

# Quality and Efficiency in Swedish Cancer Care

Regional Comparisons  
**2011**





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## **Quality and Efficiency in Swedish Cancer Care**

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# Foreword

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Each year the Swedish National Board of Health and Welfare (NBHW) and the Swedish Association of Local Authorities and Regions (SALAR) publish a joint report entitled *Quality and Efficiency in Swedish Health Care – Regional Comparisons*. The Government has now mandated the NBHW to collaborate with SALAR on a special edition for cancer care.

The joint organisation created by the NBHW and SALAR to develop and promote open comparisons of the healthcare system has assumed responsibility for compiling the report.

The dual purpose of the report is to provide supporting data for decision makers at various levels who are attempting to improve cancer care while offering the general public insight into what publicly financed cancer care is accomplishing.

The project coordinator at the NBHW has been *Mona Heurgren*. The project managers have been *Göran Zetterström* (NBHW) and *Katarina Wiberg Hedman* (SALAR).

The project has been accompanied by a dialogue with contacts at each of the 21 county councils.

Many of the indicators proceed from external databases and other sources, primarily national quality registers for cancer care. Our special gratitude goes to representatives of the registers, the regional cancer centres, and others who contributed to the report.

*Lars Erik Holm*

Director-General

Swedish National Board  
of Health and Welfare

*Håkan Sörman*

Executive Director

Swedish Association of  
Local Authorities and Regions

# Summary

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This is the first time that open comparisons have been presented that reflect care quality for ten common forms of cancer in Sweden. The report compares the various counties in terms of medical outcomes, patient experience and waiting times.

## **Survival rates among cancer patients are increasing**

The percentage of cancer deaths has declined over the past 40 years, while survival rates have risen. The relative five-year survival rate among men increased from just over 50 per cent in 1990–1994 to almost 70 per cent in 2005–2009. For women, the survival rate increased from 60 to 68 per cent.

Patients with breast cancer and malignant melanoma had the highest survival rates. The relative five-year survival rate among breast cancer patients was 87 per cent in 2005–2009. The survival rate for malignant melanoma was 93 per cent among women and 86 per cent among men during the period.

Lung cancer claims more Swedish lives each year than any other form of the disease. Relative survival rates are low but have increased, particularly the one-year rate, since the early 1990s. The relative five-year survival rate is approximately 15 per cent among women and 12 per cent among men.

No county consistently stands out in terms of survival rates for multiple types of cancer as well as for both sexes. However, lung cancer and bladder cancer show major variations between counties.

## **The frequency of multidisciplinary team meetings varies**

Multidisciplinary team meetings are often important for assessing a patient's medical needs and setting up an individual treatment plan. The report demonstrates that the number of new patients who receive such an assessment varies from 4 to 100 per cent between the different counties, as well as between the different forms of cancer. Multidisciplinary team meetings are not indicated or expedient prior to emergency surgery for colon cancer and in certain other situations.

## **Waiting times vary significantly**

The report shows that waiting times vary significantly among counties and forms of cancer. For instance, the median waiting time from receipt of a referral until the initial appointment with a specialist ranged from 17 to 43 days.

A concerted effort has been made in recent years to shorten healthcare waiting times. The waiting times presented in this report cover a period when this effort was beginning but had not been fully implemented. The data can now be used for future comparisons.

### **Diagnostic methods are more effective in some areas**

Assessment and diagnosis of cancer has improved in some areas. Here are a few examples:

- The number of patients who underwent bone scintigraphy for low-risk localised prostate cancer decreased from 38 to 4.5 per cent in 2000–2009 (few such patients actually need the examination)
- A total of 83 per cent of all kidney cancer patients had CT scans, which is very close to the clinical practice guidelines target
- Almost all counties met the lung cancer guidelines that biopsies be performed for 99 per cent of patients

### **Some cancer care outcomes**

Most indicators in the report reflect medical quality, such as the use of various treatment options, as well as postoperative outcomes and complications. Following are some examples:

- The number of patients with medium to high-risk prostate cancer who received curative treatment increased from 48 per cent in 2000 to 68 per cent in 2009
- Use of the sentinel node technique to identify breast cancer cases in which complete removal of lymph nodes from the armpit area is indicated rose to 80 per cent in 2009
- A total of 1.5 per cent of breast cancer cases were reoperated in 2009 due to bleeding, infection or other complications; the percentage has remained essentially unchanged in recent years
- A total of 8.7 per cent of colon cancer cases and 10.8 per cent of rectal cancer cases were reoperated in 2007–2009

### **Open comparisons offer a snapshot**

This report is descriptive in nature and strives to present a snapshot of current cancer care.

The dual purpose of the report is to provide supporting data for decision makers at various levels who are attempting to improve cancer care while offering the general public some insight into what publicly financed cancer care is accomplishing.

County outcomes for each of the indicators are shown in ranked diagrams, but no weighted ranking of the counties based on overall quality and efficiency is pre-

sented. The choice is intentional, given that no nationally confirmed method of weighting indicators has yet been devised. The outcomes should be interpreted in light of data quality and the other considerations discussed in connection with each indicator.

The report omits certain areas, including rehabilitation, nursing and psychosocial care, as well as patient experience of health and disease after treatment (patient-reported outcome measures). Registers, other data sources and indicators need to be developed for these areas before they can be included in future comparisons.



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# Introduction

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## Open comparisons of cancer care

Each year the Swedish National Board of Health and Welfare (NBHW) and the Swedish Association of Local Authorities and Regions (SALAR) publish a joint report entitled *Quality and Efficiency in Swedish Health Care – Regional Comparisons* based on a series of indicators. The report compares counties with respect to medical outcomes, patient experience, waiting times and costs. Available national healthcare statistics provide the basic data for the report.

In 2010, the Government mandated the NBHW to collaborate with SALAR on a special edition for cancer care.

The overall purpose of the report is to promote local, regional and national improvement efforts by comparing the quality of cancer care throughout the country. The comparisons should encourage the counties to perform in-depth analyses of their outcomes in order to further improve the quality and efficiency of the cancer care they provide. The report offers healthcare decision makers and administrators data and knowledge support for managing and monitoring the activities of their organisations. It is also intended to provide the general public with insight into what publicly financed cancer care is accomplishing.

The Government's national cancer strategy has taken the initiative for the implementation of several new measures, including an emphasis on knowledge support and monitoring of cancer care outcomes. Open comparisons represent one approach to collecting and presenting data that can be used for follow-up and improvement purposes.

Knowledge support includes national guidelines to promote the adoption of evidence-based methods by the healthcare system. Sweden has national guidelines for breast, colon, rectal, prostate and lung cancer.

The report covers the following ten forms of cancer:

- breast
- ovarian
- kidney
- bladder
- prostate
- colon
- rectal
- lung
- head and neck
- malignant melanoma

A total of 70 indicators are presented, 4–10 for each form of cancer.

## **SWEDEN HAS A DECENTRALISED HEALTHCARE SYSTEM**

Twenty counties and regions, as well as one municipality, are responsible for providing their citizens with hospital, primary, psychiatric and other healthcare services. A county council tax supplemented by a government grant is the main means of financing the healthcare system. In addition, small user fees are paid at the point of use. Long-term care for the elderly is financed and organized by the municipalities. Each county and region is governed by a political assembly, whose representatives are elected for four years in general elections.

The counties and regions are of different size. With populations between one and two million each, Stockholm, Västra Götaland and Skåne are considerably larger than the rest. Gotland is smallest, with about 60 000 inhabitants. Most of the other counties have populations between 200 000 and 300 000.

