry. Representatives of the Commission of Inquiry have also visited sites in Sweden, Norway, the United Kingdom and the Netherlands for study purposes. A special working group made up of representatives of the patient organisations has regularly contributed material and opinions. The Inquiry has also ordered background material in support of its work. This is listed in Annex 2.

The first part of the report, Background (Chapters 2–5) contains a broad description of cancers, cancer care and cancer research in Sweden. The first part of the report also identifies a number of issues of particular significance for the future.

The second half of the report, Proposals (Chapters 6–11) presents the considerations and proposals of the Commission of Inquiry on the contents of the cancer strategy and proposals for overarching goals and types of follow-up and implementation.

Part I Background

Cancers

Cancer is a collective term for the 200 or so diseases currently known that are characterised by uncontrolled cell growth. Knowledge of cancer has steadily improved over the years, leading to some new methods of treatment. This trend, based on a whole series of advances in clinical and preclinical research, has been accompanied by a steady improvement in treatment outcomes.

The mechanism by which most forms of cancer arise is multifactorial. Several different risk factors have been identified. These include certain lifestyle factors, heredity, various carcinogenic substances, radiation, viruses and hormones. Among lifestyle factors, the significance of smoking in cancer is well documented. Obesity, physical inactivity and high alcohol consumption are other lifestyle factors that pose an increased risk of cancer, although the correlations are not fully understood. Exposure to ultraviolet radiation from the sun increases the risk of developing certain types of cancer.

Just over 50 000 malignant cancer cases were diagnosed in Sweden in 2007. Breast cancer is the most common type of cancer in Swedish women, accounting for 29 per cent of diagnosed cases in the same year. Among men, prostate cancer is the most common type of tumour, accounting for 34 per cent of diagnosed cases. Together with lung and colorectal cancer, these groups account for just over half of all new cancer cases for men and women combined.

Skin cancer, comprising both malignant melanoma and other skin cancers, is the type showing the greatest increase, and the average annual rate of increase is greater for women than for men. Lung cancer among women is increasing almost as much as skin cancer. On the other hand, cases of lung cancer in men have decreased in recent years.

Cancer survival has improved, but certain types of tumour still have a very poor prognosis, for example pancreatic cancer and certain types of brain tumours.

Lung cancer in women is showing an adverse trend, and for a few years has been the type of cancer that causes most deaths among women. Lung cancer deaths among women rose by 75 per cent between 1987 and 2006. Among men, prostate cancer is the type that causes the greatest number of deaths.

Cancer morbidity rates in Europe largely reflect those in Sweden. Relative five-year survival for all cancers has improved, and differences between countries have narrowed. Survival for the four most common cancers, breast, prostate, lung and colorectal cancer, and for ovarian cancer, were highest in the Nordic countries (with the exception of Denmark) and in Central Europe.

The Centre for Epidemiology at the National Board of Health and Welfare has made projections on our behalf for the number of individuals who at different times between now and 2030 will be diagnosed with cancer (cancer prevalence) and for the risk of developing cancer (incidence). Projections of future morbidity are obviously subject to uncertainty, but can nevertheless provide a picture of a likely trend.

The projections presented indicate that

- the number of men with cancer in 2030 will be nearly 130 per cent higher than today,
- the equivalent increase for women is around 70 per cent,
- population changes (size and age structure of the population) explain just over half of the increase for men and just under half for women,
- the risk of developing cancer will also increase; for women this trend is dominated by lung cancer and skin cancer, while the increase for men principally relates to prostate cancer and other less common types of cancer and
- a relative shift will take place for women from less serious to more serious cancers (among other things because of an increase in the share of lung cancer), while a shift will take place in the opposite direction for men (as the proportion of prostate cancer cases detected early increases).

Cancer care and cancer research

Swedish cancer care generally stands up well in international comparisons and is notable in particular for good outcomes in terms of lower mortality and longer survival. The care is highly decentralised and involves all levels. Surgery and radiotherapy are still the principal curative methods of treatment. Medicines are used for many cancers, principally as adjunct therapy.

