The development of regional cancer centres

An overall assessment of a four-year follow-up

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Foreword

Based on proposals in the official report by the Swedish Government, *A National Cancer Strategy for the Future* (SOU 2009:11), the Swedish Government introduced the establishment of regional cancer centres (RCC) in each and every healthcare region. The aim of the RCC is to increase healthcare quality and improve care results, as well as increase the efficiency of the use of health and medical care resources. One basis for the work by the RCCs has been the ten criteria stating what should characterise a regional cancer centre and provides a four-year timescale. Between 2013 and 2016, the Swedish National Board of Health and Welfare was commissioned to follow up and support the establishment of regional cancer centres based on these criteria, and submit an annual progress report to the Government (Ministry of Health and Social Affairs) with details of their development.

In 2016 the National Board of Health and Welfare was also commissioned to submit an overall assessment of the development of RCCs, following the work with the criteria presented in this report. The report is primarily aimed at the government, however it may be of interest to the RCCs, county councils and regions, patient organisations and other interested parties.

Special thanks go to Göran Henriks and colleagues at Qulturum for their support in the work on the matter of how to approach the assessment of change and improvement work.

The project has been conducted by project leader, Helena von Knorring and Göran Zetterström. In charge was temporary unit manager, Inger Lundkvist.

Olivia Wigzell
Director General

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Summary

In collaboration with county councils and regions, the government has focused longitudinal efforts on establishing regional cancer centres (RCC). Its basis was the challenges faced by society as cancer morbidity increases and as improved treatments mean that those affected by cancer are able to live longer. Great demands are placed on preventative measures and effective use of resources in health and medical care.

Fundamental to the effort has been the official government report, ‘A National Cancer Strategy for the Future’ (SOU 2009:11) and targeted government support driven by ten criteria to be met by the RCCs. The National Board of Health and Welfare has closely followed the development through its annual assignment of following up and supporting the establishment of RCCs. This report was commissioned by the Government to provide an overall assessment of the RCCs’ establishment.

A successful investment in RCCs

The National Board of Health and Welfare believes that the joint efforts between the government, county councils and regions have been firmly grounded, comprehensive and carefully implemented. One important requirement has been the dialogue and clarity of what is to be achieved and the follow-up of the work conducted.

All RCCs are now fully established after their four-year implementation period. On the whole, they have successfully met all 10 of the of the established criteria – or at least the majority of them. RCC organisation is flexible and efficient, with developed process work.

The National Board of Health and Welfare believes that formulation of methods used to establish the regional cancer centres can serve as a generic model within other areas.

Success factors

A number of success factors characterise the work of the RCCs. One example is how each healthcare region has mutual development plans for cancer care in their particular counties/regions. Sweden currently has a national cancer strategy with six regional cancer plans based on the local development needs. Other significant success factors include

- patient centering and patient participation,
- profession-driven development with a solid grounding,
- an established knowledge management model,
- increasing nationwide collaboration,
- new conditions for good, more equal healthcare,
- high levels of skills at RCCs and in the Confederation of Regional Cancer Centres in Sweden (national collaboration group, CRCC).

Effects

Several effects have been felt from the work by the RCCs, for example

- patients and their next of kin contribute to the development of cancer care
- 29 national practice guidelines
- process work with local discussions for more knowledge-based healthcare
- a total of 19 national healthcare units for highly specialised care, as of 1 January 2017
- completed regional-level structuring in several regions.

Some additional examples of development to cancer care that RCCs have contributed to, together with county councils/regions include:

- more contact nurses in cancer care
- more patient evaluations in multi-disciplinary conferences (MDC)
- more individual healthcare plans in the form of "My Care Plan" [Min vårdplan]
- an online portal for ongoing clinical studies that makes it easier for healthcare professionals and patients to find suitable studies.

Continued challenges

The establishment of RCCs has been a success. Nevertheless RCCs and cancer care continue to face challenges.

The National Board of Health and Welfare has noted that there are examples of certain county councils and hospital and clinic management that are less involved in RCC development. According to the interviews we conducted, these are thought to be increasingly fewer and more people express the advantages of RCCs.

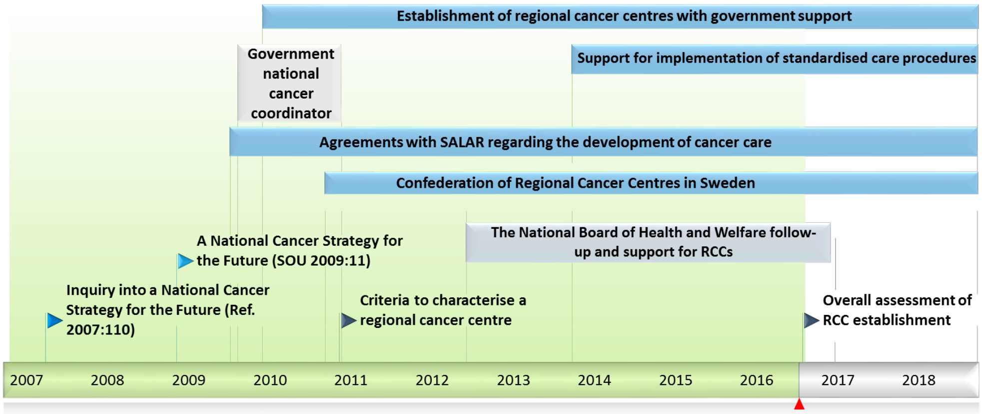
One criterion that has been difficult to successfully fulfil has been the provision of skills, as many actors have an individual responsibility for this. Other areas that continue to face challenges include level structuring and preventative measures.

Certain regions have expressed concern about the future of the RCC as this is unclear after 2018. The Government intends to provide support for RCCs, at least during their current term. At the start of the venture, it was stated that support would be given during the implementation period. Since county councils/regions have yet to decide on the full financing of RCCs after 2018, there is an increasing risk that the extent of regional cancer centres will significantly decline once government support is withdrawn.

Introduction

The government venture for the development of cancer care began with an enquiry for a national cancer strategy that was adopted in 2007. Since then, through agreements with the Swedish Association of Local Authorities and Regions (SALAR), the Government has continued to support the development of cancer care and the current government intends to continue these efforts for the remainder of their term. The image shows the national efforts in the form of milestones and ongoing processes since 2007.

Development of national efforts since 2007



A more in-depth description of these efforts is provided below.

A national cancer strategy for the future

An inquiry is appointed

Due to the expected increase in cancer morbidity and survival rates, in July 2007 the government appointed the inquiry, *A National Cancer Strategy for the Future* (Ref. 2007:110), with the aim of reducing morbidity and mortality rates as well as improving the quality of care for patients with cancer.

The leader of the inquiry would propose an evidence-based strategy from an overall perspective that includes primary and secondary prevention, early discovery, diagnostics and treatment, palliative care, increased knowledge and its dissemination. The commission also included the matter of strengthening the patients' perspective, for example through a chain of healthcare built on consideration of the patient's need for consistency, accessibility, predictability, reliable decisions and clear information.

Official government report: A National Cancer Strategy for the Future

In February 2009, the leader of the inquiry submitted the report, *A National Cancer Strategy for the Future* (SOU 2009:11).

The report identifies vital issues for the future and proposals for the content of a national cancer strategy. It also includes comprehensive goals and formulations for its follow-up and implementation. Some of the proposals for the future included how

- a long-term strategy is necessary in response to a future increase in prevalence
- society must increase its investments in prevention – the most significant element in reducing cancer morbidity and mortality
- creation and dissemination of knowledge in cancer care and prevention must be improved
- the organisation of cancer care needs to be developed
- national coordination is becoming increasingly necessary and must be put on a firmer footing
- cancer care must meet the needs of future patients for information and quality of care
- special efforts need to be made to reduce differences between demographic groups
- development will place great demands on priority-setting and attitudes towards types of funding.

Five goals of the strategy

A strategy needs clear goals to drive its implementation and to be able to evaluate whether the intended effects have been attained. The report included five overarching goals for the strategy:

1. reduce the 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.

A number of proposals for measures were submitted in the report. Amongst the proposals was the establishment of regional cancer centres (RCC).

Establishment of regional cancer centres

According to the government assessment, the most strategically important of the proposals submitted in the inquiry was the establishment of regional cancer centres (RCC), as this is a concrete way to strengthen the development and dissemination of knowledge within cancer care. The government opted to develop the proposal. The aim of establishing RCCs was to stimulate an organisation of health and medical care in the form of regional cancer centres in order to achieve improved healthcare quality and results alongside more efficient use of health and medical care resources. The government implemented several measures to facilitate the establishment of regional cancer centres.

The report suggested that regional cancer centres be established in connection with university hospitals. RCCs should

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

Furthermore the report deemed it desirable for one or two of the RCCs to achieve such a level of quality and strength that they qualify as 'Comprehensive Cancer Centres' (CCC) fulfilling established international criteria. RCCs should have both information support and implementation roles in cancer care. Meanwhile the role of the RCC was changed in step with the negotiations between county councils and regions during the establishment of the criteria to characterise a regional cancer centre.

A national cancer coordinator

To facilitate the establishment of regional cancer centres, in 2009 the government appointed a national cancer coordinator tasked with bringing the process together and furthering the development of the RCCs. The assignment also included creating criteria for what is to characterise an RCC based on the principles stated in *A National Cancer Strategy for the Future*.

After discussions with the trustees and other interested parties, the cancer coordinator proposed that each healthcare region should have its own RCC. Such a solution would make it possible to utilise existing structures to steer the healthcare region. The RCCs' work to reinforce Swedish cancer care could therefore be initiated without delay being caused by discussions of geographical distribution. The cancer coordinator also emphasised the importance of collaboration across healthcare regions. RCCs would subsequently be established as organisations to support knowledge alongside healthcare rather than at university hospitals. They would therefore be able to simultaneously provide the care proposed in the report for a national cancer strategy.

Criteria to characterise a regional cancer centre (RCC)

In January 2011, the government's national cancer coordinator presented the memorandum, *Criteria to characterise a regional cancer centre*. In the work to establish these criteria, consideration was paid to the opinions of the referral bodies, meetings with representatives from health and medical care trustees, patient associations, professionals and other interested parties within Swedish cancer care.

The memorandum contains ten criteria and a description of their content. It stipulates what RCCs are to achieve based on the principles in the report, A National Cancer Strategy for the Future. The criteria are split into three sections

- patient-centred criteria
- education, knowledge management and research criteria
- criteria for the organisation of RCCs

The criteria form the basis for the RCCs' work with the development of cancer care. The criteria also state that RCCs are to have a clear management organisation that is closely connected to the county councils and regional management in their respective healthcare regions.

The criteria also present a four-year timescale for the project's completion. After these four years, the RCCs are to be viewed as having been fully established. Now that these four years have passed, RCCs – alongside their county councils and regions – are at the end of the initial phase of the work to support the development of cancer care. See further information about the criteria in Appendix 1.

Financial stimulus for establishing RCCs

Since 2010, the government has allocated financing to stimulate the creation of six RCCs. In recent years, each RCC has received annual government support of SEK 8 million. Funding is provided through the National Board of Health and Welfare. See chapter *On the right track – good use of resources?*

National collaboration

At the same time, government financing has also been provided to SALAR through agreements for national coordination and assignments within specific areas of cancer care. The Confederation of Regional Cancer Centres in Sweden (CRCC) was established by instruction of the county council network of directors in December 2010. The CRCC comprises RCC management and SALAR coordinators, and is tasked with contributing to the completion of the cancer strategy.

The National Board of Health and Welfare has been commissioned to support the establishment of RCCs.

Between 2013 and 2015, the National Board of Health and Welfare was tasked with following up and supporting the establishment of regional cancer centres, using methods such as dialogue and annual site visits, plus the annual submission of a report to the Government with details of how the establishment of RCCs is developing. The annual report also presents assessments by the interested parties of the success factors, challenges and need for continued efforts. Three reports have been submitted by the National Board of Health and Welfare:

- Follow-up of regional cancer centres 2013
- Follow-up of regional cancer centres 2014 – establishment, strengths and challenges

- Follow-up of regional cancer centres 2015 – preventative measures and early detection, research and innovation.

In December 2015, the National Board of Health and Welfare was commissioned to continue the follow-up and support the establishment of RCCs in the fourth and final year of the implementation period.

The National Board of Health and Welfare assignment for overall assessment of the establishment of RCCs

In the assignment from December 2015, the National Board of Health and Welfare was also tasked with conducting an overall assessment of RCC establishment based on the existing criteria. This report builds upon the experiences of the National Board of Health and Welfare obtained through, amongst other things, the annual follow-up of the RCCs' work, interviews conducted with various interested parties and the relevant documentation from the respective RCCs, county councils and regions.

Methodology

In the work with the overall assessment, the National Board of Health and Welfare has followed a method in which the evaluation has drawn upon:

- previous reports submitted by the National Board of Health and Welfare on the follow-up of RCCs
- interviews with various interested parties about the development
- documentation obtained from RCCs, such as websites and other sources
- data collected from various registers

The National Board of Health and Welfare has conducted 360 interviews over the years during which we have been commissioned to follow up on and support the establishment of RCCs. The interviews have been conducted with politicians, county council and regional management, representatives from the professions, patients and their next of kin, as well as operational managers and employees at the RCCs. Some participants were interviewed every year, meaning we have been able to follow their opinions on the development; this applies to RCC managers, representatives from the collaboration board and regional healthcare management, in addition representatives for patients and their next of kin. We have systematically collected and compiled the interviews based on the groups of interviewees, and sought out areas where the same opinions have been voiced by different people within and between the different groups. In addition to these interviews, a number of interviews have been conducted in conjunction with an overall assessment. Moreover, we have held annual meetings with the central patient organisations to find out their opinions on the development.

The National Board of Health and Welfare has chosen to present the data significant to the development towards the goals in the report for a national cancer strategy. These data can however not be directly tied to results attained by the RCCs, as an RCC is a knowledge centre that submits proposals to county councils and regions, but is often unable to decide on their implementation. The development of cancer care and population health depends upon the actions of both regions and county councils as well as other actors. Furthermore, it is important to highlight that it is too early to see the effects of the RCCs' work, as they are at the end of the establishment phase.

The report provides examples of measures conducted by RCCs. The examples often relate to individual RCCs and do not necessarily mean that they have been implemented by all RCCs – they merely serve as an example to visualise RCC activities. For further information about the activities of each RCC, see previous reports from the National Board of Health and Welfare and the joint RCC website, www.cancercentrum.se [in Swedish].

Triple Aim

The National Board of Health and Welfare has chosen to implement a *Triple Aim* approach for the work with the chapter titled *On the right track?.*

Triple Aim is a concept for optimising the performance of the healthcare system and has been developed by the Institute for Healthcare Improvement (IHI) [1]. IHI believe that many reforms or change processes can benefit and be strengthened through the Triple Aim approach. The method involves applying three dimensions to new initiatives – improvement work, follow-up and evaluation:

- improve population health (knowledge and preventative measures)
- improve patient care (quality and satisfaction)
- effective use of resources (organisation, experts, equipment, costs).

The IHI Triple Aim is illustrated by a triangle, where each corner represents one of the dimensions. According to IHI, the systematic work with all three dimensions is essential for achieving effective change processes. When positive effects in all three dimensions are achieved, the foundations are then set to assess whether improvement work has been successful.

Triple Aim in the National Board of Health and Welfare report

The five objectives in the report, *A National Cancer Strategy for the Future*, form the starting point with the National Board of Health and Welfare's work with the chapter titled *On the right track?.* Additional starting points include the purpose of the investment in RCCs and the ten criteria for what RCCs are to achieve. The purpose of the investment in RCCs is to stimulate an organisation within health and medical care in the form of regional cancer centres that ultimately will achieve a higher quality of care and improve patient outcomes, use health and medical care resources more efficiently and reinforce patient perspective in cancer care.

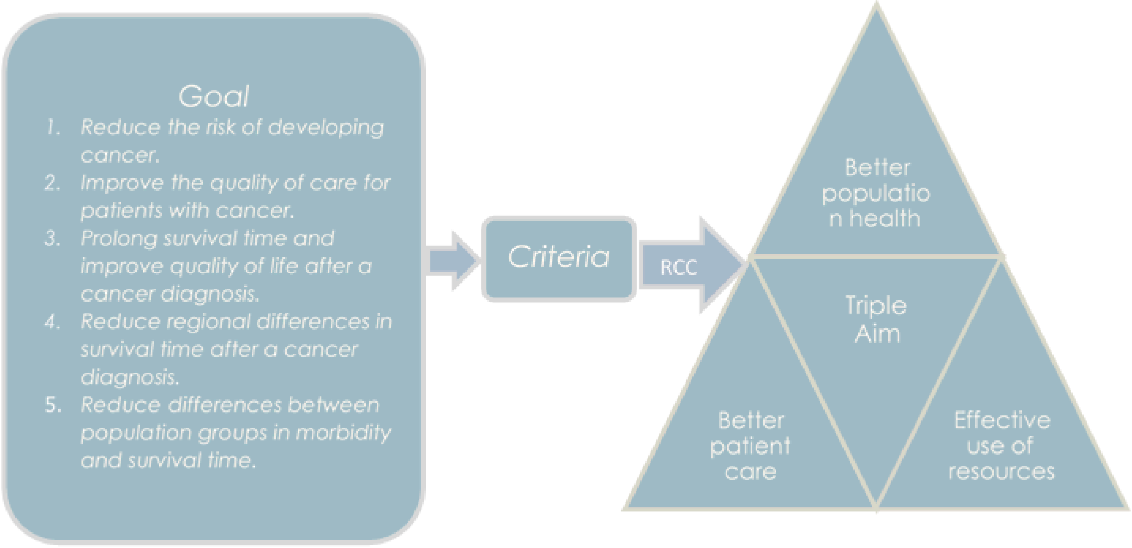
The criteria that are to characterise an RCC have been divided into three areas that are largely in-line with the three dimensions in the Triple Aim and apply to:

- patient-centred criteria,
- criteria related to education, knowledge management and research,

- criteria for the organisation of RCCs.

The concepts used by the National Board of Health and Welfare in the Triple Aim model are, *Better population health*, *Better patient care* and *Effective use of resources* that describe what the investment in RCCs entails and the strategy and goals that they aim towards. We illustrate this in the following image.

The image shows how the National Board of Health and Welfare uses Triple Aim in the report



Goal

1. Reduce the risk of developing cancer.
2. Improve the quality of care for patients with cancer.
3. Prolong survival time and improve quality of life after a cancer diagnosis.
4. Reduce regional differences in survival time after a cancer diagnosis.
5. Reduce differences between population groups in morbidity and survival time.

Structure of the report

Parts of the report

The report includes a summary, an introductory section with a description of the background for the establishment of RCCs, the tasks of the National Board of Health and Welfare and methodology description for the work with the report. The following chapters are then presented,

1. Overall assessment of efforts on RCCs
2. On the right track – Better population health?
3. On the right track – Better patient care?
4. On the right track – Effective use of resources?

Chapters 2-4 provide the foundations for the overall assessment presented in Chapter 1. Chapter 1 provides reflections on the development of RCCs.

Chapters 2-4 are based on an approach referred to as “Triple Aim”. This chapter presents the respective dimensions highlighted in the National Cancer Strategy for the Future; the criteria that are relevant examples of investments from the RCCs and CRCC and examples of measures that can indicate the development for achieving the goals in the report for a national cancer strategy.

- the respective dimensions highlighted in the National Cancer Strategy for the Future
- the criteria that are relevant
- examples of common initiatives and actions implemented by RCC and RCC in collaboration
- some examples of measures that can indicate the development for achieving the goals outlined in the National Cancer Strategy

The National Board of Health and Welfare has opted for a national perspective without presenting each respective RCC. For a more comprehensive view of the RCCs' activities and the work conducted at the respective RCCs (see the previous reports by the National Health and Welfare and the RCC website www.cancercentrum.se [in Swedish]).
The following appendices are included in the report:

- criteria to characterise a regional cancer centre
- reference list
- selection of data in relation to Triple Aim
- list of national practice guidelines
- approved and recommended national care units

Overall assessment

In collaboration with county councils, the government has focused longitudinal efforts on the establishment of regional cancer centres (RCC). Since 2013, the National Board of Health and Welfare has been commissioned with following up and supporting the RCCs' work to meet the criteria that are to characterise a regional cancer centre. The criteria set out a four-year timescale for the establishment of the RCCs. On this basis, we have been tasked with conducting an overall assessment. The foundation for the assessment was the memorandum from the Ministry of Health and Social Affairs, *Criteria to characterise a regional cancer centre* (see Appendix 1).

The criteria relate to the establishment of RCCs in healthcare regions, hence there is large focus on the structures, for example, plans for the different areas created by the RCCs based on the conditions in their particular healthcare region. According to the criteria, the RCCs shall now be fully established. As RCCs are so new, it is too early to comment on the results from the RCCs' work in cancer care at the patient level. Nevertheless, the National Board of Health and Welfare sees success regarding structure and process.

Through annual site visits and a large number of interviews, we have been able to closely follow the establishment of all RCCs.

RCC – A successful investment

All RCCs have now been established and have successfully fulfilled the majority of the ten criteria that are to characterise an RCC. Regionally, they have a well-functioning organisation that reaches out to the local levels in their regions and nationally through the CRCC. The National Board of Health and Welfare believes that the establishment of regional cancer centres has a solid foundation that is clear, comprehensive and governs process.

The National Board of Health and Welfare is of the opinion that different parts have formed the basic conditions for the establishment of RCCs:

- The report, *A National Cancer Strategy for the Future* (SOU 2009:11) with the descriptions of challenges, goals and suggestions for initiatives.
- The implementation of a national cancer coordinator who, in consultation with the relevant actors, prepared the establishment and created timetabled criteria to characterise a regional cancer centre.
- Annual agreements with the Swedish Association of Local Authorities and Regions for national coordination and collaboration and various development projects.
- Several years of government funding for RCCs for their establishment based on the ten criteria, together with support and follow-up.

Together with the process work run by RCCs, we believe that generally, these aspects have worked well together with the support provided to RCCs from county councils and regions, where they allocated both personnel and financial resources.

RCCs have focused on the assignments highlighted in the criteria that we believe have been shown to work as a means of control for the efforts.

The National Board of Health and Welfare believes that an important factor for the success for the establishment of RCCs is the initial dialogue with the involved actors and the deep-rooted, clear understanding of what is to be attained. There has been a consensus on the efforts based on both the report's descriptions of the challenges and goals, and the ten criteria to characterise a regional cancer centre.

Success factors

The National Board of Health and Welfare is of the opinion that the concept used as the basis of the establishment can be a model for expanding local, regional and national development work and can serve as a generic model within other areas. One lesson learnt is that to introduce a similar initiative, the centres need to develop structures for the involvement of the relevant leadership levels within specialist and primary care in collaboration with county councils and regions.

The National Board of Health and Welfare particularly wishes to highlight the following areas as being success factors significant to the establishment:

- patient-centering and patient involvement
- profession-driven development with a solid grounding
- there is an established knowledge management model
- conditions for more equal healthcare
- high skills and acceptance
- increasing nationwide collaboration
- wide task provides a comprehensive view

Here we will review our conclusions in these areas.

Patient-centering and patient involvement

One of the greatest merits of the RCCs is the strengthened patient participation and patient-centering that has grown during the establishment of RCCs. RCCs have worked with patient participation and patient-centering in all aspects of the criteria to characterise a regional cancer centre. The National Board of Health and Welfare particularly wishes to draw attention to the following six aspects, the patient perspective, participation from the patient and their next of kin, contact nurses, my care plan, patient-reported measures and multidisciplinary conferences (MDCs).

Patient perspective

The first aspect we wish to highlight relates to the RCC process work, characterised by a patient perspective where patient needs and safety are placed at the centre and are to a great extent, based on medical results for patients, the patients' descriptions and experiences. This is clear in areas such as the work with developing care processes, level structuring and patient information. Another example is how, in cooperation with care providers, RCCs can carry out projects with patient diaries to receive insight into patient experiences and needs.

The National Board of Health and Welfare has noted that patient-centering varies somewhat; it differs and has reached different stages in different processes. Nevertheless, we believe that development is continuous and positive. The National Board of Health and Welfare is of the opinion that RCCs should continue to maintain strong focus on patient perspectives in development work.

Participation from patients and their next of kin

The second part applies to participation from patients and their next of kin in the development of cancer care.

The RCC's council for patients and their next of kin is the foundation for their influence and involvement in the development of cancer care. Representatives from the council for patients and their next of kin are included in the regional process groups, participate in local development projects, issue statements on care programmes and practice guidelines and the information material produced by the RCC. Council representatives are also included in the RCC boards/steering committees.

In the interviews conducted by the National Board of Health and Welfare throughout the RCC follow-up period, professionals, patients and their next of kin have emphasised the strength of the RCCs' collaboration with patients and their next of kin. They believe that the quality of RCC projects and care process work improves when the knowledge from patients and their next of kin is utilised. The National Board of Health and Welfare believes that RCCs have employed a well-developed structure for patient and next-of-kin participation by offering them initiatives such as educational packages and task descriptions.

Introduction of contact nurses in cancer care

The third part addresses the trend towards more contact nurses. Even though not all quality registries currently report the development of how contact nurses are offered, the RCCs, representatives for patients and their next of kin and representatives from cancer care clinics all express a positive development.

The RCC has driven the development of the allocation of contact nurses and has also formulated the task description and higher education courses for contact nurses. However, interviews have revealed that in practice, the assignments do not always meet the nationally established assignment description, nor has everybody received an assignment description. It has also come to light that it is important that sufficient time is allocated to be able to succeed in all areas of the assignment. The National Board of Health and Welfare believes it is important that the contact nurses' assignments are streamlined and the contact nurses have enough resources allocated to them to be able to successfully complete their tasks. It is also important that access to contact nurses increases, so all patients with cancer can be offered a contact nurse.

The report notes that patients need a continuous contact person throughout the investigation and treatment periods. A cancer patient may be transferred between several care units. Contact nurses are currently linked to the respective care units. This has meant that there has been continuous work to actively transfer patients between units. It may be better for the patient to receive one contact nurse throughout the healthcare chain; here the National Board of Health and Welfare believes that the organisational perspective has taken presidence over the patient perspective. On the other hand, the contact nurses themselves state that they believe it is important that they are specialised within the area for which the clinic is responsible, so they will be able to provide the expected support. As patients must change contact nurses between the care units, this can also cause difficulty with the follow-up in evaluating the extent to which a patient has been offered a contact nurse throughout the entire chain of care.

The RCCs have acted on the behalf of, and recommended that county councils and regions introduce contact nurses. However, not all care units follow the recommendation and several believe that just one set care contact is sufficient, as legislation states. However, a set care contact does not have the same tasks as a contact nurse. The National Board of Health and Welfare believes that if care is to be equal, all patients with cancer should be offered a contact nurse.

A health economics evaluation commissioned by Region South presents several advantages of the introduction of contact nurses. For example, the provision of contact nurses leads to significantly positive consequences for healthcare's organisation, such as the release of resources for other personnel categories, doctors in particular [2]. Positive effects are felt by both patients and the care organisation.

Introduction of My Care Plan

The fourth part addresses the development and introduction of *My Care Plan*, which is to be established in cooperation with the patient. My Care Plan enables the patient to actively participate in their care to the extent they wish. The plan is to make the patient feel secure and well-informed, give them an influence on their care and understand what happens during the investigation and treatment. My Care Plan is to be available from the moment when the patient receives a diagnosis, through treatment and during rehabilitation or palliative care. The contact nurse is often responsible for My Care Plan.

The National Board of Health and Welfare has noted that the implementation of My Care Plan has been arduous and time-consuming. Over the years, the RCCs have worked in different ways to develop a national digital My Care Plan to be able to follow the patient over county borders. For the past year, there has been ongoing development of a digital My Care Plan in the Support and treatment database in collaboration with 1177. Three county councils conduct pilot projects.

There are few quality registries that can report on the development with regard to whether patients are offered My Care Plan, hence why we are unable to state fully how far the implementation has come. Nevertheless, good examples exist; projects that have led to 100 per cent of patients being offered My Care Plan. A high portion of women with breast cancer receive My Care Plan. My Care Plan is more comprehensive than the care plans currently being used and that care providers often believe to suffice. We are of the opinion that continued effort is needed from care providers to ensure that all patients with cancer are offered My Care Plan – it is important to make the patient more involved in their care and be well-informed.

Development of patient-reported measures

The fifth area we wish to highlight addresses the development of investigations into patient experiences and follow-up of the quality registry, known as the patient-reported experience and outcome measures (PREM and PROM respectively). This enables the continual collection of cancer patients' experiences. Patient-reported measures can provide important knowledge and be used for follow-ups and continued development of cancer care. They are a vital complement to the knowledge and collaboration provided by patients and their next of kin. Several such investigations are carried out by the RCCs. Within the framework for efforts to reduce waiting times, a national PREM survey has been developed and is currently sent to all patients who have been evaluated with the standardised care procedure.

The National Board of Health and Welfare is of the opinion that the development and use of patient-reported measures have only made minimal progress. Nevertheless, continued efforts are required from several actors to increase so knowledge about patient experiences. Yet continued work to develop PREM and PROM remains, as does the creation of adaptations to the respective diagnosis groups, and an increase in the use of patient-registered measures in the quality registries.

Development of multidisciplinary conferences

The sixth aspect we wish to highlight relates to the development of multidisciplinary conferences (MDCs). RCCs have stimulated an increased application through expanding the possibilities for MDCs at the regional healthcare and national levels. The national practice guidelines state which patients should be included in MDCs.

Increasing numbers of MDCs are developed through the work with level structuring. MDCs increase the opportunities to more carefully prepared patient care plans. Several quality registries present the development of MDCs and the National Board of Health and Welfare sees that an increased number of patients are being assessed in MDCs.

Professionally driven development with solid foundation

Alongside the collaboration with the patient and next of kin mentioned above, we especially wish to emphasise the systematic working methods developed by the RCCs in which the care profession is involved in the development of the care from the local to the regional and national levels. The majority of development work includes people who participate in cancer care daily and who are highly skilled in their field.

The development driven by the care profession takes leave in its connection to real life and issues that directly affect those working in the profession and who are invested in the matters. This has a beneficial impact on the care profession, as personnel are directly involved in the work. The interviews have revealed that when people are aware of who has participated in establishing a care programme for example, it also receives high acceptance in the profession.

Knowledge management with process work

One aim of the RCC is to achieve increased quality of healthcare and improved care results. This means that care is based on current knowledge; that the right care and treatment goes to the right patient, at the right time. It is also a prerequisite for health and medical care resources to be used more efficiently. Good knowledge management, together with skills provision and resources for the implementation are decisive factors for attaining effective, high-quality health and medical care.

Knowledge management and process work are two things that the National Board of Health and Welfare wants to place particular emphasis on as success factors in the establishment of the RCCs.

The knowledge management model developed by the RCCs is well thought out and coherent. It builds a chain starting at the national level, with guidelines and practice guidelines, which is then transferred to the regional level and reaches all the way into the care units with help from local process managers and their teams. Work is run in collaboration within and between the care professions and patient and next of kin representatives. It is also rooted in administration and healthcare management. The National Board of Health and Welfare has not found such a cohesive approach in any other area of care.

The use of the knowledge management model has reached different stages in the county councils and works to varying degrees in the care processes. Efforts to reduce waiting times have led to the national/regional/local levels being brought together in their efforts to improve the patients' care process. In several instances, the introduction of standardised care procedures has been the key to improved care process work.

The difficulties attaining the use of guidelines and practice guidelines are well known. The National Board of Health and Welfare therefore assesses that it is vital that the knowledge management model is implemented to the greatest extent possible in all regions to increase the opportunities for the implementation of the practice guidelines.

The CRCC has ordered an assessment of how well the practice guidelines have been implemented. The report is expected in November 2016, but preliminary results suggest that the practice guidelines [3]

- have been highly accepted within the care professions where they are believed to be of high medical quality
- used to a great extent by doctors (with the exception of doctors in the early stage of their specialist training)
- used by contact nurses, depending on whether independent patient responsibility is included in the task
- used in training (such as section and clinical training, doctors' specialist medical training, regional meetings)
- used to a high extent during MDCs

The development of the quality registries is decisive for the follow-up and improvement work

In the work with the implementation of the practice guidelines and plans for different areas, the RCCs have developed an anchoring process with follow-ups of dialogues with various regional management levels and care personnel. The quality registries are frequently used as support for these dialogues. The National Board of Health and Welfare believes it is important that dialogues about the quality of care are constantly active and it is important that the quality registry can provide a basis for these dialogues. The development of the quality registry has therefore had a decisive role on the basis for the continuous dialogues, for example, patient-reported measures need to be developed.

The RCC is a registration centre for the 30-or-so quality registries and collaborations with the registries' management groups. The National Board of Health and Welfare believes that the collaboration between the registrars, process managers and RCC support teams has led to the quality registries being awarded an even clearer, more important role within cancer care. It has been a great advantage that the quality registry function lies with the RCCs.

Conditions for more equal healthcare

Several of the goals set in the national cancer strategy report apply to equal care and health. The National Board of Health and Welfare is of the opinion that RCCs have had a positive focus on equality in certain areas, such as the various surveys of differences between population groups and geographical differences to care and treatment.

Several projects aimed at different population groups are being conducted. For example, this has been clear in screening activities where the RCCs have worked with accessibility and the development of adapted information. Another example is the project in areas lacking socioeconomic resources.

Through attempts with increasingly nationwide work, such as the creation of national practice guidelines – where RCCs have gone one step further than the criteria require, and raised the establishment of practice guidelines from regional to national levels – which means that information support is the same throughout the country. By using the quality registries as a follow-up, differences can be detected in the implementation and increase the conditions for more equal care. The premise is that all patients shall be given access to the same good quality and equal care.

Another example is the national preparation of the data for level structuring, with suggestions for regional level structuring based on nationally compiled criteria for the assessment of the need for level structuring. The RCC work with national-level structuring, with concentration on highly specialised cancer care in fewer areas of the country, has a clear link to more equal care, as it will create access to the absolute best expertise for all patients in the country.

In the interviews, the National Board of Health and Welfare has heard several people emphasise that equal care is an important development area within cancer care.

High skills level at RCCs

One of the conditions to be accepted in the care profession and achieve success in the establishment has been the high level of skills in the management of all RCCs and the CRCC. This is something that has recurred continuously over the course of years in the majority of interviews conducted by the National Board of Health and Welfare. Examples of such that are provided in the interviews include high academic skills, clinical experience and ability to work with the criteria. In addition, many mention the involvement, motivation and focus of management on the right issues for cancer care, plus good structures for the work.

Increasing regional and national collaboration

The National Board of Health and Welfare has observed that increasing numbers of projects are being lifted from the regional to the national level. At present, around 60 projects are being run nationally, where experts from all regions in the country are collaborating.

The RCC has developed a structure for local, regional and national collaborations. It has been possible to achieve synergies by performing more of the work with the criteria at the national and the regional level, for example.

Through increased collaboration at the regional healthcare level, streamlining can be achieved by 6 – rather than 21 – people conducting the work, for example when creating the plans within the different development areas, projects and follow-ups.

Correspondingly, this national collaboration has increased the number of times where only one process is necessary, where otherwise there would have been 21 or 6. This means that instead of each individual county council (21 times) or healthcare regions (6 times) establishing knowledge bases and practice guidelines and building infrastructure, such as the cancer portal et al., this work is conducted only once at the national level and is made available for all regions. The National Board of Health and Welfare feels it is reasonable to believe that resources are saved when more of the collaboration takes place in healthcare region or the national level.

Wide task provides comprehensive view

Through the ten criteria, the assignment for the RCCs has been broad with regard to prevention, care and treatment; rehabilitation and palliative care in addition to research and education. The National Board of Health and Welfare believes that the broad task of following the criteria has been a success factor for the work with the majority of the RCC's areas of operation. This also means that RCCs have worked with a holistic view of the patient. This is also shown in the work carried out with patient perspective, continuity, integrity and reception. In addition, it has been clear as prevention, rehabilitation and palliative care have been included in the work with national practice guidelines; the impact goes beyond being just medical. There are also projects offering support for the patient in their day-to-day life living with cancer. Here the collaboration takes place with actors such as Försäkringskassan, childcare, schools, employers, etc.

The interviews often reveal how the broad task of the RCC is an advantage and without this, the RCC would not have achieved so much in all areas. At the same time, there are also people who believe that RCCs cannot do everything; the example often provided has been prevention for which it is believed that other actors should take responsibility.

The National Board of Health and Welfare believes that the work of RCCs should continue to include all the areas included in the criteria. The criteria descriptions sometimes include aspects that the RCCs cannot easily influence. For example, these include the parts of the criteria regarding research, however in this case the RCCs have interpreted and worked with the criteria wisely based on the conditions they have.

On the whole, the government has received what they had originally intended from the efforts.

The RCCs have been tasked with meeting the ten criteria established by the Ministry of Health and Social Affairs prior to the efforts. The RCCs have met the majority of these criteria. The National Board of Health and Welfare is currently following up on two areas – care processes and level structuring, which will be reported in March 2017.

During the establishment period, the RCCs have focused on the criteria in their organisations and some examples of what the allocated resources have led to include:

- six regional cancer plans
- 29 national practice guidelines
- strong patient orientation and participation
- process work with local discussions for more knowledge-based healthcare

- increased use of quality registries in the improvement work
- more decisions for regional-level structuring, half of the healthcare regions have implemented their plans
- decision for national-level structuring. As of 1 January 2017, there will be 19 national healthcare units in place
- *Cancer Studies in Sweden* [Cancerstudier i Sverige] – a register of ongoing clinical studies

On target?

The National Board of Health and Welfare has decided to describe the progress towards the goals of the cancer strategy, however emphasis is placed on how the development cannot be directly attributed to the establishment of RCCs. Progress towards the goals is dependent upon several actors and the trends are long. We have chosen to implement certain crackdowns on a small number of measures for the development in cancer care and population health.

Cases of cancer are increasing over time and morbidity is also higher amongst men. A positive development can be seen for several other measures:

- The average life expectancy in Sweden is increasing. Furthermore the total of healthy life years is increasing faster than the average lifespan.
- Mortality that can be influenced by healthcare policy is decreasing, as is the difference between the sexes.
- The relative five-year survival rate for cancers is increasing over time, there are small differences between the sexes.
- Cancer mortality rates are decreasing, as is the difference between sexes – mortality is decreasing more rapidly for men than for women.

Further prevention efforts are needed to reduce the incidence of cancer.

Challenges facing RCCs

The establishment of RCCs has been a success. Nevertheless, RCCs and cancer care continue to face challenges.

In the work to follow up and support the establishment of RCCs, the National Board of Health and Welfare has noted that there are examples of certain county councils and hospital and clinic management that are less involved in RCC development. According to the interviews we conducted, these are thought to be increasingly fewer and more people express the advantages of RCCs.

We have chosen to highlight three areas as continued challenges, these apply to the criteria of skills provision, parts of the criteria for preventative measures and early detection of cancer, plus the future of the RCCs. There are also additional challenges within the criterion for level structuring, however for the time being there is a positive development within the area.