Within the framework of national legislation and varying healthcare policy initiatives by the national government, the counties and regions have substantial decision making powers and obligations to their citizens. The Swedish healthcare system is decentralised. Thus, focusing on the performance of the individual counties and regions is a logical approach.

All ten forms are very uncommon in children and adolescents. Thus, the report does not cover this population.

Open comparisons should include the entire care chain in order to ensure an overall perspective. However, this report does not examine nursing, rehabilitation and certain other methods for treatment and care of cancer patients. Nor do any of the indicators reflect patient-reported outcome measures (PROMs).

### **Data sources**

The conditions for register-based performance measurement are unique in Sweden. Thanks to the identity number assigned to each Swedish resident, various national healthcare databases can be linked to each other and provide access to comparative outcome data.

The data sources used in the report are presented along with the description of outcomes. Further on in this chapter is a separate chart of the data sources that have been used.

The medical quality indicators are based primarily on data from the Swedish cancer register – which started in 1958 – as well as national quality registers. Information about these sources is available at [www.socialstyrelsen.se](http://www.socialstyrelsen.se) and [www.kvalitetsregister.se/cancer](http://www.kvalitetsregister.se/cancer). All data about patient experience are taken from the National Patient Survey ([www.skl.se/nationellpatientenkat](http://www.skl.se/nationellpatientenkat)). The health data registers (Swedish Cancer Register, National Patient Register, etc.) and national quality registers contain data about individuals and unique care events. Reporting is mandatory to the health data registries and optional to the quality registers.

## DATA SOURCES

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### Swedish National Board of Health and Welfare

Swedish Cancer Register  
National Patient Register  
Swedish Prescribed Drug Register  
Cause of Death Register

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### Swedish Association of Local Authorities and Regions

National Case Costing Database  
National Patient Survey

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### National Quality Registers

Swedish Register of Palliative Care  
National Breast Cancer Register  
National Quality Register for Gynecological Onkology  
National Swedish Kidney Cancer Register  
Swedish Bladder Cancer Register  
National Prostate Cancer Register  
National Colon Cancer Register  
National Rectal Cancer Register  
National Lung Cancer Register  
Swedish Head and Neck Cancer Register  
Swedish Melanoma Register

## Remarks on regional comparisons

Every indicator is accompanied by a diagram and brief description. The diagrams are generally horizontal bar charts on which the counties appear in descending order. The national average is also presented in a separate colour. The counties at the top of the diagram have usually shown the best outcomes. Outcomes and therefore rankings can be affected by poor data quality and small differences between counties whose data lack statistical significance.

Ranking is easy to justify when it comes to mortality, complications and certain other indicators, but additional factors – such as the health of the general population and case mix at the hospitals – must always be taken into consideration. County populations were age standardised for some indicators to ensure more comparable outcomes. Such standardisation corrects for regional variations in age structure. However, no corrections were made for differences in health status or morbidity that do not correlate with age.

The report identifies regional variations in outcomes as measured by a series of quality indicators. The variations may be due to superior organisation and administration of health care by certain counties; such observations can be used as a basis

for improvement efforts. Variations may also stem from differences in terms of population health status or case mix, not to mention random fluctuations. Most of the diagrams show a 95 per cent confidence interval with a black line by the bar of each region. The lines represent the statistical uncertainty associated with the region's actual performance.

Thus, ranking the counties in the diagrams consistently presents certain difficulties. If unreliable data quality or other interpretation problems call the ranking into question, the description of the indicator mentions or discusses it.

Some indicators have access to national guidelines or other material for evaluating outcomes. The discussion of such indicators contains an assessment of whether the outcomes as a whole meet the recommendations of the guidelines or their equivalent. With the exception of lung cancer, the national guidelines do not include formal targets. Any targets set by a medical speciality association or the like are specified for the indicator in question.

### **The national average is not a yardstick**

The diagrams usually rank the counties without explicit targets but highlight the national average. Viewing the average as a standard for an acceptable or passable outcome would be a misconception.

The national average is not a yardstick for evaluating regional outcomes. A region may have performed very well even though its outcome was far below average. The most important conclusion in such cases is that the outcomes for all counties are favourable. The converse is true as well. If the national average is low relative to individual Swedish hospitals, other countries or potential outcomes, a county may perform poorly and still end up at the top of the diagram.

If one or more large counties perform poorly, the national average may be far below the median. It may be better under such circumstances to base comparisons on the median county; outcomes must nevertheless be compared from a broader point of view than the national average or the median.

In other words, readers should not assume that the national average or the median represent a good or optimum outcome. Regardless of rank, outcomes should be analysed in relation to performance over time or in comparison with other counties as a means of identifying potential for improvement.

## **ADDITIONAL MATERIAL AND CONTACTS**

This report may be downloaded in PDF format from [www.skl.se/compare](http://www.skl.se/compare) or [www.socialstyrelsen.se/publications](http://www.socialstyrelsen.se/publications)

For information about the report and the ongoing work of the joint project *Quality and Efficiency in Swedish Health Care – Regional Comparisons*, write to

Bodil Klintberg, Swedish Association of Local Authorities and Regions  
([bodil.klintberg@skl.se](mailto:bodil.klintberg@skl.se))

Mona Heurgren, Swedish National Board of Health and Welfare  
([mona.heurgren@socialstyrelsen.se](mailto:mona.heurgren@socialstyrelsen.se)).



# General Indicators

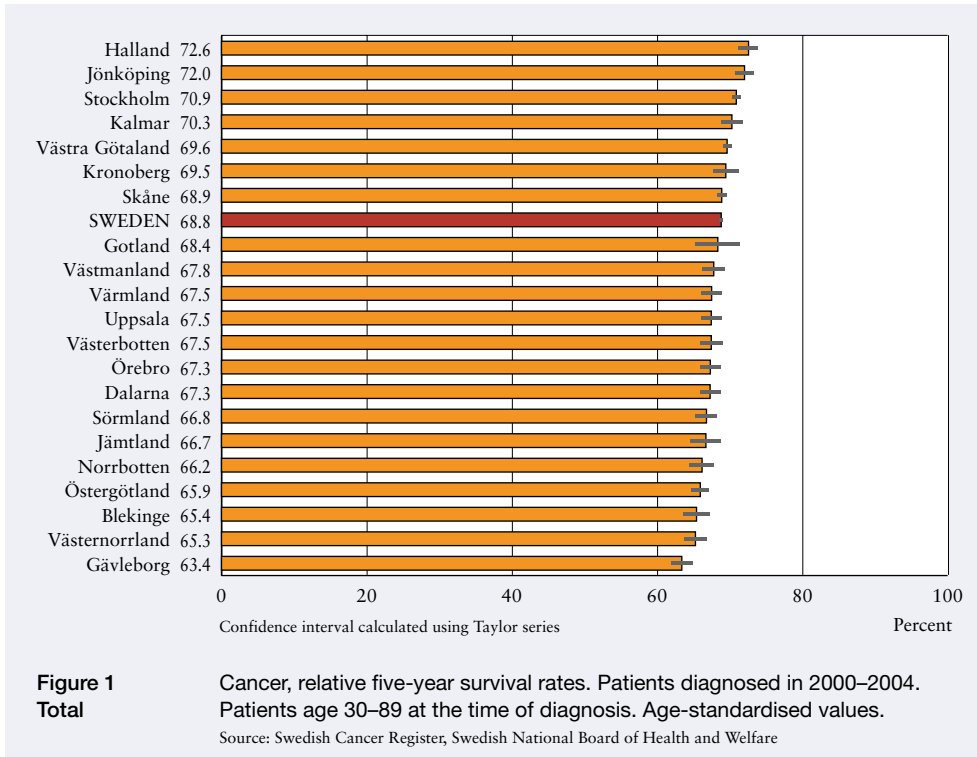
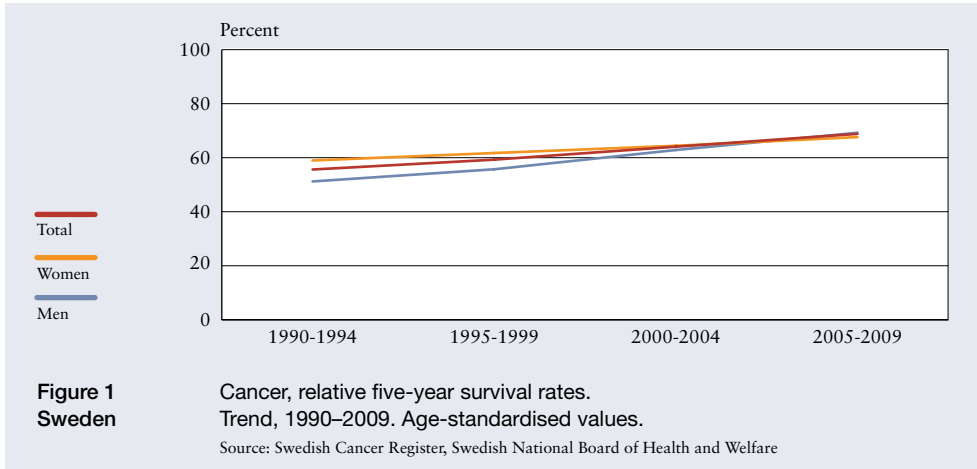
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One out of every three Swedes has cancer at some point in their life. The disease occurs with approximately equal frequency in both sexes, but women and men develop different forms. Prostate cancer is most common in men and breast cancer in women. Prostate, breast, lung, colon and rectal cancer account for half of all new cases in the adult population.