Cancer care is a distinctly multidisciplinary activity. A number of different specialties are involved, from diagnostics to rehabilitation, follow-up and palliative care. Uncertainty of access to pathologists, radiologists, oncologists and urologists poses a significant problem. The supply of doctors, according to National Board of Health and Welfare projections, will increase more slowly over the next fifteen years than in the past decade. The projections for specialties of significance to cancer care are uncertain.

Despite increased knowledge of risk factors and causal connections and progress achieved in cancer treatment, cancer morbidity and mortality continue to pose a great challenge for research. Successful research is of key significance to the future development of cancer care. The Swedish Research Council has recently assessed Swedish cancer research as outstanding in such fields as growth biology, tumour immunology, cancer genetics and cancer epidemiology. There are several outstanding research teams at the major universities. Swedish clinical research has, however, lost ground in an international comparison.

The Swedish Cancer Registry and the national quality registries in the field of cancer are the most important starting points for the follow-up of cancer care.

In comparison with other EU Member States, Sweden is middle-ranking with regard to the population's satisfaction with health and medical care in general. Reliable information is lacking on public and patient perception of quality of care and courtesy and of the ability of the system of care to adapt to the needs of the individual. There is criticism of inadequate continuity and fragmentary care with long waiting lists, resulting in anxiety and uncertainty.

Several county councils/regions in Sweden have taken decisions on action plans or similar measures for cancer care. Common features include an emphasis on primary prevention, supply of expertise and better utilisation of existing expertise, care processes and costs of medication.

Several countries have adopted national action plans in the area of cancer, often as a consequence of an anticipated increase in incidence and prevalence. Other reasons for doing so have been fragmented care and differences in access to care, poor treatment outcomes and increased costs, for instance for new medicines.

Part II Proposals

Why is there a need for a national cancer strategy for the future?

On the basis of the current situation in the area of cancer and anticipated future development, we have identified the following issues as being of key significance for the future.

A long-term strategy is necessary in response to a future increase in prevalence

Projections point to a doubling of cancer prevalence by 2030. Future projections are obviously subject to some uncertainty. Changes in people's lifestyles, breakthroughs in research and treatment and changes in other morbidity are all factors that may develop differently than has been assumed in the calculations. It is also difficult to predict what the increase in prevalence will mean in terms of resources needed in medical care. An increase does not automatically mean an equivalent increase in care needs.

It is, however, evident that a long-term and purposeful strategy to respond to the trend is essential if outcomes are to be maintained and improved in cancer care.

Society must increase its investments in prevention – the most significant element in reducing cancer morbidity and mortality

Although great progress has been made in the medical treatment of cancer and further improvements will undoubtedly be made, it is preventive efforts that can produce the greatest gains in saving lives and reducing suffering. Early detection is of great significance for good treatment opportunities.

Our view is that society must increase its investment in prevention through sustained and coordinated investments and through support for research on effective preventive methods and the implementation of these methods.

Creation and dissemination of knowledge in cancer care and prevention must be improved

Government appropriations for cancer research to the universities or via the research councils need to be increased if Sweden, in the interests of future patients, is to continue to conduct its own high-quality research in international cooperation. The prospects for research of no commercial interest also need to be improved. Interdisciplinary research approaches need greater support, for example to bring about knowledge on how to influence risk behaviour or how to increase take-up in public screening programmes.

It is already difficult for those involved in medical care to keep themselves informed about the development of knowledge in cancer care, cancer research and medical technology. An increasing future volume of information will make further demands on the ability to absorb new knowledge and put it into practice.

The organisation of cancer care needs to be developed

The present-day organisation needs to be developed towards both centralisation and decentralisation, on the basis of a deliberate level structuring. Preclinical and clinical research and clinical activity need to be brought closer together. Cancer care should be notable for multidisciplinary case management and be undertaken on the basis of a comprehensive perspective.