Skills provision

RCCs have been tasked with establishing and supporting the implementation of skills provision plans for their healthcare regions. The National Board of Health and Welfare finds that this criterion has been a great challenge for the majority of RCCs, however there are examples of RCCs that have been successful. Several RCCs are working with the matter in stages within different diagnostic areas, otherwise they have established a basis for how to work with skills provision. The National Board of Health and Welfare is of the opinion that RCCs should be able to increase their efforts with this criterion, in collaboration with other actors such as HR, universities and HEIs, as skills provision poses a great challenge for cancer care. It is also a challenge for the RCCs that HR departments' planning of skills provision must be formulated from an overall perspective, of which cancer care is a part.

In the interviews, several people express that it is a complex and difficult area, as it is very similar to the work with level structuring. They also believe that universities and HEIs lack interest in cooperating with skills provision. Several of those interviewed also questioned the criterion and believed that each county council has the responsibility for these matters and that measures also need to be taken on a national level. This in turn leads to a lack of commitment to and interest in working with skills provision at the regional level. Despite this, several believe that there is a need for a joint plan for their healthcare regions and that RCCs can contribute with a knowledge basis and methods for this work.

Reduce the risk of developing cancer

According to the WHO, up to 30 per cent of all cancer cases can be prevented. The report for a national cancer strategy makes reducing the risk of developing cancer a high priority. This is also evident in the strategy goals, of which two concern preventing cancer. One goal is to reduce the risk of developing cancer, the other is about reducing differences between demographic groups developing the disease.

In the effort of cancer prevention, RCCs have targeted efforts on smoking, alcohol consumption, being overweight or obese, physical activity, food habits and sun exposure habits – alongside efforts for HPV vaccination and screening. However, the efforts related to living habits are fragmented and the National Board of Health and Welfare believes that work to prevent cancer should be given higher priority. It should be noted that RCCs do not have the opportunity to directly contact the public as part of their work with living habits, instead they work together with or via other actors. However, the National Board of Health and Welfare believes that screening work conducted by RCCs throughout the years has been systematic.

The development of living habits amongst the population varies. Overall, the progression shows that there is a need for powerful efforts from several society actors to be successful in reducing the risk of developing cancer.

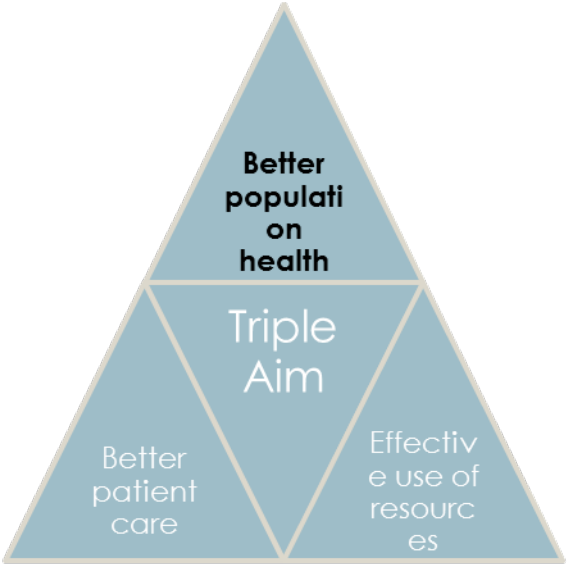
The RCCs’ Future

During interviews conducted by the National Board of Health and Welfare, certain healthcare regions have expressed concern about the future of RCCs once government funding is withdrawn. They state that the government support has been targeted and bound to the criteria that state what is to be accomplished, together with the follow-up. Consequently, they believe that RCCs have been able to keep up with the work. They have also highlighted that SALAR works on behalf of general – not targeted – government contributions to municipalities and county councils and furthermore, non-financed initiatives should be phased out, thus strengthening uncertainty amongst those interviewed.

Therefore, it can be an advantage for the RCCs to show their value to the county councils/regions via three dimensions: better population health; better patient care and good or effective use of resources.

One challenge is establishing and presenting indicators that can follow the development and that describe how properly allocated resources have led to better health amongst the population along with better patient care.

On the right track – better health amongst the population?



This chapter presents the dimension, *Better population health,* which aims to strengthen public health in order to reduce the risk of developing cancer, but also for those who have already been diagnosed with cancer to be able to cope with their treatment as well as possible and reduce the risk for relapse.

The dimension is tied to the goals in the national cancer strategy for the future report in order to:

- reduce the risk of developing cancer,
- reduce differences between population groups in morbidity and survival time.

The dimension also ties in with the public health policy goal to *Create the social conditions for good health on equal terms for the whole populace.* There are eleven goals to be followed up on that are included in the national targets. Several of the goals are essential to the work with reducing the risk of developing cancer.

A national cancer strategy for the future

The *National Cancer Strategy* report emphasises the importance of preventative measures to reduce the risk of cancer. Even though only a portion of the causes of cancer are explained, according to the report there is sufficient knowledge about the risk factors and preventative methods to be able to influence the future development of cancer morbidity and mortality. Primary prevention and early detection of cancer were highlighted as fundamental areas for continued initiatives. The report suggested the following:

For living habits:

- That all primary healthcare units offer easily accessed, effective smoking cessation programmes by 2014.
- That all patients are questioned about their tobacco habits and that details about smoking are included in patient records.
- Increased efforts on information and education about tobacco for health and medical care personnel and school staff.
- Increased efforts aimed at those who smoke the most.
- That the government reflects upon the introduction of other tobacco-related political measures, such as price increases and a ban on advertising.
- Measures to increase the number of tumours discovered at an early stage, for example, by making it easier for the general public to have changes to their skin examined.
- A more suitable role distribution between dermatologists and general practitioners upon diagnostics.
- That a minimum age for using tanning salons be considered.

For screening and vaccination

- That existing and forthcoming screening programmes should be continually followed up on, so quality and participation can be evaluated and improved.
- That future screening programmes should be introduced, coordinated and structured to avoid regional differences.
- That the national rate of cervical screening tests should reach at least 85 per cent.
- That the national mammography participation rate of at least 80 per cent should be attained nationwide as a first stage whilst awaiting the establishment of a national follow-up.
- Specific efforts to reach out to groups that currently participate to a lesser extent than others.

The report emphasises the importance of focusing on socioeconomic differences, as those living with worse socioeconomic conditions are at higher risk of developing and dying of cancer. The differences are primarily linked to interacting factors, such as different lifestyle elements. However, they can also be a result of information and other preventative measures not being adapted to different social groups. There is an indication that suggests an increase in social health-related inequality in the future. Furthermore, according to the report it is clear that preventative measures that successfully reach all social groups offer a good chance of reducing the total level of morbidity, e.g., tobacco prevention drives.

RCC tasks as per the criteria

The criterion being worked on with by RCCs that is relevant to the dimension of Better population health are the *preventative measures and early detection of cancer.*

According to the criterion, the RCCs are to formulate and implement a plan for the healthcare region's work with preventative measures and early detection of cancer. The plan must also include systems to follow up on the effects.

The plan must contain specific steps to attain increased equality between population groups based on sex, age, socioeconomic circumstances and place of residence – both with regards to cancer risk and early detection of cancer. The description of the criterion states that combined and persistent preventative measures are needed to prevent cancer.

Preventative measures and early detection

Below we describe the structure of the RCCs' work, plus examples of measures taken by RCCs and the CRCC in connection with the work with this criterion. We have also chosen to provide examples of the development as regards vaccinations, screening, obesity, lifestyle habits and population. Together with the county councils, RCCs are one of the many actors to influence the development. We cannot say that the progress is definitely attributed to the RCC, however we believe it is valuable to somehow reflect the development effort against the goals in the cancer strategy.

RCCs' structure for the work

All RCCs have established work plans with the criterion that includes preventative measures regarding vaccination, living habits, screening and alarm symptoms.

All RCCs have process managers (employed to different extents from 20 per cent part time and up to full-time) and national workgroups that drive the development of the work to prevent cancer. The process managers also lead the work to improve screening programmes and national workgroups for developing these areas. RCCs have additional networks and workgroups with other public health actors within the county council and collaborations with other actors within their healthcare regions.

RCCs have mapped risk behaviours – and the work to prevent them – surrounding lifestyle habits including tobacco usage, at-risk levels of alcohol consumption, sedentary lifestyle or low physical activity, unhealthy food habits and unhealthy sun exposure habits.

Where relevant, the national practice guidelines established by the RCCs also include preventative measures.

Increased equality between demographic groups

General health promotion and disease prevention measures do not always reach all groups to the same extent. One group that tends to be disadvantaged by general initiatives (aimed at all groups) are individuals with low levels of education or from socioeconomically disadvantaged groups. There are several plausible explanations for the instances of such differences. Often it is a case of accessibility (especially physical), reception, trust, barriers (language, cultural, social) and what is known as "health literacy" (the ability to acquire, understand and use information about health and illness and consequently make well-founded health-related decisions both when healthy and ill). Individuals in socioeconomically vulnerable situations generally place less trust in others and have lower confidence in their own abilities. Hence it is vital that health and medical care professionals are highly skilled in their approaches towards others, and good knowledge of the strategies available to support and motivate individuals [4].

Health promoting measures within cancer care often involve screening, vaccinations and health-promoting, disease preventing efforts.

RCC initiatives for increased equality

In the work to increase equality amongst the population groups, several RCCs are working with projects targeted at children and their parents, such as the *sola sunt* [tan safely] project, initiatives aimed at young people focusing on safer sex to reduce the risk of HPV infection and anti-tobacco efforts in schools. Other examples include smoking cessation projects for young women with low levels of education and patients being treated within psychiatry services (there are often more smokers amongst this patient group). Furthermore, one RCC has developed the cancer perspective in a regional development plan for psychiatry services.

There are also other examples of projects in collaboration with several other actors that operate in areas where socioeconomic resources are low. For example, these include projects with a multicultural focus, where training and information drives are conducted with help from health guides to increase knowledge about cancer risk factors, the importance of participating in screening programmes and better access to screening. There are also projects focusing on providing information to people who have recently arrived in Sweden.

Several RCCs work with different mapping projects looking at social and regional differences in lifestyle habits and instances of cancer, and the differences in cancer treatment and outcomes. The aim is to identify the areas of a region with an increased risk of cancer morbidity and then implement targeted measures there. Mapping of prevention measures is also being conducted.

There is also an example of where an RCC has trained all of its personnel in equal care and equal health and where requirements have been placed on all the RCC's cancer care processes to present the effects of equality in their work by using the RCC cancer database as support.

RCCs are also spreading the European Code Against Cancer that contains 12 recommendations or suggestions for reducing the individual risk for cancer.

A description of the development of vaccinations, lifestyle habits and screening is presented below and these sections also provide some examples of RCC efforts.

Vaccination

There is a prophylactic vaccine against the viruses that cause cervical cancer, the Human Papillomavirus (HPV). HPV vaccination is included in the childhood vaccination programme. Starting in 2012, Sweden has also offered all girls born between 1993-1998 the HPV vaccination free of charge, known as the “Catch-up” vaccination programme and run by the county councils.

RCC vaccination efforts

The RCCs support the county councils’ work in the Catch-up project to contact all girls who have chosen not to be vaccinated against HPV through collaboration with school healthcare services.

RCCs have also worked with the evaluation of primary preventative effects of the HPV vaccination for boys within the process work for penile cancer and head and neck cancer, as a basis for a position on offering the HPV vaccination to boys.

Living habits

A large portion of the work to prevent cancer includes efforts to create healthy living habits amongst the population. This chapter provides a description of the RCCs’ efforts regarding the implementation of *National Guidelines for Methods of Preventing Disease.* A selection of the indicators that the CRCC suggest that the healthcare regions follow is presented at the end of each chapter.

The World Health Organisation (WHO) has estimated that lifestyle habits such as tobacco and alcohol use, physical activity and food habits cause up to 30 per cent of all cancer deaths. A person who adopts a healthy lifestyle lives an average of 14 years longer than a person with unhealthy lifestyle habits. The four lifestyle habits have the greatest contribution for the combined disease burden in Sweden.

One way for health and medical care to work with lifestyle habits is to follow the recommendations in the National Guidelines for Methods of Preventing Disease. In these guidelines, the National Board of Health and Welfare recommends that health and medical care make use of offering advice or discussions to help the patient chance their unhealthy lifestyle habits.

In cancer care, health-promoting discussions are an important tool for motivating patients towards changes in their lifestyle habits. Healthy lifestyle habits can improve the prognosis, for example, by reducing risks associated with surgery, increase the effectivity of radiotherapy and improve the prognosis.

RCC support in the work with disease prevention methods

Recommendations in the national guidelines are the starting point for the RCCs’ work with disease prevention methods.

RCCs support the implementation of the National Guidelines for Methods of Preventing Disease, for example by training contact nurses in motivational discussions. RCCs also carry out conferences about the guidelines

Tobacco smoking

The following cancers are associated with smoking tobacco: lung cancer, oral cancer, ear, nose and throat cancer, paranasal sinus and nasal cavity cancer, liver and gallbladder cancer, primary hepatocellular carcinoma, leukaemia, renal cancer and cancer of the urinary tract, ovarian cancer, uterine cancer, bladder, bowel and colorectal cancers, pancreatic cancer and gastric cancer. There is additional support to suggest that tobacco smoking is also linked to breast cancer [5].

RCC efforts against tobacco smoking

The RCC runs work to prevent the use of tobacco in different ways. One example is the work to spread the “TobaksfriDuo” (tobacco-free) concept, targeted at schools. Tobaksfri duo is an anti-tobacco programme taking place in around 70 Swedish municipalities. The method includes a concept where pupils sign contracts with tobacco-free adults to be tobacco free until the end of year nine of their compulsory schooling.

RCCs have also provided smoking cessation support prior to operations and radiotherapy through a collaboration with the process owner, process manager and coordinating nurse for smoking cessation.

Other examples include smoking cessation projects for young women with low levels of education and patients being treated within psychiatry services (there are often more smokers amongst this patient group).

RCCs train contact nurses in methods for motivational discussions as part of the work to implement National Guidelines for Methods of Preventing Disease.

Within the CRCC, a National Tobacco Action Plan has been established and the RCCs are involved in the Tobacco End Game campaign for a smoke-free Sweden by 2025. RCCs have also developed the module to register tobacco habits in patient medical records.

Alcohol consumption

Cancers related to alcohol consumption include: oral cancer, oesophageal cancer, liver, bowel and colorectal cancers and breast cancer [5].

Therefore, working towards low alcohol consumption amongst the population is pressing. A diagram is presented below that shows the portion of the population estimated to have high risk consumption of alcohol based on three questions in the *Health on equal terms* questionnaire.

RCC efforts against alcohol consumption

Alcohol consumption is a prioritised area in the RCC plans to prevent cancer and is included in the mappings they carry out.

Efforts carried out by the RCC with regard to alcohol are primarily part of the work to introduce National Guidelines for Methods of Preventing Disease.

There are also examples of where RCCs have established networks to limit the use of alcohol in their healthcare region.

Obesity

Several types of cancer are linked to being overweight or obese. These are bowel and colorectal cancers, renal cell cancers, oesophagal cancer, pancreatic cancer, gallbladder cancer, breast cancer in (post-menopausal) women, uterine cancer and ovarian cancer [5].

RCC efforts against obesity

One RCC-initiated project is *Viktiga supportrar i träning (ViSiT)* [Important supporters exercise], that is aimed at overweight sports fans. The project is a collaboration between sports associations and clubs.

One RCC is working to create regional guidelines for obesity and being overweight. The proposal includes measures for different care levels, plus practical tools for individuals and for the care profession from both adult and child perspectives. The guidelines also contain suggestions to follow up on national quality registries for childhood obesity and weight loss surgery.

Healthy eating habits

Several types of cancer are related to diet and being overweight; bowel and colorectal cancers, breast cancer, uterine cancer, oesophagal cancer, renal cancer, oral and oesophagal cancers. WHO recommendations include eating high amounts of wholegrain foods, legumes, vegetables and fruit whilst avoiding foods with high calorie and fat content, sweet drinks, processed meats, red meats and foods with high amounts of salt. Following the fruit and vegetable recommendations are a good indicator of healthy eating habits in general [5].

RCC efforts to promote healthy eating habits

RCC cancer prevention plans include measures for healthy food habits. RCC efforts involve training contact nurses in methods for motivational discussions as part of the work to implement National Guidelines for Methods of Preventing Disease.

RCCs have also mapped unhealthy eating habits in their healthcare regions.

Physical activity

Physical activity reduces the risk of developing bowel and colorectal cancers and breast and uterine cancers. Physical activity also promotes healthy weight, which is indirectly linked to renal cancer, oesophagal cancer, pancreatic cancer, gallbladder cancer and ovarian cancer [5].

RCC efforts for physical activity

Physical activity is included as a prioritised area in the RCC plans for preventative measures.

For example, RCCs have developed an information pack with details about physical activity during cancer treatment.

Physical activity is also included in the work to implement disease prevention methods; RCCs train contact nurses in methods for motivational discussions.

Sun exposure habits

Dangerous solar radiation can lead to skin cancer and the particularly dangerous malignant melanoma. Skin cancer is the type of cancer presently showing the biggest increase.

RCC efforts for sun exposure habits

Efforts conducted by RCCs focusing on sun exposure habits include the *Sola sunt* project. This is a collaboration between RCCs and child healthcare services that provides advice about how people can protect themselves and their children from harmful UV rays. This project is now being rolled out across the country. RCCs have also contributed to the distribution of information about healthy sun exposure habits on 1177.se.

The CRCC has established an action plan against dangerous UV radiation.

Minimise the delay in discovering cancer – alarm symptoms

It is important to increase the awareness of alarm symptoms amongst primary care and the population in order to limit the delays in discovering cancer. Alarm symptoms may include:

- anaemia
- rectal bleeding (blood in stools)
- dysphagia (difficulty swallowing)
- haematuria (blood in the urine)
- haemoptysis (coughing up blood)
- lump(s) in breasts
- suspected malignant prostate palpation
- post-menopausal gynaecological bleeding

An interim report from a research project shows that the majority of patients who develop one of the seven most common cancers approached primary care in the year prior to diagnosis. Both the number of appointments and symptoms increased prior to the cancer diagnosis. Of the patients to be diagnosed with cancer, 87 per cent had contacted primary healthcare providers at least once in the year prior to their diagnosis. Both the number of appointments and total of diseases and symptoms in the form of diagnosis codes also increased 50-100 days prior to the diagnosis. The study is expected to be complete in 2018 and aims to find symptoms and combinations of symptoms that can point to cancer, as well as establish a risk evaluation tool for primary care [6].

RCC efforts for alarm symptoms

In the work to minimise delayed cancer detection, RCCs have developed information and training for alarm symptoms specifically aimed at primary care. There are also examples of where regional medical guidelines for well-founded suspicion of cancer have been created for early discovery of alarm symptoms within primary care.

One RCC conducted the project *Röda telefonen* [the Red Telephone], which provided a fast-track for patients with visible blood in their urine. The project has now been introduced as being standard. Another RCC has developed a reference document aimed at general practitioners presenting the general and alarm symptoms that may signal cancer. It includes a list of symptoms per diagnosis and suggestions for investigation.

One RCC is running a research project on early cancer detection.

Other examples of where RCCs have contributed to the development of early detection include

- mapping primary care's ability to diagnose cancers
- developing a new way to reduce waiting times for confirmed diagnoses
- increasing collaboration between primary and specialist care
- working to establish diagnostics centres to speed up examinations and diagnoses for patients with unclear symptoms
- supporting the development of mole clinics and teledermoscopy (image transfer) for early detection of malignant melanoma skin cancer

Minimise the delay in discovering cancer – screening

Screening is when asymptomatic people in a certain age group are offered an examination with the aim of discovering the early stage or pre-stages of cancer whilst the disease can still be cured.

Sweden currently operates national screening programmes for breast and cervical cancers. The National Board of Health and Welfare also recommends screening for bowel and colorectal cancers.

RCC work with screening

Through the CRCC, two national workgroups have been established – one for mammography and another for cervical screening. The groups are tasked with

- working towards regional and national collaboration
- defining quality indicators and establishing target levels
- assuming responsibility for developing a national quality registry for mammography

The work applies to the entire healthcare chain, from the invitation to screening to other responsible clinics. In the work to develop and streamline the work with the screening programme, RCCs have taken several steps:

- RCCs have created a national invitation package that contains document templates for the respective screening programmes. These documents include the invitation, various response letters, reminders, FAQs and information before the first appointment. The package also includes in-depth information about the benefits and disadvantages of screening.
- Invitations to screenings have also been developed and now include invitations in several languages and simple Swedish.
- RCCs also provide support for the implementation of HPV testing as part of the screening for cervical cancer. A large coordination project is being carried out and a care programme, amongst other things, has been established. Preparations for personnel training have been implemented and information for the general public via 1177 will be updated.
- Several efforts for better accessibility have been conducted, for example cervical screening weeks, where information is spread and special screening busses are available, opening hours are improved and a development of the appointment booking system.

- Additionally, steps are being taken regarding accessibility for specific groups such as people with disabilities.

A large national bowel cancer screening study (SCREESCO) is currently being conducted in Sweden. In this study, new methods to improve bowel cancer screening are being investigated and 19 county councils/regions are participating in the study. Otherwise the screening programmes are already in place or their implementation is ongoing. The bowel cancer study also involves a preparation of screening within these county councils. The study belongs to an initiative by the CRCC and has been approved by 19 of the included county councils/regions and the CRCC operates as the steering group.

A national mammography quality registry is under development. The work to create a national quality registry has been one of the most important tasks for the national mammography workgroup. The purpose of the quality registry is to achieve more equal healthcare in Sweden within radiological breast diagnostics. Additionally, the purpose of the register is to also contribute to meeting the requirements now placed on the screening programmes.

Under the leadership of the national mammography workgroup, there is an ongoing project to set up a national mammography network. The long-term aim of the network is to improve radiologists' skills within breast diagnostics and create the opportunity for simple collaboration between mammography units.

The mammography workgroup have also drafted recommendations that form an important part of the RCCs' continuing work with screening in each region. The combined recommendations state that all county councils should issue reminders and analyse participation, so where possible groups or areas where uptake is low can be identified and where appropriate, conduct targeted efforts.

Identification of individuals with hereditary cancer is also being carried out and aims to offer at-risk individuals preventative measures and is included in the RCCs' work with cancer prevention. There are examples of hereditary cancer clinics that organisationally belong to RCCs. There are special investigation and follow-up programmes available to people at risk of hereditary cancers. This can be seen as screening of high-risk individuals, often including more comprehensive testing than general screening. One RCC has also conducted an inquiry for suggestions for a regional centre for hereditary cancer, however this is not yet established.

On the right track!

An assessment will now be presented based on the above descriptions that outline how the dimension of Better population health has been developed.

On the right track Triple Aim: Better population health

When combined, the Better population health dimension shows that overall development is good. The National Board of Health and Welfare wishes to highlight three aspects, the development of health and the development of health determinants based on contributions from many actors as well as work by RCCs with the criterion for preventative measures and early cancer detection. The National Board of Health and Welfare concludes that the

- RCCs have fulfilled the criterion.
- Overall improved health over time. The goals in the evaluation tables below are green, with the exception of where cancer morbidity is increasing.
- The development of chosen determinants (e.g., obesity and living habits) shows varying results. The National Board of Health and Welfare believes that powerful efforts are needed to reduce the risk of developing cancer.

On the right track in A National Cancer Strategy for the Future?

The goals set for better population health are to reduce cancer morbidity and the differences between population groups regarding morbidity and survival rates.

Population health – a contradictory development?

A positive development of health is generally observed over time; mortality rates that can be influenced by healthcare policy are decreasing, the relative 5-year cancer survival rate is increasing and cancer related fatality is decreasing. Nevertheless, the portion of the population developing cancer is on the rise. For more information and a diagram of the development, see Appendix 2.

By 2040, over 100,000 people are expected to receive a cancer diagnosis, an increase of 86 per cent in comparison to 2014 [7].

Better population health?	Differences between population groups	Direction
Total number of healthy life years increasing faster than life expectancy	differences between the sexes are decreasing	🟩
Cancer morbidity per 100,000 members of the population increasing over time	Higher mortality rate amongst men than women	🟥
Mortality rate of cancer decreasing	differences between the sexes are decreasing	🟩
The relative five-year survival rate is increasing over time	differences between the sexes small and have decreased	🟩

Efforts promoting healthy living habits must increase

The National Board of Health and Welfare believes that comprehensive efforts are needed from all participating actors to reduce the risk of cancer morbidity, by achieving healthy living habits amongst the population.

Increased efforts against obesity need to be taken. Continuing the work to reduce the number of smokers in the population is pressing, as are the needs for measures to reduce at-risk alcohol use. Rates of healthy living habits, such as one hour of physical activity per day plus consumption of fruits and vegetables, are low and need to increase to strengthen public health.

The National Board of Health and Welfare have presented a selection of indicators applicable to the determinants for public health. The selection has been made based on indicators chosen by the RCC to follow the development. This applies to obesity, smoking, alcohol consumption, eating habits, physical activity and sun exposure habits. A summary and assessment of the development of these factors over time is presented below. The result varies and indicates a need for continued initiatives. For further information, see Appendix 2.

Development regarding determinants for population health	Differences between population groups	Direction
Levels of daily smoking have decreased	Decreasing in all groups, large differences between the groups based on level of education, more women than men	🟩
At-risk levels of alcohol consumption are stable	Men are at higher risk than women	🟨
The rate of obesity is increasing amongst the population. One in six is estimated to be overweight	Increasing in all groups, large differences based on level of education and differences increasing.	🟥
Healthy eating habits are stable at a low level. One in four eats fruit/vegetables at least three times per day	More women than men have healthy eating habits, large differences between the groups based on levels of education	🟨
Physical activity is stable at a low level. One in three is physically active	No great difference between the sexes or levels of education	🟨
Healthy sun exposure habits. Four in ten have been tanning for less than ten years	Forthcoming questionnaire will show clearer differences between the groups	🟩
HPV vaccination, target level of 90 per cent, national average of 81 per cent	Included in the childhood vaccination programme, no county council has met the target level, variation between county councils 76-89 per cent	🟨
Screening – cervical cancer, target level of 85 per cent, national average of 82 per cent	Increasing, but no county council has reached the target level, variation between county councils 69-91 per cent	🟩

RCC on the right track towards the criteria?

The National Board of Health and Welfare believes that work with preventative measures is often fragmentary and there is the opportunity for continued development work to attain the intentions in the criterion to prevent cancer. Nevertheless, the National Board of Health and Welfare is of the opinion that all RCCs meet the requirements stipulated in the criterion. Continued efforts are also needed to further increase participation in vaccination and screening programmes to meet the target levels.

At the same time, we see that there are on-going discussions about who actually holds the responsibility to implement the steps to prevent cancer. RCCs may need further support from county councils and regions. Contributions are also required from many other actors to fully achieve the intentions in the report.

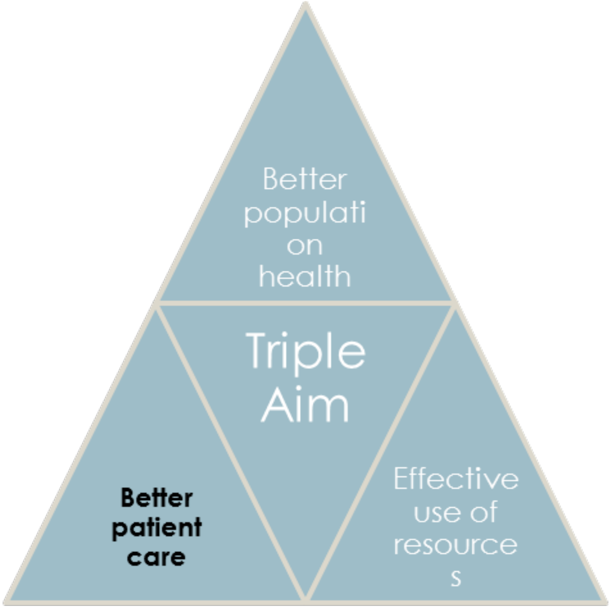
How RCCs meet the criterion for preventative measures and early detection	RCC efforts	Criterion
Plan for preventative measures and early detection	All RCCs have a plan	🟩
Implementation of primary prevention	Implementation on-going	🟨
Implementation early detection (alarm indications and screening)	Many efforts completed	🟩

The plans that have been established are long-term and contain suggestions for efforts and how they can be followed up. The plans have only recently been decided, hence their implementation is on-going.

Nevertheless, the RCC work to support development within screening and early detection is systematic and in full swing, both regarding the project for increasing participation in screening and for structures within the county council. Continued efforts are needed so the cancer strategy goals can be attained.

The assessment grounds for the above tables	
🟩	Criterion met, or development on target
🟨	Individual efforts or weak/off target
🟥	As yet no efforts, or the development towards the goals is going in the wrong direction

On the right track – better patient care?



With the dimension *Better patient care,* health and social care is intended to be

- Knowledge-based and characterised by building upon the best skills available.
- A safe, risk-preventative activity that prevents healthcare-related injuries.
- Tailored to the individual and provided with respect for the specific needs of the individual, their expectations and integrity. The individual shall be given the opportunity to participate.
- Healthcare shall be supplied and allocated on equal terms for everyone.
- Accessible and provided within a reasonable time frame; nobody is to need to wait an unreasonable time for health or social care.

These aspects build upon the National Board of Health and Welfare's good care model.

The dimension ties to the goals in the national cancer strategy for the future report to

- improve the quality of cancer patient management
- prolong survival time and improve quality of life after a cancer diagnosis
- reduce regional differences in survival time after a cancer diagnosis

A national cancer strategy for the future

Rehabilitation and palliative care

Rehabilitation targets differ considerably throughout the different stages of cancer. The type of rehabilitation also varies depending on the form of cancer, however, for example, symptom relief during cytostatic treatment is one joint goal in the rehabilitation for several forms of cancer. The majority of cancer patients are in need of rehabilitation, according to the report.

As regards palliative care, the report calls attention to the

- resources being allocated to palliative care so it will be able to meet the future increased needs and reduce regional and local differences
- steps are being taken to strengthen knowledge management and follow up on the quality of palliative care.

Patient's position in cancer care

In order to improve the information and communication between the patient and caregivers to strengthen the patients' opportunity for participation in the care, the report proposes that

- upon diagnosis, each patient is allocated a set contact person at the clinic where they are receiving treatment
- a multidisciplinary care team participates in the care of each cancer patient right from the start
- every patient receives an individual care plan

The report emphasises that it is important that information for patients and their next of kin pays consideration to the different ways people can process information depending on their age, level of education, language, religious and cultural characteristics, etc. Furthermore, the contact nurse can play an important role in interpreting and tailoring the cancer information and therefore increase its usefulness for patients and their next of kin.

Knowledge management and research

The report states that there is a clear need to reinforce knowledge development and management within the cancer field. A resource that can receive and evaluate new findings and provide the basis for decisions on implementing and discarding medical methods. Education, clinical cancer research, implementation of new findings and follow-up and evaluation within cancer care should, according to the report, be both functional and integrated. With this in mind, according to the proposal in the report, all regional cancer centres – excluding their clinical area and research activities – should contain a strong resource that meets the future increased needs for knowledge development. The report proposed that the following details be included in this assignment:

- collaboration with the government knowledge management in the field of cancer, including support for the implementation of national guidelines
- support in the work with national practice guidelines

- coordination of the regional work with practice guidelines for cancer diseases
- stimulate the spread of knowledge within the cancer field in each region,
- efforts to improve the work with data reporting (both content and routines) to national and regional registers for cancer care
- follow-up of care programmes and guidelines for cancer care
- support to epidemiological, pre-clinical and clinical research, resources for biostatistics and health informatics
- collaboration with centres belonging to other disciplines and fields of knowledge (for example, for development of "improvement knowledge" and other change processes).

According to the report, continued, long-term and powerful efforts are needed to support cancer research. Research breakthroughs are being made in several fields and new opportunities for prevention, diagnostics and treatment are within reach. Translational research (i.e., disease problems identified within medical care forming the basis for research) should be supported and RCCs should form an important hub of this development.

Education and skills provision

According to the report, the county council/region or healthcare region should devise a plan for skills provision within cancer care, at least up until 2020, paying consideration to the increased care needs and retirement levels amongst personnel.

Furthermore, according to the report, healthcare personnel should be used in a more flexible way, which should in turn result in higher efficiency in the medical care system. Caregivers should assess the possibility of using experts from other professional groups outside of traditional health and medical personnel for different work processes and supporting functions, e.g., technology, IT and logistics.

Level structuring

The report states that the expected increase in the number of cancer patients provides strong grounds for both the centralised and decentralised distribution of work tasks between primary care, county council medical care and RCCs/university hospitals. The increased specialisation means that a large number of future patients will need the investigation and treatment capacity that only regional centres will be able to offer. The increased number of people living with cancer and the resulting increase in care volumes will demand increased capacity in both county medical care and primary care. Certain aspects of the care process should be localised close to the patients, for example, different rehabilitation measures, palliative care, check-up examinations and supplementary medical treatment of varying forms.

The future requires a clearer division of responsibilities between the university hospitals and other hospitals in the region, plus reciprocality between hospitals to achieve a sufficient concentration of both patients and resources. This particularly applies to advanced surgical procedures, rare cancers and highly expensive technology. The report is of the opinion that each healthcare region should create a regional strategic plan for the division of responsibility and level structuring within cancer care.

RCC tasks as per the criteria

RCCs' work within the dimension, *Better patient care*, includes the criteria

- care processes
- rehabilitation and palliative care
- Patient's position in cancer care
- knowledge management
- clinical research and innovation
- education and skills provision

The criteria are described in more detail in the respective chapters below.

Care processes

According to the criterion, the RCCs' task is to lead and coordinate the healthcare region's work to streamline cancer care processes. The criterion for healthcare processes places large focus on the patient perspectives of good reception, integrity, continuity, patient safety, accessibility and wait times.

The RCCs' work with this criterion is currently being followed up on by the National Board of Health and Welfare. Further information about the RCCs' work will be included in the report *Follow-up of regional cancer centres 2016* that will be presented to the government in March 2017.

RCC efforts with care processes

The RCC work with patient processes is included in the areas highlighted by the criterion. The different stages of a patient's journey are developed in the patient processes, through care, with a view to achieve an effective, cohesive chain of care for the patient.

There are examples of patient representatives employed by RCCs to manage development projects to strengthen the patient perspective in care, for example, *I am more than just cancer – materials for organisations who want to improve meetings with people affected by cancer.* The materials address matters of what characterises good interaction and reception, how different actors – from primary care, employers, schools, preschools, Försäkringskassan, Arbetsförmedlingen and CSN – can collaborate to provide better support and how the matter of meeting those affected by cancer from a comprehensive point of view can be developed. The material also includes a film about interaction with patients. An additional information brochure about interaction with cancer patients, *This is what we want*, has been created with help from all RCC patient and next of kin councils. One RCC has also created an *Action plan for better patient interaction and to combat cancer-related prejudices*, which is now being implemented.

The CRCC has developed the information about cancer on 1177. There is also information and telephone numbers for local cancer advice services run by one RCC.

To develop cancer care, RCCs together with care providers organise projects with patient diaries to gain insight into patient experiences and needs.

Since 2013, all RCCs have monitored waiting times for treatment using the quality registries as a basis. RCCs are also working with the drives currently being conducted by the Government to reduce waiting times within cancer care. Together with members of the profession, the CRCC has created standardised care procedures (SVF) now being introduced to several cancer diagnoses, with the aim of reducing waiting times from the moment cancer is strongly suspected until the start of the first treatment. Each RCC has a project leader who supports the county council with the introduction of the SVF.

One area that is important for patient safety grounds and with which the RCCs are working is the effort of keeping patients from smoking and drinking leading up to an operation – as this reduces the risk of complications. For the safe handling of cytostatics, RCCs have created "regimen libraries" (see p. 51). RCCs have also created a training course for a cytostatic "operating licence" for safe handling for both the patient and personnel. An additional area important to patient safety relates to the access to multidisciplinary conferences. MDCs have been shown to improve the quality of care and increase the conditions for administering the correct type of care. Amongst other things, the RCCs have worked to increase the potential for regional healthcare and national MDCs.

Psychosocial support, rehabilitation and palliative care

The criterion states that RCCs are to have a plan that assures cancer patients access to high-quality psychosocial support, rehabilitation and palliative care within the entire healthcare region. The criterion further states that RCCs shall work to develop the support available to cancer patient's next of kin.

In the work with rehabilitation and palliative care, the RCCs have included psychosocial support.

Rehabilitation

Cancer rehabilitation aims to prevent and reduce the physical, psychological, social and existential consequences of cancer and its treatment. The efforts are to provide the patient and their next of kin with the support and conditions to be able to live the best life possible. Cancer rehabilitation means looking at the whole person placed in the context of their own life.

RCC efforts within rehabilitation

Each RCC has developed plans for rehabilitation work in their healthcare region. RCCs also have specially appointed process managers to develop cancer rehabilitation.

National practice guidelines have been established for cancer rehabilitation. Furthermore, the diagnostics-specific national practice guidelines are adapted with diagnosis-specific rehabilitation. Indicators and target levels are included in the national practice guidelines for rehabilitation. It is suggested that the indicators be included in existing quality registries and are thereafter followed up for local, regional and national comparisons.

RCCs have created structures for collaboration between county councils. RCCs are also preparing comprehensive regional routines for cancer rehabilitation that are additionally adapted to diagnosis group where specific requirements exist. RCCs have set targets for the entailed work, for example, the number of patients whose cancer rehabilitation is included in My Care Plan. The contact nurse is assigned a key role in identifying the need for rehabilitation efforts. Some RCCs have initiated and supported the development of separate specialised cancer rehabilitation centres.

During 2016, all RCCs have created project plans for improved rehabilitation of pelvic complications as part of the agreement between SALAR and the government concerning women's health.

Palliative care

High-quality palliative care towards the end of life refers to the ameliorating steps that can be taken once treatment and cure can no longer be offered. Certain people live with an incurable disease for several years, whereas others are asymptomatic until they only have a short while left to live. Hence it is important to note that palliative care is more than just care in the last few weeks of life.

RCC work with palliative care

Each RCC has established plans for the work with palliative care in their healthcare region. RCCs have specially appointed process managers to develop palliative care. There is a national workgroup and regional and local palliative councils have been founded in several areas.

The national practice guidelines for palliative care, in cooperation with the national supporting information for good palliative care towards the end of life devised by the National Board of Health and Welfare form the basis for the entailed work at the regional level. The indicators and target levels in the supporting information are used for any necessary follow-up and development work.

RCCs also work to ensure that palliative experts are available and participate in MDCs, early cancer investigations or in complex problems.

There are also examples of where RCCs have introduced wider training in palliative care for county council and municipal personnel.

Mappings carried out by RCCs have shown there to be differences in access and accessibility of palliative care.

Patient's position in cancer care

According to the criterion, RCCs are to work to:

- create an individual written care plan for each cancer patient
- support cancer patients with a contact nurse or equivalent contact person
- collect patient reported information and use it in practice to develop cancer care

- increase the knowledge about a patient's right to a new assessment amongst health and medical care personnel, and ensure that patients are informed about this right.

My Care Plan

My Care Plan is a combined document that is to be continually updated. The name, "My Care Plan" makes it clear that the plan is written for and with the patient. The contact nurse is often the person who has the task of creating an individual care plan together with the patient. Appendix 3 provides an outline of My Care Plan within breast cancer care.