Statistics for 2009	Women	Men
Number of diagnoses	25 721	28 890
Prevalence, total	228 665	183 294
Relative five-year survival rates	67.6%	69.2%
Number of deaths	10 769	11 686

# 1 Cancer survival rates

The percentage of cancer deaths has declined over the past 40 years, while survival rates have risen. One reason for the improvement is that the healthcare system is better able to make early diagnoses and offer effective treatment.



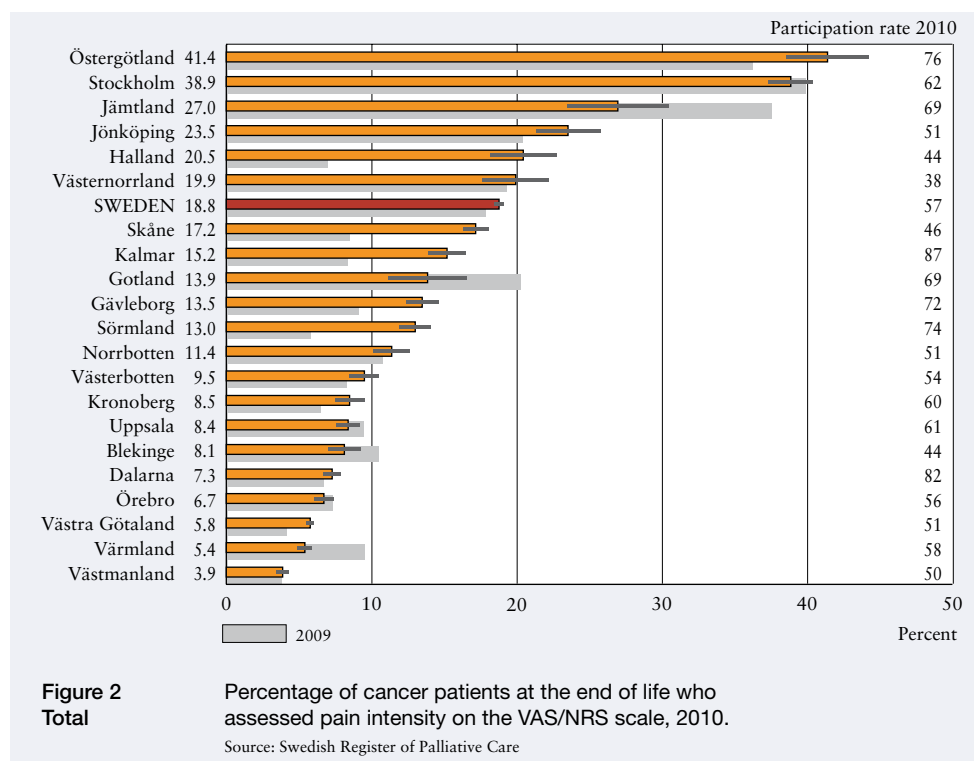
## PALLIATIVE CANCER CARE

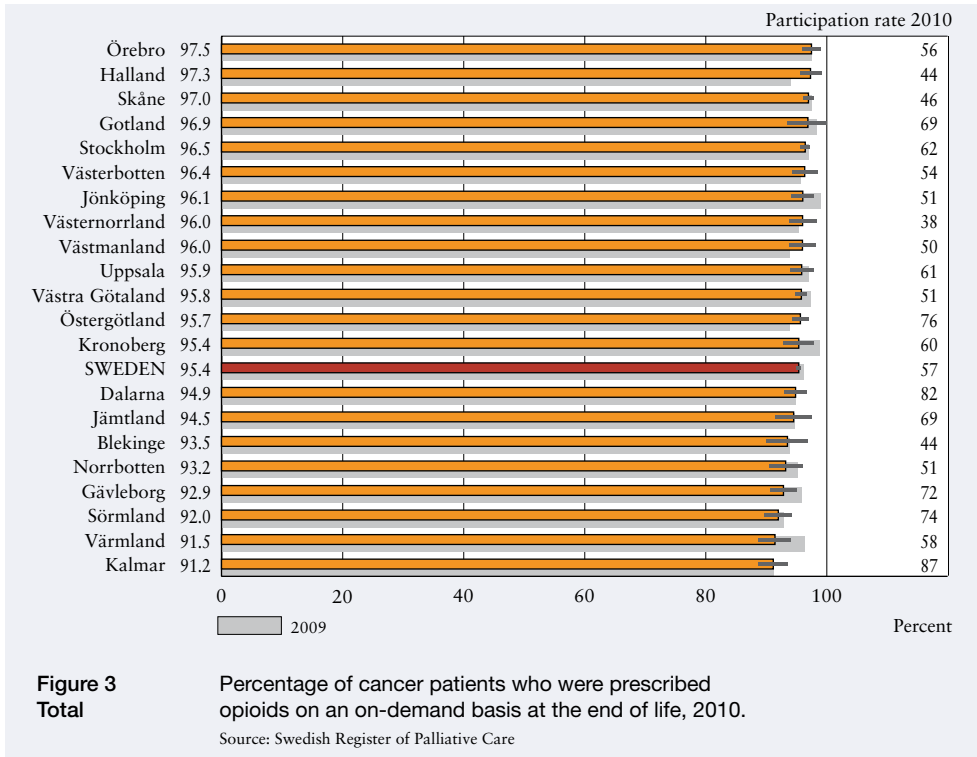
The NBHW national guidelines for breast, colorectal and prostate cancer care include palliative care. The guidelines assign top priority to estimating and assessing pain severity, prescribing opioids on demand at the end of life and certain other measures. They also contain indicators for those two particular measures. Data have been taken from the Swedish Register of Palliative Care, which started in 2005 and covered 42 per cent of all deaths after the first quarter of 2011. The participation rate was higher (over 57 per cent) for expected cancer deaths.