National coordination is becoming increasingly necessary and must be put on a firmer footing

There is an ever stronger trend towards cooperation at national level on issues which for various reasons cannot or should not be dealt with solely at regional and local level. This applies, for example, to standards of treatment, expertise networks and follow-up of activities. Much of this to date has, in the main, been professionally driven.

en. Such positive activities should be put on a firmer footing, with the aim of ensuring future quality and provision.

Cancer care must meet the needs of future patients for information and quality in case management

Swedish cancer care achieves good medical outcomes, and patients are generally satisfied with medical care. But patients also criticise certain shortcomings in cancer care, criticism that is shared by many people involved in the provision of care.

It is necessary for future cancer care to be organised and carried out so that the patient has confidence in the care provided and is treated with respect for reasonable wishes and requirements. The organisation of care and the systems for valuation of care need to be developed to support a combined and patient-focused care process.

Special efforts need to be made to reduce differences between population groups

People living under poorer socioeconomic conditions are at greater risk of developing and dying from cancer. The differences are mostly linked to contributory factors such as lifestyle. The population of Sweden is now heterogeneous in terms of ethnic and cultural background. Information and other preventive efforts should be adapted accordingly. There are signs of increased social inequalities in health in the future, including exposure to cancer risks and access to the best care.

Greater attention needs to be paid to the socioeconomic differences in the future. Alongside ethical and democratic reasons for doing so, there is great potential here to reduce total cancer morbidity and mortality.

Development will make great demands on priority-setting and attitudes towards types of funding

The Medical Management Centre at Karolinska Institutet, on behalf of the Inquiry, has conducted a future analysis of non-medical trends and other factors that may have a significant bearing on

Swedish cancer care. This largely entails issues of a political nature, which have not come within our terms of reference.

In view of the anticipated trend, a number of necessary positions are adopted on prioritisation: prioritisation of health and medical care in relation to needs in other sectors of society, prioritisation of resources for prevention, treatment and care in the final stage of life and prioritisation of cancer care in relation to other areas of disease.

It is also noted in the future analysis that there is an increasing tendency among patients to pay for private care. A question for the future will be to what extent patients wish to and have to pay for parts of public care themselves. The number of private companies offering medical services is likely to increase, depending on the willingness of politicians to prevent or facilitate such a trend. New types of private organisations may require new forms of government regulation in order to guarantee quality and patient safety.

What is a national cancer strategy for the future?

A national strategy means that the issues raised are of common and national interest, where proposed measures necessitate coordination and support at national level.

A strategy for the future is aimed at bringing about and supporting long-term solutions that foster the ability to meet future challenges and influence development in a favourable direction. The strategy is thus not an action plan for solving present-day problems.

A strategy for cancer may also be usable in other contexts. Most aspects, from risk factors to care and research, are common to several and sometimes all disease groups. We have tried, as far as possible, to make proposals that, in any case in the longer term, need not be limited to the field of cancer.

We have divided cancer strategy into three parts: cancer from a public perspective, cancer from a patient perspective and supply of knowledge and expertise.

Cancer from a public perspective

Primary prevention

Although only some of the causative factors for cancer have been clarified, there is sufficient knowledge of risk factors and preventive methods today to be able to influence the future trend in cancer morbidity and mortality. WHO estimates that at least a third of all cancers are caused by risk factors that are preventable.

Our view is that far greater attention must be given to smoking, obesity, lack of physical activity, high alcohol consumption and excessive exposure to UV radiation in public-health policy.

There is a need for combined and sustained preventive efforts. This work must be pursued towards goals that can be followed up, so that it can be continuously evaluated and if necessary revised, in particular as new knowledge emerges on correlations and preventive methods. Our assessment is that public-health policy lacks the clear goals and structures needed to prevent lifestyle-related morbidity from cancer and other major common diseases. Opportunities to influence future development in a positive direction are thus not exploited as much as they could be.

In our judgement, there is reason for central government to take greater responsibility for combined primary prevention activity, including that which takes place in health and medical care. The costs of preventing deaths from cancer, and other diseases, should be judged in relation to costs in other sectors of society to prevent deaths, i.e. on the basis of horizontal prioritisations. The county councils /regions do not have the same opportunities to undertake such overarching horizontal priority-setting, while care, according to Swedish Parliament guidelines, must be accorded higher priority than prevention.