My Care Plan is to contain:

- Contact details for doctors, a contact nurse, counsellors and other important people.
- Times for examinations and treatment, plus a description of when different steps will take place.
- Support, advice and steps during treatment and rehabilitation.
- Answers to practical questions about what the patient can do themselves.
- Information about patient rights, for example, the right to a new medical opinion.
- Upon completion of treatment: Clear information about how the follow-ups will be structured, such as whom the patient is to contact.
- Upon completion of treatment: A summarised description of the care undergone by the patient and what is important to keep in mind.

RCC work with My Care Plan

The work with My Care Plan was one of the first projects to be run in the CRCC. The project devised a template for what is to be included in My Care Plan.

The CRCC has appointed a national workgroup tasked with running the continued development work for My Care Plan in cancer care. Several different projects are being run to develop My Care Plan, both related to its digitalisation and projects to adapt My Care Plan to different diagnoses.

RCCs are also running projects to stimulate the increased use of My Care Plan, for example for gynaecological cancers where the plan has been introduced for all gynaecology patients in one of the healthcare regions.

Contact nurse

The access to a contact nurse provides patients with support for continuity, integrity and interaction. The contact nurse has the overall responsibility for the patient and their next of kin throughout the entire chain of care.

The role and tasks of a contact nurse are, according to the RCC task description, to be clearly allocated and accessible, monitor wait times and inform the patient about the forthcoming steps of their procedure, arrange contact with other professional categories, assume responsibility for the general nursing and detect psychosocial and rehabilitation needs early on.

Appendix 3 provides an overview of the number of patients with breast cancer, prostate cancer or malignant melanoma who have been offered a contact nurse.

RCC work with contact nurses

All RCCs work to increase access to contact nurses, for example by stipulating the need through proposals for action and setting targets in the plans for cancer care within the healthcare region.

RCCs have also created task descriptions and training for contact nurses.

The CRCC has appointed a national workgroup tasked with running the continued development work with contact nurses in cancer care.

Patient reported measures

Patient reported measures can provide important information for the follow-up and continued development of cancer care. They are usually separated into two areas. One area describes the patient's experiences of the care and the other area describes how the patient experiences their illness and health.

Patient Reported Experience Measures (PREM) are a way to measure a patient's experience and satisfaction with care. This may include interaction, participation, information, trust in the caregiver and accessibility.

Patient Reported Outcome Measures (PROM) are a measure of how the patients themselves perceive their illness and health after treatment or other intervention. The measures include symptoms, functional ability and health-related quality of life.

RCC work with patient reported measures

The PROM centre at Linköping University and RCCs have developed and validated a patient survey, *What are your experiences of cancer care? Help us to improve them.* The aim is to measure patient experience of care in its different stages and provide ideas for developing care. The survey includes the following areas:

- waiting time
- information of diagnosis
- contact and coordination (participation)
- information
- symptom relief, rehabilitation and support and
- interaction and confidence

A specific national PREM questionnaire has also been developed for the patients included in standardised care procedures that is now being introduced. It follows the routines for county councils' work with the national patient survey, NPE.

Several of the quality registries carry out the work by creating and registering PROM and PREM. So far only the National prostate cancer register has begun open reporting of this.

Right to new assessment

The right to a new medical assessment – "a second opinion" – is set in the Swedish Patient Act (2014:821). In the event of a life-threatening or particularly serious illness or injury, the patient may have the opportunity to discuss their individual illness and treatment with an additional doctor from any county council.

RCC work with the right to new assessment

The RCC template for My Care Plan includes information about patient rights, for example the right to a second opinion.

The cancer related pages of 1177.se developed by the RCCs also include a link to information about a second opinion.

Information for care personnel can be found on cancercentrum.se (in Swedish).

Knowledge management

According to the criterion for knowledge management, it is the task of the RCC to

- Participate in national practice guidelines and, where necessary, prepare regional practice guidelines.
- Support regional implementation of national guidelines and practice guidelines throughout the healthcare region, this also includes national target levels.
- Use national quality registries to develop activities and organisation within cancer care.

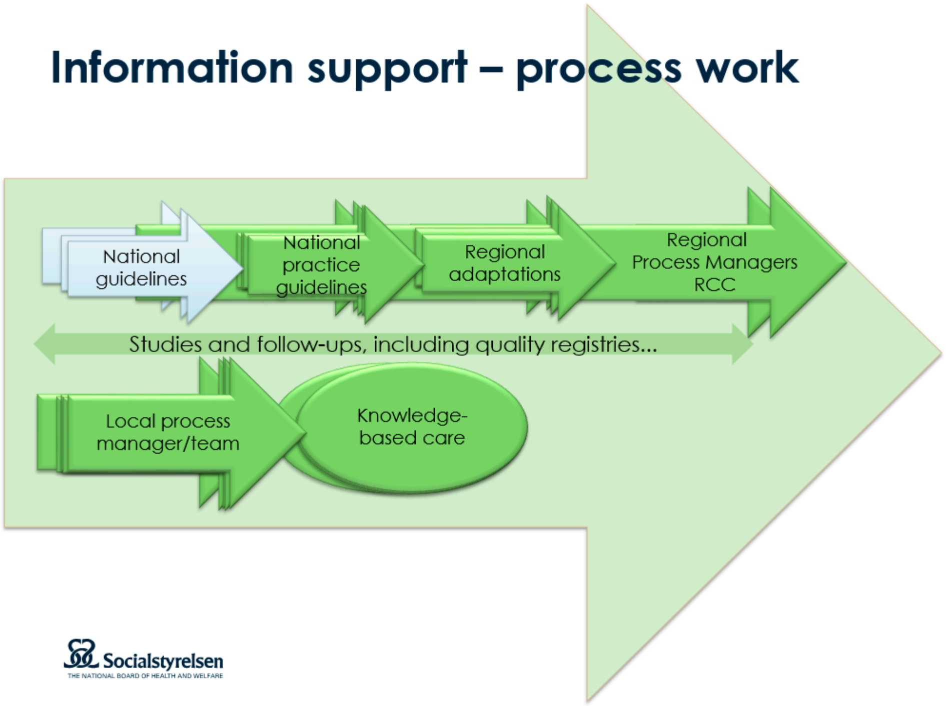
In the work with knowledge management, it is important to follow the development of the quality indicators presented in national guidelines and national practice guidelines. The National Board of Health and Welfare has chosen to present a small selection of these to provide insight into the development, see Appendix 3.

RCC work with knowledge management

Prior to the establishment of RCCs, there were already organisations and routines for managing knowledge both within the county councils/regions and healthcare regions, for example for receiving and introducing national guidelines. The criteria established that it would be the task of the RCC to be responsible for knowledge management in the healthcare regions' cancer care.

The RCCs' work with this criterion has been comprehensive and has resulted in a development of process-oriented methods where the RCC, together with both professional and patient and next of kin representatives, drive the development. With the goal of equal care in mind, the RCC has taken the initiative to establish national practice guidelines instead of regional practice guidelines required by the criterion.

The image below shows how supporting information is created at a national level that is then implemented with help from process managers at hospitals, clinics and healthcare centres.



This method provides the patients with the new information quickly. This concept is described in more detail below and what has been prepared by the RCC is unique to medical care. This does not just include the creation of supporting information at the national level, it also includes their implementation through active process work with the follow-up of regional (healthcare region) and local level (county council/region and hospital/clinic healthcare centre). The National Board of Health and Welfare does not see this type of integrated approach that is applied throughout national cancer care in any other care area. The following is a brief description of the image:

National guidelines

The National Board of Health and Welfare establishes National guidelines Representatives from the profession, patient associations and medical care trustees participate in this process. There are currently five national guidelines for cancer. The most recent were released in 2014 and include cancer of the breast, prostate, bowel and colon. In 2015 certain updates were made to the guidelines. There are also national guidelines for lung cancer. The guidelines include recommendations, quality indicators and target levels.

Work is currently aimed, together with the trustees and RCCs, at assessing and evaluating controversially limited areas of cancer care that can be of decisive importance for the RCC work with national practice guidelines. One example of such a completed assessment and recommendation from the National Board of Health and Welfare is HPV testing as part of cervical cancer screening.

National practice guidelines

The Confederation of Regional Cancer Centres in Sweden creates the national practice guidelines. A process description and templates as support for creating and modifying a care programme has been developed. Regional representatives are appointed for the work with the practice guidelines. These representatives are often the regional process managers. Moreover, patient representatives are always included and often representatives from primary care, nursing and pathology are also involved.

The practice guidelines build upon the best medical knowledge and provide recommendations for investigation, treatment, nursing, rehabilitation and follow-up. The practice guidelines also include quality indicators and target levels.

A proposal for practice guidelines is then issued to professional organisations and patient organisations on referral. The proposal is then updated and sent to the medical care trustees for consideration for evaluation of the organizatory and financial consequences. After wide consultation, a final proposal is established and adopted by the CRCC. It is then submitted to each RCC, healthcare region and county council/region for approval and implementation.

There are currently 29 national practice guidelines. An additional 10 practice guidelines are currently being developed. The practice guidelines are reviewed annually and updated where necessary.

Regional adaptations

At the regional healthcare level, adaptations, if any, are made to the practice guidelines.

Regional Process Managers/RCC

Each RCC has a regionally appointed process manager. It is their task to implement the practice guidelines throughout the entire region and follow up on the development of care within the area of diagnosis. Additionally, each RCC has a regional process manager with an overall responsibility for prevention, rehabilitation and palliative care.

Local process manager/team

The regional process managers collaborate with local process managers or teams at hospitals/clinics/healthcare centres. The local process managers/teams are appointed by their own organisation.

In several of the RCCs, the regional and local process managers carry out regular local "quality dialogues" – follow-ups that take place based on details obtained from the quality registries. The local dialogues focus on the implementation of the practice guidelines and the results obtained by the clinic or hospital. The closest manager to the organisation also participates in the quality dialogues.

Needs that are observed at the local level can be passed on to regional healthcare or the national level via the process managers and can then be dealt with for further actions.

National quality registry

Representatives from the national quality registries also participate in the work with practice guidelines. Documents from the quality registries are important when practice guidelines are created and followed up on, on the national, regional and local levels.

RCCs also include a registry support that develop follow-up systems and provide details to the local quality dialogues-

RCC work with medicines

The criteria do not include specific descriptions of medications, however the CRCC has taken several initiatives.

Planned introduction of medicines into the cancer field.

The CRCC is working to introduce cancer medicines into Swedish medical care quickly and fairly. Costs of the medicines are expected to increase, so it is important that new, effective medication can reach the patients who may benefit from them. SALAR's inquiry for a model for the planned introduction of new medicines has resulted in the creation of the NT Council (New Therapies), which all county councils and regions have joined. The model also means there will be a collaboration with pharmaceutical companies and government agencies such as the Swedish Medical Products Agency and the Dental and Pharmaceutical Benefits Agency, TLV.

The CRCC has also appointed a national workgroup for cancer medicines (NAC). The NAC supports RCCs in the work with the practice guidelines amongst other things. The NAC are also advisories to the NT council regarding cancer medication.

In several instances, the work with the planned introduction has sped up the introduction of new cancer medicines. The collaboration model has also led to quick recommendations to county councils to no longer use a certain medicine.

National regimen library

Certain medicines with anti-tumoral effects (medicine administered to reduce tumours and/or prevent their growth) are high-risk medications, i.e., there is minimal room for error. Clear and uniform descriptions of how to administer doses and combine anti-tumoral medicines is therefore essential and an important step of the work with quality and patient safety.

Until now, regimens (dosage and combination of medicines) have been created and stored locally, which has resulted in local treatment guidelines. Through national collaboration, a national regimen library has therefore been established. The project started as part of the agreement between the Government and the Swedish Association of Local Authorities and Regions related to *Even better cancer care*. The regimen library is jointly run by the six regional cancer centres. Currently there are around 100 regimens in the national regimen library.

Quality registry for medicines

The tumour medicines registry began in 2009 and has been run by an RCC since 2015. The tumour medicines registry maps the use of medicines for different cancer diagnoses. Over the years, the registry's functionality has improved. All clinics in the country can register with the new version of the registry.

Clinical research and innovation

According to the criterion, the RCC is to create a plan for how clinical research and innovation within regional cancer care can be strengthened.

RCCs will work to create an organizational structure that strengthens clinical cancer research and innovation. RCC:

- should have a function that monitors that cancer patients are given the opportunity to participate in studies
- shall develop structures for collaboration with academic research and the research industry
- shall strive for research of the very best quality
- shall strive to share scientific progress quickly and in a structured way with the cancer patients.

RCC efforts within research

All RCCs have established plans for research and innovation. It is common for this to be included in the development plan for regional cancer care, however there are often special action plans. The plans focus on research and less so on innovation, however RCCs operate several innovative projects.

Participation in treatment studies has proven to be advantageous for patients. Not just because they are given access to new and improved medication or other treatments as a result, but also because in these cases follow-ups are often more comprehensive. According to the criteria, the RCC should have a specific function that monitors that patients are provided with the opportunity to participate in studies. There are examples of RCCs that develop structures in care that include such a function. Some examples of the number of patients who have participated in treatment studies are presented in Appendix 3.

The RCCs' opportunities to contribute to organisational support structures have concerned the further development in their regions with regard to networks, access to research nurses and their networks, development of joint study protocols, development of healthcare region biobanks and in several ways, the creation of healthcare region clinical trials units for cancer. RCCs also collaborate with the regional research hubs that have recently been set up within the framework for the national efforts on the coordination of clinical studies.

There are examples of times where RCCs have worked with Study Services, which have been a way into healthcare regions for research projects, to recruit patients to studies. RCCs receive applications and investigate the interest throughout the healthcare region and mediates contact. A national workgroup investigates the conditions for applying the methods to several RCCs or nationally.

At a national level, RCCs have set up:

- The National Cancer Portal – which has been developed in collaboration with representatives from industry. The portal combines data from the quality registries and biobanks and is therefore a unique source for research. Lung cancer is a pilot project, the plan is that the portal will be further developed with several diagnosis areas.

- Cancer studies in Sweden – which collect ongoing clinical studies in Sweden to make it easier for patients and care professionals to find suitable studies.

RCCs promote research by developing the value of the quality registries, supports structured collection of samples for biobanks and development of biobank registries, as well as the support the RCCs provide to researchers carrying out registry studies. Many RCC employees also conduct research.

RCCs also participate in doctoral education related to research methodology, such as Good Clinical Practice courses. They also finance a research school in clinical research with clinical epidemiological methodology.

RCCs also run annual research conferences and weekly research seminars about current research. These are available online.

The CRCC is also a steering group for the national bowel cancer screening study, see page 35.

Education and skills provision

According to the criterion for education and skills provision, RCCs are to devise and implement an education and skills provision plan for the healthcare region's cancer care. The criterion places requirements on decisions from county council/regional management. The plan will secure long-term access to qualified personnel within the healthcare region's cancer care. According to the criterion, RCCs are also tasked with coordinating courses for patients and their next of kin.

RCC work with education and skills provision

The 2014 follow-up by the National Board of Health and Welfare found that only one RCC fully met the criterion and three were on the right track. The National Board of Health and Welfare believes that the work requires greater cooperation with HR functionaries in the healthcare region and with universities and HEIs. Work is ongoing, but big challenges can still be seen for this criterion.

To facilitate the work with skills provision, the CRCC has created a nationwide comprehensive plan, *National plan for skills provision within cancer care*, and also a plan for skills provision within pathology.

RCCs have also established and offer training for the handling of cytostatics, palliative care, radiotherapy and training for contact nurses, often in collaboration with the university hospitals.

Training jointly created by the RCCs is also available on the joint RCC YouTube channel.

Training for patient and next of kin representatives

Each RCC also offers training for its patient and next of kin representatives. The training is to contribute to increased patient influence and strengthen the opportunity for individuals to work as patient representatives in the cancer field.

Through the CRCC, a training pack for patient and next of kin representatives has been created.

A number of educational films have been made that are primarily aimed at patient representatives at regional cancer centres. They provide the conditions for the national patient representative training, created in 2013 by SALAR and RCCs on the initiative of cancer associations in collaboration. The themes of the films are based on the requests from patient organisations and address aspects such as

- health and medical care organisation and management
- role of patient representatives and the task
- patient rights
- the cancer strategy
- knowledge management
- E-health
- research, development and evaluation
- contact nurse and My Care Plan
- early detection, cancer rehabilitation and palliative care.

Conferences and lectures

In addition to the courses, several RCCs also organise annual conference days with lectures and discussions about cancer care in the future. They are aimed at managerial functions in cancer care, care personnel, patients and next of kin and researchers. RCCs welcome doctors, researchers and care personnel with an interest in oncology to participate in a seminar series that is broadcast via video approximately once per month, aiming to spread knowledge about new findings within cancer research.

Level structuring

According to the criterion for level structuring, RCCs are to prepare a plan for level structuring of cancer care in the healthcare region and support the work to implement the plan. The plan is to be approved by county council/regional management.

Level structuring may include both concentration and decentralisation of care. A concentration of cancer care may have several advantages from a research and quality perspective. The advantages refer to increasing skills, general quality improvement and increased opportunities for research and development. Decentralisation may be advantageous for patients in the form of geographical closeness. Level structuring is an area that requires constant attention in step with the development of cancer care.

RCC work with level structuring

The National Board of Health and Welfare is currently tasked with following up the work with implementing the plan for level structuring that should be approved by the second year of the establishment. The result of the follow-up will be presented in a report to the Government at the end of March 2017. A description of the experiences so far is provided below.

In their previous work with the follow-up of work with level structuring, the National Board of Health and Welfare has been of the opinion that it is a complicated area that, upon proposals for decisions of concentrations of care, often conveys challenges in the form of conflict situations in the profession and competition between county councils, alongside the risk of negative influence on other care.

RCCs are working with the development of work distribution/level structuring in their regions. This has been a difficult area for the majority of healthcare regions and as yet, not all RCCs have plans. Nevertheless, level structuring has been conducted to some extent, despite this. There are several examples of RCCs where the approved plans have largely been implemented.

Work with level structuring has primarily focused on surgery. Some regions have also established diagnostics centres for patients with unclear symptoms and centres for cancer rehabilitation.

One of the areas developed by RCCs is that of regional and national multidisciplinary conferences.

Multidisciplinary conferences

A portion of the RCC work with level structuring also addresses increasing the possibility for regional multidisciplinary conferences.

RCCs have worked to increase the opportunities for clinics to connect with regional and national multidisciplinary conferences, including the access to premises with the equipment and support for establishing timescales.

The CRCC has created a framework for national MDCs that describes the process, confidentiality, skills, techniques, financing, etc. The initiative arose through an agreement between the Government and SALAR in 2014, which included establishing a model for national multidisciplinary conferences. All newly discovered cases of cancer or patients who have relapsed at the national care unit should be assessed at a national MDC.

Changes to the work with regional level structuring

The National Board of Health and Welfare has noted that there has been a change in the work with level structuring at the regional level. Through the national work with level structuring in the CRCC, suggestions for regional level structuring have now also been submitted.

Level structuring through the CRCC

The initial work with level structuring at the national level through the CRCC has been slow. Since 1 January 2015, treatment of penile cancer has been concentrated in two areas of the country, Örebro University Hospital and Skåne University Hospital.

Through the CRCC, work with national-level structuring has continued to develop and has now gained momentum. The criteria for national level structuring have been established and several decisions regarding level structuring have been made.

Based on the difficulties experienced by several RCCs when trying to achieve success in the work with regional level structuring, in the past year proposals for regional healthcare level structuring have been highlighted in the national work with level structuring carried out by the CRCC. As such, county councils and regions have received a common basis with proposals for both national and regional healthcare level structuring. This means that the criteria for the proposals for regional healthcare level structuring will be the same throughout Sweden and proposals will be submitted about the number of places where a specific measure should be implemented in the healthcare regions.

In February this year, the CRCC recommended that county councils/regions concentrate unusual and complicated measures for a number of cancer diagnoses. This in part applied to the national level structuring and in part to regional level structuring. The work has received active support from cancer care patient organisations throughout the process. All county councils/regions have now decided to follow the RCC recommendation to concentrate a further six measures within cancer care in fewer areas of the country. The national care units will be ready as of 1 January 2017 when there will be a total of 19 national care units in Sweden.

The CRCC intends to conduct a follow-up of the national care units' work and results two years after their implementation. They will also monitor how the regional recommendation has been managed by the healthcare regions.

On the right track – better patient care!

Based on the above descriptions, the National Board of Health and Welfare has assessed how the Better population health dimension has developed. Two of the criteria, care processes and level structuring have not been assessed as they will not be met until the fourth year of the establishment phase.

On the right track Triple Aim: Better patient care?

When combined, the Better patient care dimension shows that overall development is good. Positive development can be seen for all measures presented. RCCs have met the majority of the criteria, however the criterion of skills provision has been difficult for RCCs to meet, partly as it has been difficult to achieve collaboration with all involved actors.

The majority of the evaluation tables below are green; work is in full swing and on target, however there are large differences between the county councils.

On the right track to the goals in A National Cancer Strategy for the Future?

The goals for better patient care address:

- improving the quality of care for patients with cancer
- prolonging survival time and improve quality of life after a cancer diagnosis
- reducing regional differences in survival time after a cancer diagnosis

The National Board of Health and Welfare has chosen to present the development within certain areas such as the overview, the choice made based on the goals and based on what the criteria require. These are to be seen as examples and often cannot be directly attributed solely to the work of the RCCs – several actors determine the development. The development with regard to survival has been presented in the previous chapter. For more information and diagrams, see Appendices 2 and 3.

Positive development in healthcare

To assess whether the development is on target, consideration should be paid to the fact that more people are living longer after receiving a cancer diagnosis (see previous chapter). Consideration also needs to be paid to the patient's own experiences of both the care and their own health and wellbeing. As yet, the development of PREM and PROM in the quality registries has not reached the stage where a longitudinal comparison can be conducted. The National Board of Health and Welfare cannot speak for the development within the entire cancer care, however, based on the assessment of the process measures presented in Appendix 3, it is believed that the conditions for even further improved care and looking-after of cancer patients has increased.

The trend is positive for all the measures we present. On the other hand, occasionally, the differences between county councils are large and this can also be seen at the regional healthcare level. There are indicators that speak for continued measures for the efforts to be able to reach all patients so healthcare can become more equal. For the national average, no large differences can be seen between men and women; the differences have been small over time.

Better patient care? Trend	**Regional differences**	**Direction**
The number of transition point discussions has increased from 63 to 74 per cent in the last five years.	Differences between county councils 61-80 per cent 2015	🟩
Pain estimation increasing, from 23-48 per cent in the recent five years	Differences between county councils 28-65 per cent, 13 county councils are below the national average	🟩
PRN of opioids increasing, from 94-96 per cent in the recent five years	Differences between county councils is 93-98 per cent, nine county councils are below the national average	🟩
Individual care plan, national average is 90 per cent for individual care plan for breast cancer	Differences between county councils lies around 24-100 per cent, six county councils below national average	🟩
Offer of contact nurse showing positive development 2014-2015. Diagnoses included are pancreatic cancer, oesophageal and gastric cancers, prostate cancer, bladder and urinary tract cancer	Differences between healthcare regions	🟩
97 per cent of women with breast cancer have been offered a contact nurse	Differences between county councils 54-100 per cent, six county councils are below the national average	🟩
70 per cent of men with prostate cancer were offered a contact nurse	Differences between county councils 31-95 per cent, eight county councils are below the national average,	🟩
50 per cent of patients with malignant melanoma have been offered a contact nurse	Differences between county councils 9-91 per cent, 11 county councils are below the national average	🟩
Multidisciplinary conferences for breast cancer have increased, from 90 to 98 per cent, 2008-2015	differences between county councils 95-100 per cent, 9 county councils are below the national average	🟩
Multidisciplinary conferences for men with prostate cancer have increased, from 31 to 52 per cent, 2012-2015	differences between county councils 17-100 per cent, nine county councils are below the national average	🟩
Multidisciplinary conferences for patients with bowel cancer have increased, from 26 to 95 per cent, 2007-2015	differences between county councils 74-98 per cent, seven county councils are below the national average	🟩
Multidisciplinary conferences for patients with colorectal cancer have increased, from 74 to 97 per cent, 2007-2015	Differences between county councils 93-100 per cent, 14 county councils are below average	🟩
Multidisciplinary conferences for patients with lung cancer have increased, from 50 to 76 per cent, 2002-2015	Differences between county councils 44-95 per cent, 13 county councils are below the national average	🟩
Multidisciplinary conferences for patients with malignant melanoma, national average 34 per cent for certain statuses	differences between county councils 7-96 per cent, nine county councils are below	Comparisons unavailable

Overall, improved results have been seen for 2014-2015 within various quality indicators for different diagnoses. One indicator chosen per diagnosis for diagnosing AML, breast cancer, malignant lymphoma, prostate cancer, bladder and upper urinary tract		🟩
An increase is seen over time regarding the number of patients in studies for bowel and colorectal cancers (oncological studies not included). National averages at 20 and 35 per cent respectively	There are large differences between county councils, from 0 to 73/83 per cent.	🟩

RCC on the right track towards the criteria?

For the work with the criteria within the 'Better patient care' dimension, the National Board of Health and Welfare believe that the RCCs have met the majority of the criteria. Plans exist and implementation is ongoing.

Strong development has occurred regarding the management of knowledge in cancer care. RCCs have developed a strategy where practice guidelines are created on a joint national level. Implementation takes place via the process work with regional and local process managers and teams. This enables the practice guidelines to reach clinics and surgeries. The practice guidelines are anchored at all levels. Work with the standardised care procedures has strengthened the local process work.

Other positive results we see include increased focus on rehabilitation, psychosocial support, development and training of contact nurses, increased participation in research activities and increased use of quality registry data.

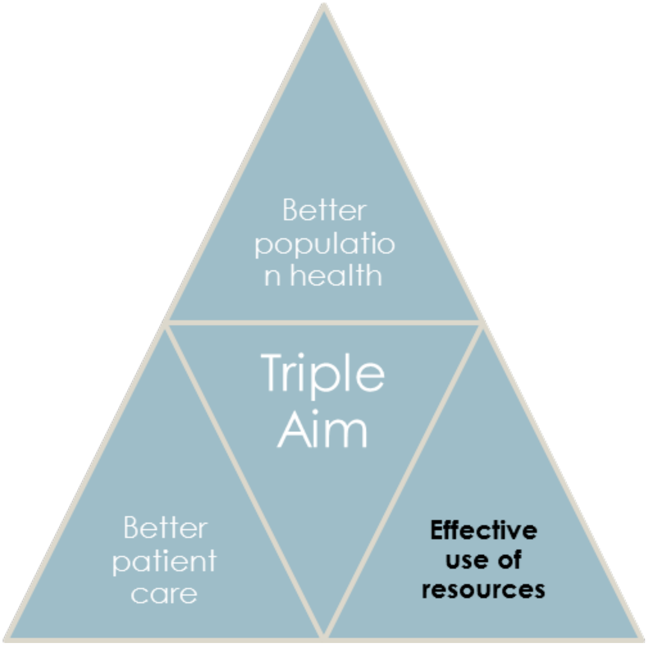
Level structuring of care takes place to varying degrees within the healthcare regions. Through the work at the national level, the county councils have approved six new areas to be concentrated in a few areas of the country. It is too early to say what this will mean for the patients, however the starting point is that higher proficiency will be developed and more research will take place within these areas. Overall, patient care is thought to be safer and better.

The criteria for education and skills provision and level structuring respectively continue to be challenges for RCCs. At the same time, the work with level structuring at the national level facilitates the work at the regional level, as the CRCC now also submits proposals for regional level structuring. Using nationally established criteria for the evaluation of the need for level structuring increases the conditions for more equal care.

The criteria	RCC Work	
RCCs shall coordinate the healthcare region's work to streamline cancer care processes.	Much work is ongoing; the National Board of Health and Welfare is currently working with the follow-up of care process work.	Assessed 2017
Psychosocial support, rehabilitation and palliative care	Plans exist and implementation is ongoing	🟩
Patient's position in cancer care – work for an individual written care plan, access to contact nurses, collection of patient-reported information, awareness about the patient's right to a second opinion.	Efforts in all areas are ongoing	🟩
Knowledge management – national guidelines and practice guidelines, use of quality registries in organisational development	The knowledge management model with practice guidelines and process work developed	🟩
Plan for clinical cancer research and innovation	Plans exist implementation is ongoing	🟩
Education and skills provision plan for the healthcare region's cancer care	Individual RCCs have a plan, implementation ongoing CRCC has created an overarching national plan	🟨
Plan for level structuring of cancer care in healthcare regions	Several RCCs have such plans and have implemented them, but not all of them. National work supports the regional level	Assessed 2017

The assessment grounds for the above tables	
🟩	Criterion met, or development is on target
🟨	Individual efforts or weak/off-target ones
🟥	As yet no efforts, or the development towards the goals are going in the wrong direction

On the right track – Effective use of resources?



In this case, the dimension of the effective use of resources addresses meeting the targets in relation to efforts by RCCs, and is tied to all goals in the report for a national cancer strategy for the future.

In this report, the effective use of resources refers to how well the respective county council and regional resources are used and how well the RCCs have worked with the criteria linked to resource use for development in cancer care.

A national cancer strategy for the future

Development plan for the region's cancer care

In the report for a national cancer strategy, it was suggested that each healthcare region establish a regional strategic plan for their future cancer care, with the proposals in the national strategy as the lowest common denominator.

Monitoring care results

The follow-up of care performance and results is, according to the report, central for all forms of clinical development. Cancer care has been a pioneer in the structure of organisational follow-ups through the Swedish cancer registry and regional oncological centres. The work with processing, analysing and using the information is, according to the report, insufficient. There are deficits in several registries, which means that they cannot be used to their full potential. Several registries also have a low uptake.

According to the report,

- Existing health data and quality registries, plus databases should be strengthened, improved and better utilised.
- With support from their strengthened structures for knowledge development, the regional cancer centres should have a superior responsibility for the quality and organisational follow-ups within their region.

Resources for cancer care

The report emphasises the importance of a range of standpoints

- Prioritising of health and medical care in relation to the need in other social sectors.
- Prioritisation of the resources for prevention, treatment and care in the final stages of life.
- Prioritisation of cancer care in relation to other illnesses.

According to the report, sufficient or adequate resources must be implemented in cancer care to overcome the challenges it faces.

Structure and resources for RCCs

The report states that within the RCCs there should be appropriate structures and adequate resources to support knowledge development within the cancer area of the region.

Furthermore, according to the report, existing resources in oncology centres (ROC) should be included in RCCs and the resources allocated to ROCs need to be doubled. This would mean an additional SEK 75 million per year for the RCCs.

The criteria

The criteria that are linked to effective use of resources address the organisation of RCCs and long-term development of the cancer care in healthcare regions. The criteria are

- the development plan for cancer care in the healthcare region
- management function, RCC collaboration and follow-up of quality in cancer care

In this report, areas of the follow-up on the quality of cancer care have been placed under the criterion for the development plan for cancer care in the healthcare region.

In the report, the National Board of Health and Welfare highlights two perspectives, the government control of the investments to establish regional cancer centres and the organisation of RCCs.

Furthermore we have chosen to add a section about the costs in cancer care and the development of healthy life years that can influence the future costs.

Development plan for the healthcare region's cancer care

According to the criterion, the RCC is to create a long-term development plan for cancer care in the healthcare region. The criterion, which is based on the healthcare region's conditions and specific challenges, is that a plan is to be established that describes the basis of the RCCs' long-term work with

- preventative measures
- cancer care
- matters of education and skills
- matters of research and innovation
- strategies for collaborations with other RCCs and otherwise national and international work.

The plan shall be approved by the participating county councils and regions.

According to the management function criterion, the RCC shall also have a system to monitor the quality of cancer care.

RCC work with the development plan for cancer care

In accordance with the criterion and in wide collaboration within their healthcare region, each RCC has established development plans for cancer care in their healthcare regions.

The RCC work with the criteria has led to there currently being six healthcare region plans that are based on regional conditions. All plans are accepted by the participating county council and region and form the basis for the RCC and county council/regional work with support for the development of cancer care.

Several RCCs have managed to update their plans and are already on their second or third version. The plans include directions, targets and methods as well as feedback. The implementation of the plan is also regularly monitored.

Overall, the National Board of Health and Welfare believes that there should be a continuation of the existing structures in the approved plans that are being used and monitored. The concerns noted by National Board of Health and Welfare during a number interviews in combination with the creation of the plans – i.e., that they would be left on the shelf – are to be viewed as unwarranted. One success factor is the anchoring and feedback that takes place, alongside how management has begun to demand results in care.

Follow-up of quality in cancer care

According to the criterion, a follow-up should be done operationally and clinic-wide from a patient perspective, which includes the following flow process.

RCC work for follow-up systems

For the work with following up on the quality of cancer care, the continual development of the quality registries has been decisive; the work has taken place in close collaboration between the registrars and RCCs.

The aim of the national quality registry is to facilitate the follow-up and evaluation of health and medical care results and the quality as a basis for improvement work. A national quality registry within the cancer field includes individual-based details about diagnoses, treatments and results.

Organisation of national quality registries

National cancer quality registries are built up by professional groups with a registrar/chairperson and steering committee. The steering groups collaborate with the RCCs' establishment, management and maintenance of the registries. Establishing targets is a mutual method for all registers through national support teams comprising various experts. The development of the respective quality registries has resulted in the registrar having the ultimate responsibility.

Within the collaboration, registrars and RCCs work to see that the registry is used in care improvement work and increase the use of registry data in clinical activities. The registrar is responsible for providing the progress report and the registry's annual report that presents the development of the quality indicators.

The coordination of the RCCs' work with the quality registries takes place in a workgroup known as the AKI, *Workgroup for quality registries and INCA*. The databases for all cancer registries are located on the IT platform, INCA for the management of incoming and outgoing data.

Through collaboration, the quality registries are linked to the RCCs' work with patient processes, practice guidelines and quality indicators.

Management function and RCC collaboration

The criteria for the structure of RCC organisation state that RCCs are to have a clear management organisation that is closely connected to the county councils and regional management of their particular healthcare regions. Furthermore, it is understood that RCCs will collaborate with other RCCs.

The organisation structure for the respective RCC can be formed in different ways, taking the various regional conditions into account. However, one joint requirement is that the management function has a distinct mandate, which means that, amongst other things, the division of roles towards county council and regional line organisations (and, in future cases, ordering organisations) shall be clear.

The management organisation can, according to the criterion, be composed of a board or steering group and an executive managerial function.

According to the criterion, representatives for cancer patients and their next of kin are represented within the RCC organisation in the deciding or advising body with reference to the importance of collaboration with research, academic researchers shall also be represented in the board/steering group.

Work with RCC organisation

Management

All six RCCs are led by an organisation manager. As a means of support, five out of the six RCC managers have a steering group/board comprising representatives for the county councils/regions involved, often healthcare or medical directors or the person appointed on their behalf. The board also includes patient and next of kin representatives, representatives from universities and HEIs and RCC representatives – managers and employees with key functions.

Patient and next of kin council

All RCCs have a patient and next of kin council, with representatives for both patients and next of kin. They participate in the development of cancer care and they are included in the majority of processes run by the RCC.

The patient and next of kin council have been developed at different rates and with different functions, from direct participation in development work, or sometimes a more of a referral body.

RCCs have a collaboration structure with the patient and next of kin representatives, amongst other things, an agreement is to be signed between the patient and next of kin council and the RCC for each task.

Regional Process Managers

All RCCs have regional process managers for the work with diagnosis-specific and general diagnosis process work. Each RCC has approximately 20-35 process managers. They are often employed within care, but a portion of their working hours are with the RCC. RCCs has created assignment descriptions and signed agreements with their process leaders.

Confederation of Regional Cancer Centres in Sweden

According to the criterion and report, RCCs are to collaborate with other RCCs and on a national scale.

To facilitate the collaboration between all RCCs, the *Confederation of Regional Cancer Centres in Sweden* has been established at SALAR, upon the instruction of the county council network of directors and after the agreement between the Government and the Swedish Association of Local Authorities and Regions (SALAR) for government funding for the development project.

The Confederation of Regional Cancer Centres in Sweden comprises a national cancer coordinator at SALAR and the managers of the respective RCCs. National cancer coordinators are responsible for presidency of the group and have the task of supporting the development of cancer care.

The *Confederation of Regional Cancer Centres* in Sweden has enabled the collaboration with the RCCs to develop and more work is being conducted on a national level. Several workgroups have been created, with tasks in a number of areas such as the development of national practice guidelines, development within research including the *Cancer Studies in Sweden* registry and *Cancer portal*, primary and secondary prevention, level structuring, quality registry collaboration, establishing standardised care procedures, etc. At present, there are around 60 national workgroups being run on behalf of the CRCC [12].

The Confederation of Regional Cancer Centres in Sweden also acts as an advisory body to SALAR, the National Board of Health and Welfare and the Ministry of Health and Social Affairs and collects data and creates reports for the county council directors' group.

Transparency

As RCC and CRCC collaboration has evolved, it has been important to be open with all information, it has been seen as being significant for the creation of trust.

Everything from proceedings, referrals and decisions, to distributing news and supporting information has all been published on the joint website that is primarily aimed at care personnel and leaders of patient organisations [12].

Resources for RCC development

Government efforts as basis for the establishment

From a resource point of view, the Government has taken several steps to meet the challenges facing future cancer care. Several of these initiatives have provided considerable resources for the RCC's work with developing cancer care at local, regional healthcare and national level. The most important aspects to highlight include

- the Official Government report: A National Cancer Strategy
- for the Future (SOU 2009:11)the appointment of a national cancer coordinator
- the creation of criteria to characterise a regional cancer centre
- agreements with SALAR with regard to specific efforts and national coordination
- annual funding for an RCC establishment
- the National Board of Health and Welfare's commission to follow-up on and support the establishment

A large portion of the above is described in more detail in the introduction to the report.

Agreements with SALAR.

Since 2009, a number of agreements have been signed between the Government and SALAR related to efforts within the cancer field and national work through the CRCC.

Government funding to each RCC

The Government has commissioned the National Board of Health and Welfare with managing applications and disbursing funding to each RCC upon agreement with the trustees about the criteria that form the basis of the structuring of RCCs.

Since 2010, each year has seen the allocation of government funding for the establishment of RCCs. So far approximately SEK 293 million has been paid to support the establishment of regional cancer centres (see Table 1 below for breakdown of distribution of funding). Since 2013, government support for regional cancer centres has reached SEK 48 million annually. This means that the government has contributed with over half of the financing of SEK 75 million annually as suggested in the report.

Table 1. Government funding to the respective RCC 2010-2016, total SEK million

RCC	2010	2011	2012	2013	2014	2015	2016	Private or other funding
RCC North	4.0	7.0	7.9	8.0	8.0	8.0	8.0	Yes
RCC Uppsala-Örebro	4.0	5.3	8.2	8.0	8.0	8.0	8.0	Yes
RCC Stockholm-Gotland	4.0	4.0	7.9	8.0	8.0	8.0	8.0	Yes
RCC Southwest	4.0	5.0	7.2	8.0	8.0	8.0	8.0	Yes
RCC West	4.0	5.3	6.0	8.0	8.0	8.0	8.0	Yes
RCC South	4.0	5.4	7.8	8.0	8.0	8.0	8.0	Yes
Total	**24.0**	**32.0**	**45.0**	**48.0**	**48.0**	**48.0**	**48.0**	Yes

Source: National Board of Health and Welfare

The funding is intended to be used to stimulate the establishment of RCCs. There have been no co-financing requirements, however county councils and regions have contributed funding to the RCC, exceeding that which was previously provided to the ROC, but to different extents.