### 2 Percentage of patients for whom VAS/NRS was used to assess pain severity during the last week of life

Proper alleviation of pain requires structured treatment, including uniform assessment methods. Routine, structured assessments enable effective treatment. The Visual Analogue Scale (VAS) and Numeric Rating Scale (NRS) are recommended instruments for assessing pain.

The results should be interpreted with caution given that the register generally had a limited participation rate in 2010, while some counties had a low participation rate and few reported cases.





### 3 On-demand prescriptions for pain at the end of life

Most patients who die of cancer experience pain during the last week of life. Much of the pain can be alleviated by means of opioid treatment as soon as it develops. The national guidelines specify that options for administering drugs be prescribed in advance. The Swedish Register of Palliative Care contains the number of patients who received an on-demand prescription up to 24 hours before death.

## PATIENT EXPERIENCE

SALAR conducts the National Patient Survey on behalf of Sweden's county councils and regions. This report presents the results of the survey with respect to specialised medical care during appointments at oncology clinics or stays at oncology departments in 2010. The survey contains questions about the information patients received, the caregiver attitudes they encountered and their degree of participation in the care process. Patients were given the opportunity to describe their appointment or stay and to grade their experience.

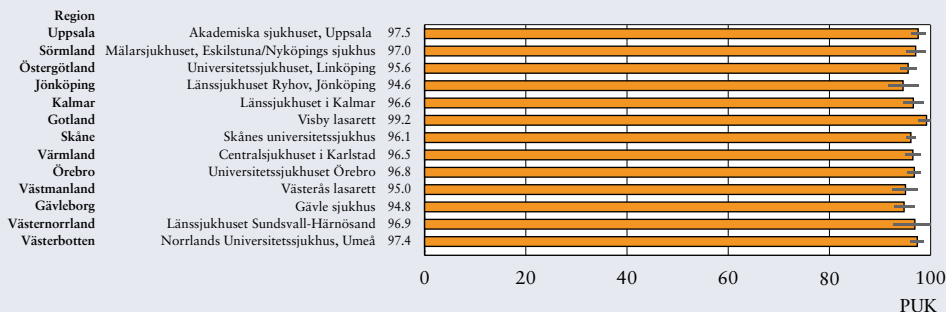
Approximately 200 000 questionnaires were sent to a random sample of people who had received outpatient or inpatient medical care during specific weeks in spring 2010. Approximately 88 000 outpatients and 34 000 inpatients responded. The national response rate was 61 per cent among outpatients and 67 per cent among inpatients.

Neither the Stockholm nor Norrbotten County Council were included but are participating in the 2011 survey.

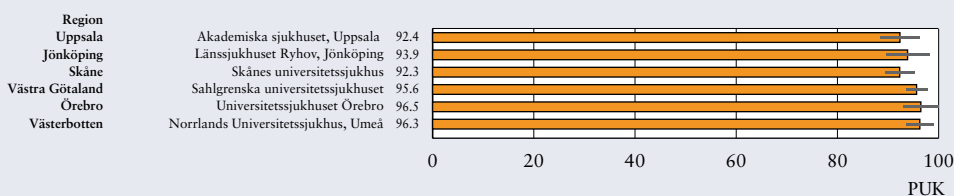
The data for this report have been taken from the National Patient Survey, but only a few hospitals are able to provide outcomes for their oncology clinics or departments. The response rate was 75 per cent for both clinics and departments. This report does not cover cancer patients who had an appointment with a non-oncological outpatient clinic or were admitted to a non-oncological department during the period. However, those who had not been diagnosed with cancer but went to an oncology clinic or department were included.

The indicators in this report that are based on the National Patient Survey reflect caregiver attitudes, patient participation and information received in both outpatient (clinic) and inpatient (department) care. Outcomes are also presented with respect to the physician in charge of inpatient care, as well as planning for continued outpatient care. The outcomes are shown at the hospital level for those that report an oncology clinic or department separately.

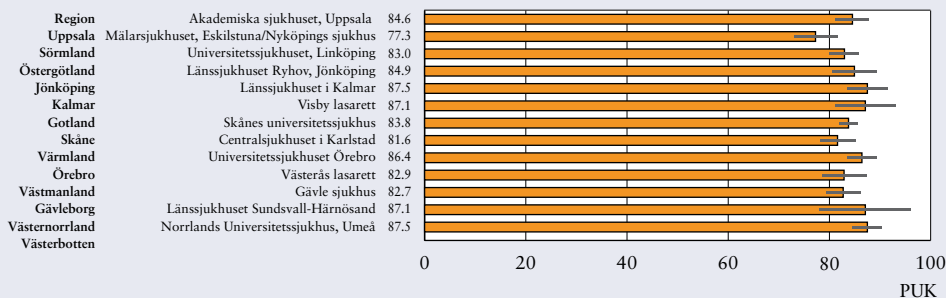
Outcomes that are based on the National Patient Survey are presented as weighted patient-reported quality. An ascending scale of 1 to 100 has been used.



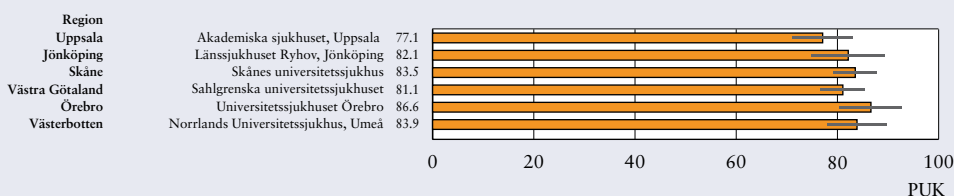
**Figure 4A** "Did you feel that you were treated respectfully and considerately?" Patient-reported quality at an oncology clinic or department, spring 2010.  
Source: National Patient Survey, Swedish Association of Local Authorities and Regions



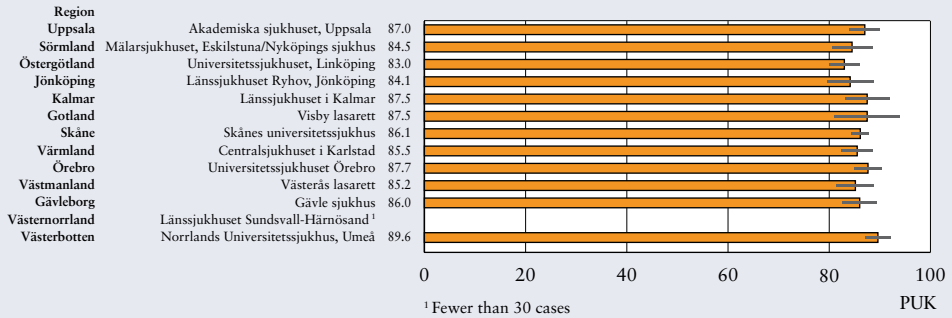
**Figure 4B** "Did you feel that you were treated respectfully and considerately?" Patient-reported quality at an oncology clinic or department, spring 2010.  
Source: National Patient Survey, Swedish Association of Local Authorities and Regions



**Figure 5A** "Did you feel as though you participated in your care and treatment as much as you wanted?" Patient-reported quality at an oncology clinic or department, spring 2010.  
Source: National Patient Survey, Swedish Association of Local Authorities and Regions



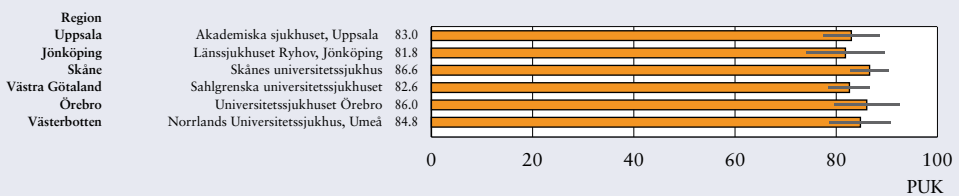
**Figure 5B** "Did you feel as though you participated in your care and treatment as much as you wanted?" Patient-reported quality at an oncology clinic or department, spring 2010.  
Source: National Patient Survey, Swedish Association of Local Authorities and Regions



**Figure 6A**  
Hospital,  
clinic

"Did you receive enough information about your condition?"  
Patient-reported quality at an oncology clinic or department, spring 2010.