Smoking is the single greatest cause of disease and premature death in Sweden. The Government has adopted a number of interim targets to reduce tobacco use by 2014: a tobacco-free start in life, halving of the number of young people who start to smoke or take snuff before the age of 18, halving of the proportion of smokers among the groups that smoke most and a situation where no one will be involuntarily exposed to smoke. A follow-up shows, however, that further efforts are needed if the goals are to be achievable by 2014.

We propose:

- that all primary care units offer readily available and effective smoking cessation programmes by 2014,
- that all patients are asked about smoking habits and that information about smoking is included in medical records,
- increased information and training initiatives in relation to smoking for staff in health and medical care and schools,
- increased efforts focused on the heaviest smokers,
- follow-up of the Government's goals under the cancer strategy and formulation of new goals after 2014 and
- that the Government should consider the introduction of other smoking policy measures such as price increases and banning of marketing.

The anticipated increase in malignant skin changes is cause for concern particularly in view of the poor prognosis for malignant melanoma. This trend is related to the fact that people, principally children and young people, are being exposed to the sun to an increased extent. Early diagnosis and check-ups where there is a risk of relapse are very important.

We propose:

- measures to increase the proportion of tumours detected at an early stage, for instance by making it easier for the public to have skin changes investigated,
- a more appropriate distribution of roles between dermatologists and general practitioners in diagnostics and
- consideration of a minimum age for solariums.

Cancer vaccines

The development of vaccines in the area of cancer has progressed slowly to date. However, a great deal of research is in progress both in pharmaceutical companies and in academic institutions on the development of new cancer vaccines in addition to the few that already exist. Preventive cancer vaccines are given to healthy individuals to avoid infection that can lead to cancer. Therapeutic vaccines are aimed at inhibiting the development of cancer in individuals who are already ill, and there are probably great treatment options for the future here.

We propose:

- that future preventive cancer vaccines should benefit everyone through national coordination
- that future therapeutic vaccines should be introduced into care according to the same model for introduction and follow-up as we propose for medicines.

Early detection

It is generally the case that the earlier a cancer is detected, the better the prognosis. Effective screening programmes are therefore very important. Our view is that the prospects of cancer being detected early through screening should be equal throughout the country and for the whole population.

We propose:

- that existing and future screening programmes should continuously be followed up so that quality and take-up rate can be assessed and improved,
- that future screening programmes should be introduced in a coordinated and structured manner to avoid regional differences,
- that a level of take-up for cervical screening of at least 85 per cent should be achieved throughout the country,
- that a take-up rate for mammography of at least 80 per cent should be achieved throughout the country, as a first stage while the establishment of national follow-up is awaited and
- special efforts to reach groups with a lower take-up rate than others.

Public access to knowledge

Our assumption is that people are willing today, and will be willing in the future, to influence and take responsibility for their own health. There is growing interest in, and ever increasing awareness and knowledge of, health issues. At the same time there is a parallel trend towards more unhealthy lifestyle habits, which can lead to greater differences in health and well-being.

The health authorities have statutory responsibility for providing information on health and how to prevent disease. We consider it crucial for the future that the information is individually adapted and takes account of people's differing opportunities to benefit from infor-

mation. We also propose that the healthcare advisory service Sjukvårdsrådgivningen SVR AB, which is owned by the county councils/regions, should develop a special information service on cancer.

Cancer from a patient perspective

Swedish cancer care in general achieves comparatively good medical outcomes. There are, however, problems with fragmentation of healthcare, long and variable waiting times and a general lack of patient focus. These problems are not in themselves unique to cancer care, but they may become particularly acute for cancer patients, as the disease often follows a prolonged course and involves many different disciplines.

A patient who develops cancer today may live for decades with and after his or her diagnosis. Good interaction between patient and healthcare provider, based on reliable information and open and trusting communication, is essential to the patient's well-being and the outcome of care. In addition, a coherent care process without unnecessary lead times should be self-evident. There is reason to anticipate that a greater number of patients in the future will fulfil a more consumer-oriented role with greater demands for information, participation and processes that work smoothly.