RCCs are also responsible for supporting the development of cancer quality registries, for which specific government support is available with joint financing from the healthcare trustees. Since 2011, the government and SALAR have signed a special agreement for support for the development of quality registries, in which the cancer registry is included.

The Government has also approved a special measure to reduce cancer care wait times by introducing what is known as a standardised healthcare procedure. SEK 2 billion have been budgeted for this effort during the currental period of the office, the years 2014-2018. The majority of this funding goes to county councils and regions for the implementation work. The CRCC has received support for the development of standardised care processes for the diagnoses concerned. The respective RCCs also received government financing for project management and support for the work to introduce standardised care procedures. The work to implement the standardised healthcare procedure is monitored by the National Board of Health and Welfare in another government commission, see the National Board of Health and Welfare report in this assignment, http://www.socialstyrelsen.se/publikationer2015/2015-11-6. The next status report will be released in 2016.

National follow-up and support for development

In addition to the task of processing applications for RCC funding, the National Board of Health and Welfare has been tasked with following up and supporting the establishment of regional cancer centres, for example through site visits during 2013-2015. In December 2015, the National Board of Health and Welfare were tasked with following up on the RCCs' work with the criteria in the fourth and final year of the timescale established in the criteria to characterise a regional cancer centre. The annual follow-up conducted by the National Board of Health and Welfare has picked up from the timescale stated in the criteria. We have submitted annual reports to the government, see:

- *Follow-up of regional cancer centres 2015 – preventative measures and early detection, research and innovation.* http://www.socialstyrelsen.se/publikationer2016/2016-2-15
- *Follow-up of regional cancer centres 2014 – establishment, strengths and challenges* The report highlights the RCCs' work with four plans: the development plan for the healthcare region's cancer care; plan for level structuring; plan for skills provision and the plan for rehabilitation and palliative care. http://www.socialstyrelsen.se/publikationer2015/2015-2-37.
- *Follow-up of regional cancer centres 2013*, http://www.socialstyrelsen.se/publikationer2014/2014-2-10.

Since 2012, the National Board of Health and Welfare has obtained a total of SEK 13.9 million for the task of

- administering the funding to the RCCs
- follow-up and actions such as visiting the sites, all in support of the establishment of RCC 2012-2016
- develop a model for assessment, implementation and follow-up of national screening programmes and implement it into the cancer field
- develop a model to establish goals for indicators and apply the model for the national guidelines within cancer care
- provide an overall assessment of the structure of RCCs.

County council efforts

In the report for a national cancer strategy, it was proposed that the support issued to Regional Oncology Centres (ROC) be included in the RCC. It has also been the case that this comprises a significant part of the county council and regional support to the RCCs. According to the report, support to the ROCs should also be doubled to ensure that RCCs would be able to successfully manage the comprehensive activities that would be run. RCCs have been allocated additional funding, however the extent varies between RCCs.

In addition to the direct financial support to the RCCs, the county council and region's part of the development work has primarily comprised the work efforts carried out by local process managers and teams. Other efforts refer to time from management functionaries for the work within the cancer council or equivalent.

County council/regional duties in the development of cancer care are, in addition to the support to RCCs, to approve the suggestions for the measures submitted by the RCCs and ensure that sufficient resources are available so changes can be made in cancer care.

Cost for cancer care

Cancer is one of the most widespread diseases in Sweden and the number of cancer cases is increasing each year. Yet today, many cancers can be treated successfully and information from the National Board of Health and Welfare shows a gradually decreasing cancer mortality rate (see Appendix 2 *On the right track – better population health?),* partly thanks to earlier diagnostics, new, more effective treatments and preventative measures. The cost of cancer can be divided into time and resources for both those affected (patients and their next of kin) and for society as a whole (healthcare, health insurance, working life) [7].

Socioeconomic cost of cancer in Sweden

The Swedish Institute for Health Economics (IHE) has calculated the socioeconomic costs of cancer in Sweden during 2013 [7].

According to the report, in 2013 cancer costs reached SEK 36 billion. The greatest cost was production losses that reached SEK 15.9 billion (44 per cent) in 2013. In 2013, the total incidences of cancer (total new cancer cases) was 61,297.

Table 2. Cost of cancer in 2013 divided into cost areas

Cost area	SEK Billion	Portion of total costs, per cent
Production losses	**15.9**	**44**
Inpatient care	**6.5**	**18**
Informal care	**4.6**	**13**
Specialist outpatient care	**4.1**	**11**
Medications	**2.8**	**8**
Palliative care	**1.2**	**3**
Screening	**0.6**	**2**
Primary care	**0.3**	**1**
Total	**36**	**100**

Source: IHE

The development of the cost of cancer over coming years will depend on several factors such as the number of people developing cancer, the length of time a person can live after diagnosis, which treatments are available and their effectivity and use in healthcare, how future cancer morbidity will affect people's ability to participate in the labour market, etc.

The cost of cancer in 2040 in the IHE report builds upon the prognoses for the number of people who develop cancer and the number of people who live with cancer. For additional factors that affect costs, the prognosis from the 2013 cost structures. According to the report, cancer will cost approximately SEK 68 billion in 2040 (in 2013 pricing terms), which corresponds to a cost increase of around 90 per cent.

The IHE states that according to Statistics Sweden, the total cost of health and medical care in 2013 was SEK 415 billion. Of these, SEK 15.5 billion make up cancer care according to IHE calculations (the IHE has previously conducted equivalent calculations for heart disease at SEK 61.5 billion in 2010 and skeletal and joint disorders at SEK 102 billion in 2012).

Positive development of number of healthy life years

There are several factors that influence the development of resource use/resource needs within health and medical care. For the future development of the incidences of cancer, the work with preventative measures is essential, as is the work with general lifespan development and the total of healthy life years.

When compared against healthy life years which are an indicator measured by the EU within the ECHI health indicators framework, a positive development can be seen in Sweden, see Table 3 below. Healthy life years are a measurement of the number of years a person of a certain age can be expected to live without disability. The indicator is used to

- follow the health situation as a productivity factor and economic factor, and introduce the concept of quality of life
- measure the employability of older employees
- follow up on progress regarding accessibility, quality and long-term stability of health and medical care

Healthy life years (HLY) is believed to be a solid indicator to differentiate between life years free of activity limitation and the number of years with at least one activity limitation and is therefore linked to quality of life.

Chronic illness, weakness and disability tends to be more common amongst the higher age groups, however if HLY is increasing faster than a population's life expectancy, they will also live for a larger part of their lives without an activity-limiting disability. Such development can include changed patterns of resource use within health and medical care, and more comprehensive effects on consumption and production in the entire economy. The indicator is important for decision makers so they can be aware of the alternative costs (i.e., missed advantages), that they are not doing enough to prevent illness, which results in the use of limited resources within health and medical care for diagnoses, treatment and management of preventable illnesses and injuries. The tables below present the development of both the expected total of healthy life years and life expectancy of women and men from birth and 65 years of age, respectively [8].

Table 3. Development of number of healthy life years

Sex	**Remaining healthy life years at birth**		**Remaining healthy life years at age 65**		**Total new healthy life years since 2006,**
	2006	2014	2006	2014	from birth/from age 65
Women	67.5	73.6	14.2	16.7	6.1/2.5
Men	67.3	73.6	13	15.2	6.3/2.2

Source: EUROSTAT

The table below also shows the development of life expectancy. A positive trend can also be seen here.

Table 4. Life expectancy from birth and remaining life expectancy from the age of 65 respectively

Sex	Life expectancy at birth		Life expectancy from the age of 65		Total new years of life since 2006,
	2006	2014	2006	2014	from birth/from age 65
Women	83.1	84.2	20.9	21.6	1.1/0.7
Men	78.8	80.4	17.7	18.9	1.6/1.2

Source: EUROSTAT

The tables show a clear and dramatic positive trend in the number of expected healthy life years, compared to the development of life expectancy. The number of healthy life years from birth has increased by 6.1 years, whilst life expectancy increased by 1.1 years for women during the 2006-2014 period. Corresponding data for men show that the total of healthy life years from birth has increased by 6.3 years, whilst life expectancy has increased by 1.6 years in the same period. When compared to the remaining healthy life years after the age of 65, there has been an increase of 2.5 years for women and 2.2 years for men, whilst the total lifespan has increased by 0.7 years for women and 1.2 years for men. It is worthy to note that the gap between men and women for both healthy life years and life expectancy is decreasing. This positive development of the total number of healthy life years in relation to increasing life expectancy can be assumed to provide positive results for the use of health and medical care resources.

RCCs have developed tools as support for the prioritisations

The population’s living habits are important factors that can be influenced for many cancer diagnoses and have a particular significance to future ill health. For certain cancer diagnoses, data regarding population living habits together with epidemiological methods can provide relatively accurate prognoses for future morbidity.

In collaboration with Uppsala University, RCCs have developed the Cancer Prevention Calculator that makes simulation possible for how changes in people’s living habits influence cancer morbidity and what effects these have on the combined economic cost of cancer. The Cancer Prevention Calculator was launched recently and is used to, amongst other things, support the work with regional cancer prevention plans. For more information (in Swedish) visit http://www.cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/prevention/cancerpreventkalkylator/

On the right track – Effective use of resources!

Effective use of resources builds upon the effectiveness in relation to expended resources. RCCs have received government funding to meet the criteria that are to characterise a regional cancer centre.

On the right track Triple Aim – Effective use of resources?

The National Board of Health and Welfare believes that the RCCs have fulfilled the majority of the ten criteria and the development towards the goals in the cancer strategy are on the right track, at least when compared against the measures presented in this report.

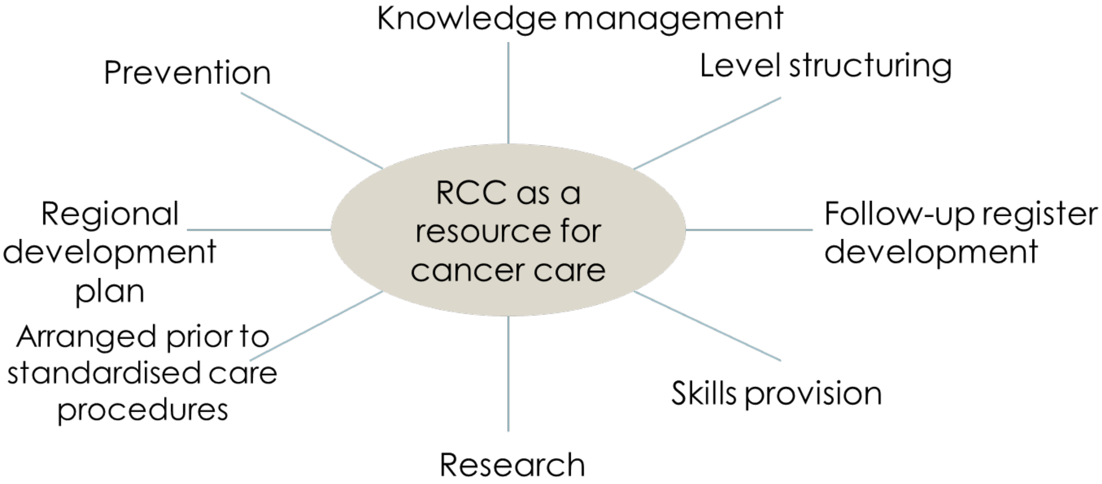
The National Board of Health and Welfare believes that by appointing government funding, the targets have been attained, i.e., the majority of criteria have been fulfilled and so the resources have been well used from a government perspective.

Overall, the National Board of Health and Welfare believes that RCCs have become a resource for county councils/regions on regional levels. The establishment of RCCs has resulted in an increased interaction over national, regional and local levels that convey a good use of resources. This is described in the next two sections.

RCC as a resource for cancer care

RCCs have become a supporting resource for the development of cancer care within several areas, see examples in the illustration below.

RCC as a resource for developing cancer care



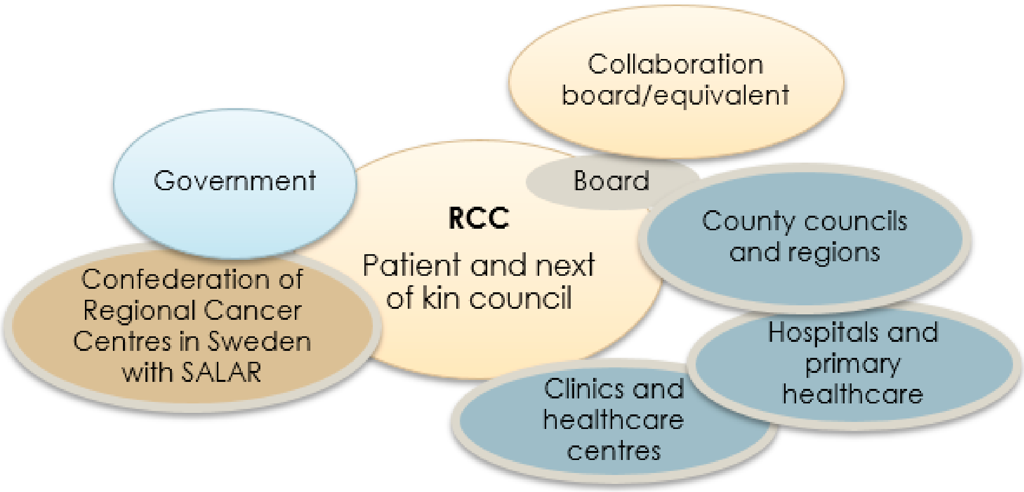
Interplay over national, regional and local levels

Each regional cancer centre has been established as a knowledge centre – a resource for cancer care development work at the regional healthcare level.

RCCs receive support from, collaborate with and are dependent upon a number of actors who themselves are resources to be able to succeed in the endeavours to meet the criteria.

The main actors are the state, with the government decision for support to RCCs and the National Board of Health and Welfare's task to follow up and support the establishment: SALAR via national coordination, the RCC's own board or steering group, the RCC patient and next of kin council, the collaboration board that make policy decisions, county councils and regions where policy and administration steer the resources in healthcare and therefore the care providers. The actors are presented in the following image.

Role of RCCs in the structure of actors



Sound use of resources and skills through increased collaboration

Increased collaboration shares resources and skills. At the regional healthcare level, efficiency can be achieved by having 6 people conduct a task rather than 21. Similarly, the job is conducted once in the national collaboration instead of 6 or 21 times. This means that instead of producing knowledge and practice guidelines, building infrastructure such as the cancer portal et al. taking place within each individual county council (21 times) or healthcare regions (6 times), work takes place only once at the national level. The National Board of Health and Welfare feels it is reasonable to believe that resources are saved when more of the collaboration takes place at the regional healthcare or national level. Around 60 development projects are ongoing within the CRCC.

RCCs have established regional healthcare cancer plans that are based on the conditions of the county councils/regions and the needs containing goals and prioritisations. Subsequently, the plans have formed an important aspect of the county councils' work to prioritise resources within cancer care.

On the right track towards the goals?

In this report, the National Board of Health and Welfare has chosen to present the development towards the goals in the report for a national cancer strategy.

As shown in the previous section, on the whole, positive development has been seen in population health and the conditions for better care for cancer patients. However, more people are developing cancer and the efforts to reduce this risk need to be increased.

RCCs on the right track for the criteria of effective uses of resources!

The National Board of Health and Welfare believes that the RCCs meet the two criteria included in an effective use of resources that apply to the establishment of a development plan for regional cancer care and the criterion for the leadership and organisation of RCCs.

How the RCCs have met the criteria	Example of RCC efforts	
The RCCs shall create a long-term development plan for regional cancer care	All six RCCs have established a plan approved by county council and regional management	🟩
RCCs shall have systems to follow up on the quality of cancer care	The follow-up plans are found in cancer plans and the quality registries are used for systematic dialogues in the regions	🟩
RCCs are to have a clear management organisation, closely grounded in county council and regional management in the healthcare regions	Structures for the anchoring will develop in every way	🟩
RCCs shall collaborate with other RCCs	Confederation of Regional Cancer Centres in Sweden	🟩
Representatives for cancer patients and their next of kin are represented within the RCC organisation in the deciding or advising body	All RCCs have patient and next of kin councils and the representatives from these councils are included in the RCC board/steering group	🟩
Representatives from academic research shall also be included in the RCC organisation	The RCC board/steering group include representatives from academic research	🟩

The assessment grounds for the above tables	
🟩	Criterion met, or development on target
🟨	Individual efforts or weak/off target
🟥	As yet no efforts, or the development towards the goals is going in the wrong direction

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Appendix 1 Criteria to characterise a regional cancer centre

Overview of the criteria

Patient-centred criteria	**Education, knowledge management and research criteria**	**Criteria for the organisation of RCCs**
Preventative measures and early detection of cancer	Education and skills provision	Management function, RCC collaboration and follow-up of quality in cancer care
Care processes	Knowledge management	Development plan for cancer care in the healthcare region
Psychosocial support, rehabilitation and palliative care	Clinical cancer research and innovation	Level structuring
Patient's position in cancer care		

Patient-centred criteria

Preventative measures and early detection of cancer

RCCs are to formulate and implement a plan for the healthcare region's work with preventative measures and early detection of cancer.

Care processes

RCCs are to lead and coordinate the healthcare region's work to streamline cancer care processes.

Psychosocial support, rehabilitation and palliative care

- RCCs are to have a plan that assures cancer patients access to high quality psychosocial support, rehabilitation and palliative care within the entire healthcare region.
- RCC shall work to develop the support available to cancer patients' next of kin.

Patient's position in cancer care

RCCs shall work to

- create an individual written care plan for each cancer patient,
- support cancer patients with a contact nurse or equivalent contact person,
- collect patient reported information and use it in the work to develop cancer care,
- increase the knowledge about a patient's right to a new assessment amongst health and medical care personnel, and ensure that patients are informed about this right.

Criteria regarding education, knowledge management and research

Education and skills provision

RCCs are to devise and implement an education and skills provision plan for the healthcare region's cancer care.

Knowledge management

- RCCs shall participate in national guidelines and, where necessary, prepare regional practice guidelines.
- RCCs are to support the work with the implementation of national guidelines and practice guidelines and other front-line knowledge within cancer care throughout the healthcare region. This includes the regional implementation of the forthcoming national target levels.
- RCCs shall work to use national quality registries to develop activities and organisation within cancer care.

Clinical cancer research and innovation

- RCCs are to work to strengthen the clinical cancer research in the healthcare region and nationally, and to ensure that cancer patients quickly benefit from progress in the academic community.
- RCCs shall develop structures for collaboration with academic research and the research industry, as well as promote innovations within cancer care.

Criteria for the organisation of RCCs

Management function, RCC collaboration and follow-up of quality in cancer care

- RCCs are to have a clear management organisation, closely connected to county council and regional management in the healthcare regions.
- RCCs shall collaborate with other RCCs.
- RCCs shall have systems to follow up on the quality of cancer care.

Development plan for cancer care in the healthcare region

RCCs are to develop a strategic development plan for cancer care in the healthcare region.

Level structuring

RCCs are to prepare a plan for level structuring of cancer care in the healthcare region and support the work to implement the plan.

Timescale for establishing RCCs

At start of RCC

There is a project plan and a project organisation for the establishment of RCCs.

One year from an RCC's launch

- An RCC organisation is built up.
- There is a regional programme for cancer prevention and early detection of cancer.
- Work to streamline the care processes is on-going.
- An inventory of the healthcare region's resources for psychosocial support, cancer rehabilitation and palliative care has been made.
- There is a description of how patient opinion will be strengthened and RCC work in this area has begun.
- The work with a programme for education and long-term skills provision has begun.
- There is also an organisation for the healthcare region's knowledge management within cancer care.
- There is also a plan for how clinical research and innovation within the healthcare region's cancer care will be strengthened and it has been prepared in the collaboration between universities and HEIs in the healthcare region.

Two years from an RCC's launch

- There is a long-term development plan for the healthcare region's cancer care that has been approved by county council and regional management.
- There is a plan for level structuring, approved by county council and regional management.
- There is a plan for high-quality psychosocial support, cancer rehabilitation and palliative care throughout the healthcare region and work to implement the plan has begun.
- A programme for education and long-term skills provision has been approved and the work to implement the programme has begun.

Three years from an RCC's launch

- The regional programme for cancer prevention and early detection can generally be compared and there are follow-up systems.
- There is also an organisational structure that strengthens clinical cancer research and innovation.

Four years from an RCC's launch

- Streamlining work is complete for all larger care processes.
- A level structuring plan has been completed.

Appendix 2 On the right track – better health amongst the population?

Cancer morbidity, mortality and survival

As of 2014, over 478,600 people in Sweden either have or have previously had cancer; approximately 255,040 women and 223,560 men. The number of people living with a cancer diagnosis is expected to increase in the future, thanks to increased diagnostics, longer survival and population changes (mainly the size and age structure of the population).

One way to present the situation in relation to the goals set in a national cancer strategy to reduce cancer morbidity and increase survival is to show the development of

- The number of cancer cases per 100,000 citizens
- The rate of cancer mortality per 100,000 citizens
- The relative five-year survival rate

Cancer morbidity and mortality

Cancer often affects older people, with approximately 60 per cent of those with cancer being aged 65 or older. Nevertheless, people of all ages can be affected by cancer, even if the disease is incredibly rare amongst children and young people.

Diagram 1 shows the total number of cases and deaths from cancer per 100,000 citizens from 1998 to 2014. The diagram shows how, at the same time as the number of new cancer cases increased during the period, the number of fatalities has remained the same or decreased over time. Diagram 2 shows the number of cases per healthcare region.

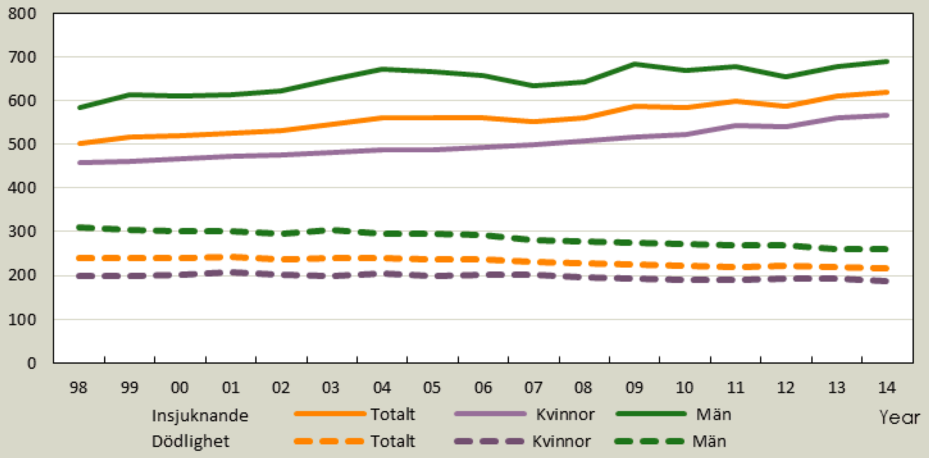


Diagram 1. Insjuknande och dödlighet i cancersjukdom, 1998-2014

Antal fall respektive dödsfall per100 000 invånare, ålderstandardiserade värden

Källa: Cancerregistret, Socialstyrelsen

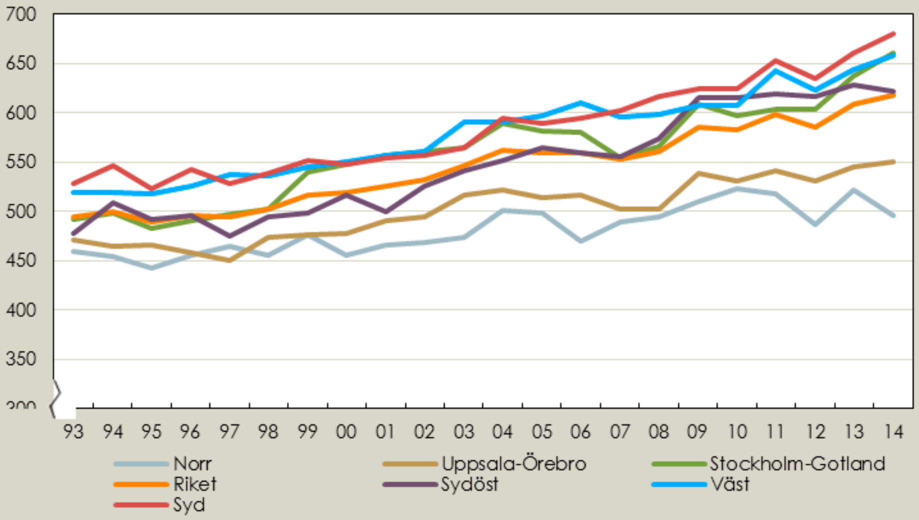


Diagram 2. Insjuknande i cancersjukdom, 1993-2014

Antal fall per 100 000 invånare, ålderstandardiserade värden

Södra Halland ingår i Syd och Norra Halland i Väst
Källa: Cancerregistret, Socialstyrelsen

Relative five-year survival rate

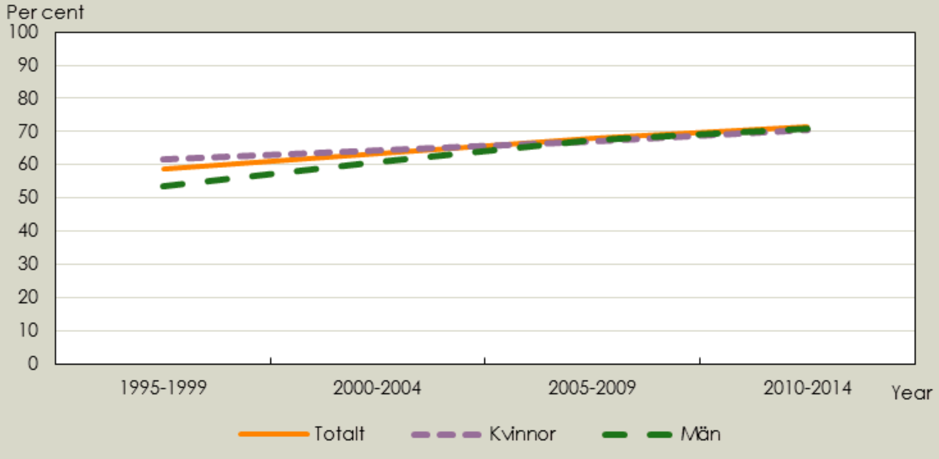
Cancer mortality has dropped over the past 40 years and survival after diagnosis has increased. These improvements are partly related to care having received better possibilities to establish an early diagnosis and offer more effective treatment.

The diagram below presents the relative 5-year survival rate. Trend diagrams will be presented first, followed by county council diagrams. If the relative 5-year survival rate for patients with a certain type of cancer is 50 per cent, this means that they have half the chance of surviving for five years or more after cancer diagnosis when compared to a population group similar in age and sex.

Relative survival has increased amongst cancer patients since the beginning of the 1990s, moreso for men than women. Diagram 3 shows that the relative survival rate amongst men increased by almost 17 percentage points from 1995-1999 to 2010-2014 and for women, by approximately 9 percentage points. This applies to all forms of cancer. The total relative 5-year survival level was 71 per cent from 2010 to 2014.

Diagram 3. Relativ 5-årsöverlevnad vid cancersjukdom

Avser patienter 30 – 89 år vid diagnos, ålderstandardiserade värden



Källa: Cancerregistret, Socialstyrelsen

If the two most common cancers for women and men – breast and prostate cancer – are omitted, as well as Squamous cell carcinoma (which as a rule has a very good prognosis), the five-year survival rate for women was 59 per cent and 55 per cent for men in the years 2010 to 2014.

Avoiding mortality through healthcare policy

Mortality that can be avoided through healthcare policy refers to mortality that can be remedied through preventative measures. In order to follow the development of preventable mortality, an indicator has been developed that consists of mortality in a number of selected diagnoses and causes of death that are believed to be affected by broader healthcare policy efforts, for example, smoking cessation campaigns and better alcohol habits. The diagnoses and causes of death included are lung cancer, oesophagal cancer, cirrhosis of the liver and road traffic accidents.

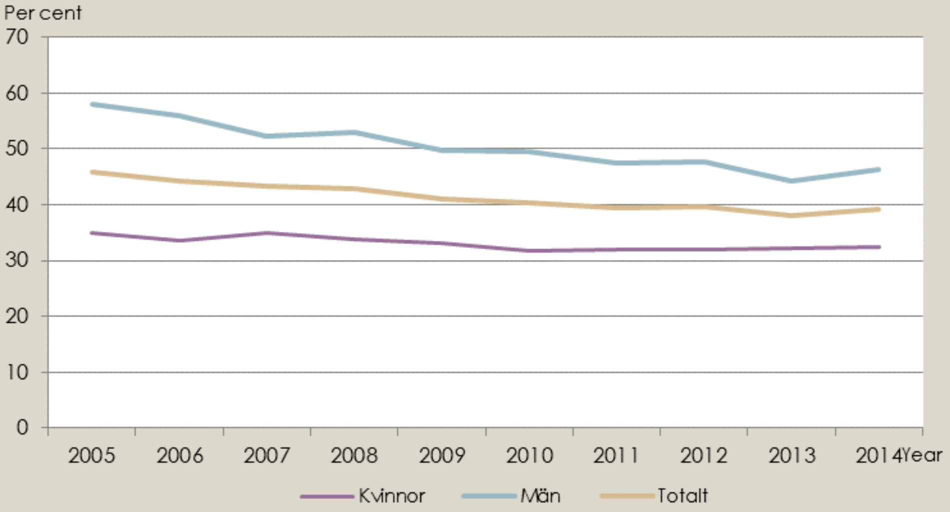
The purpose is for the knowledge that is available about the cause of certain diseases and the effectivity of different treatment methods to be transformed into practice, in one way by focusing on how population mortality can be influenced.

Diagram 4 below shows the number of deaths per 100,000 residents aged 1-79 that could be avoided through healthcare policy, compiled for the years

2011 to 2014 for a more reliable comparison. The diagram shows the changes between 2005 and 2014. Caution should be used when interpreting the data as the way diagnoses are established can differ between the county councils. Smaller county councils also tend to receive more unstable values.

The diagram shows a decrease in mortality that can be avoided through healthcare policy for men of 11 per cent. There is also a decrease for women, but not as large.

Diagram 4. Hälsopolitiskt åtgärdbar dödlighet, dödsfall per 100 000 invånare 1-79 år, från år 2005 till 2014. Riket.



Källa: Dödsorsaksregistret, Socialstyrelsen

Diagram 5 below shows the deaths that could be avoided through healthcare policy measures, per the county council.

Diagram 5. Avoiding mortality through healthcare policy, deaths per 100,000 residents aged 1-79. Age-standardised values, years 2005-2014.

Källa: Dödsorsaksregistret, Socialstyrelsen

The comparison has been age-standardised, meaning that adjustments have been made to differences in the population's age structure between county councils.

Vaccination

There is a prophylactic vaccine against the viruses that cause cervical cancer, the Human Papillomavirus (HPV). HPV vaccination is included in the childhood vaccination programme. Starting in 2012, Sweden has also offered all girls born between 1993 and 1998 the HPV vaccination free of charge, known as the "Catch-up" vaccination programme and run by the county councils.

According to HPV vaccination statistics for 2015 for girls born between 1999 and 2003, the average uptake for at least one vaccination dose was 81 per cent, meaning that no county council has hit the target of over 90 per cent. Variation between county councils was 76-89 per cent (although some under-reporting may take place).

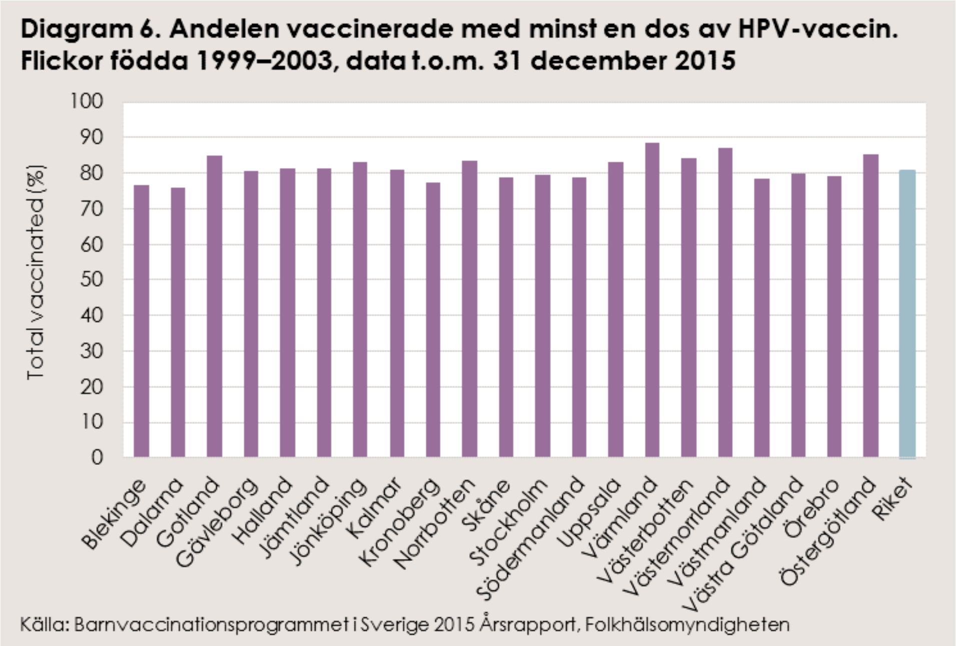


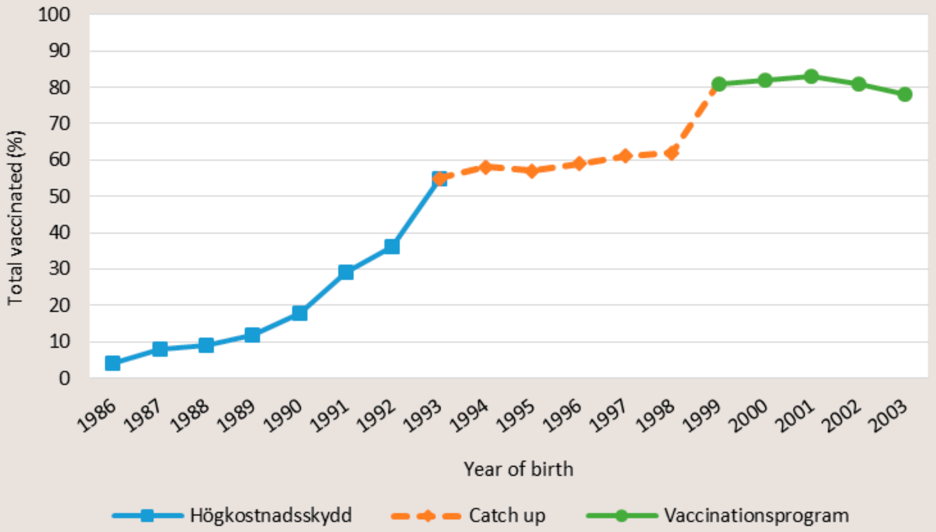
Diagram 6. Andelen vaccinerade med minst en dos av HPV-vaccin. Flickor födda 1999–2003, data t.o.m. 31 december 2015

Källa: Barnvaccinationsprogrammet i Sverige 2015 Årsrapport, Folkhälsomyndigheten

For girls born between 1993 and 1998 (catch-up vaccination), the average uptake for at least one vaccination dose was unchanged compared to the statistics for 2014 (59 per cent). Amongst the women born before 1993, the number of those vaccinated is low. See diagram 7 below. The uptake is however higher than the national average in the counties where vaccination has been offered to women up to the age of 26 free of charge [9].

Diagram 7. Andelen vaccinerade med minst en dos HPV-vaccin per födelsekohort.

Andel flickor och kvinnor födda 1986–2003, uppföljning t.o.m. 31 december 2015, riket.



Källa: Barnvaccinationsprogrammet i Sverige 2015 Årsrapport, Folkhälsomyndigheten

Living habits

A large portion of the work to prevent cancer includes efforts to create healthy living habits amongst the population. A selection of the indicators that the CRCC suggest the healthcare regions follow is presented in this chapter.

The World Health Organisation (WHO) has estimated that lifestyle habits such as tobacco and alcohol use, physical activity and food habits cause up to 30 per cent of all cancer deaths. A person who adopts a healthy lifestyle lives an average of 14 years longer than a person with unhealthy lifestyle habits. The four lifestyle habits have the greatest contribution for the combined disease burden of Sweden.

Tobacco use

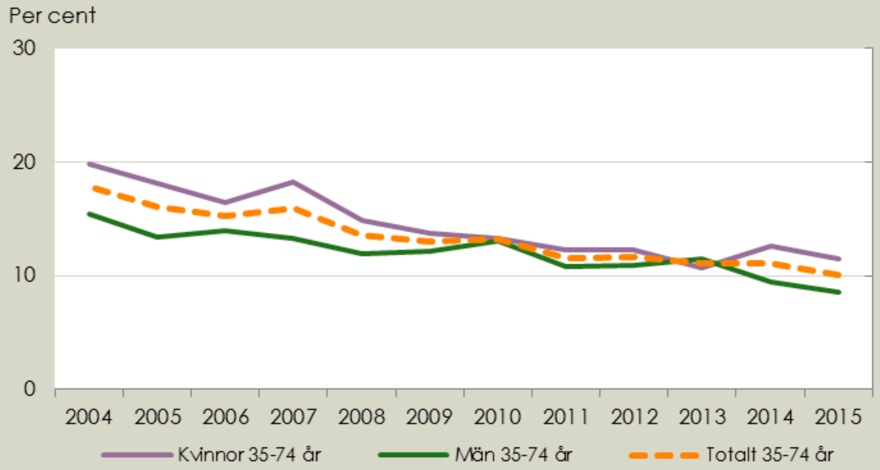
Number of women and men who report smoking daily

The annual questionnaire, *Health on equal terms* that has been conducted by the Public Health Agency of Sweden since 2004 shows that the number of those who smoke daily has decreased over the 2004-2015 period. In 2015, 12 per cent of women and 9 per cent of men smoked daily. Smoking daily is most common amongst people aged 45-64, of whom 13 per cent are daily smokers. Nevertheless, the number has reduced in all but the highest age groups. It is more common for young people to be occasional smokers, in 2015 approximately 18 per cent state they smoke sporadically. No changes have occurred over time regarding the number of people who smoke occasionally.

Below a trend diagram is shown with the results for the number of individuals aged 35-74 that stated that they smoke daily, in the period of 2004-2015, the national total and portion of women and men respectively.