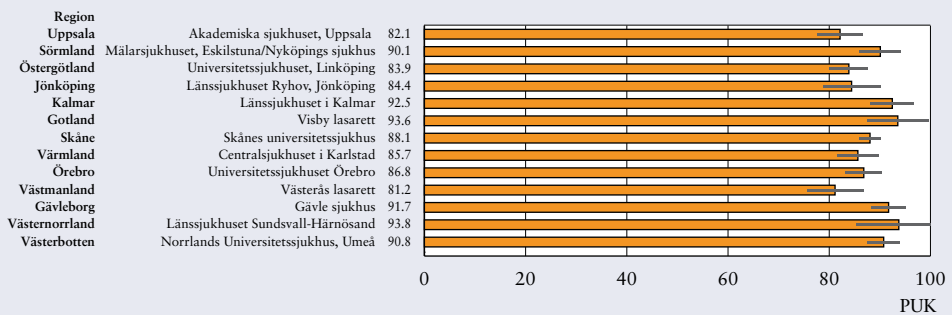
Source: National Patient Survey, Swedish Association of Local Authorities and Regions



**Figure 6B**  
Hospital,  
department

"Did you receive enough information about your condition?"  
Patient-reported quality at an oncology clinic or department, spring 2010.

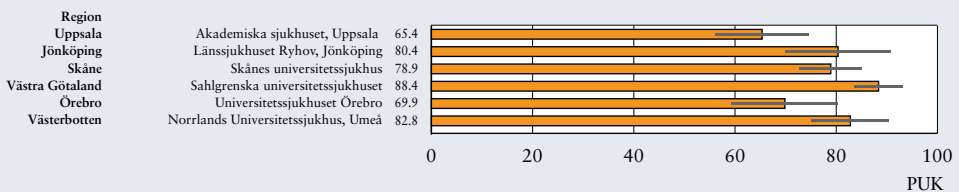
Source: National Patient Survey, Swedish Association of Local Authorities and Regions



**Figure 7**  
Hospital,  
clinic

"Were any plans made for your ongoing care during the appointment?"  
Patient-reported quality at an oncology clinic or department, spring 2010.

Source: National Patient Survey, Swedish Association of Local Authorities and Regions



**Figure 8**  
Hospital,  
department

"Do you know which doctor was responsible for your care?"  
Patient-reported quality at an oncology clinic or department, spring 2010.

Source: National Patient Survey, Swedish Association of Local Authorities and Regions

# Indicators specific to particular forms of cancer

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This chapter presents the indicators for the ten forms of cancer covered by the report. The comparisons include both general indicators – cancer survival rates, waiting times, frequency of multidisciplinary team meetings, etc. – and those that are specific to particular forms of cancer.

The section on each form of cancer starts off with a brief overview of its frequency in 2009, the last year for which data are available from the cancer register and cause of death register. The next segment presents the outcomes for the various indicators.

## BREAST CANCER

Statistics for 2009	Women
Number of diagnoses	7 380
Percentage of all cancer cases	29%
Prevalence, total	88 825
Relative five-year survival rate	87%
Number of deaths	1 378

Breast cancer is the most common form of the disease in middle-aged women. A total of 7 380 women were diagnosed with breast cancer in 2009, and Sweden currently has approximately 88 800 survivors. The average age at the time of diagnosis was 60. A total of 1 378 women died of breast cancer in 2009.

In very rare cases (30 in 2009), men develop breast cancer as well. This report covers women only.

Almost all breast cancer in Sweden is operable. The breast cancer register's follow-up for 2008 showed that 93 per cent, a figure that varied by only 1–2 per cent among the different counties, of patients had undergone surgery.

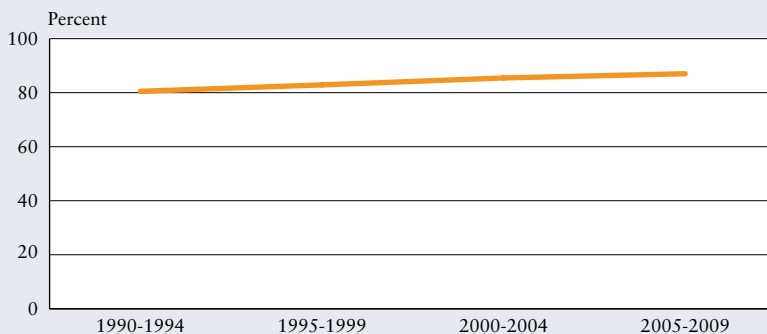
This report presents nine breast cancer indicators, four of which concern the quality of surgery. One indicator reflects survival, two reflect the frequency of multidisciplinary team meetings and two reflect waiting times. With the exception of the survival rate indicator, which used the Swedish Cancer Register, data were taken from the National Breast Cancer Register.



The Swedish Association for Breast Cancer Surgery (SFBK) has put together guidelines that contain both process and outcome measures. The SFBK proposes specific targets for indicators for which ranges have been set up.

## 9 Breast cancer – relative survival rates

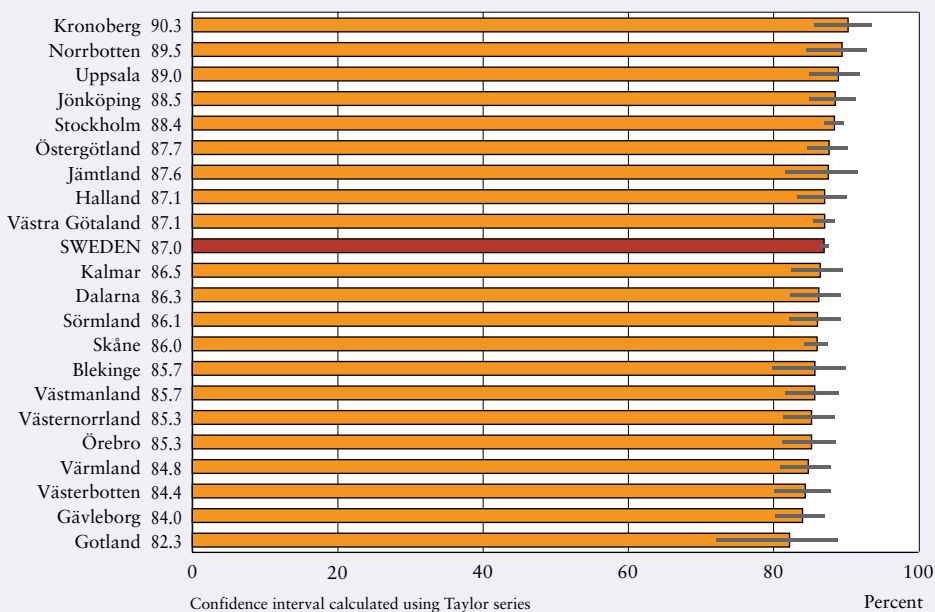
Relative survival rates for breast cancer patients have been high since the early 1990s. Figure 9 shows that the relative five-year survival rate rose from approxi-



**Figure 9**  
**Sweden**

Breast cancer – relative five-year survival rates. Trend, 1990–2009. Age-standardised values.