We have identified a number of measures aimed at strengthening the position of the patient in cancer care. In our judgement, the measures are based on sufficient knowledge and experience to justify early implementation. We additionally propose a national trial to develop and test new measures and initiatives.

To improve information and communication between patient and carer, we propose:

- that each patient should be allocated a specific contact at the cancer-care clinic at the time of diagnosis,
- that a multidisciplinary care team should be involved in the care of each cancer patient from the outset and
- that an individual care plan should be drawn up for each patient.

To reduce lead times in cancer care, we propose:

- that limits are defined for the lead times from the issuing of a referral to the first appointment with a doctor in a specialist clinic, from diagnostic action to notification of diagnosis and from treatment decision to therapeutic action and

- that information on lead times is included in all national quality registers in the field of cancer.

To strengthen follow-up and evaluation from a patient perspective, we propose:

- that measures of health-related quality of life and patient satisfaction are included in all national quality registries in the field of cancer and
- that a national patient study among patients with cancer is carried out.

To improve management and activity development in a patient perspective, we propose:

- that quality registry data on lead times, health-related quality of life and patient satisfaction are included in the management information,
- that healthcare providers consider appointing care coordinators to monitor patient flows and lead times and
- that patient representatives are given new opportunities to take part in the planning and design of cancer care.

Activities centred on the cancer patient are being tried out today in many parts of the health service. However, there is a lack of scientifically proven experience of how coherent and patient-focused care processes in cancer care can be designed. We therefore propose that trials should be conducted in some selected county councils/regions in 2010–2012. The trials are to be assessed, conducted and evaluated according to scientific criteria. The focus should be on measures to counteract the fragmentation and logistic problems of cancer care. An important element is to test reimbursement models and classification systems that support the coherent care process.

Children and young people

Survival for children and young people with cancer has improved substantially over the past few decades. This is the result of intensive medical development in both diagnostics and treatment. The improved treatment outcomes mean that the number of people who survive cancer in childhood and adolescence is increasing. However, they are at risk of being affected by complications later in life, both

from their disease and from treatment which in some cases makes heavy demands on them. Many people need specialist care and rehabilitation for a long time after their treatment has been completed.

To meet future needs it is, in our view, crucial that greater effort is put into research and development of knowledge on side-effects. Adequate resources and expertise are required to meet the increased need for follow-up, care and support in the event of late complications.

Palliative care

Palliative care has improved over the past decade, but there are still shortcomings and differences in both availability and quality, and equivalent care cannot be offered across the country.

Palliative care is based on multidisciplinary collaboration between doctors, nurses, rehabilitation staff, social workers etc. Both county councils/regions and local authorities are usually involved, which makes smooth collaboration all the more important. Knowledge and expertise have developed, but not to a sufficient extent.

In accordance with the Swedish Parliament guidelines for priority-setting, palliative care should be accorded high priority in the health service. Despite this, needs for resources are evidently neglected. In view of the poor baseline situation combined with the future resource-related challenges, there is a serious risk of palliative care continuing to be under-resourced in the future in relation to needs and the high priority this area ought to be accorded.

Our view is that resources must be allocated to palliative care to meet future needs and reduce differences in availability and quality. Insofar as central government might consider general grants for the funding of cancer care, there is reason for this to be directed to palliative care.

Access to and use of medical technology

Medicines and medical devices and methods will become an increasingly important element in future cancer care. Over the next few years, the number of new cancer drugs introduced into care will rise from two to three per year at present to around five to ten

per year. Medical devices are becoming increasingly significant in both cancer diagnostics and treatment.

In our view it is essential that access to medicines should not be dependent on where in the country the patient lives. It is just as important, not least with the future development of new medicines in mind, that drugs that have been introduced into care are used cost-effectively. There is a need for health-economic assessments prior to the introduction of in-patient medicines paid for by the health authorities, which applies to the majority of new cancer drugs.