Diagram 8. Röker dagligen

Andel individer i åldern 35–74 år som uppgivit att de röker dagligen



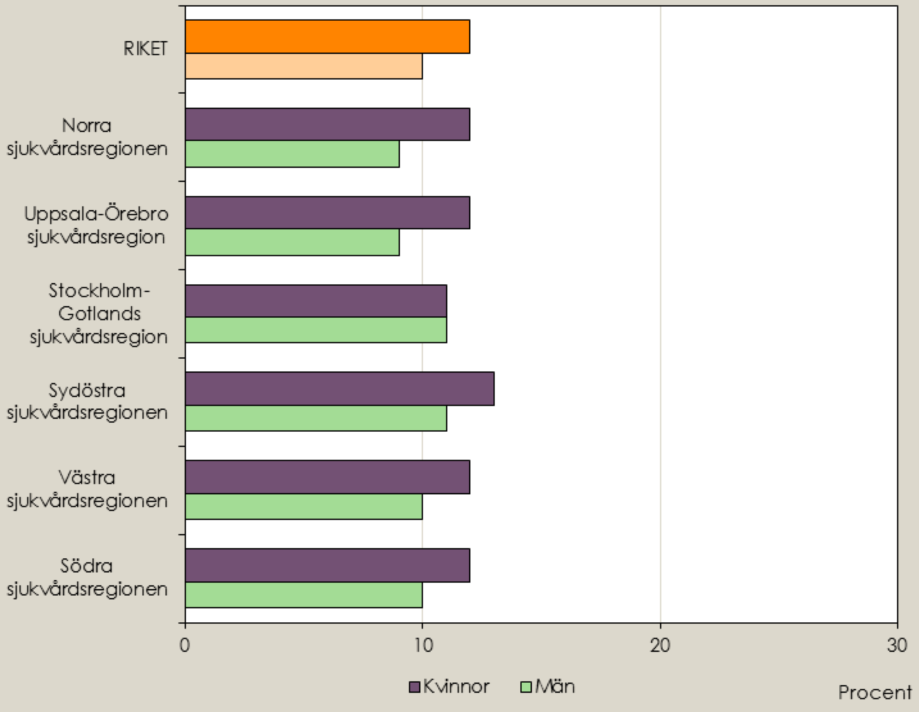
Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Diagram 9 below shows the number of individuals aged 35-74 who stated that they smoke daily, 2012-2015 divided by gender and healthcare region.

The diagram shows that in the majority of healthcare regions, more women than men report smoking daily.

Diagram 9. Röker dagligen

Andel individer i åldern 35–74 år som uppgivit att de röker dagligen , 2012-2015.



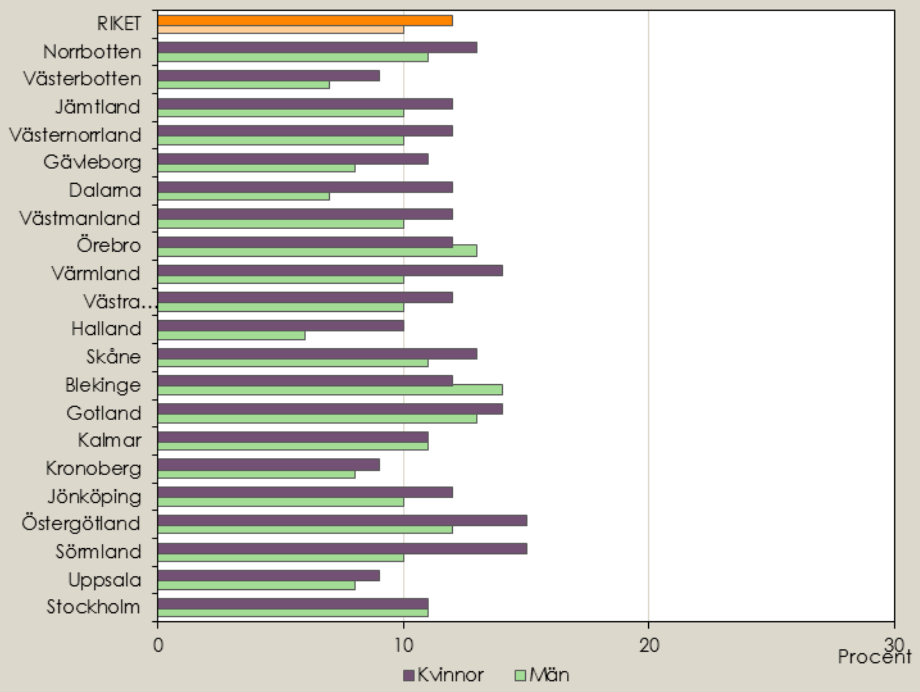
Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Diagram 10 below presents the number of women and men who state they smoke daily, divided into county council.

The largest portion of women who report smoking daily, 15 per cent, can be found in Sörmland and Östergötland counties. The highest portion of men who report smoking daily can be found in Blekinge, where 14 per cent of men state they smoke daily.

Diagram 10. Röker dagligen

Andel individer i åldern 35–74 år som uppgivit att de röker dagligen , 2012-2015.



Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

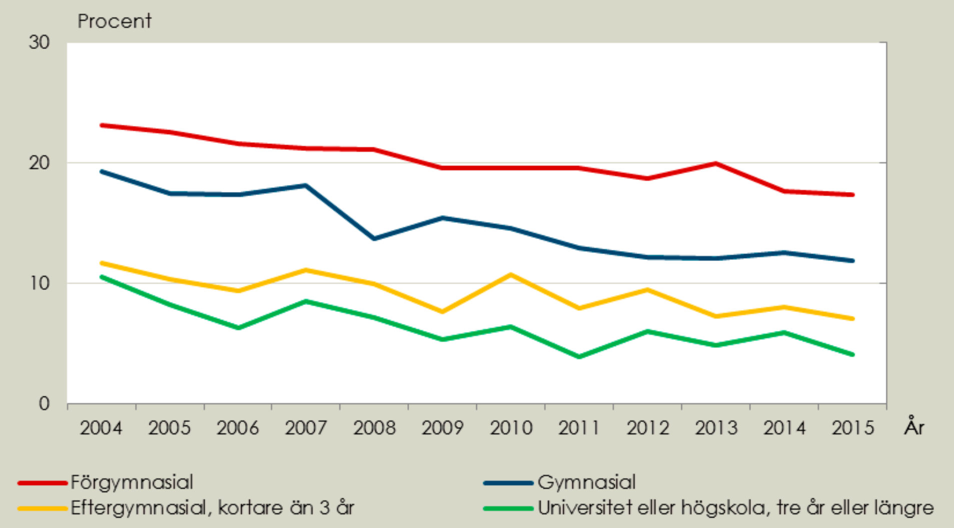
Total who report smoking daily, divided by level of education

Diagram 11 presents the development of the number who report smoking daily, divided by level of education. Levels of education are divided into four groups

- Compulsory school (pre-upper secondary): this group includes those with fewer than two years of upper secondary education
- Upper secondary education: this group includes those with at least two years of upper secondary education or more
- Post upper-secondary education: this group includes those who have studied at university for fewer than three years
- University or HEI: this group includes those with a minimum of three years of study at university or higher education institution level

The number of those reporting smoking daily decreases over time in all groups. However large differences can be seen for daily smoking in relation to education levels amongst the population. The higher the level of education, the lower the number of individuals who report smoking daily. There are more than four times the number of people who report smoking daily amongst those with pre-upper secondary education – 17 per cent – compared to those who attended university or HEI, where 4 per cent report smoking daily.

Diagram 11. Smoke daily



Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Trend of smoking amongst young people

It is also important to follow the trend amongst young people. The Swedish Council for Information on Alcohol and Other Drugs (CAN) conducts annual investigations into drug habits amongst pupils in year 9 of compulsory school and year 2 of upper secondary school.

The tobacco data collected from the school inquiries point to a considerably reduced level of tobacco consumption amongst pupils in year 9 during the early 2000s. As in previous investigations, this year's survey showed more girls than boys who smoke, whereas the use of snus is higher amongst boys.

Alcohol consumption

Cancers related to alcohol consumption include: oral cancer, oesophageal cancer, liver, bowel and colorectal cancers and breast cancer [5].

Therefore working towards low alcohol consumption amongst the population is pressing. A diagram is presented below that shows the portion of the population estimated to have high-risk consumption of alcohol based on three questions in the *Health on equal terms* questionnaire.

At-risk levels of alcohol use – women and men

The total consumption of alcohol in Sweden has decreased since the start of the year 2000. The national trend diagram, diagram 12 below, shows a weak decrease since 2004 of the portion of men deemed to be at-risk consumers, from 18 to 16 per cent, whereas the level remains stable at 10 per cent for women.

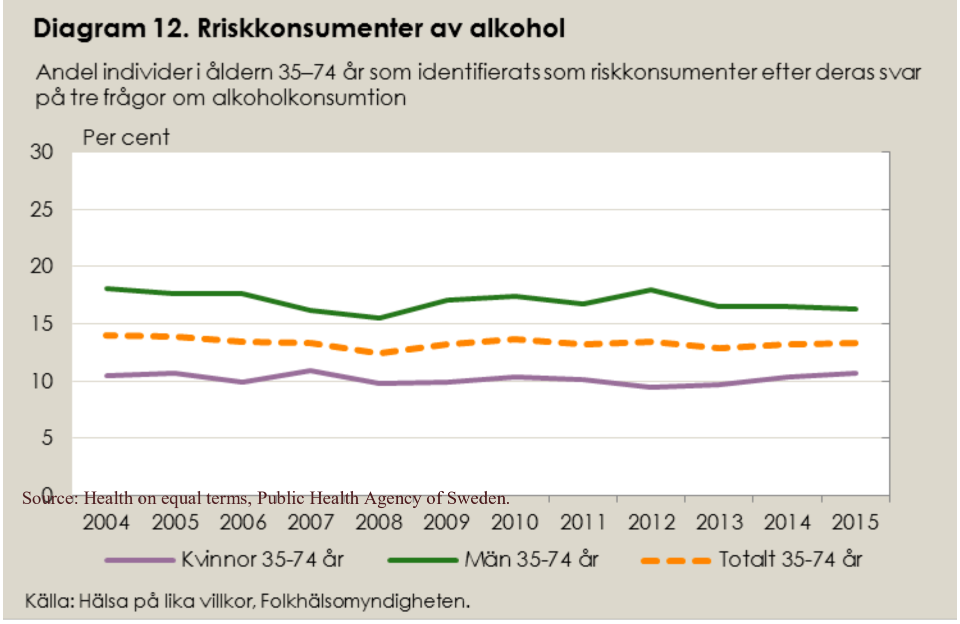


Diagram 12. Riskkonsumenter av alkohol

Andel individer i åldern 35–74 år som identifierats som riskkonsumenter efter deras svar på tre frågor om alkoholkonsumtion

Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Source: Health on equal terms, Public Health Agency of Sweden.

Diagram 13 below shows the number of individuals identified as at-risk consumers based on their responses to three questions about alcohol consumption 2012-2015, divided over the respective healthcare region.

The diagram shows that in all healthcare regions, the total number of men with at-risk consumption is higher than for women. The largest difference between the sexes is in the Southeast healthcare region, where 19 per cent of men and 8 per cent of women are estimated to be at-risk consumers of alcohol.

In the Stockholm-Gotland healthcare region, the highest portion of women, 14 per cent, have been determined to be at-risk consumers of alcohol. This rate is almost as high as that for the men in the healthcare region, 15 per cent.

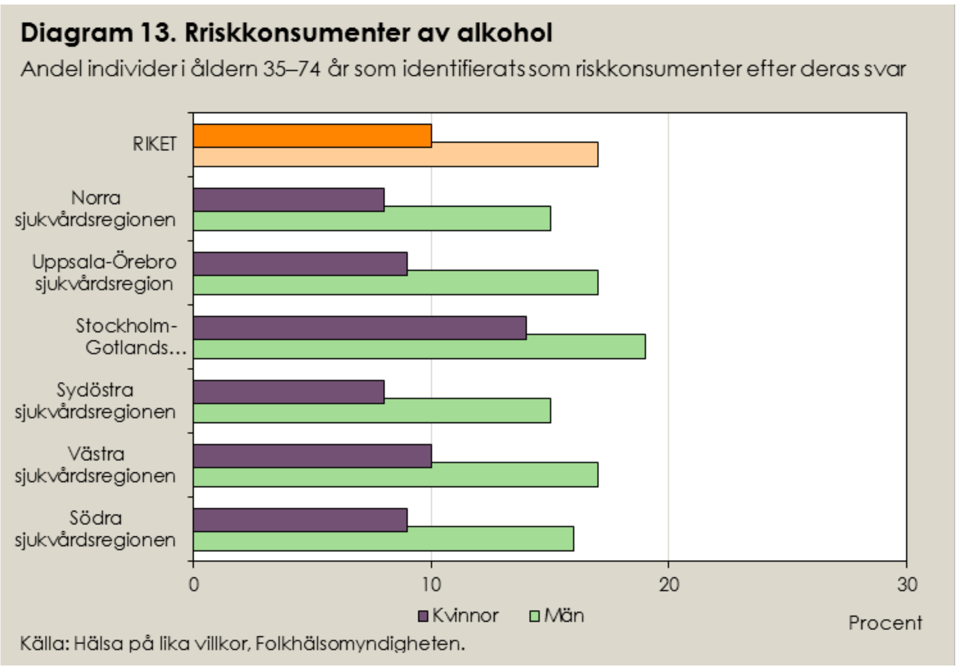


Diagram 13. Riskkonsumenter av alkohol

Andel individer i åldern 35–74 år som identifierats som riskkonsumenter efter deras svar

Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

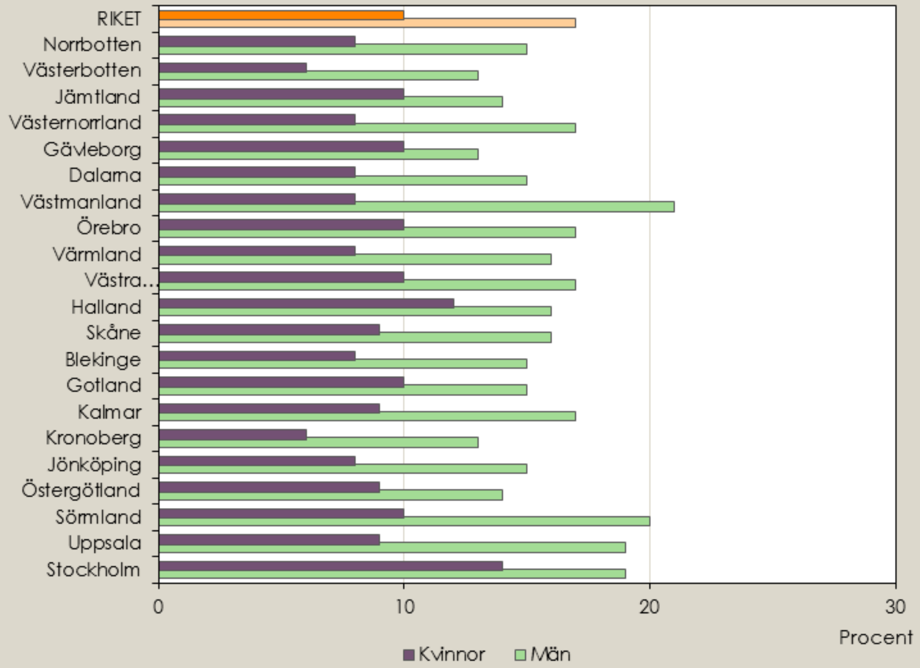
Diagram 14 below shows the number of men and women with at-risk consumption per county council.

There are large variations in the portion of men and women with at-risk consumption of alcohol. The highest portion of men estimated to have dangerous levels of alcohol consumption can be found in Västmanland and Sörmland, 21 and 20 per cent respectively.

The highest portion of women estimated to have at-risk levels of alcohol consumption is in Stockholm county, 14 per cent and Halland, 12 per cent.

Diagram 14. Riskkonsumenter av alkohol

Andel individer i åldern 35–74 år som identifierats som riskkonsumenter efter deras svar på tre frågor om alkoholkonsumtion, 2012-2015.



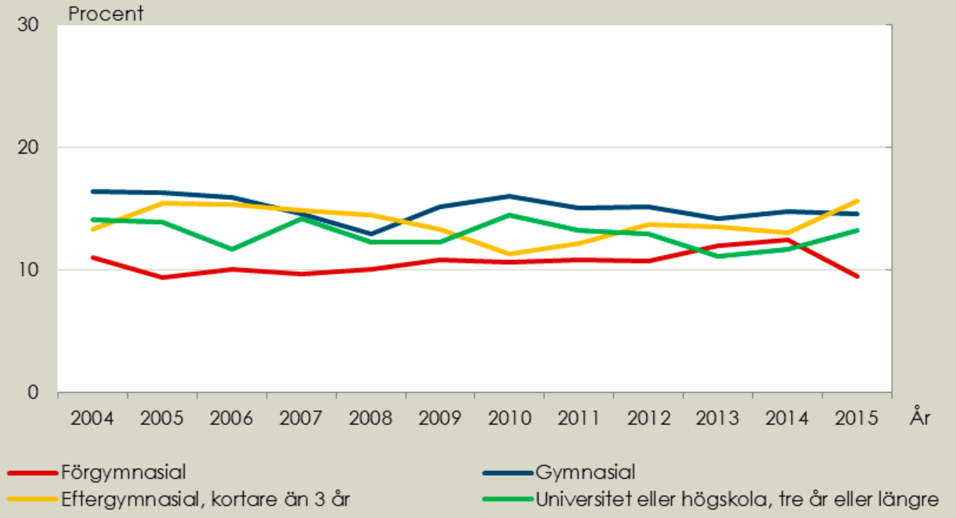
Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

At-risk use of alcohol – level of education

In contrast to other living habits where those with pre-upper secondary education are often more unhealthy, this group has the lowest rate of at-risk alcohol consumption, with the exception of the 2013-2014 period. Those with upper-secondary and fewer than three years of post-upper secondary education are estimated to have the highest level of at-risk alcohol use.

Diagram 15. Riskkonsumenter av alkohol

Andel individer i åldern 35–74 år som identifierats som riskkonsumenter efter deras svar på tre frågor om alkoholkonsumtion



Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Alcohol habits amongst young people

The Swedish Council for Information on Alcohol and Other Drugs (CAN) conducts annual investigations into alcohol habits amongst pupils in year 9 of the compulsory school and year 2 of the upper secondary school. CAN present a clear trend showing that alcohol consumption has decreased significantly amongst teenagers since the year 2000.

In 2015, 42 per cent of pupils in year 9 of the compulsory school reported that they had consumed alcohol in the past 12 months, compared to 46 per cent in 2014. This figure is the lowest to be recorded since records began.

More girls than boys have shown to be larger consumers of alcohol in recent years. In 2015, 44 per cent of girls and 40 per cent of boys stated that they had consumed alcohol in the last 12 months.

The number of alcohol consumers has also decreased amongst upper secondary school pupils since records began in 2004; down from approximately 90 per cent to 75 per cent in 2015. The number of consumers dropped amongst both boys and girls in 2015, compared to 2014 (girls from 82 per cent to 76 per cent; boys from 76 per cent to 73 per cent and the total for both sexes, 79 per cent to 75 per cent).

The number of high and at-risk consumers and total of intensive consumers has decreased considerably over the recent decade, both in year 9 of the compulsory school and year two of upper secondary school. These are the lowest recorded since the surveys began [10].

Obesity

Several types of cancer are linked to being overweight or obese. These are bowel and colorectal cancers, renal cell cancers, oesophagal cancer, pancreatic cancer, gallbladder cancer, breast cancer in (post-menopausal) women, uterine cancer and ovarian cancer [5].

Obesity – women and men

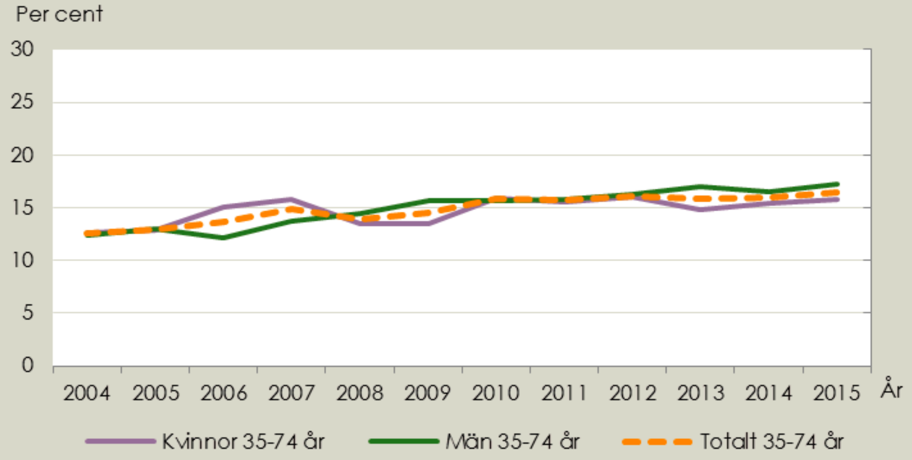
The number of obese adults has doubled since 1990. According to the WHO prognosis for 2015, the total of obese people in Sweden will double over 15 years – one in four men and one in five women are expected to be obese by 2030. Currently, approximately 50 per cent of all men and one in three women are estimated to be overweight. There are also socioeconomic differences associated with weight. Obesity is more common amongst those who state having financial problems and amongst people with lower levels of education. The development of being overweight and obesity are linked to other social factors, such as our genes and living habits [5].

If a person has a BMI over 30, they can be classified as obese (entirely healthy, muscular people can nevertheless have a BMI of over 25 and 30 without being considered overweight or obese). Below, diagram 16 shows the national trend, diagram 17 per healthcare region and diagram 18 per county, divided by sex.

The trend diagram below shows a national increase for both men and women for the number of individuals with a BMI above 30. There are no large national differences by gender.

Diagram 16. BMI högre än 30

Andel individer i åldern 35-74 år som beräknats ha ett BMI (Body Mass Index) 30 eller högre



Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Diagram 17 below shows the number of individuals aged 35-74 estimated to have a BMI of 30 or above, divided by regional healthcare level.

The number of women and men with a BMI of 30 or above is highest in the Northern healthcare region, 19 per cent.

The number of men with a BMI of 30 or above is just as high in the Uppsala-Örebro healthcare region and Stockholm-Gotland healthcare region as for men in the Northern healthcare region.

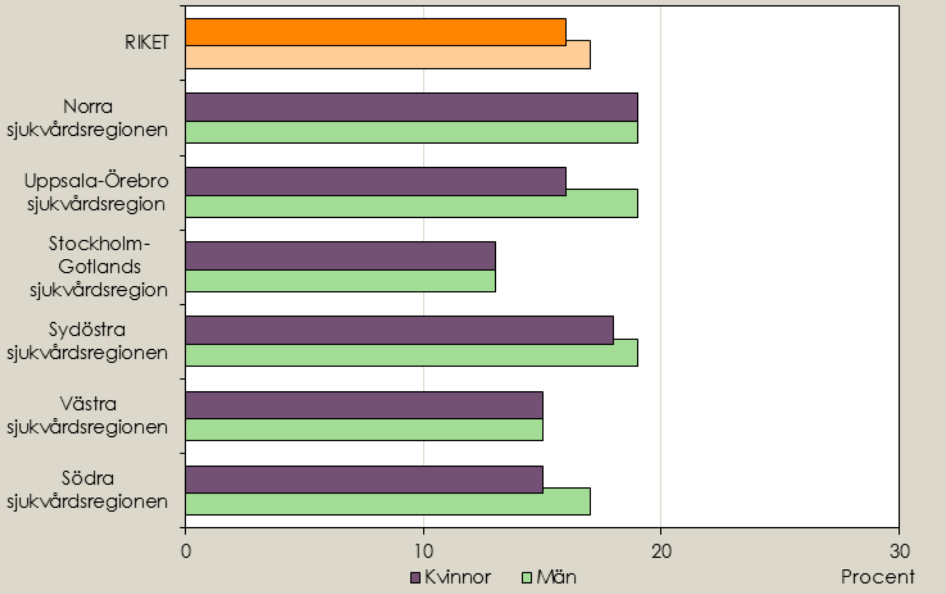


Diagram 17. BMI högre än 30

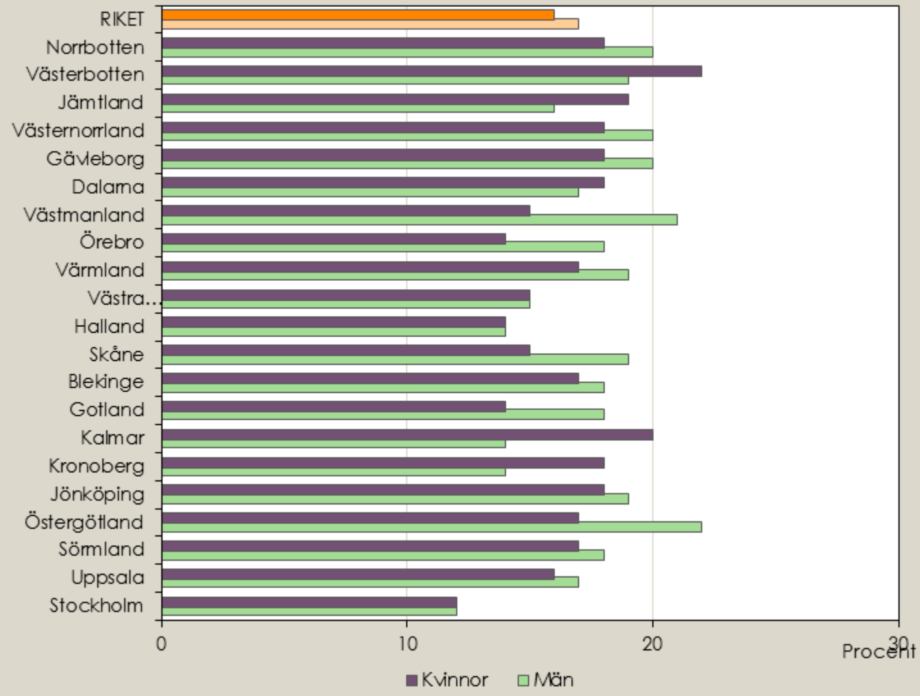
Andel individer i åldern 35-74 år som beräknats ha ett BMI (Body Mass Index) 30 eller

Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Diagram 18 below shows the equivalent at the county council level. Västerbotten County has the highest portion of women, 22 per cent, with a BMI above 30. Östergötland County has the highest portion of men, 22 per cent, with a BMI above 30.

Diagram 18. BMI högre än 30

Andel individer i åldern 35-74 år som beräknats ha ett BMI (Body Mass Index) 30 eller högre, 2012-2015.



Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

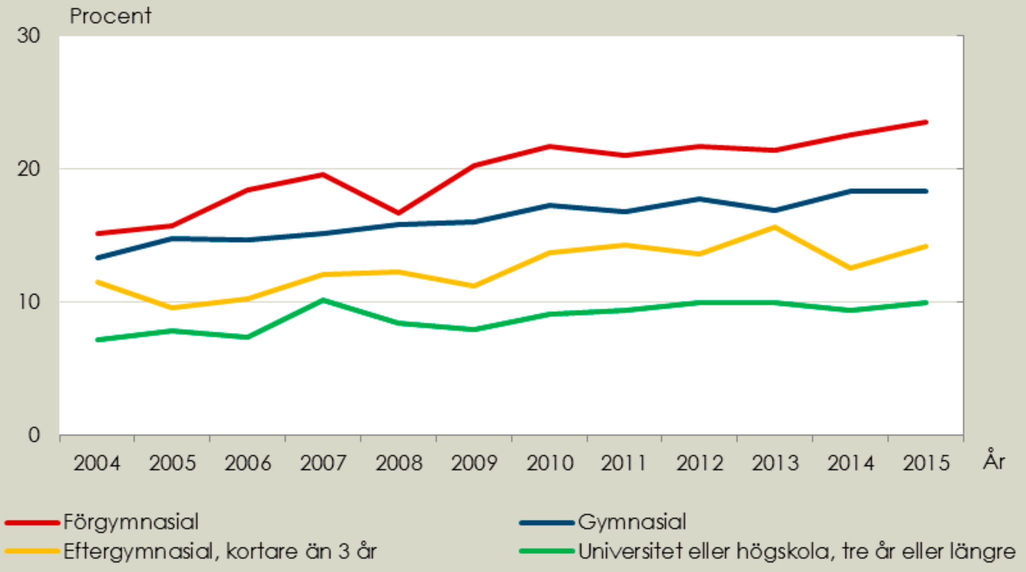
Obesity – level of education

Diagram 19 below shows a trend of the development in the number of individuals aged 35-74 estimated to have a BMI above 30, divided by level of education.

The trend shows an increase in the number of people with a BMI of over 30 across all education groups, furthermore the differences between the groups are increasing. The highest number of individuals with a BMI over 30 can be found amongst the group with pre-upper secondary education, 23 per cent.

Diagram 19. BMI högre än 30

Andel individer i åldern 35-74 år som beräknats ha ett BMI (Body Mass Index) 30 eller högre



Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Healthy eating habits

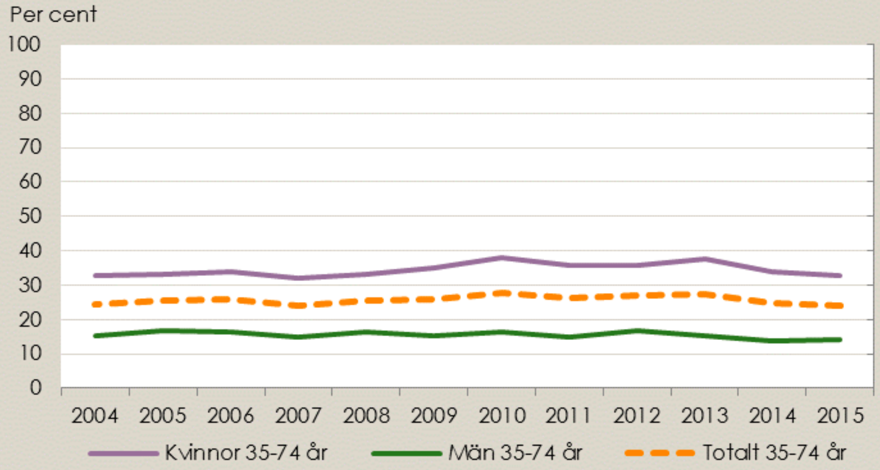
Several types of cancer are related to diet and being overweight; bowel and colorectal cancers, breast cancer, uterine cancer, oesophagal cancer, renal cancer, oral and oesophagal cancers. WHO recommendations include eating high amounts of wholegrain foods, legumes, vegetables and fruit whilst avoiding foods with high calorie and fat content, sweet drinks, processed meats, red meats and foods with high amounts of salt. The following fruit and vegetable recommendations are a good indicator of healthy eating habits in general [5].

Fruit and vegetable consumption – women and men

The questionnaire *Health on Equal Terms* asks questions about eating habits. The questionnaire shows that the number of individuals who eat fruit and/or vegetables at least three times per day is low. A total of 25 per cent state they eat fruit/vegetables at least three times per day. A higher number of women than men, 33 and 14 per cent respectively, state that they eat fruit/vegetables at least three times per day. See diagram 20 below.

Diagram 20. Äter frukt och/eller grönsaker mer än 3 gånger per dag

Andel individer i åldern 35–74 år som uppgivit att de äter frukt och/eller grönsaker mer än 3 gånger per dag

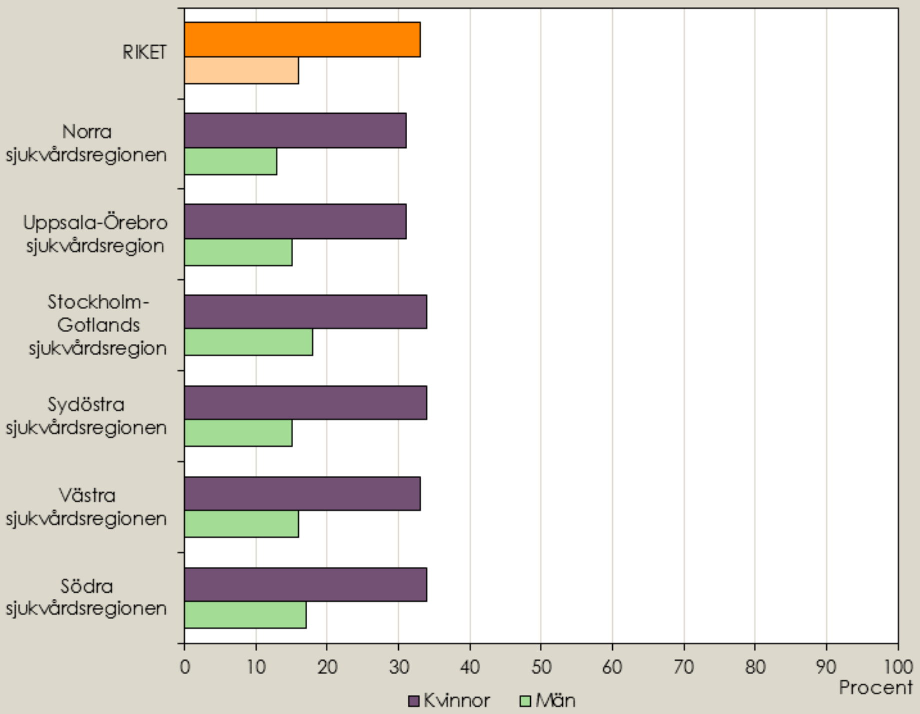


Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Diagram 21 below presents the number of women and men who report eating fruit/vegetables at least three times per day, divided into healthcare regions.

Diagram 21. Äter frukt och/eller grönsaker mer än 3 gånger per dag

Andel individer i åldern 35–74 år som uppgivit att de äter frukt och/eller grönsaker mer än 3 gånger per dag, 2012-2015.



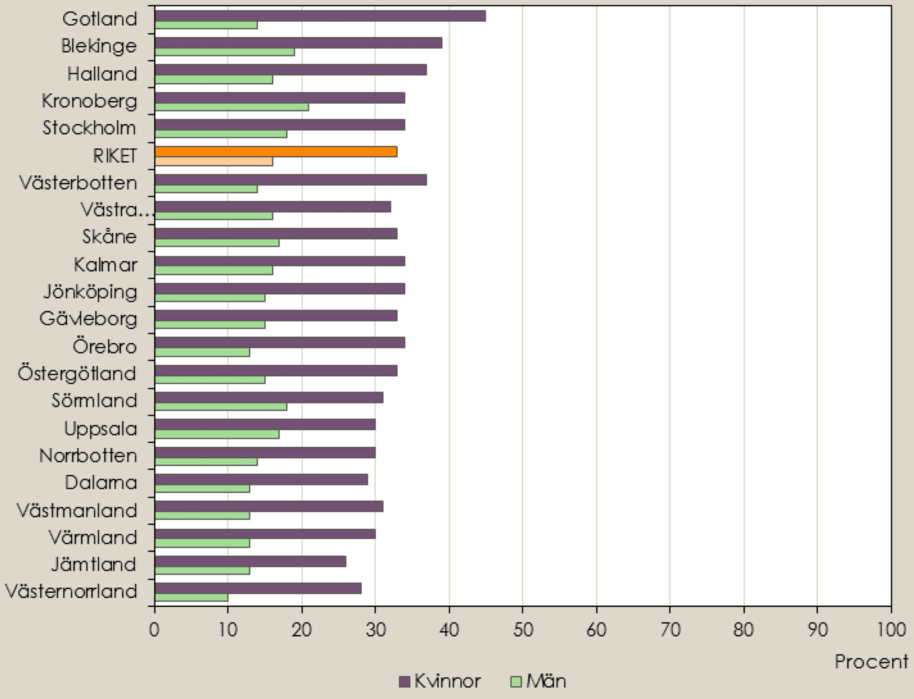
Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

It appears to be similar throughout Sweden; more women than men – 31-34 per cent and 13-18 per cent respectively – report eating fruit/vegetables at least three times per day.

Diagram 22 below shows the equivalent at the county council level. The lowest number of people who eat fruit/vegetables three times per day are men from Västernorrland, ten per cent.

Diagram 22. Äter frukt och/eller grönsaker mer än 3 gånger per dag

Andel individer i åldern 35–74 år som uppgivit att de äter frukt och/eller grönsaker mer än 3 gånger per dag, 2012-2015.



Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Consumption of fruit/vegetables – level of education

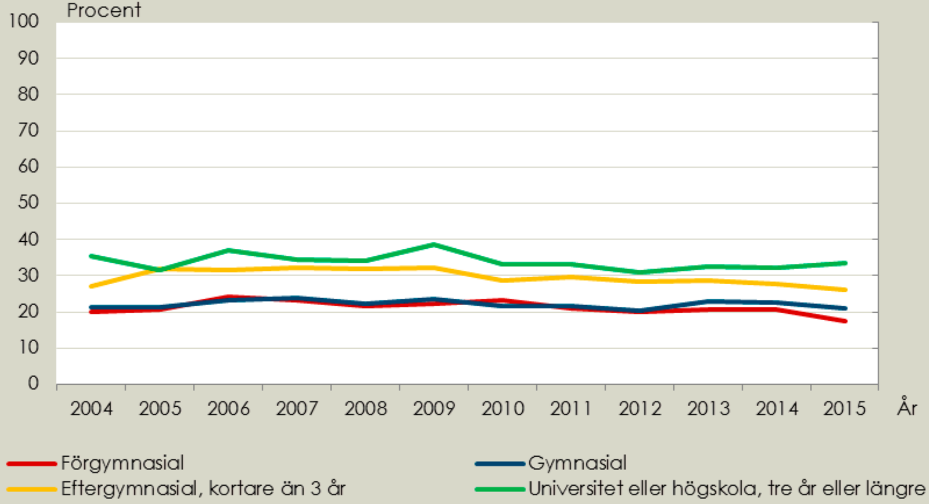
Diagram 23 below shows the number of individuals aged 35-74 who stated they eat fruit/vegetables at least three times per day, divided into education levels nationally.

The diagram shows large differences between the groups. The group with the highest level of education have the highest number of individuals, – 34 per cent in 2015 – who eat fruit and/or vegetables at least three times per day. Furthermore, it is solely in this group that fruit consumption is increasing – albeit slowly.

The lowest number of individuals who state they eat fruit/vegetables at least three times per day can be seen amongst those with pre-upper secondary school education alone, 17 per cent in 2015.

Diagram 23. Äter frukt och/eller grönsaker mer än 3 gånger per dag

Andel individer i åldern 35–74 år som uppgivit att de äter frukt och/eller grönsaker mer än 3 gånger per dag



Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Physical activity

Physical activity reduces the risk of developing bowel and colorectal cancers and breast and uterine cancers. Physical activity also promotes healthy weight, which is indirectly linked to renal cancer, oesophagal cancer, pancreatic cancer, gallbladder cancer and ovarian cancer [5].

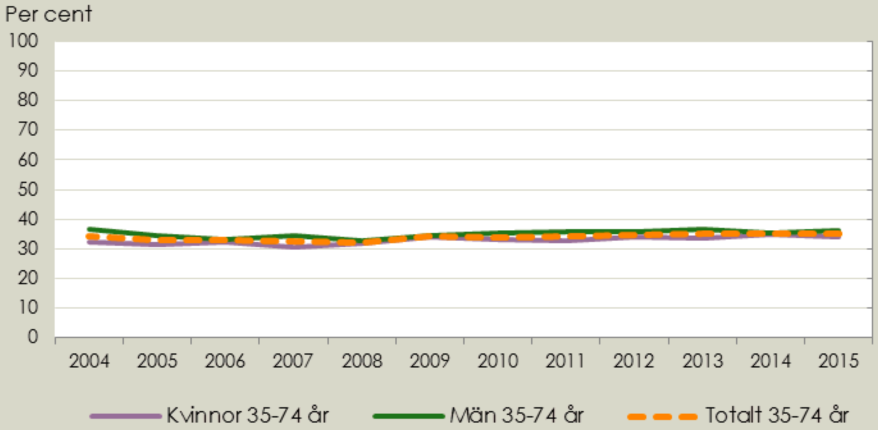
Number who participate in physical activity at least one hour per day, total for women and men

According to the *Health on Equal Terms* questionnaire, 34 per cent of the population are physically active for at least one hour per day. At the same time, 14 per cent of the population are sedentary in their free time.