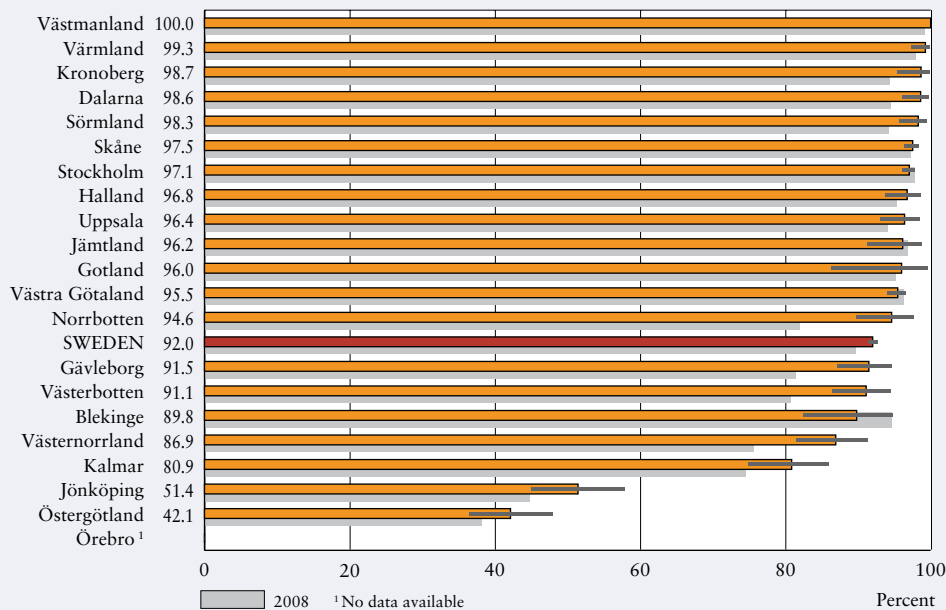
Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



**Figure 9**  
**Women**

Breast cancer – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values.

Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



**Figure 10 Women** Percentage of patients who had a multidisciplinary team meeting prior to decision to treat breast cancer, 2009.

Source: National Breast Cancer Register

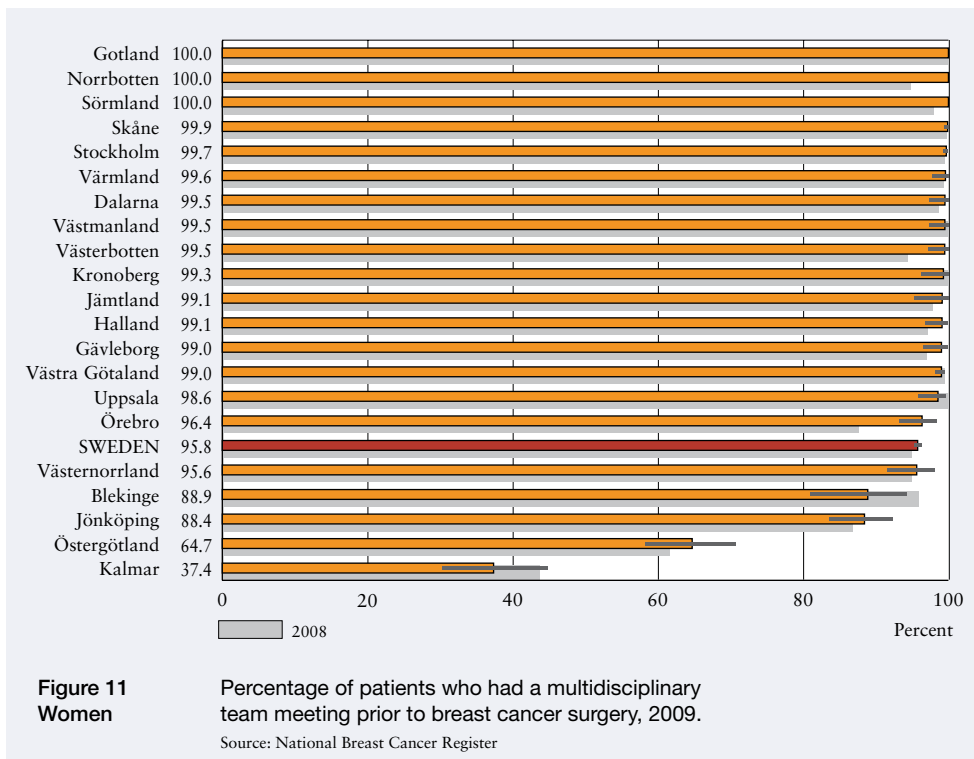
mately 80 per cent in 1990–1994 to 87 per cent in 2005–2009. The regional differences were negligible – 97.0–97.7 per cent for one-year survival and 85.9–88.3 per cent for five-year survival. As indicated by Figure 9, the gap between counties was somewhat wider.

The relative five-year survival rate was 65 per cent in the mid-1960s. The number rose to 84 per cent for patients diagnosed in the 1990s and to 87 per cent in 2005–2009.

The most interesting observation about this indicator is that outcomes have been both uniform and impressive throughout the country.

### 10–11 Multidisciplinary team meetings

Primary breast cancer treatment may be preceded by a multidisciplinary team meeting, a comprehensive assessment for the purpose of optimising the intervention. Surgery, oncology, radiology and pathology specialists, as well as nurses, may participate. The NBHW national guidelines for breast cancer care recommend a multidisciplinary team meeting both before commencement of treatment and postoperatively.



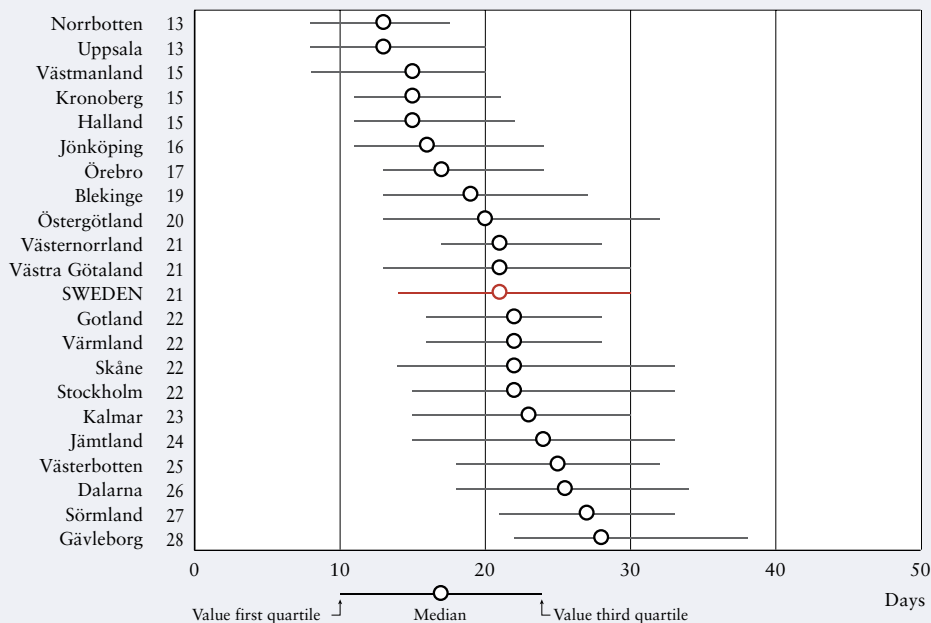
The comparison finds excellent outcomes for the great majority of counties. Both pre- and postoperative multidisciplinary team meetings are much more frequent for breast cancer than for most other forms of the disease.