There is also a need for follow-ups of patient benefit and cost-effectiveness for medicines after they have been introduced into care, which generally requires a substantially larger patient population than an individual county council can provide.

We propose that:

- the healthcare authorities coordinate the introduction of new medicines,
- the Dental and Pharmaceutical Benefits Agency should make health-economic assessments of in-patient medicines and
- nationally coordinated follow-up should be introduced.

We also consider that new medical devices, in the same way as medicines, should be evaluated nationally on the basis of a health-economic perspective to assist the healthcare authorities in decisions on whether or not to introduce them. Consideration should be given to which authority or authorities is or are suitable for such an assignment.

Supply of knowledge and expertise

During the course of the inquiry we have gained an insight into the rapid development of knowledge in cancer care, medical science and technology. The increase that has taken place in the survival of cancer patients is linked to improvements in secondary prevention, diagnostics and treatment. With a continued commitment to research and other development of knowledge, progress in the cancer care will be slower in the future.

The number of patients with cancer will increase sharply, which together with other anticipated challenge necessitates pro-active measures, long-term planning and new approaches to ensure good future access to knowledge and expertise. The cancer patients of

tomorrow, regardless of where they live and who they are, must benefit from evidence-based treatment.

Cancer centres and level structuring

We consider there to be a need for a better basis than at present for the development of new knowledge for prevention, diagnostics and treatment. In particular, the transfer of knowledge between preclinical research, clinical research and clinical activity needs to be facilitated. There is also a need for a more multidisciplinary approach in both care and research. An important element in these efforts is strong and creative environments, where the workforce, by virtue of its numerical and combined competence, can develop advanced cancer care and research, where there are good opportunities for in-depth study and specialisation. Other measures are concerned with improvements to the infrastructure of research, for example laboratory facilities, biobanks, health data registries, quality registries and various types of IT support.

We propose the development of regional cancer centres (RCCs) alongside the university hospitals. RCCs are to

- provide diagnostics, treatment and population-oriented research, preclinical and clinical research and training,
- promote the transfer of knowledge between research and care,
- feature multidisciplinary case management and be run on the basis of a comprehensive perspective and
- take responsibility for information and training in relation to county medical care and primary care in the region.

There should be appropriate structures and adequate resources in RCCs to support development of knowledge in the area of cancer in the region. Existing resources in present-day oncology centres (ROCs) should be transferred to RCCs.

We do not consider it possible to specify a particular number of RCCs. It may, for example, be appropriate for two nearby regions to opt for a joint RCC in order to attain sufficient size. A clear mutual division between RCCs should gradually take place so that expertise and equipment can be put to the best possible use from a national point of view and to enable large investments to be made. We consider it natural and desirable for one or two RCCs in the longer term to attain such quality and strength that they qualify as

Comprehensive Cancer Centres (CCCs) according to established international criteria.

The anticipated increase in the number of cancer patients is a strong reason for both centralising and decentralising the distribution of work tasks between primary care, county medical care and RCCs. The increased specialisation means that a greater proportion of the patients of the future need the investigation and treatment capacity that only regional centres will be able to offer. It will not, however, always be necessary for the patient to attend an RCC as technological progress continues. Increased prevalence, with consequent volumes of care, will necessitate increases in capacity in both county medical care and primary care. Some parts of the care process should be located close to the patients, for example various types of rehabilitation, palliative care, check-ups and complementary medical treatment of various kinds.

We consider

- that each medical care region should draw up a regional strategic plan for the sharing of responsibilities and level structuring in cancer care on the basis of RCC principles.

Commitment to cancer research

A special commitment to strategic research in the field of cancer is proposed in the Research and Innovation Bill recently adopted by the Swedish Parliament. In addition, commitments to other areas of significance to cancers are proposed. Our view is that continued, long-term and large investments to support cancer research are needed. Research breakthroughs are taking place in several areas, and new opportunities for prevention, diagnostics and treatment are in prospect. Translational research should be supported, and RCCs should be important hubs in this development.

The Clinical Research Inquiry (U 2007:4) has proposed that SEK 200 million annually should be allocated to clinical studies and interventions which for various reasons are not of commercial interest. We wish to emphasise that this is very important for the field of cancer.