A small difference can be seen between the sexes, where 36 per cent of men and 34 per cent of women stated that they are physically active for at least one hour per day (see Diagram 24).

Diagram 24. Fysiskt aktivitet minst en timme om dagen

Andel individer i åldern 35–74 år som har fysiskt aktivitet minst en timme om dagen



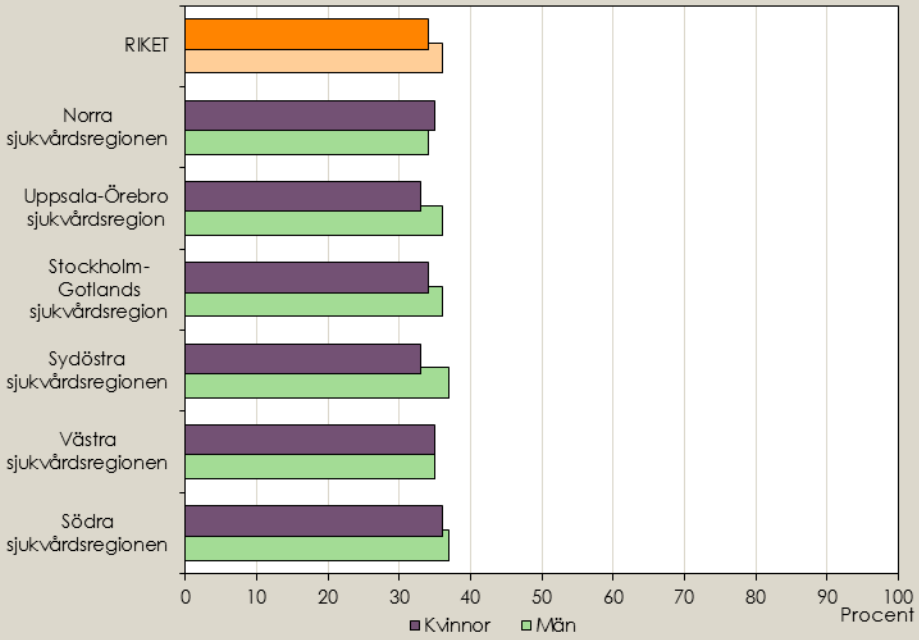
Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Diagram 25 below presents the number of women and men who reported being physically active for at least one hour per day, divided into healthcare regions.

The diagram shows no great difference between the sexes throughout the respective healthcare regions or between them.

Diagram 25. Fysiskt aktivitet minst en timme om dagen

Andel individer i åldern 35–74 år som har fysiskt aktivitet minst en timme om dagen,



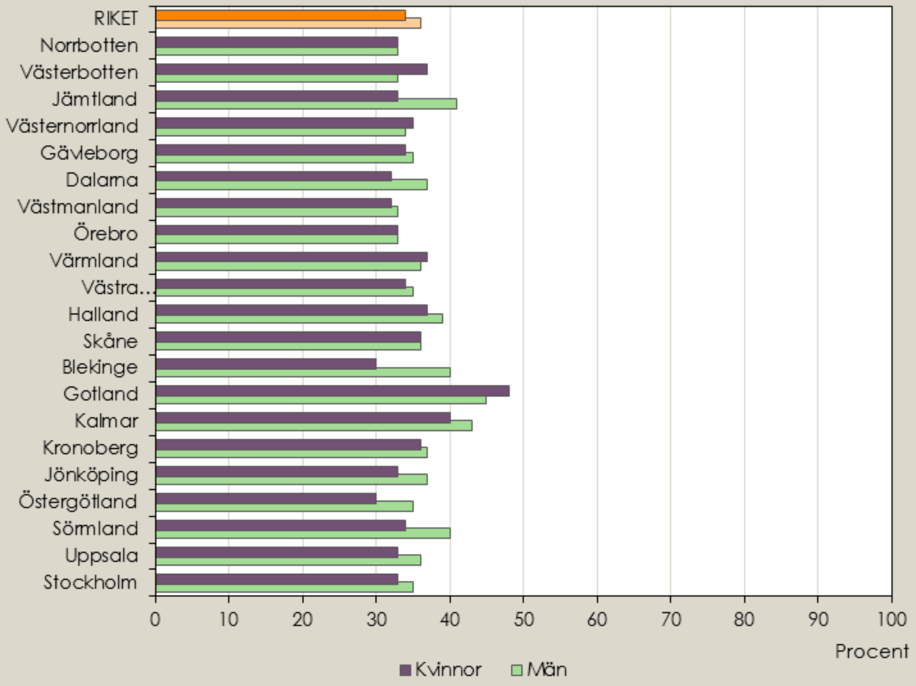
Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

The diagram below shows the number of physically active women and men respectively, divided into county councils. The least physically active are women in Östergötland and Blekinge counties. The most physically active are women in Gotland, 48 per cent.

Some counties show somewhat bigger differences between men and women when compared with the diagram for healthcare regions. On a county council level, it is more common for men to be physically active for more than one hour per day.

Diagram 26. Fysiskt aktivitet minst en timme om dagen

Andel individer i åldern 35–74 år som har fysiskt aktivitet minst en timme om dagen, 2012-2015.



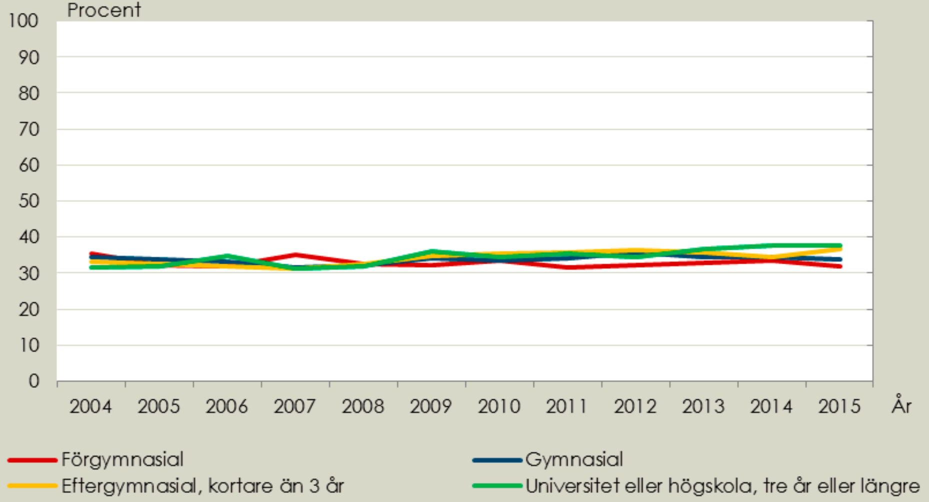
Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Physical activity – levels of education

No large differences can be seen regarding physical activity between the groups with different levels of education.

Diagram 27. Fysiskt aktivitet minst en timme om dagen

Andel individer i åldern 35–74 år som har fysiskt aktivitet minst en timme om dagen



Källa: Hälsa på lika villkor, Folkhälsomyndigheten.

Sun exposure habits

Dangerous solar radiation can lead to skin cancer and the particularly dangerous malignant melanoma. Skin cancer is the type of cancer showing the biggest increase.

It is important to follow the population's sun exposure habits. In a study by the Swedish Radiation Safety Authority, it was found that it is more common for men to get sunburnt when abroad.

Four out of ten state that they tan themselves less today than they did five years ago. This was shown in a study conducted amongst 2,600 people by the Swedish Radiation Safety Authority. According to the study, Swedish people appear to have become better at protecting themselves from the sun and avoiding getting sunburnt. Fifty-seven per cent stated that they always or frequently take breaks from the sun to avoid getting sunburnt. Close to four in ten people (39 per cent) stay in the shade to avoid getting sunburnt. However it appears as though far too many people rely on suncream being sufficient protection to avoid sunburn[11].

It will be possible to follow the development of sun exposure habits amongst the population further as questions about sun exposure habits are now included in the Public Health Agency of Sweden questionnaire, *Health on Equal Terms* (HLV).

Minimise the delay in discovering cancer – screening

Screening is when asymptomatic people in a certain age group are offered an examination with the aim of discovering the early stage or pre-stages of cancer whilst the disease can still be cured.

Sweden currently operates national screening programmes for breast and cervical cancers. The National Board of Health and Welfare also recommends screening for bowel and colorectal cancers.

Cervical cancer

Cervical cancer is fairly uncommon in Sweden compared to the world in general. In 2014, 549 women developed cervical cancer in Sweden. The disease often develops slowly over many years. The median age for developing cervical cancer is approximately 50 years, and almost one in three women is under the age of 40. The annual morbidity rate of cervical cancer has in absolute terms more than halved since the end of the 1960s, when cervical screening tests were introduced.

Cervical screening tests aim to prevent cervical cancer by detecting and treating abnormal cells. The National Board of Health and Welfare suggests that county councils invite women aged between 23 and 64 to participate in screening.

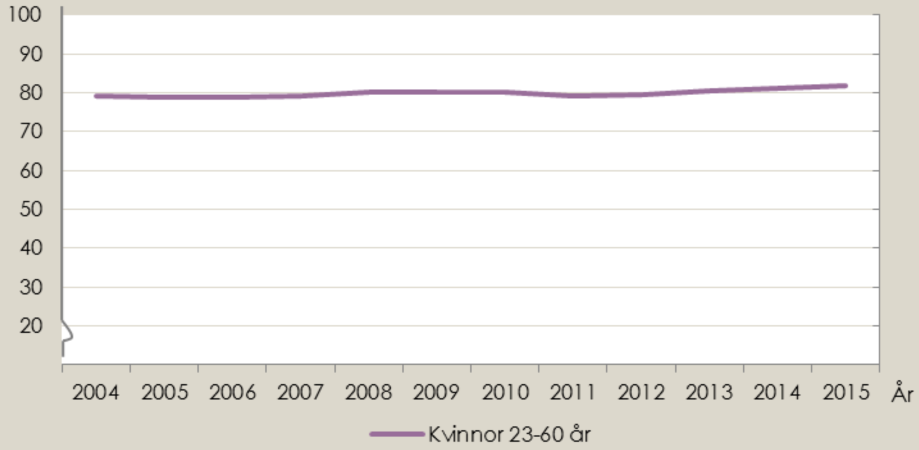
The diagram below presents the uptake of cervical screening tests. The data include both the screening tests conducted after invitation and those taken during other appointments with health and medical care services, for example at gynaecology clinics. “Uptake” refers to the number of women in the population in the specific age group who have participated in cervical screening following the recommended time intervals.

Nationally, uptake has been around 80 per cent over the past ten years. In 2015, cervical screening test uptake was 82 per cent amongst women aged 23-64. See Diagram 28. Variations between the county councils ranged from 70 to 91 per cent. The national cancer strategy sets a target national uptake level of 85 per cent.

Diagram 28. Andel kvinnor 23-60 år som genomgått gynekologisk cellprovtagning

Andel kvinnor 23-60 år som genomgått gynekologisk cellprovtagning

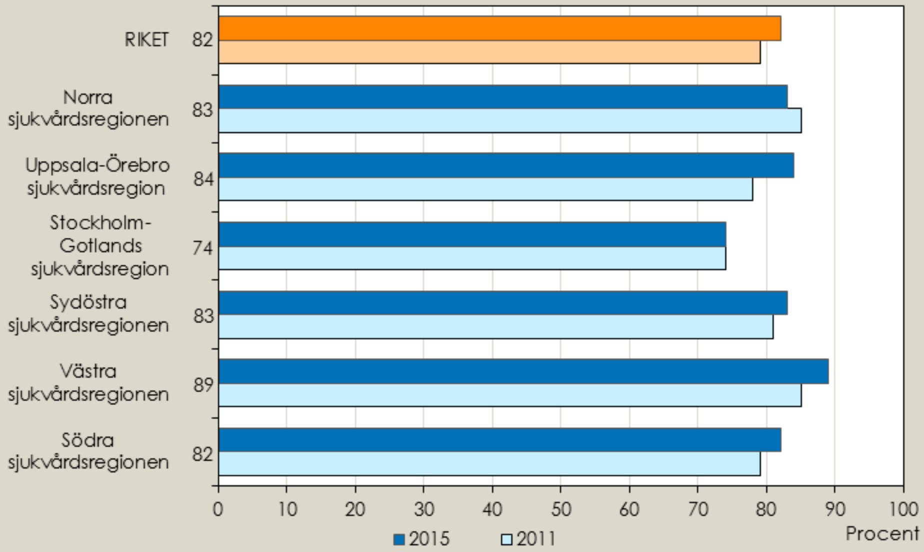
Per cent



Källa: Nationellt kvalitetsregister för cervixcancerprevention.

Diagram 29. Andel kvinnor 23-60 år som genomgått gynekologisk

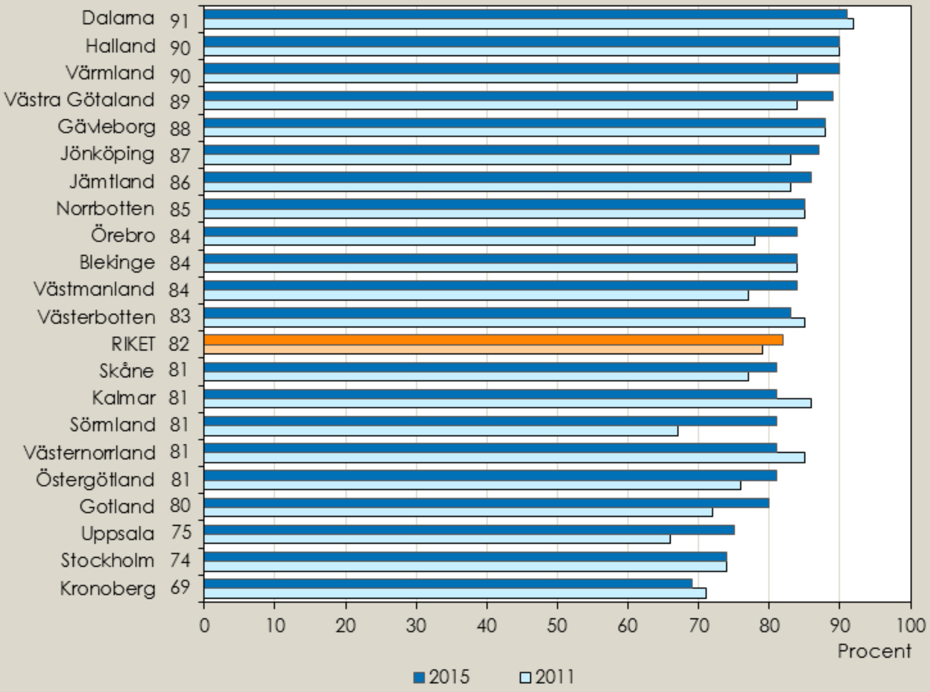
Andel kvinnor 23-60 år som genomgått gynekologisk cellprovtagning, 2015.



Källa: Nationellt kvalitetsregister för cervixcancerprevention.

Diagram 30. Andel kvinnor 23-60 år som genomgått gynekologisk cellprovtagning

Andel kvinnor 23-60 år som genomgått gynekologisk cellprovtagning, 2015.



Källa: Nationellt kvalitetsregister för cervixcancerprevention.

Appendix 3 On the right track – better patient care?

The dimension is tied to the goals in the national cancer strategy for the future report to:

- improve the quality of cancer patient management
- prolong survival time and improve quality of life after a cancer diagnosis,
- Reduce regional differences in survival time after a cancer diagnosis.

Palliative care

Good palliative care during the latter stages of life means that the patient and their next of kin are informed of the patient's illness/condition has reached a stage where treatment to slow down or cure the cancer will be stopped. Palliative care refers to the ameliorating steps that can be taken once treatment and cure can no longer be offered. Certain people live with an incurable disease for several years, whereas others are asymptomatic until they only have a short while left to live. Hence it is important to note that palliative care is more than just care in the last few weeks of life.

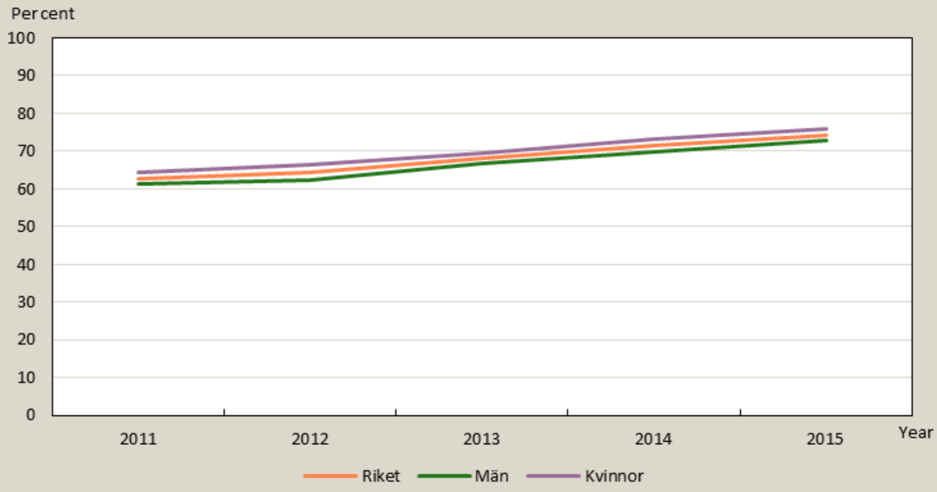
Transition point discussions

When all forms of treatment are stopped and care moves over to palliative care in the latter stages of life, a transition point discussion is conducted with the patient and their next of kin. In the support information from the National Board of Health and Welfare, transition point discussions for the care content and direction at the end of life has continually been given a high priority.

Diagrams 31 and 32 show the number of patients with cancer whose medical records contained documentation of transition point discussions having been conducted, for deaths that occurred in 2015. Of the patients registered in the cancer quality registry, 74 per cent had information about the transitional point discussions in their medical records. The differences between county councils ranged from 61 to 80 per cent. The nationwide total has increased from 63 per cent in 2011.

Diagram 31. Brytpunktssamtal

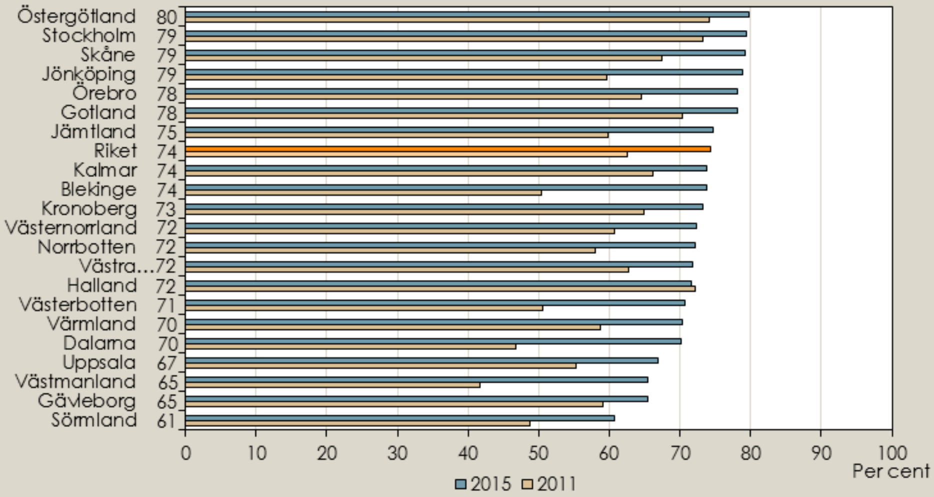
Andel cancerpatienter i livets slutskede där brytpunktsamtal genomfördes



Källa: Svenska palliativregistret.

Diagram 32. Brytpunktssamtal

Andel cancerpatienter i livets slutskede där brytpunktsamtal genomfördes, år 2015.



Källa: Svenska palliativregistret.

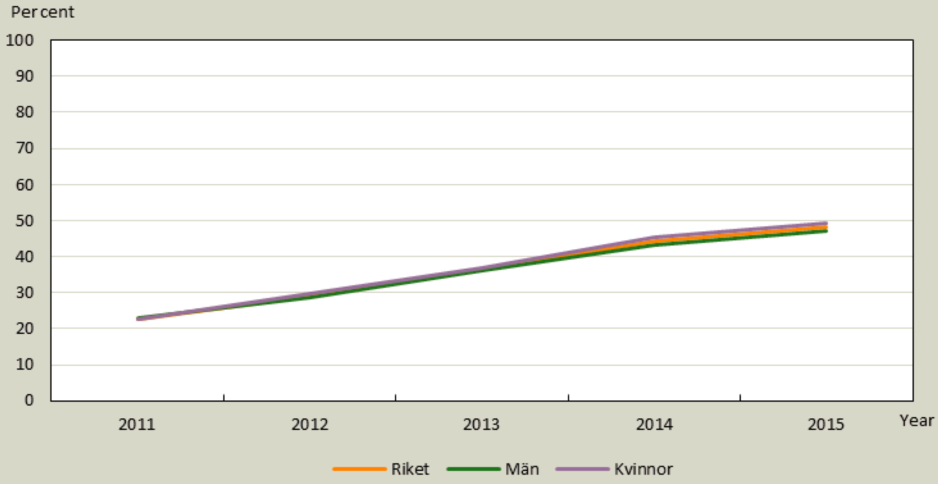
Regular estimate of pain intensity

Regular pain analysis and estimation of pain intensity are important recommendations in the National Board of Health and Welfare’s supporting information and also the national practice guidelines for quality palliative care towards the end of life. Pain left untreated reduces quality of life. It also increases the risks for medical complications.

Diagrams 33 and 34 show that of the cancer patients included in the quality registry, 48 per cent had estimated their pain levels with help from a valid symptom estimation instrument during 2015. The differences between county councils ranged from 28 to 65 per cent. The nationwide total has increased from 23 per cent in 2011.

Diagram 33. Smärtskattningsinstrument

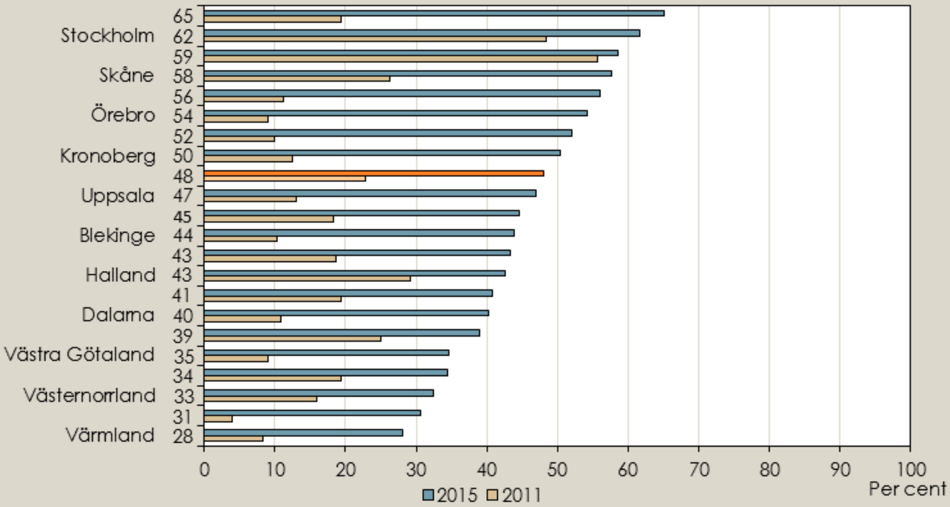
Andel patienter vars smärta skattats med validerat smärtskattningsinstrument sista levnadsveckan,



Källa: Svenska palliativregistret.

Diagram 34. Smärtskattningsinstrument

Andel patienter vars smärta skattats med validerat smärtskattningsinstrument sista levnadsveckan, år 2015.



Källa: Svenska palliativregistret.

Pro re nata (PRN) opioid analgesics

It is common knowledge that the majority of people dying of cancer need at least one injection of opioids, analgesic morphine preparation, towards the end of their lives. Hence it is important that there are individually tailored prescriptions in the event that pain develops.

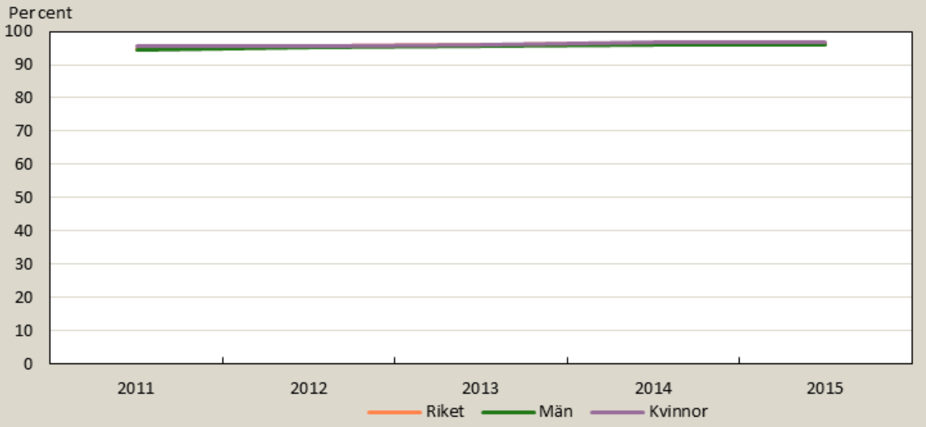
The time from when the patient requires help and alleviation to when it is administered can be unnecessarily long. If written procedures are in place for how prescriptions are issued in these cases, the number of prescriptions provided increases.

Diagrams 35 and 36 show the number of cancer patients who received PRN opioids during 2015. Of the patients registered with cancer, 97 per cent had received such a prescription. The differences between county councils ranged from 93 to 98 per cent.

The Swedish National Quality Registry for Palliative Care aims for 100 per cent of patients to receive PRN treatment with analgesics.

Diagram 35. Vidbehovsordination av opioid mot smärta

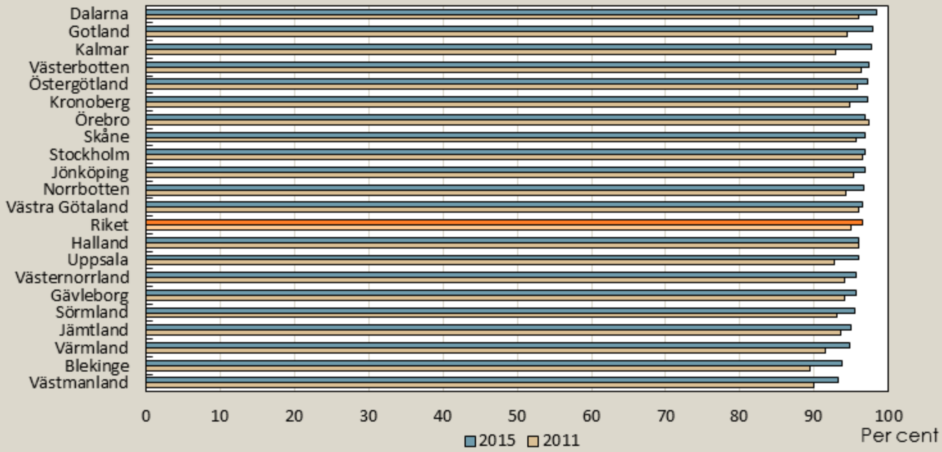
Andel cancerpatienter som hade vidbehovsordination av opioid mot smärta när de avled, år 2011-2015.



Källa: Svenska palliativregistret.

Diagram 36. Vidbehovsordination av opioid mot smärta

Andel cancerpatienter som hade vidbehovsordination av opioid mot smärta när de avled, år 2015.



Källa: Svenska palliativregistret.

My Care Plan

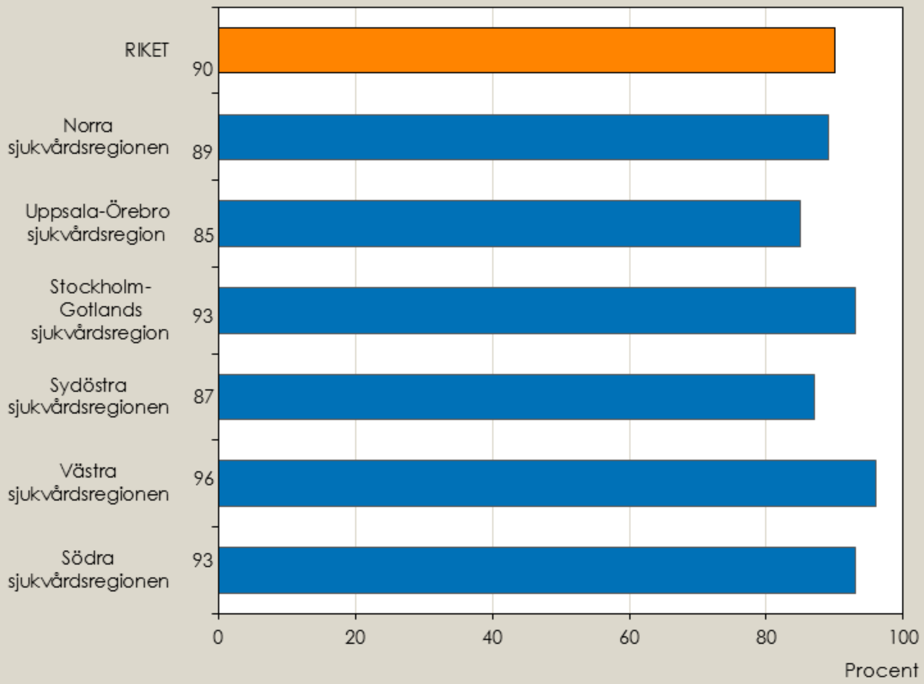
My Care Plan is a combined document that is to be continually updated. The name, “My Care Plan” makes it clear that the plan is written for and with the patient. The contact nurse is often the person who has the task of creating an individual care plan cooperatively with the patient.

Diagram 37 shows the number of cases of breast cancer with individual care plans (My Care Plan) per healthcare region. Diagram 38 illustrates per county council. Nationally, 90 per cent of patients have an individual care plan. Variations between county councils ranged from 24 to 100 per cent. The data include 7,380 women who received their diagnosis during 2015. For the majority of county councils – 16 out of 21 – more than 90 per cent of patients had a care plan.

The variable was included in the register in January 2015, hence no comparison years can be presented.

Diagram 37. Individuell vårdplan, bröstcancer

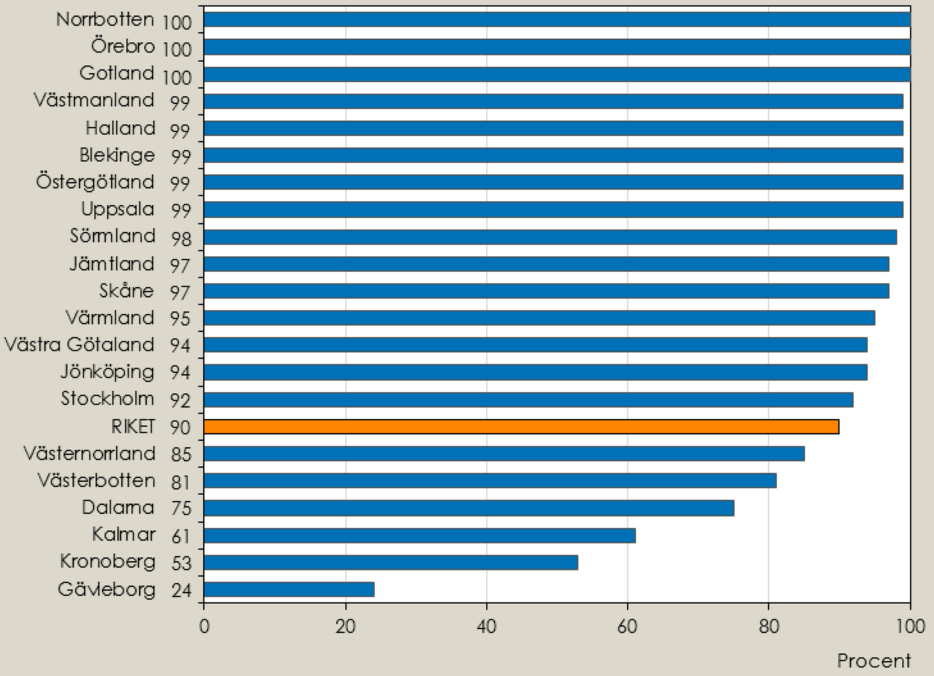
Andel patienter med individuell vårdplan (Min vårdplan), 2015.



Källa: Nationellt kvalitetsregister för bröstcancer.

Diagram 38. Individuell vårdplan, bröstcancer

Andel patienter med individuell vårdplan (Min vårdplan), 2015.



Källa: Nationellt kvalitetsregister för bröstcancer.

Contact nurse

The access to a contact nurse provides patients with support for continuity, integrity and interaction. The contact nurse has the overall responsibility for the patient and their next of kin throughout the entire chain of care.

The number of patients with breast cancer, prostate cancer or malignant melanoma to be offered a contact nurse are presented below.

Breast cancer contact nurse

Diagrams 39 and 40 below show the number of patients grouped by four diagnoses that received the offer of a contact nurse in 2014 and 2015 respectively, divided into healthcare regions.

Diagram 39. Contact nurse 2014

Total number of patients offered a contact nurse, 2014

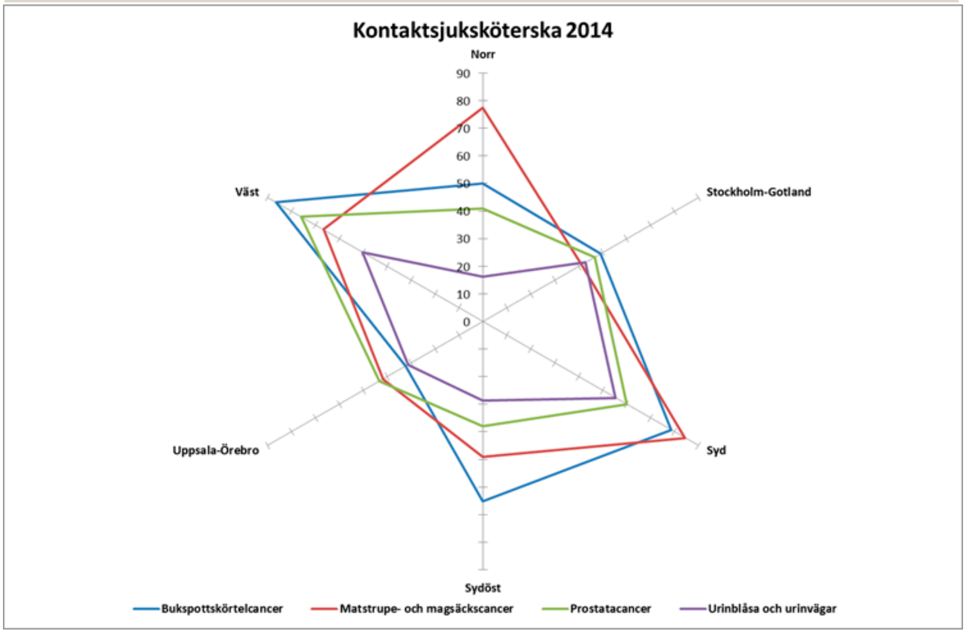
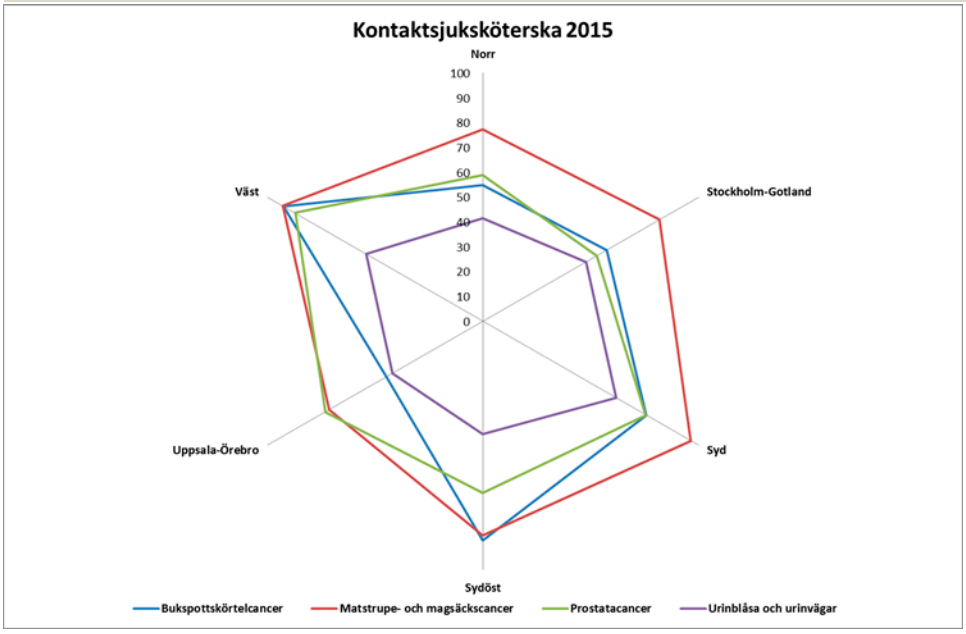


Diagram 40. Contact nurse 2015

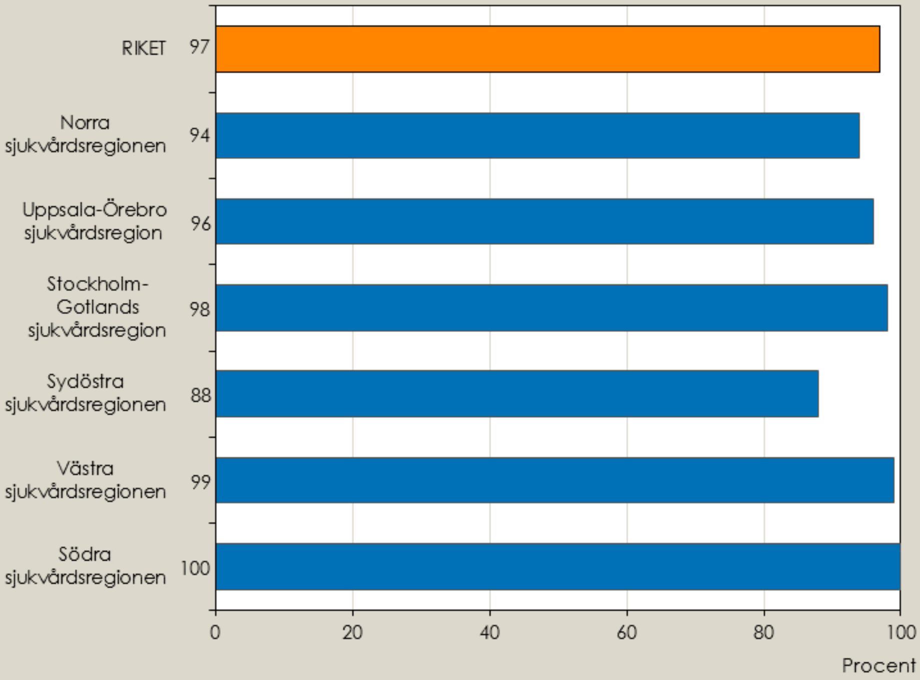
Total number of patients offered a contact nurse, 2015



Diagrams 41-42 below show the number of patients with breast cancer to be offered a contact nurse. 97 per cent of women with breast cancer in Sweden and included in the quality registry were offered a contact nurse. Variations between the county councils ranged from 54 to 100 per cent. The presentation includes 8,127 women who received their diagnosis during 2015.