### 12 Waiting time from initial appointment with a specialist until surgery

The SFBK, which advocates for a rapid care process, argues that more than 90 per cent of all patients with verified breast cancer should be offered surgery within three weeks and 100 per cent within four weeks. The indicator reflects the waiting time from the initial appointment with a specialist (surgeon) until surgery. Waiting time is affected by the local structure of the breast cancer care chain. In some counties, an assessment has begun or has already been completed before the patient is referred to a specialist clinic for treatment.

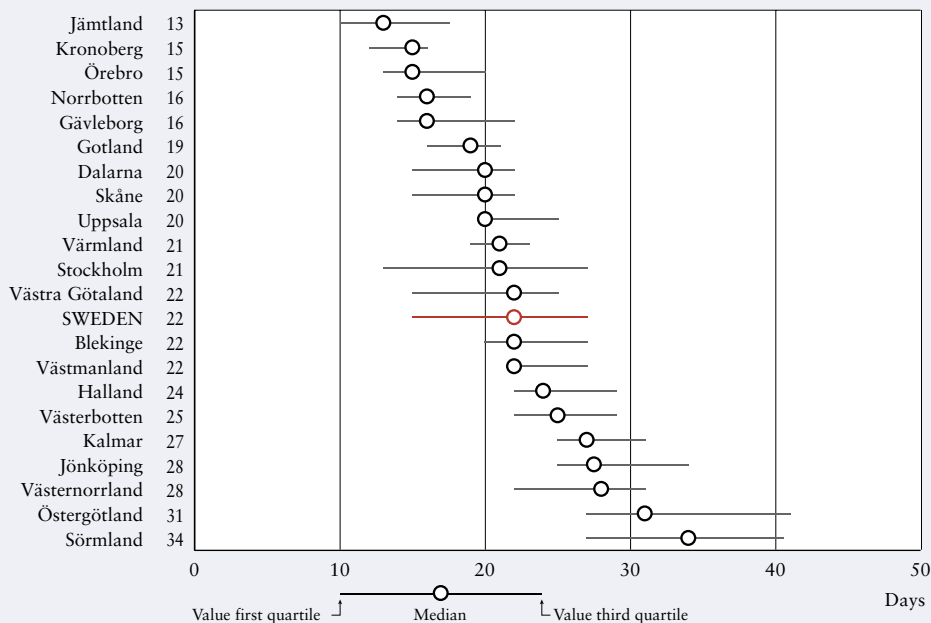
### 13 Waiting time from surgery to test results

A postoperative pathological anatomical diagnosis of the tumour, along with the surrounding tissue, is performed. The indicator shows the waiting time from surgery until the patient is notified of the test results. The SFBK targets waiting time of no more than one week. Waiting time is affected by the availability of pathologists, as well as procedures for handling tests and results.



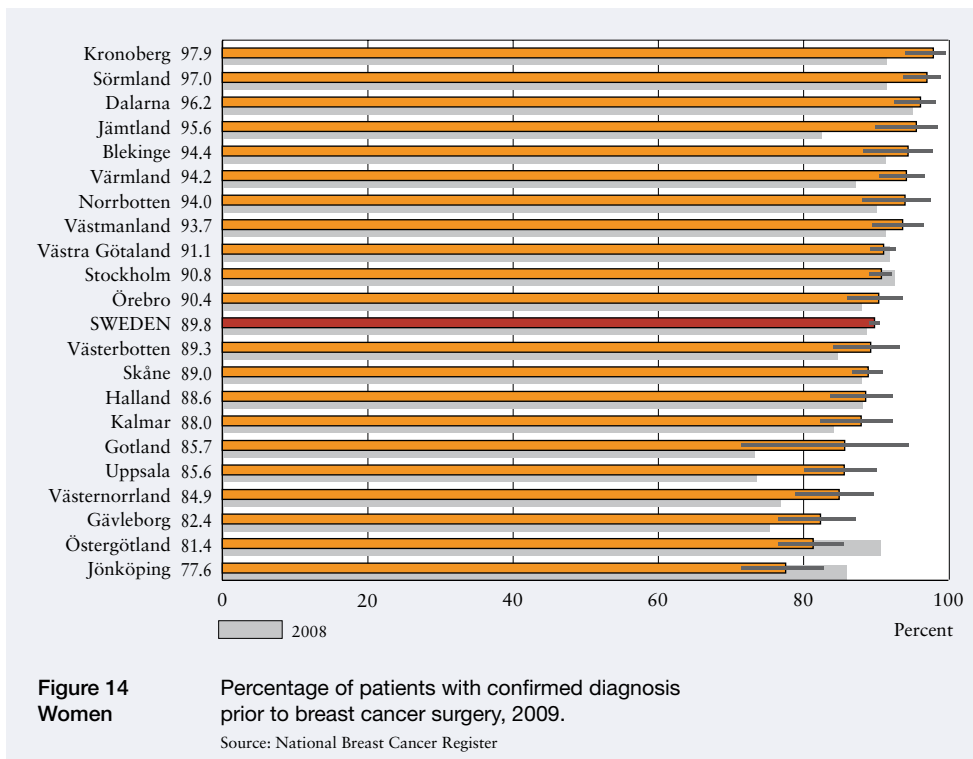
**Figure 12** Waiting time from initial appointment with a specialist until breast cancer surgery, 2009. Women

Source: National Breast Cancer Register



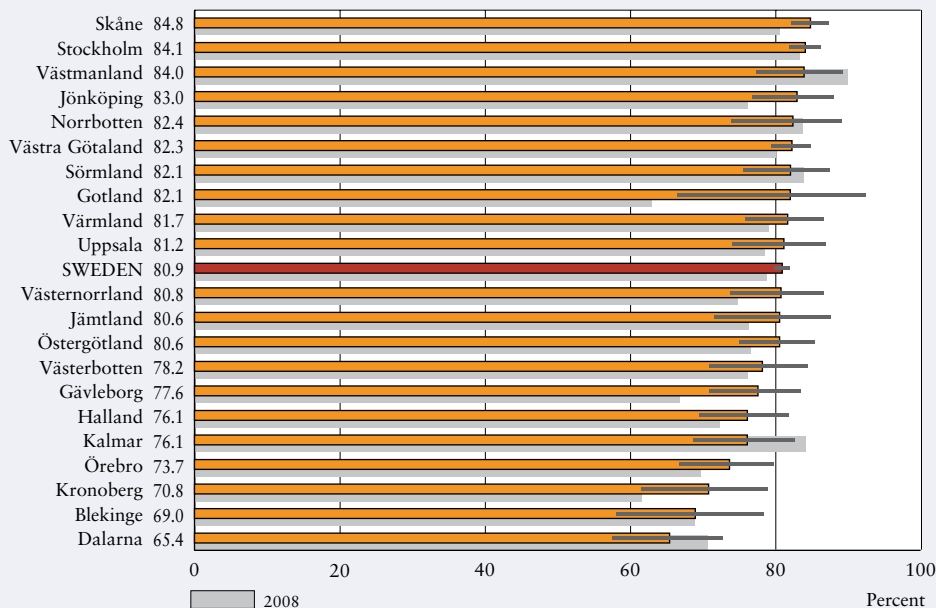
**Figure 13** Waiting time from breast cancer surgery until patient received results of PAD, 2009. Women

Source: National Breast Cancer Register



## 14 Definitive preoperative diagnosis

To minimise the risk of reoperation, assessments of changes in breast tissue when malignancy is suspected should strive to provide patients with as accurate a preoperative diagnosis as possible. The NBHW national guidelines for breast cancer care highlight definitive preoperative diagnosis of malignancy as an important indicator to monitor. According to the association, at least 90 per cent of patients should receive a definitive preoperative diagnosis.