Improved follow-up of cancer care outcomes

Follow-up of care outcomes is of key importance to all forms of clinical development. Cancer care has been a forerunner in the establishment of follow-up through the Swedish cancer registry and the regional oncology centres. At present there are more than fifteen national quality registries in the cancer areas. However, the information is inadequately processed, analysed and used. Many registries have shortcomings, so that they are not used as much as they could be. Several registries also have a low rate of coverage.

We propose:

- that existing health data and quality registries in the field of cancer should be strengthened, improved and better utilised,
- that the quality registries for cancers should serve as a model for mandatory reporting, hundred per cent coverage and in-depth reporting at hospital level and
- that RCCs be given overarching responsibility for quality and activity follow-up in the region.

The follow-up of the use of medicines merits special consideration. A rapid increase in the number of new cancer drugs can be anticipated over the next few years. Use is more “experimental” for these new drugs, with wide differences between prescribers, clinics and county councils/regions. There are therefore strong grounds for following up treatment outcomes on the basis of committed resources. Similarly, there is a national interest in following up and evaluating existing and future screening programmes. Studies of this kind often require a large population base, and national funding would therefore make it easier to set up the studies. We therefore propose that central government should be responsible for funding such studies. We wish to emphasise that the need for follow-up is not unique to cancer medicines.

Measures to ensure future supply of expertise

In a future perspective there is a great risk of the present-day problems of inadequate access to certain types of expertise worsening due to the increasing strain cancer care will face.

We propose:

- that each healthcare authority should make a plan for long-term supply of expertise in cancer care,
- that responsible authorities should draw up a long-term plan regarding content of training and training places in basic and specialist training and continuing professional development for occupational groups concerned and
- that occupational groups other than healthcare professionals should be used for supporting functions, IT, technology and logistics.

Five overarching goals for the strategy

A strategy needs to have clear goals to drive implementation and to enable an assessment to be made of whether the intended effects have been attained. We propose five overarching goals for the strategy.

These are to

1. reduce risk of developing cancer,
2. improve the quality of cancer patient management,
3. prolong survival time and improve quality of life after a cancer diagnosis
4. reduce regional differences in survival time after a cancer diagnosis and
5. reduce differences between population groups in morbidity and survival time.

The National Board of Health and Welfare should be commissioned to establish baselines for all the goals, i.e. current levels and status as a basis for continued follow-up. Goal fulfilment should be assessed on the basis of trends in other comparable countries and taking account of what it is reasonable to expect in view of new knowledge that continuously emerges.

How is the cancer strategy to be implemented?

We propose that the cancer strategy should be established under an agreement between the Government and the Swedish Association of Local Authorities and Regions. Consensus and cooperation between health authorities and central government are necessary for

successful implementation, as well as a clear structure for implementation and follow-up. The agreement should cover the investments to be made, in addition to responsibilities, funding, timetables and goals, as well as forms of support for implementation and follow-up of the strategy. The follow-up should take place continuously and be integrated with implementation and form a basis for regular revisions of the strategy.

Costs, priorities, consequences

We propose that the Government and the health authorities enter into an agreement on the national cancer strategy for the future, including how the various commitments are to be funded and prioritised in the field of cancer. This also encompasses the issue of prioritisation between the field of cancer and other parts of health-care and between medical care and other sectors of society.

We estimate that

- the costs of cancer to the national economy will increase from SEK 34 billion today to just under SEK 70 billion in 2030,
- future costs of cancer medicines over the next few years will continue to increase by between 10 and 20 per cent annually, but the rate of increase will then fall appreciably and that
- intervention programmes for smoking cessation may save billions of Swedish kronor for society, including health care.

We estimate that the more specific proposals we make in the report signify a non-recurring cost of at least SEK 120 million and annual costs of more than SEK 170 million. With regard to any central government grants to cancer care, our view is that central government in particular should wholly or partially provide funding for specific and strategically important purposes. Central government grants, managed at national level, can both simplify and accelerate desired development.