Diagram 41. Kontaktsjuksköterska, bröstcancer

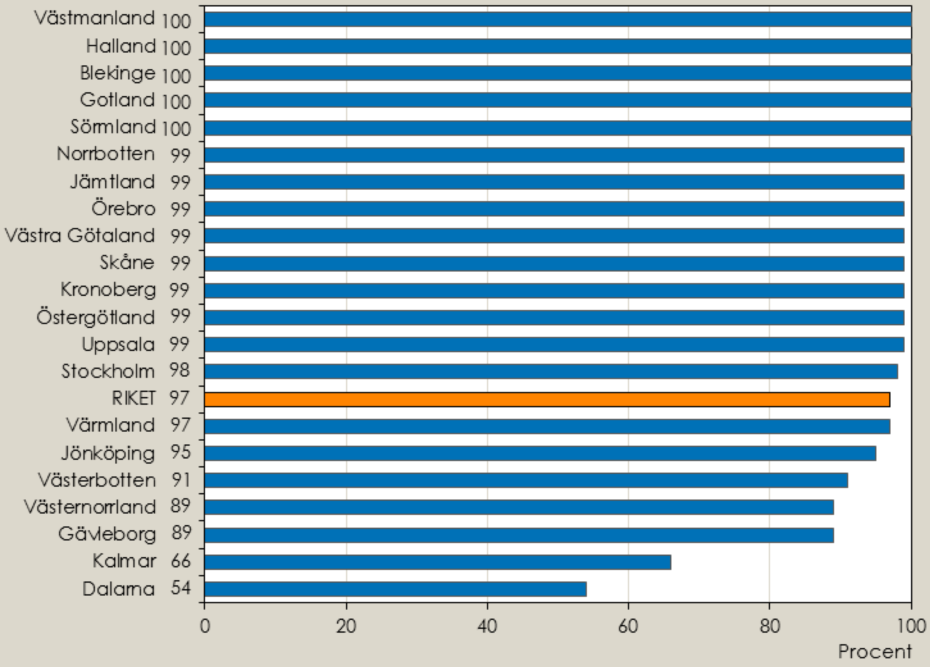
Andel kvinnor med bröstcancer som erbjudits kontaktsjuksköterska, 2015.



Källa: Nationellt kvalitetsregister för bröstcancer.

Diagram 42. Kontaktsjuksköterska, bröstcancer

Andel kvinnor med bröstcancer som erbjudits kontaktsjuksköterska, 2015.



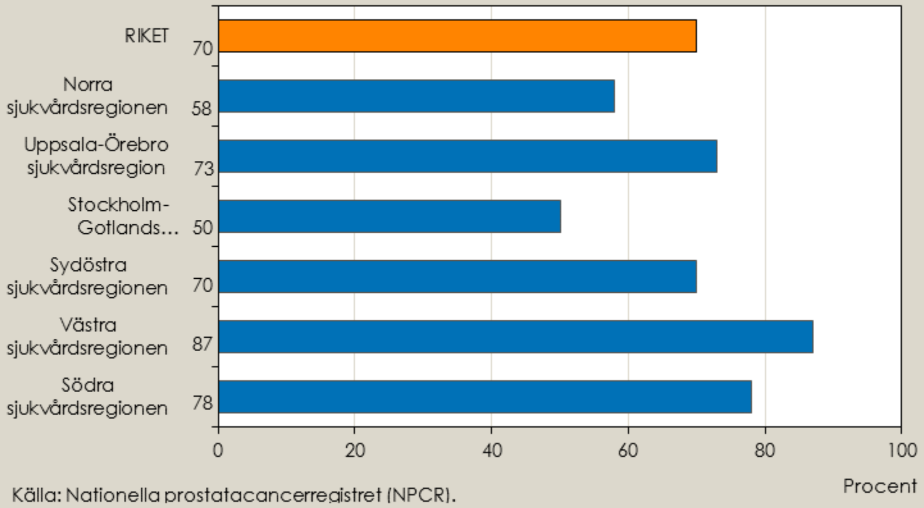
Källa: Nationellt kvalitetsregister för bröstcancer.

Prostate cancer contact nurse

Diagrams 43-44 show that 70 per cent of men with prostate cancer were offered a contact nurse. Variations between the county councils ranged from 31 to 95 per cent. The presentation includes 9,636 men who received their diagnosis during 2015.

Diagram 43. Kontaktsjuksköterska, prostatacancer

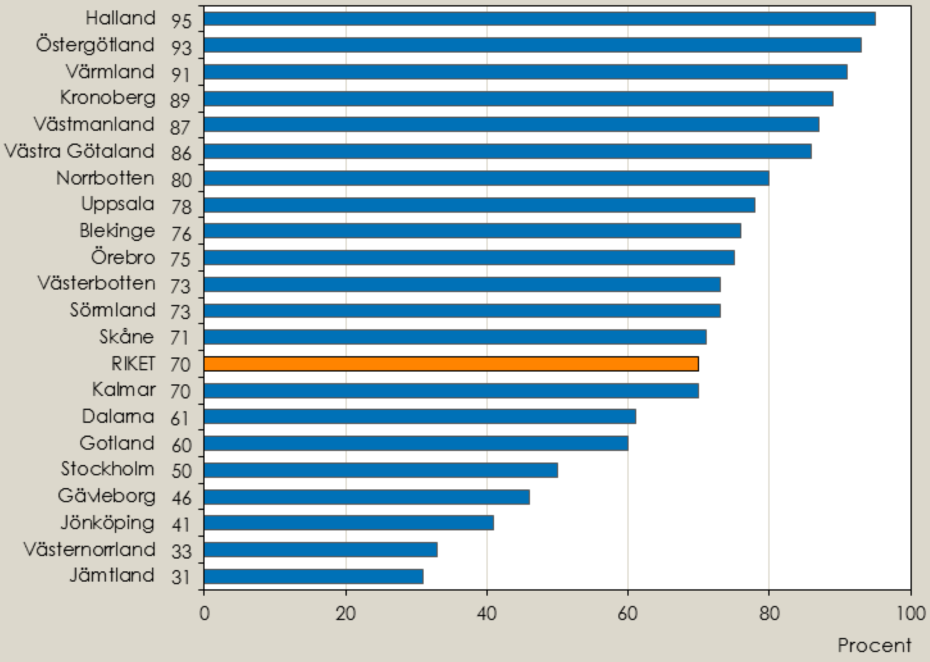
Andel patienter med prostatacancer som fått erbjudande om kontaktsjuksköterska,



Källa: Nationella prostatacancerregistret (NPCR).

Diagram 44. Kontaktsjuksköterska, prostatacancer

Andel patienter med prostatacancer som fått erbjudande om kontaktsjuksköterska, 2015.



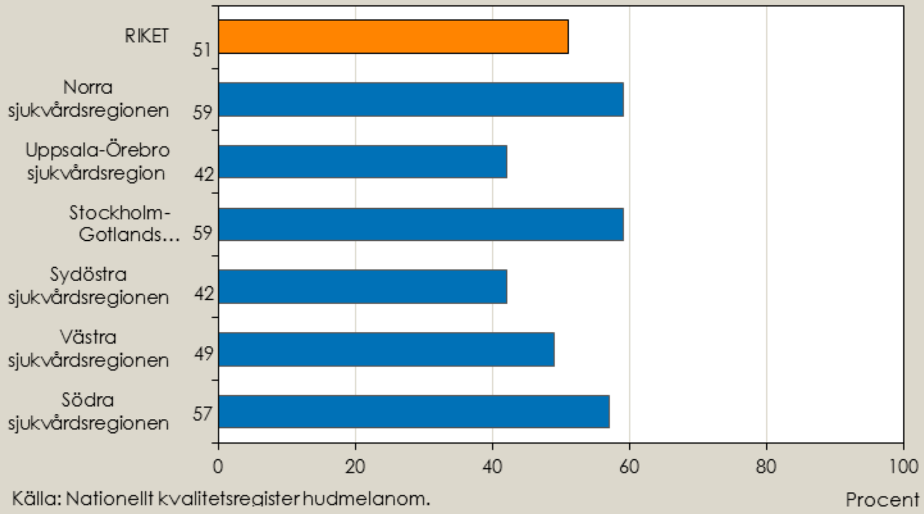
Källa: Nationella prostatacancerregistret (NPCR).

Contact nurse for malignant melanoma

Of the patients with malignant melanoma with a tumour thickness of over 1 mm, 51 per cent nationally were offered a contact nurse, see Diagrams 45-47 below. There was no large difference between the sexes. Variations between the county councils was high, ranging from 9 to 91 per cent. The presentation includes 4,426 patients. Despite the fact that the results presented refer to three years, 2013-2015, the data for several of the county councils come from relatively few details and so the result should be interpreted with caution. However, this suggests that implementation of contact nurses is ongoing.

Diagram 45. Kontaktsjuksköterska, hudmelanom >1 mm tjocklek

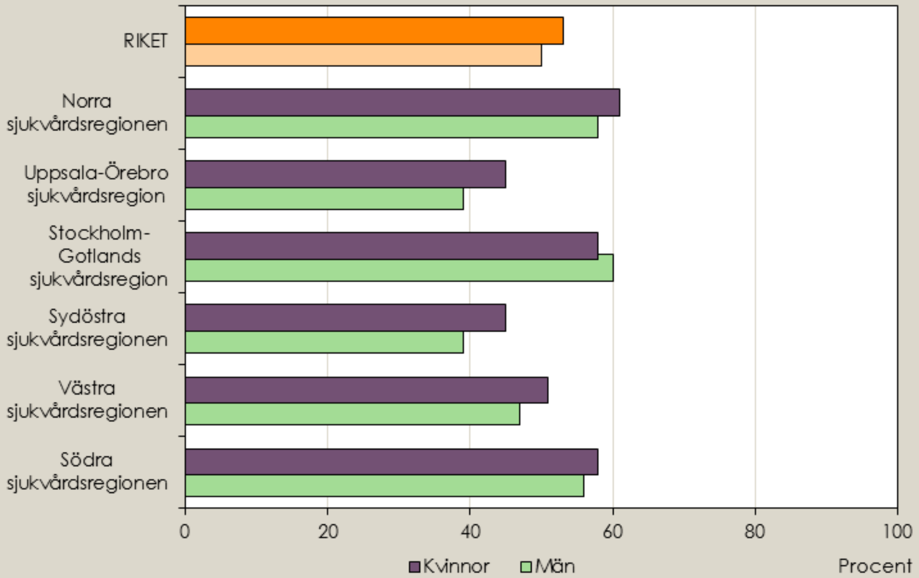
Andel patienter som fått erbjudande om kontaktsjuksköterska, hudmelanom >1 mm



Källa: Nationellt kvalitetsregister hudmelanom.

Diagram 46. Kontaktsjuksköterska, hudmelanom >1 mm tjocklek

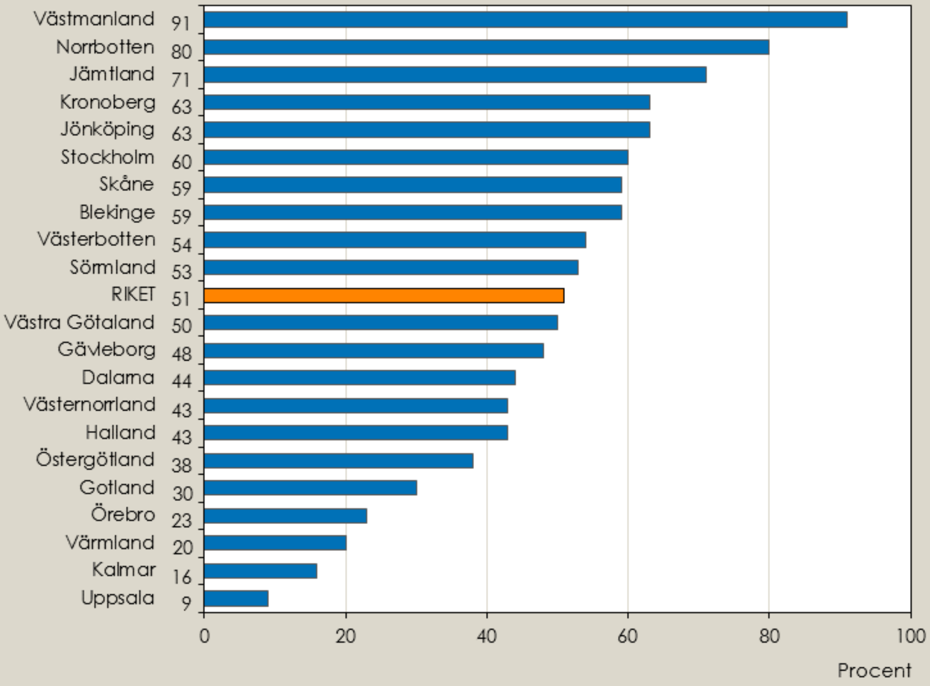
Andel kvinnor respektive män som fått erbjudande om kontaktsjuksköterska,



Källa: Nationellt kvalitetsregister hudmelanom.

Diagram 47. Kontaktsjuksköterska, hudmelanom >1 mm tjocklek

Andel patienter som fått erbjudande om kontaktsjuksköterska, hudmelanom >1 mm tjocklek, 2013-2015.



Källa: Nationellt kvalitetsregister hudmelanom.

Patient reported measures

Patient-reported measures can provide important information for the follow-up and continued development of cancer care. They are usually separated into two areas. One area describes the patient's experiences of the care and the other area describes how the patient experiences their illness and health.

Patient Reported Experience Measures (PREM) are a way to measure a patient's experience and satisfaction with care. This may include interaction, participation, information, trust in the caregiver and accessibility. The terms "satisfactory" and "experiences" can be viewed as being multidimensional concepts that require more comprehensive instruments than a single question in order to provide a good understanding of patient satisfaction or care experiences.

Patient Reported Outcome Measures (PROM) are a measure of how the patients themselves perceive their illness and health after treatment or other intervention. The measures include symptoms, functional ability and health-related quality of life.

There are still few quality registries that present such measures, however development work is ongoing.

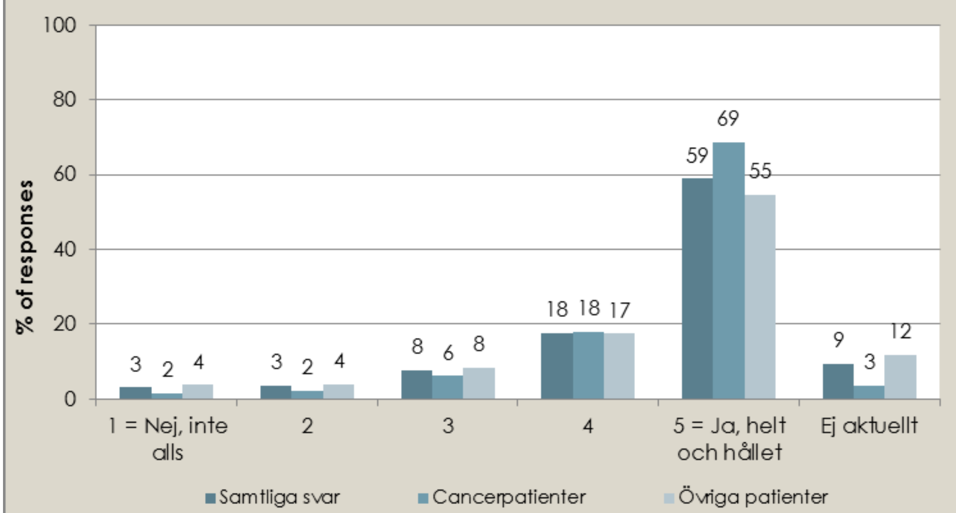
In 2016, a survey of patient experiences was conducted for the five standardised healthcare procedures (SVF) that were introduced during 2015. These are head and neck cancer, oesophageal and gastric cancers, prostate cancer, cancer of the bladder and urinary tract and acute myeloid leukaemia (AML). Questionnaires have been sent to all patients who have begun and completed an assessment in one of these SVFs as of March 2016. The national report that was published by the RCCs at the end of October is based on responses from 2,385 patients that started and completed an SVF in the March-June period of 2016. The patients whose assessment confirmed the suspected cancer diagnosis, and who began their first treatment generally provided more positive responses to the questionnaire than other patients. The most negative was the group of patients who had been assessed following the SFV for cancer of the bladder and urinary tract, and where the assessment showed it was not cancer.

The patients felt that the time from their first appointment to the start of treatment was neither too long nor too short. A very small portion, 1-2 per cent, responded that the waiting time was too short or somewhat too short.

When asked if they had received information about whether they had been assessed according to SVF, less than half of the patients responded with yes, As the patients have the right to receive information about suspected illness and the assessment content, this is something that needs improvement. Another clear area for improvement is to encourage the patient to have their next of kin present when the diagnosis is given.

Almost all patients responded that they were treated with respect and the absolute majority felt they had been treated well by care personnel throughout the assessment. The majority felt that their specific care needs had been well catered for. Of the patients that had undergone treatment (cancer patients), 90 per cent were satisfied with how their care needs had been catered for. For other patients, the corresponding figure was 82 per cent.

Do you feel that your current care needs have been met?



Källa: SKL

Knowledge management

Some quality indicators

The National Board of Health and Welfare presents a few quality indicators, in no particular orderfor each respective cancer. Only five forms of cancer are included in the diagrams. Diagrams 48 and 49 below show the development between 2014 and 2015. On the whole, a positive development between the years can be seen.

Diagram 48. Quality indicators within cancer care 2014

Total number of patients with different diagnoses.

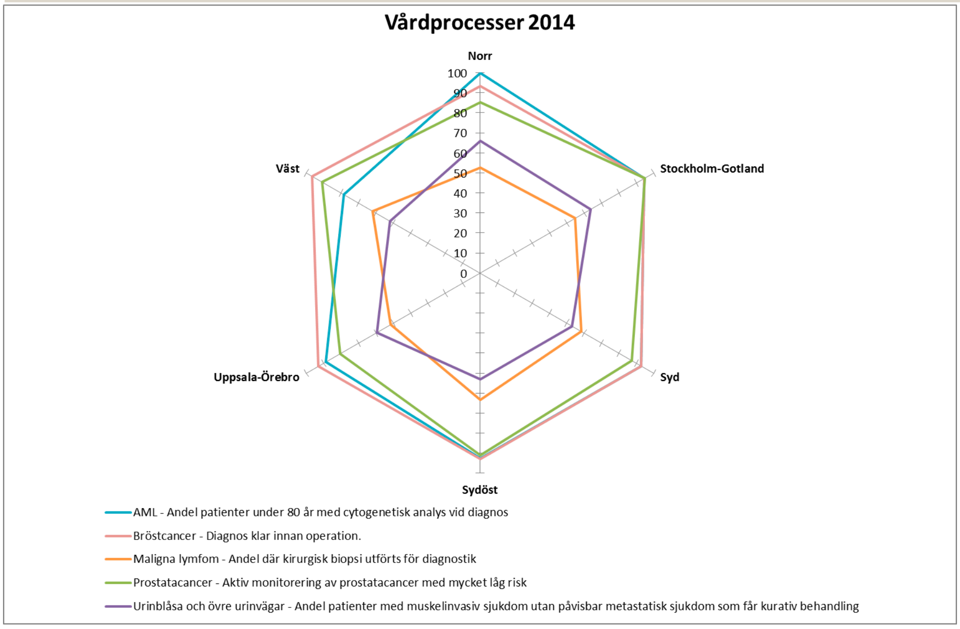
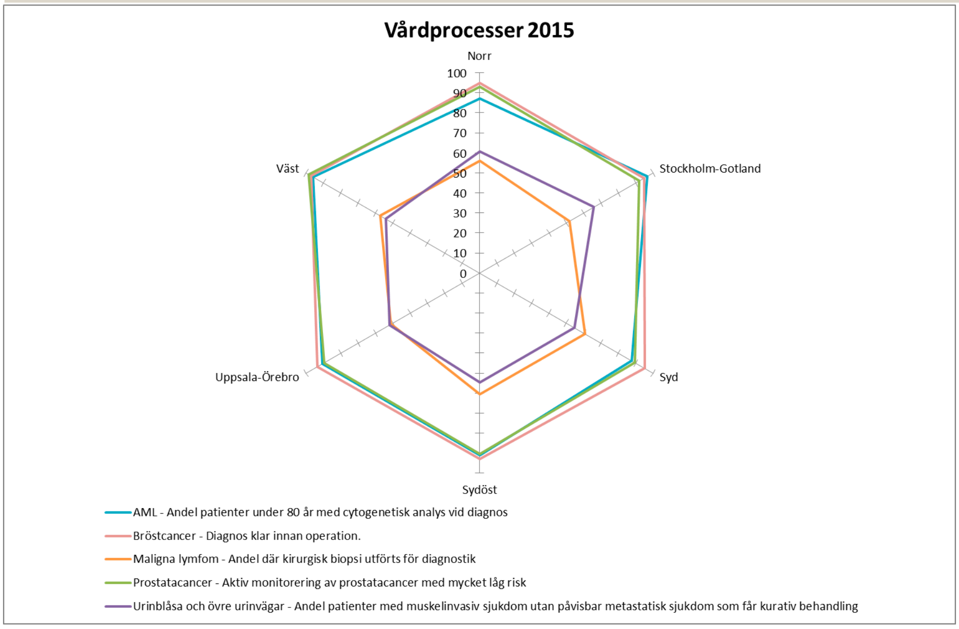


Diagram 49. Quality indicators within cancer care 2015

Total number of patients with different diagnoses.



Multidisciplinary conferences

Prior to starting treatment of newly discovered cancer, and after a primary operation, multidisciplinary conferences (MDCs) are often carried out, which form a comprehensive assessment of the cancer affecting the individual patient, to be able to optimise the treatment. MDCs are especially important for determining the correct stage of a tumour and its properties. A tumour's properties and stage can be decisive if patients will benefit from an operation, radiotherapy, pharmaceutical therapy or palliative care. Hence, several different experts participate in an MDC, e.g., diagnostics experts (such as radiologists and pathologists), surgical experts (or corresponding specialists, e.g., urologists in cases of prostate cancer), oncology experts and contact nurses. The national guidelines and practice guidelines state which experts should participate in an MDC. Furthermore, it is believed that for certain patients (depending on the severity of the cancer), it is important that MDCs are conducted.

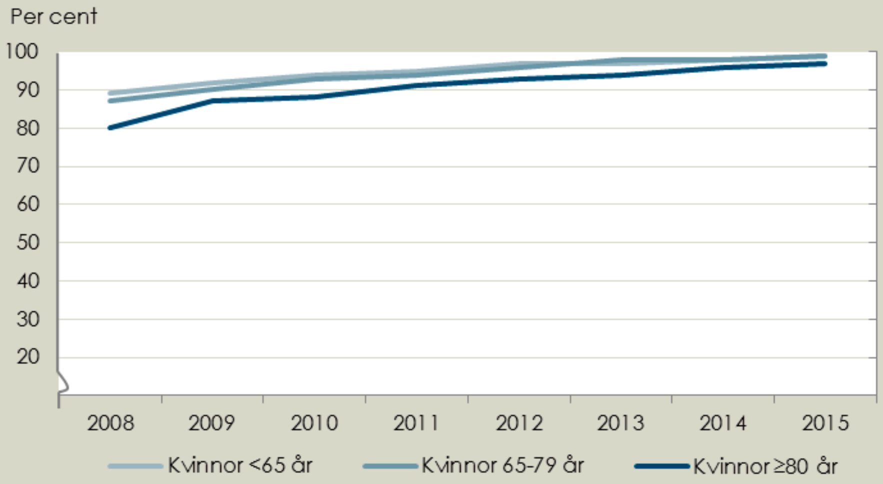
Breast cancer

According to national guidelines and practice guidelines, an MDC should be conducted both prior to treatment of recently diagnosed breast cancer and after the primary operation.

The results prior to treatment of newly discovered breast cancer are presented here. The details were obtained from the National Breast Cancer Registry, which has been available as a national quality registry since 2008. Diagrams 50-52 show that MDCs are a regular occurrence in breast cancer care. Nationwide, 98 per cent of women received an MDC assessment prior to beginning treatment of recently discovered breast cancer. Variation between the county councils was low, between 95 and 100 per cent. The data include 17,162 women who received their diagnosis during 2014 or 2015.

Diagram 50. Multidisiplinär konferens, bröstcancer

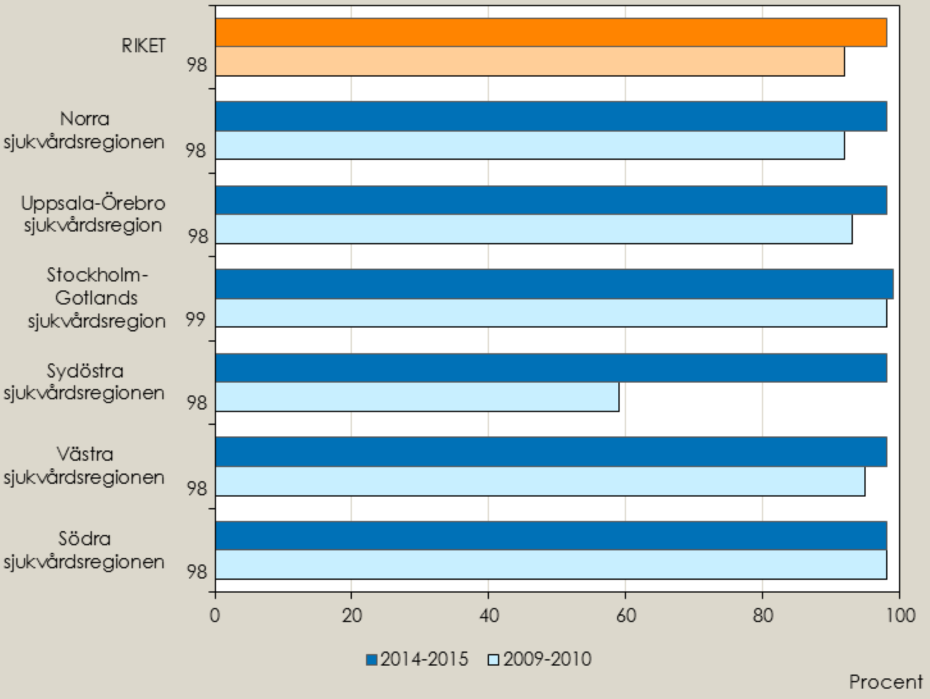
Andel kvinnor som bedömts vid MDK inför behandlingsstart



Källa: Nationellt kvalitetsregister för bröstcancer.

Diagram 51. Multidisiplinär konferens, bröstcancer

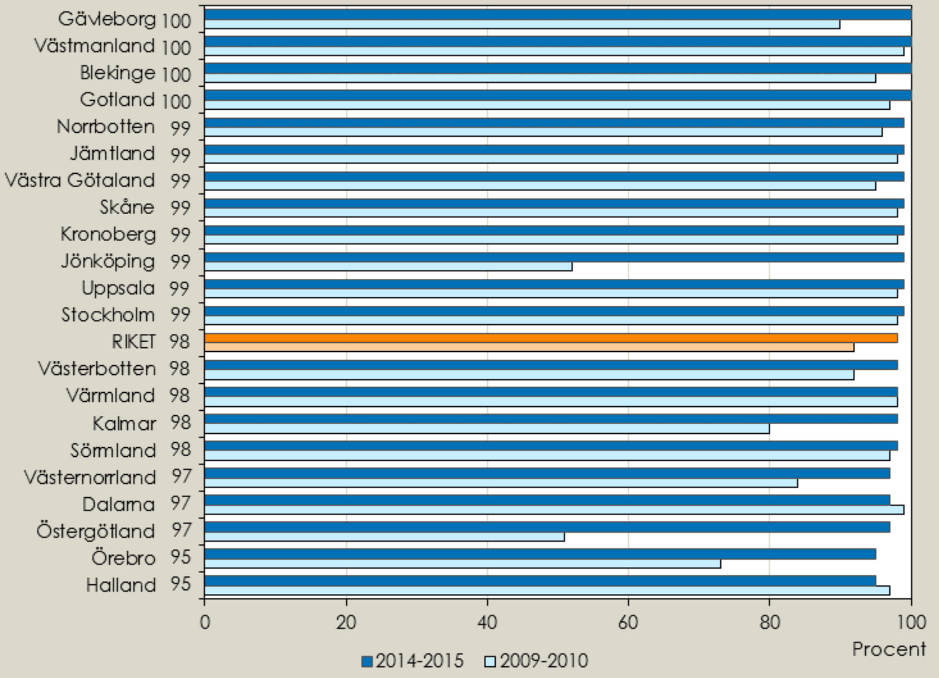
Andel kvinnor som bedömts vid MDK inför behandlingsstart, 2014-2015.



Källa: Nationellt kvalitetsregister för bröstcancer.

Diagram 52. Multidisiplinär konferens, bröstcancer

Andel kvinnor som bedömts vid MDK inför behandlingsstart, 2014-2015.



Källa: Nationellt kvalitetsregister för bröstcancer.

Prostate cancer

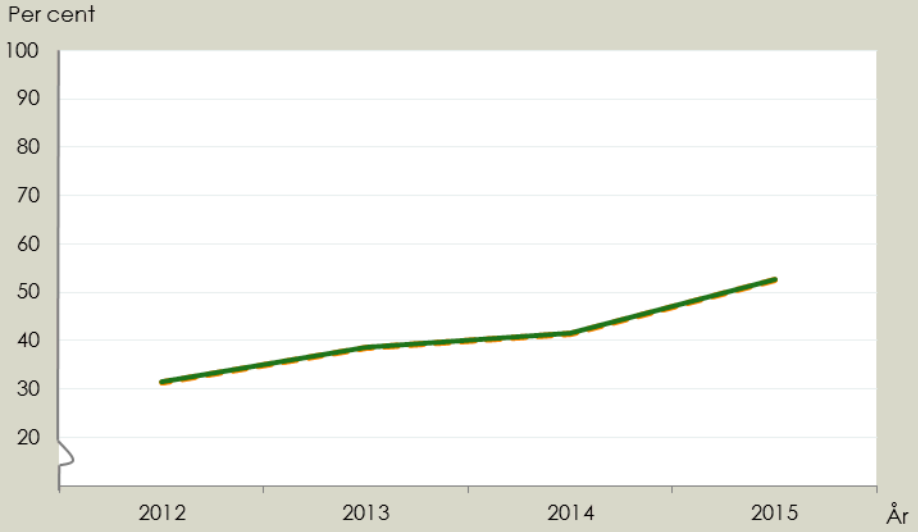
Prostate cancer that has not further metastasised is divided into three risk groups, low, medium and high. A low-risk cancer sub-group was introduced a few years ago, prostate cancer with very low risk.

According to the national practice guidelines for prostate cancer, men with high-risk prostate cancer should be assessed by an MDC. The national practice guidelines also state which experts should participate in an MDC. The recommendation in the national guidelines and practice guidelines regarding MDCs for men with high-risk prostate cancer are relatively new. This is reflected to a certain extent in the outcome of this presentation. Nationally, 41 per cent of men with high-risk prostate cancer were diagnosed at an MDC in 2015, an increase from 31 per cent in 2012. See diagrams 53-55 below.

At the county council level, this was between 17 and 100 per cent, with a national average of 47 per cent that were assessed at an MDC. The data include 2,921 men who were diagnosed with high-risk prostate cancer between 2014 and 2015.

Diagram 53. Multidisciplinär konferens, prostatacancer

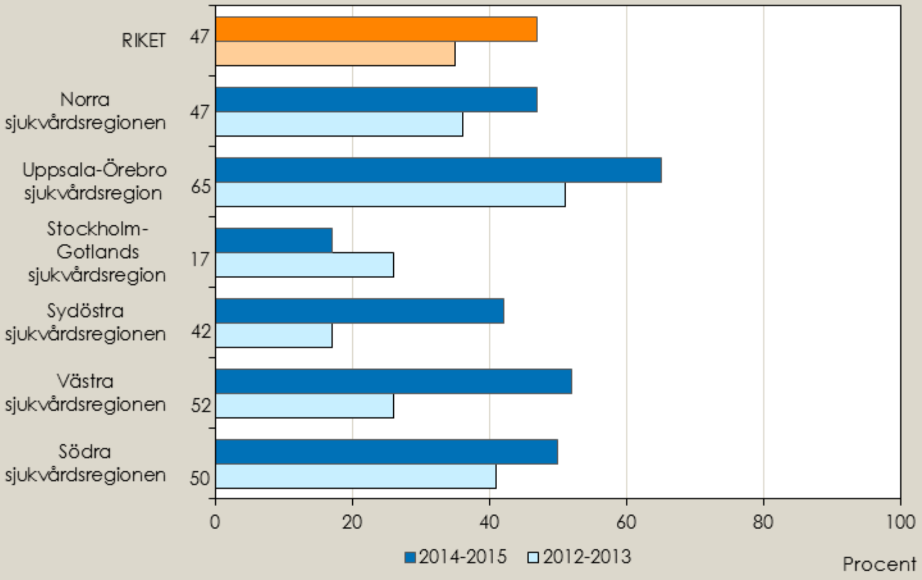
Andel patienter 80 år eller yngre vid diagnos med högrisk prostatacancer som bedömts vid multidisciplinär konferens inför behandlingsstart för prostatacancer



Källa: Nationella prostatacancerregisrtret (NPCR).

Diagram 54. Multidisciplinär konferens, prostatacancer

Andel patienter 80 år eller yngre vid diagnos med högrisk prostatacancer som bedömts vid multidisciplinär konferens inför behandlingsstart för prostatacancer, 2014-2015.



Källa: Nationella prostatacancerregisrtret (NPCR).

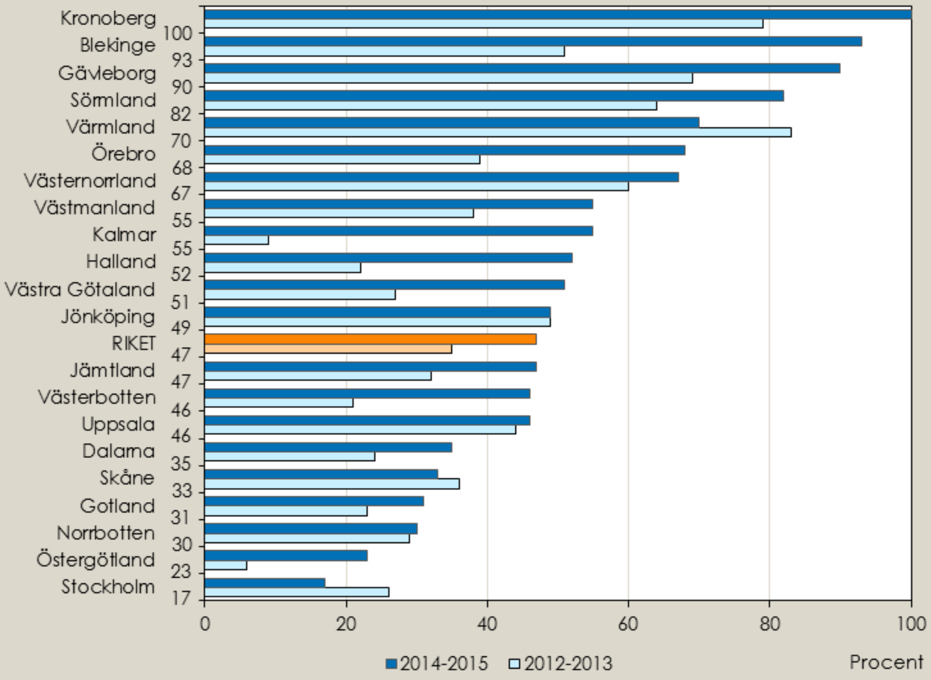


Diagram 55. Multidisciplinär konferens, prostatacancer

Andel patienter 80 år eller yngre vid diagnos med högrisk prostatacancer som bedömts vid multidisciplinär konferens inför behandlingsstart för prostatacancer, 2014-2015.

Källa: Nationella prostatacancerregisrtret (NPCR).

Bowel cancer

The national practice guidelines recommend that an MDC is conducted both prior to the initiation of treatment for recently diagnosed bowel cancer and following the primary operation. National guidelines and practice guidelines state which experts should participate in an MDC.

Diagram 56 shows a strong development towards MDCs at the start of treatment for recently discovered bowel cancer from 26 per cent in 2007 to 95 per cent in 2015. There were no large differences between the sexes.

Nationwide, 93 per cent were evaluated at an MDC 2014-2015. The variation between the county councils ranged from 74 to 98 per cent, see diagrams 57 and 58 below. 16 of the county councils had a value that was equivalent or higher to the national average of 93 per cent. Only a few county councils lagged behind, however they have improved their result considerably when compared to 2010-2011. The comparison includes all patients diagnosed with bowel cancer, with the exception of those who underwent emergency surgery or surgery for polyps.

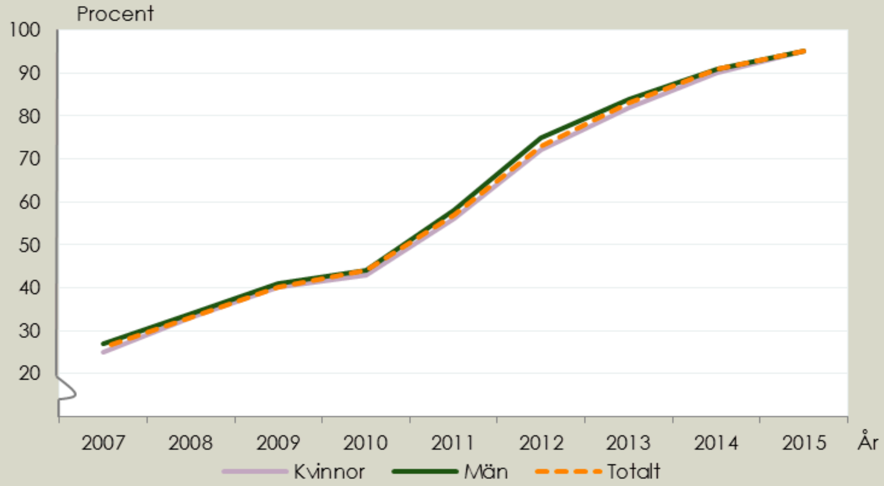
We have obtained information from the quality registry about which experts participated in an MDC. In 2015, average national participation included

- surgeons in 94 per cent of cases
- oncologists in 94 per cent of cases
- pathologists in 66 per cent of cases
- radiologists in 91 per cent of cases and

- contact nurses in 92 per cent of cases of newly diagnosed bowel cancer.

Diagram 56. Multidisciplinär konferens, tjocktarmscancer

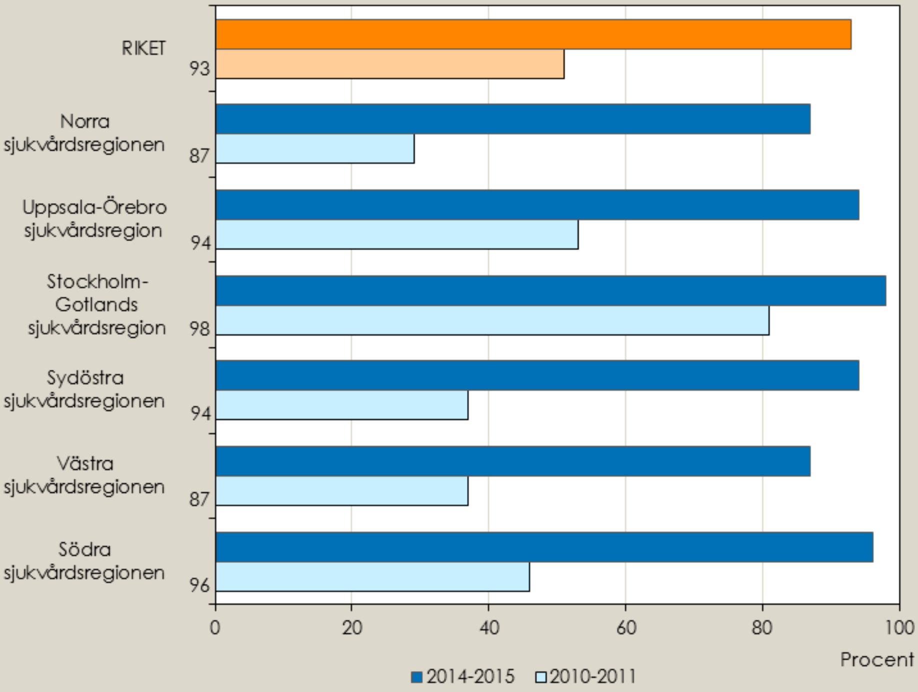
Andel patienter som bedömts vid multidisciplinär konferens inför behandlingsstart för tjocktarmscancer



Källa: Svenska kolorektalcancerregistret.

Diagram 57. Multidisciplinär konferens, tjocktarmscancer

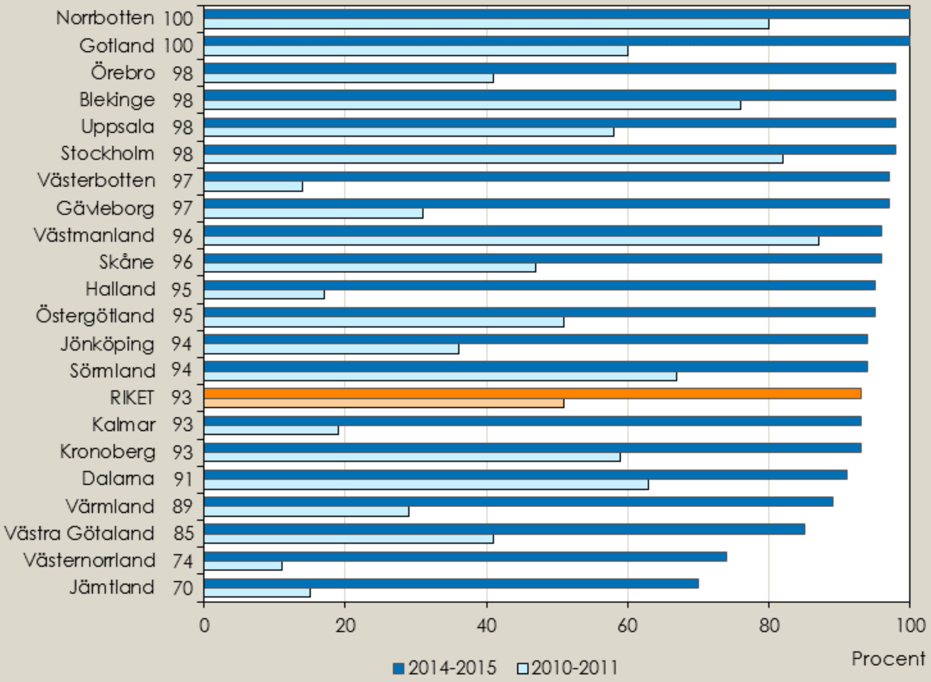
Andel patienter som bedömts vid multidisciplinär konferens inför behandlingsstart för tjocktarmscancer, 2014-2015.



Källa: Svenska kolorektalcancerregistret.

Diagram 58. Multidisciplinär konferens, tjocktarmscancer

Andel patienter som bedömts vid multidisciplinär konferens inför behandlingsstart för tjocktarmscancer, 2014-2015.



Källa: Svenska kolorektalcancerregistret.

Colorectal cancer

The national practice guidelines recommend that an MDC is conducted both prior to the initiation of treatment for recently diagnosed colorectal cancer and following the primary operation. National guidelines and practice guidelines state which experts should participate in an MDC.

MDCs are a regularly occurring routine prior to the start of treatment for newly discovered colorectal cancer. The total has increased from 74 per cent in 2007 to 97 per cent in 2015 (see Diagram 59). There was no large difference between the sexes.

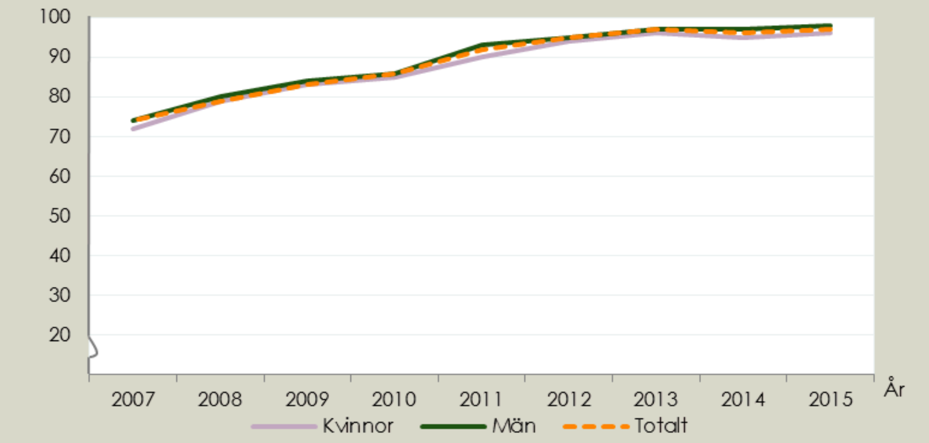
2014-2015 the variation between county councils was 93-100 per cent (see Diagrams 60-61). Compared to 2010-2011, almost all county councils have increased their number of patients assessed at an MDC.

We have obtained information from the quality registry about which experts participated in an MDC. In 2015, average national participation included

- surgeon for 97 per cent of cases
- oncologist for 96 per cent of cases,
- pathologist for 67 per cent of cases,
- radiologist for 96 per cent of cases and
- contact nurse for 95 per cent of cases of newly diagnosed colorectal cancer.

Diagram 59. Multidisciplinär konferens, ändtarmscancer

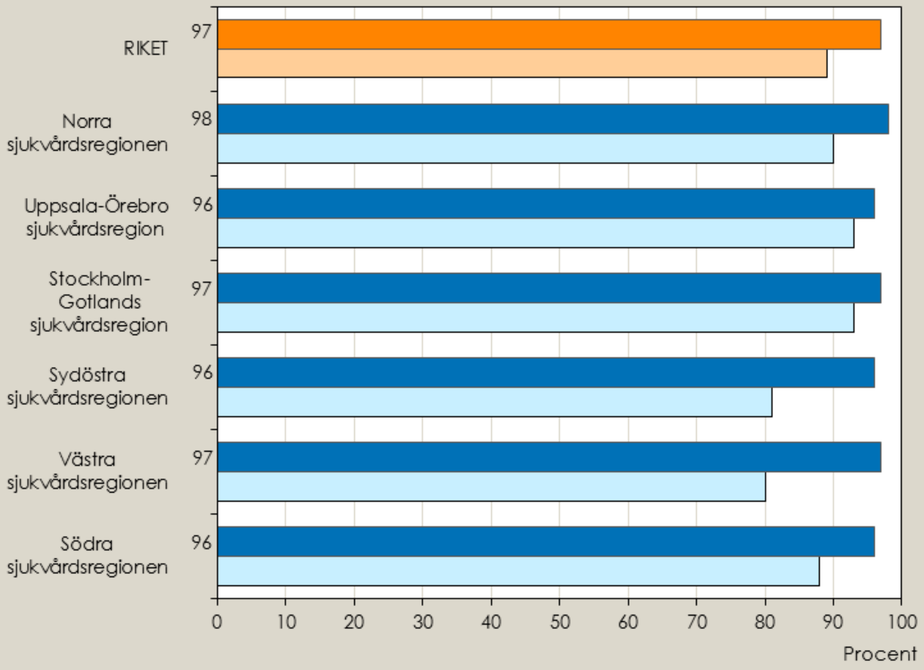
Multidisciplinär konferens, ändtarmscancer



Källa: Svenska kolorektalcancerregistret.

Diagram 60. Multidisciplinär konferens, ändtarmscancer

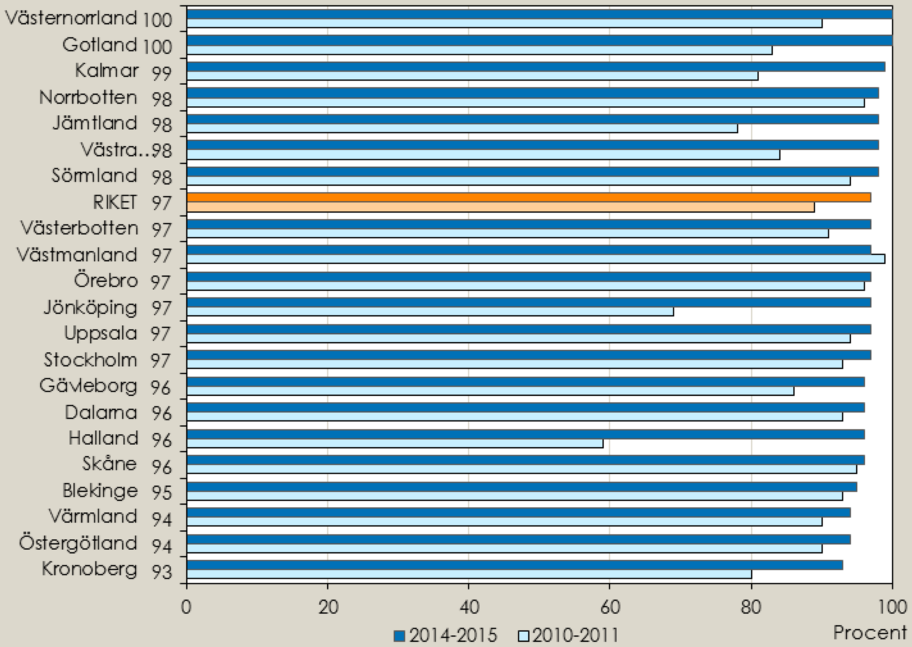
Andel patienter som bedömts vid multidisciplinär konferens inför behandlingsstart för ändtarmscancer, 2014-2015.



Källa: Svenska kolorektalcancerregistret.

Diagram 61. Multidisciplinär konferens, ändtarmscancer

Andel patienter som bedömts vid multidisciplinär konferens inför behandlingsstart för ändtarmscancer. Avser jämförelse mellan 2010-2011 och 2014-2015.



Källa: Svenska kolorektalcancerregistret.

Lung cancer

The treatment decisions established during MDCs for patients with recently discovered lung cancer are presented below. The national practice guidelines state which experts should participate in an MDC.

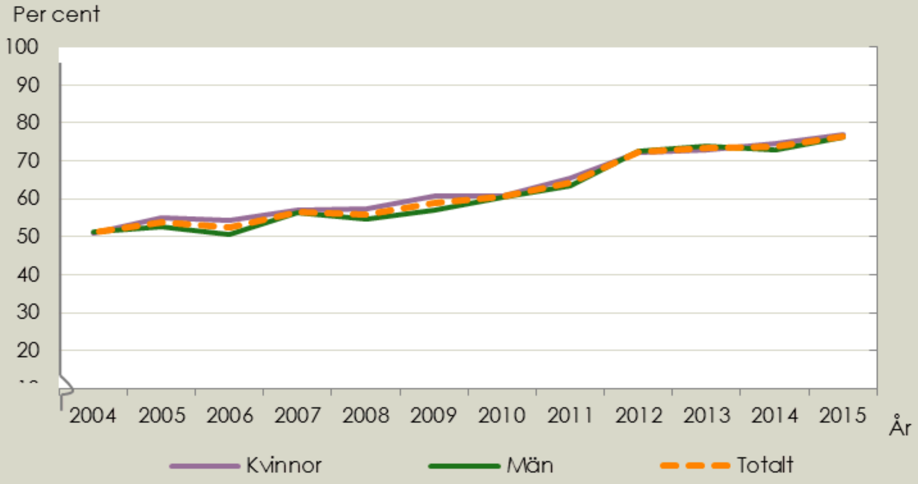
The total number nationally who were assessed at an MDC has increased from 50 per cent in 2002 to 76 per cent in 2015 (see Diagram 62). There was no large difference between the sexes.

Nationwide, 74 per cent of patients were assessed at an MDC prior to treatment during the years 2012-2015, variation between the county councils was 45-95 per cent (see Diagrams 63-64 below).

The data were obtained from the National Lung Cancer Registry and include 14,728 people who were diagnosed between 2012 and 2015.

Diagram 62. Multidisciplinär konferens, lungcancer

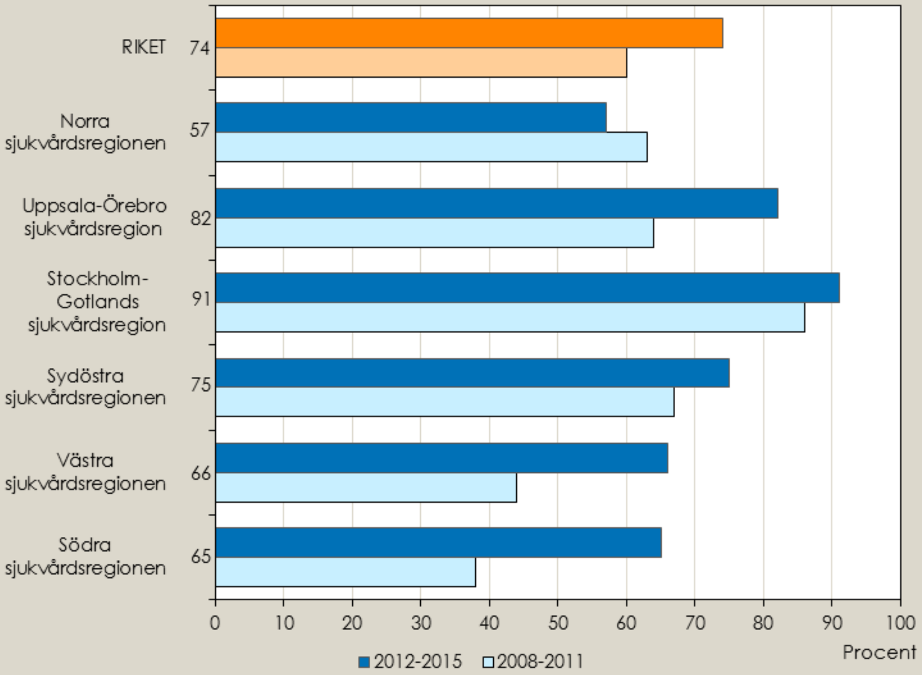
Multidisciplinär konferens inför behandlingsbeslut för lungcancer



Källa: Nationellt lungcancerregistret(NLCR).

Diagram 63. Multidisciplinär konferens, lungcancer

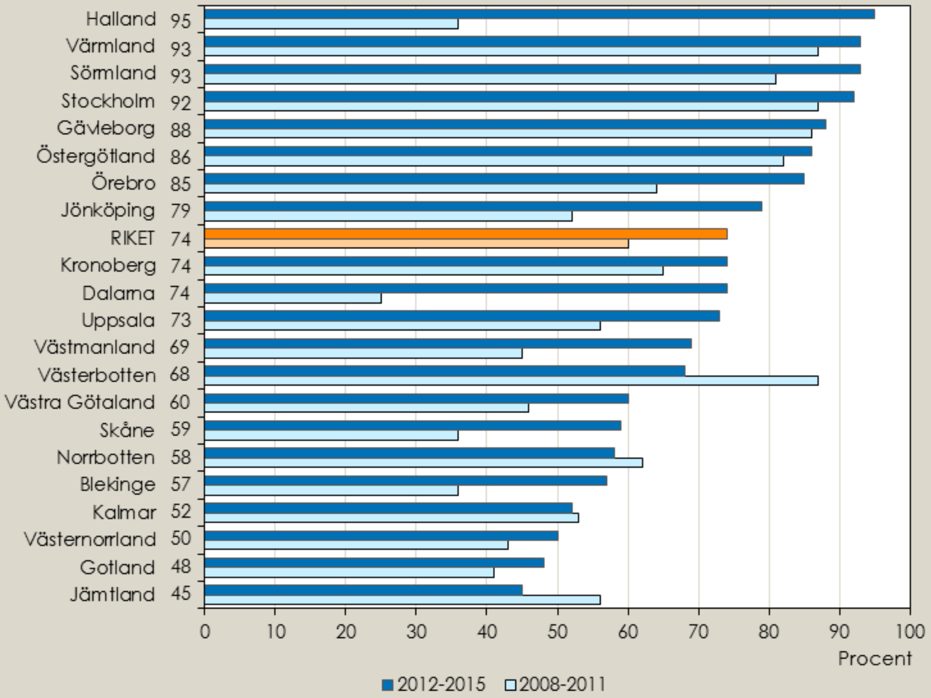
Multidisciplinär konferens inför behandlingsbeslut för lungcancer, 2012-2015.



Källa: Nationellt lungcancerregistret(NLCR).

Diagram 64. Multidisciplinär konferens, lungcancer

Multidisciplinär konferens inför behandlingsbeslut för lungcancer, 2012-2015.



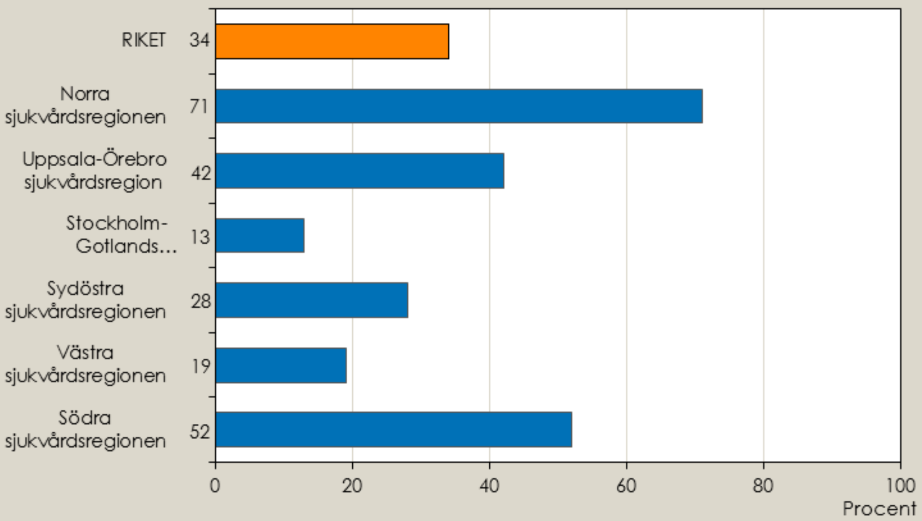
Källa: Nationellt lungcancerregistret (NLCR).

Melanoma

The number of patients with melanomas assessed at an MDC is presented below. The national practice guidelines state which experts should participate in an MDC. The data have been obtained from the National Melanoma Quality Registry and include 3,669 people diagnosed with melanoma between 2013-2015, with a tumour thickness of over 1 mm and on whom surgery was performed. Despite the details having being collected over several years, for certain county councils, the values are low and consequently the results should be interpreted with caution. Nationwide, 34 per cent were evaluated at an MDC. The variation between the county councils ranged 7 to 96 per cent, see Diagrams 65-66 below.

Diagram 65. Multidisciplinär konferens, hudmelanom > 1 mm tjocklek

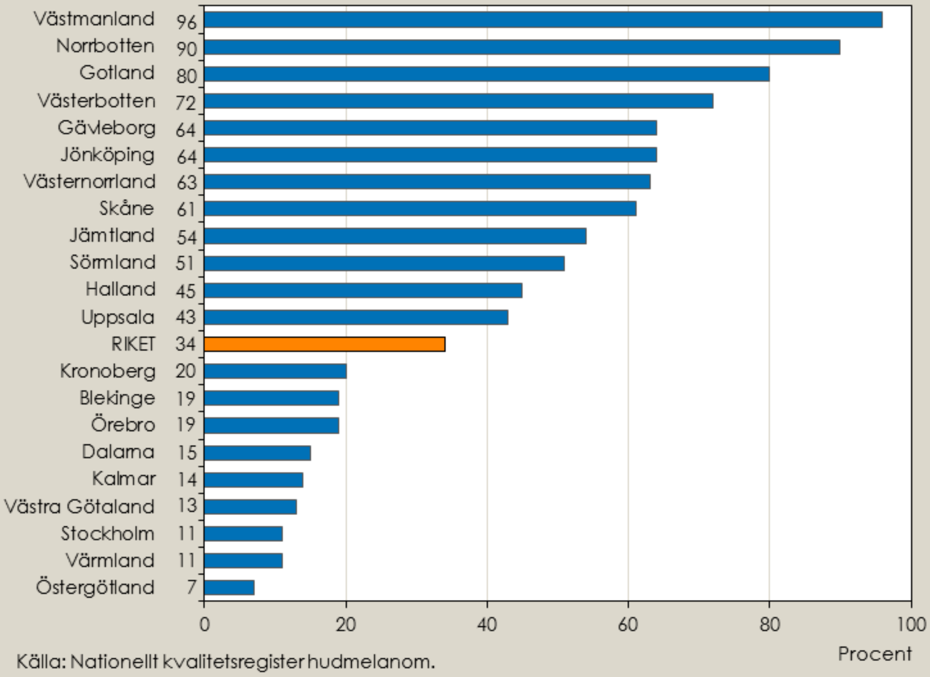
Andel patienter som bedömts vid multidisciplinär konferens, hudmelanom > 1 mm



Källa: Nationellt kvalitetsregister hudmelanom.

Diagram 66. Multidisciplinär konferens, hudmelanom > 1 mm tjocklek och invasiv kirurgi utförd

Andel patienter som bedömts vid multidisciplinär konferens, hudmelanom > 1 mm tjocklek och invasiv kirurgi, 2013-2015.



Källa: Nationellt kvalitetsregister hudmelanom.

Multidisciplinary conferences for certain diagnoses 2014 and 2015

The number of patients assessed at an MDC is presented below and includes seven diagnoses for 2014 and 2015 per healthcare region. Generally speaking, a positive trend can be seen for the majority of healthcare regions.

Diagram 67. Multidisciplinary conferences 2014 for select cancer diseases

Total number of patients offered MDC, 2014.

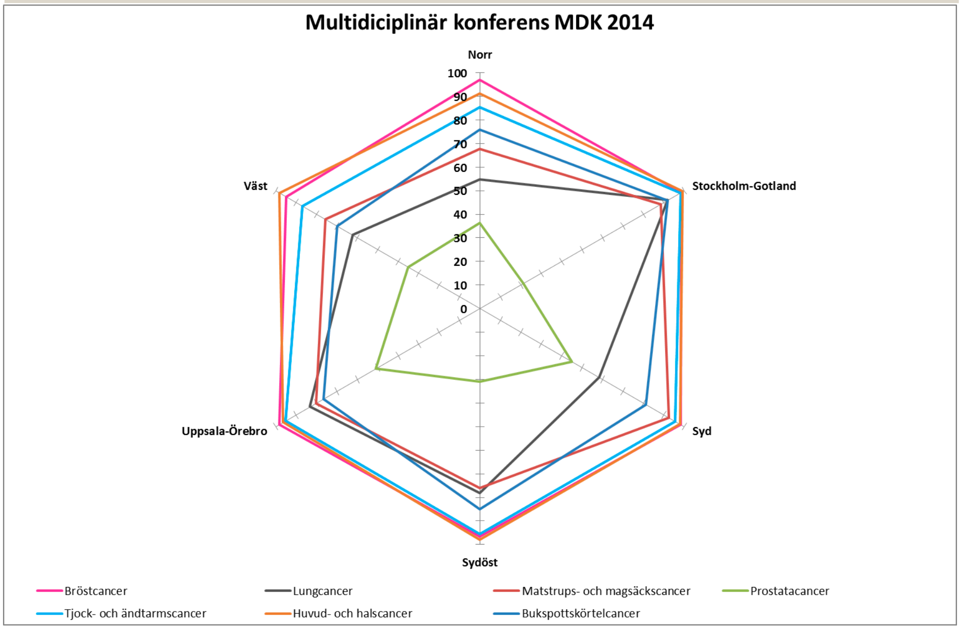
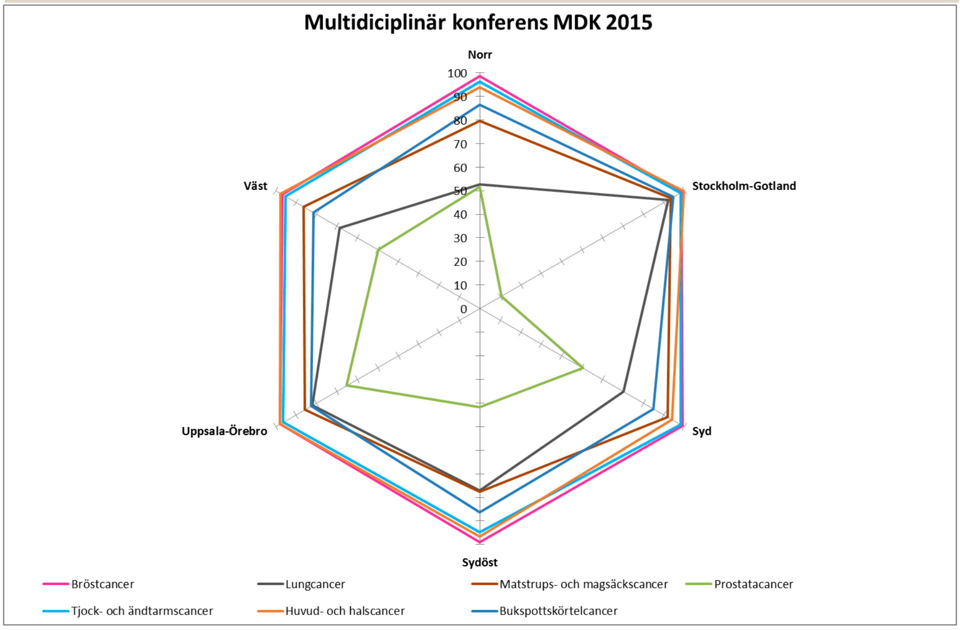


Diagram 68. Multidisciplinary conferences 2015 for select cancer diseases

Total number of patients offered MDC, 2015.



Clinical research and innovation

Participants in treatment studies

Studies are essential to safely drive development forward. Participation in treatment studies has proven to be advantageous for patients. Not just because they are given access to new and improved medication or other treatments as a result, but also because in these cases follow-ups are often more comprehensive. Therefore, the National Board of Health and Welfare presents the development related to patient participation in studies, that, for example, is shown in the number of patients who participated in treatment studies for bowel and colorectal cancer.

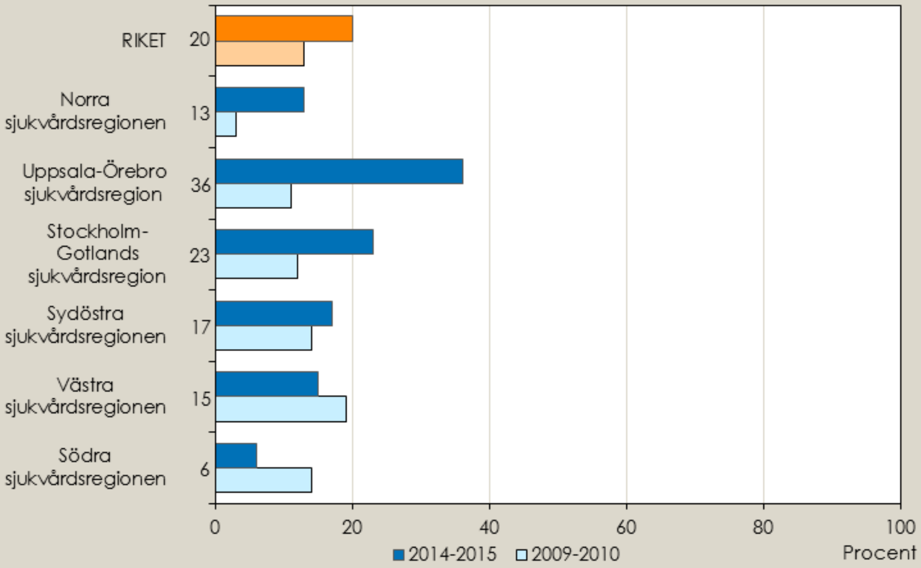
Bowel cancer

The diagrams below show the number of patients with bowel cancer who were included in a structured treatment study. The data were obtained from the Swedish Colorectal Cancer Registry and include 7,025 patients from 2014-2015. Nationwide, 20 per cent of patients participated in a structured treatment study, variation between the county councils is 0-73 per cent (see Diagrams 69-70).

One shortage in the data is that oncological studies that began after primary treatment have not been included.

Diagram 69. Strukturerad behandlingsstudie, tjocktarmscancer

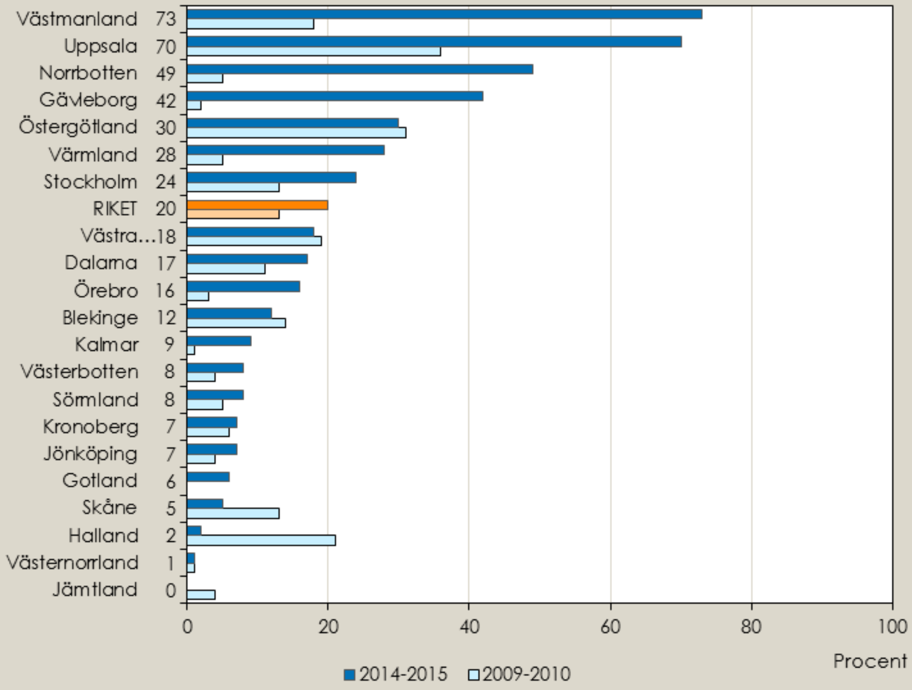
Andel patienter som deltagit i någon form av strukturerad behandlingsstudie, tjocktarmscancer, 2014-2015.



Källa: Svenska kolorektalcancerregistret.

Diagram 70. Strukturerad behandlingsstudie, tjocktarmscancer

Andel patienter som deltagit i någon form av strukturerad behandlingsstudie, tjocktarmscancer, 2014-2015.



Källa: Svenska kolorektalcancerregistret.

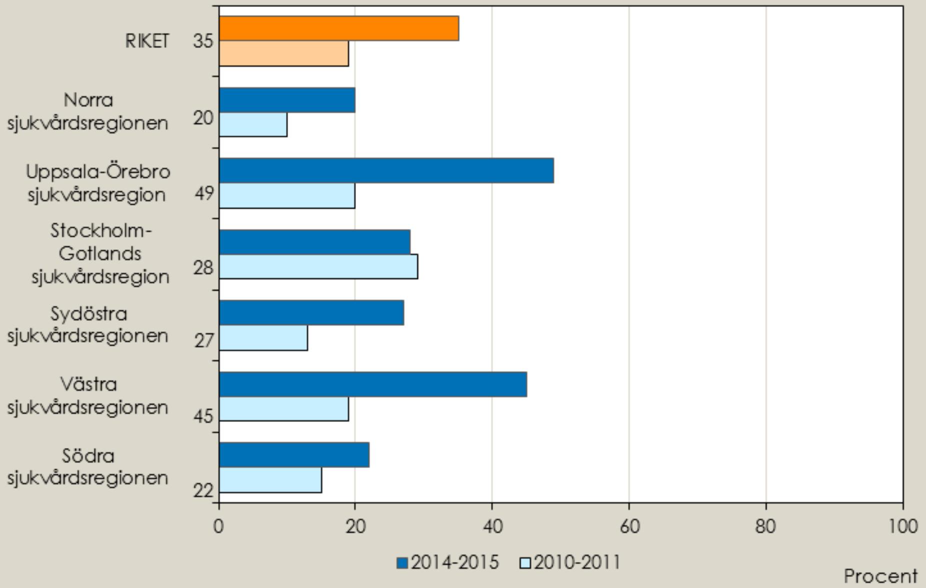
Colorectal cancer

The diagrams below show the number of patients with colorectal cancer who were included in a structured treatment study. The data were obtained from the Swedish Colorectal Cancer Registry and include 3,067 patients from 2014-2015. Nationwide, 35 per cent of patients participated in a structured treatment study and variation between the county councils is 1-83 per cent, (see Diagrams 71-72 below).

One shortage in the data is that oncological studies that began after primary treatment have not been included.

Diagram 71. Strukturerad behandlingsstudie, ändtarmscancer

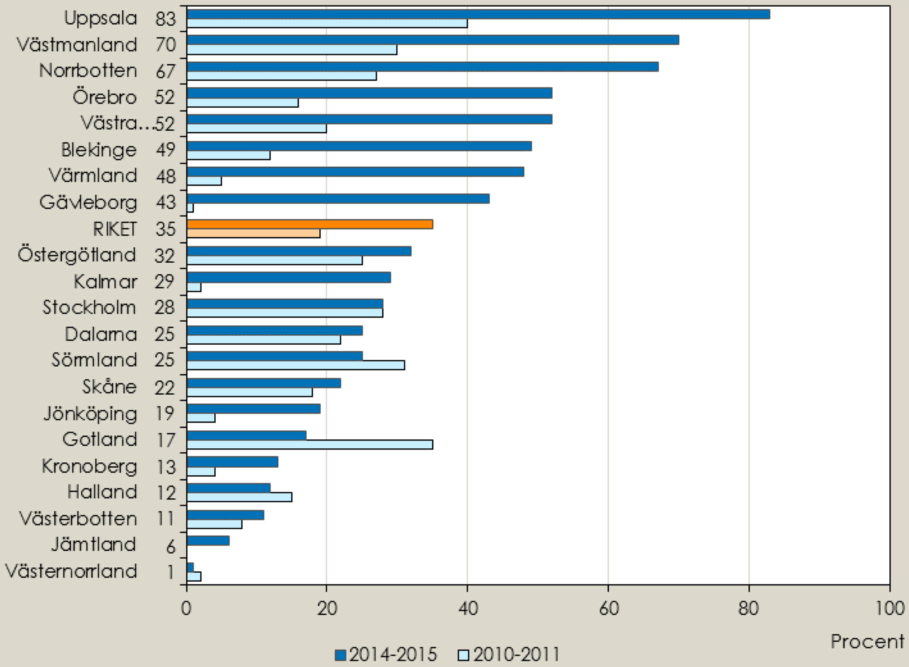
Andel patienter som deltagit i någon form av strukturerad behandlingsstudie, ändtarmscancer, 2014-2015.



Källa: Svenska kolorektalcancerregistret.

Diagram 72. Strukturerad behandlingsstudie, ändtarmscancer

Andel patienter som deltagit i någon form av strukturerad behandlingsstudie, ändtarmscancer, 2014-2015.



Källa: Svenska kolorektalcancerregistret.

Appendix 4: National practice guidelines for cancer

The Confederation of Regional Cancer Centres in Sweden creates the national practice guidelines. The aim of the national practice guidelines is for them to contribute to evidence-based, equal and quality healthcare for all patients, regardless of where they live, their gender or their socioeconomic status.

Established practice guidelines

There are currently 29 established practice guidelines:

1. Aggressive B-Cell lymphoma
2. Acute myeloid leukaemia, AML
3. Breast cancer, longitudinal follow-up
4. Breast cancer
5. Pancreatic cancer
6. Brain tumours
7. Melanoma
8. Head and neck cancer
9. Non-epithelial ovarian tumours
10. Chronic lymphocytic leukaemia (CLL)
11. Chronic myeloid leukaemia
12. Hepatocellular carcinoma
13. Uterine cancer
14. Cancer in the lungs and pleural cavity
15. Mantle cell lymphoma
16. Oesophageal and gastric cancers.
17. Multiple myeloma
18. Neuroendocrine/carcinoid tumours
19. Renal cell cancer
20. Cancer of unknown primary (CUP)
21. Palliative care
22. Penile cancer
23. Prostate cancer
24. Rehabilitation
25. Thyroid cancer
26. Bowel and colorectal cancers
27. Bladder and urinary tract cancers
28. Ovarian cancer
29. Trophoblastic diseases

Appendix 5: Approved and recommended national care units

Approved national care units

University Hospital

- Radiochemotherapy for curative purposes of anal cancer (1)
- CRS/HIPEC for cancer spread to the abdominal cavity (2)

Karolinska University Hospital

- CRS/HIPEC for cancer spread to the abdominal cavity (2)
- Surgery for oesophagal cancer, defined unusual state (3)
- Surgical and oncological treatment of vulvar cancer (4)

University Hospital of Umeå

Radiochemotherapy for curative purposes of anal cancer (1)

Sahlgrenska University Hospital

- Radiochemotherapy for curative purposes of anal cancer (1)
- CRS/HIPEC for cancer spread to the abdominal cavity (2)
- Surgical and oncological treatment of vulvar cancer (4)
- Surgery for curative purposes of anal cancer (5)
- Hyperthermic isolated profusion for malignant melanoma (6)

Skåne University Hospital

- Radiochemotherapy for curative purposes of anal cancer (1)
- CRS/HIPEC for cancer spread to the abdominal cavity (2)
- Surgery for oesophagal cancer, defined unusual state (3)
- Surgical and oncological treatment of vulvar cancer (4)
- Surgery for curative purposes of anal cancer (5)
- Surgery for curative purposes of penile cancer (7)

Linköping University Hospital

- Surgical and oncological treatment of vulvar cancer (4)

Örebro University Hospital

- Surgery for curative purposes of penile cancer (7)

Recommended national care units

Karolinska University Hospital

- Surgery for curative purposes of locally advanced pancreatic and periampullary cancer (8)
- Surgery for curative purposes of perihilar bile duct tumours (9)
- Retroperitoneal lymph node excision for testicular cancer (10)

Sahlgrenska University Hospital

- Surgery for curative purposes of locally advanced pancreatic and periampullary cancer (8)
- Surgery for curative purposes of perihilar bile duct tumours (9)
- Retroperitoneal lymph node excision for testicular cancer (10)