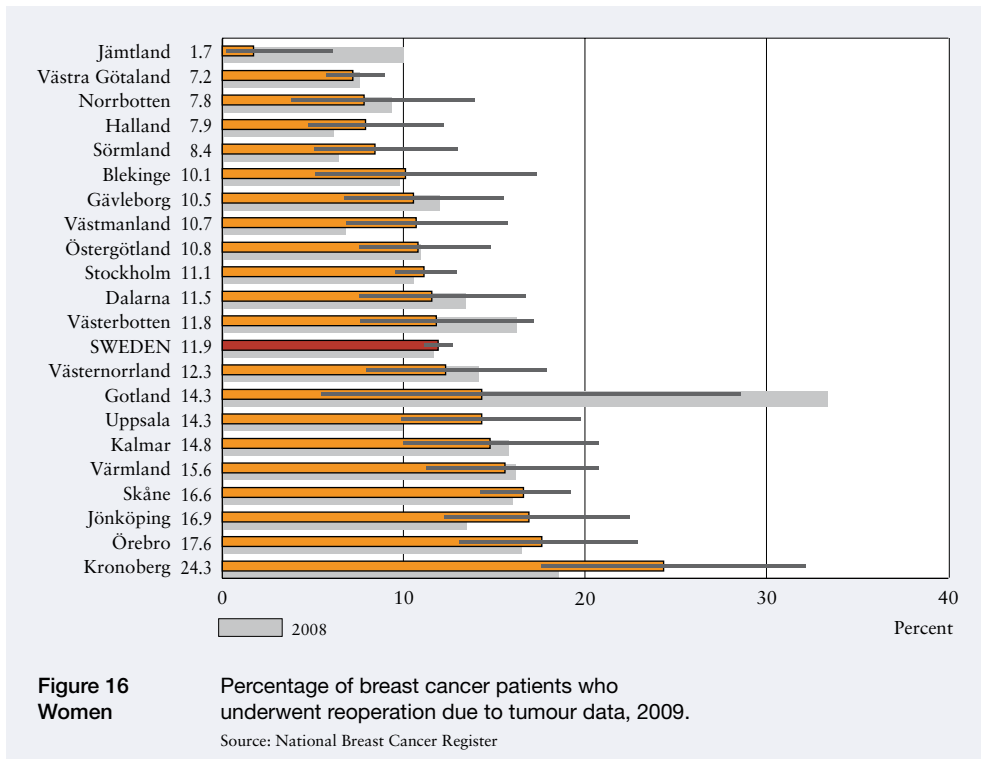


**Figure 15** Percentage of invasive breast cancer patients who underwent surgery with the sentinel node technique, 2009. Refers to tumours 4 cm or smaller. **Women**  
 Source: National Breast Cancer Register

## 15 Sentinel node surgery

Sentinel node surgery involves removal of the potentially malignant first lymph node. A tracer that is injected in the breast locates the sentinel node and shows up during surgery. The node is analysed microscopically for signs of metastasis. The procedure reduces the number of patients who undergo complete removal of lymph nodes from the armpit area, thereby reducing the risk of annoying postoperative swelling there.

According to the NBHW national guidelines, the sentinel node technique may be indicated for tumours that are up to four centimetres in diameter. It should be used in patients with invasive breast cancer, i.e., when the tumour has formed cell lines in the surrounding normal tissue. The technique has been used in Sweden since 1997 and is currently available at one or more hospitals in most counties. When it is not offered, primarily at small hospitals, the patient can go to another hospital nearby.



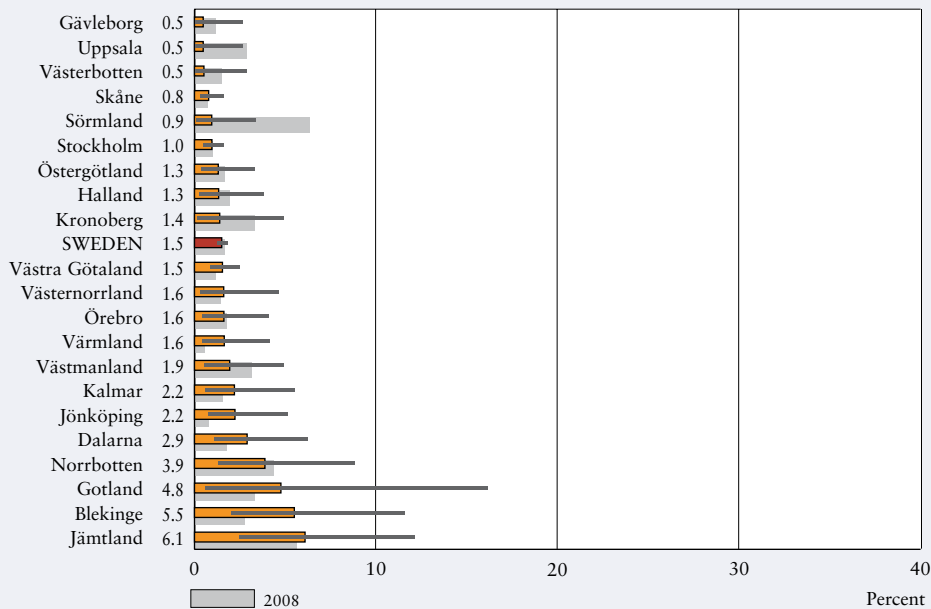
## 16 Reoperation after PAD

A postoperative pathological anatomical diagnosis (PAD) of the tumour, along with surrounding tissue (such as lymph nodes), is performed. If the analysis shows remaining tumour cells or cancer within a larger area than previously known, reoperation is recommended to minimise the risk of recurrence. The second operation may involve additional physical suffering.

The NBHW national guidelines for breast cancer care identify the percentage of reoperations after PAD as an important indicator to monitor. The indicator measures both the quality of the preoperative malignancy assessment and how successful the surgeon is in removing the tumour.

The data are based on relatively few cases, generating a broad confidence interval. Errors may also occur because not all hospitals report reoperations to the breast cancer register. Outcomes should also be related to the degree to which breast-preserving surgery, which increases the risk of reoperation, has been performed – and whether the purpose of primary surgery was to confirm a cancer diagnosis.

In the view of the Swedish Association for Breast Cancer Surgery, treatment should be as definitive as possible in order to avoid reoperation and PAD should lead to reoperation in fewer than 10 per cent of all cases. The comparison demonstrates that only five counties remained below the recommended level.



**Figure 17** Percentage of breast cancer patients who underwent reoperation within 30 days due to complications, 2009.  
**Women** Source: National Breast Cancer Register

## 17 Reoperation within four weeks due to complications

More than 90 per cent of breast cancer patients undergo surgery. The scope of surgery varies according to the location and microscopic presentation of the tumour, as well the patient's general state of health. Complications may require relatively prompt reoperation. Among such complications are bleeding, which usually occurs within 24 hours, or infection, whose symptoms appear within a week. The second operation may involve additional physical suffering. Follow-up by the breast cancer register indicates that most reoperations are due to bleeding within the first 24 hours. Given that breast cancer operations are regarded as clean surgery, infection should be rare; in fact, very few reoperations are performed as the result of surgical site infection. However, infections that do not lead to reoperations are not entered in the register.

The NBHW national guidelines for breast cancer care identify the percentage of reoperations within 30 days due to complications as an important indicator to monitor.

The data are based on relatively few cases, generating a broad confidence interval. Moreover, some hospitals may fail to report reoperations to the breast cancer register. It goes without saying that the percentage of reoperations due to unforeseen events should be as low as possible. A national average of one or two percentage points is a good target.



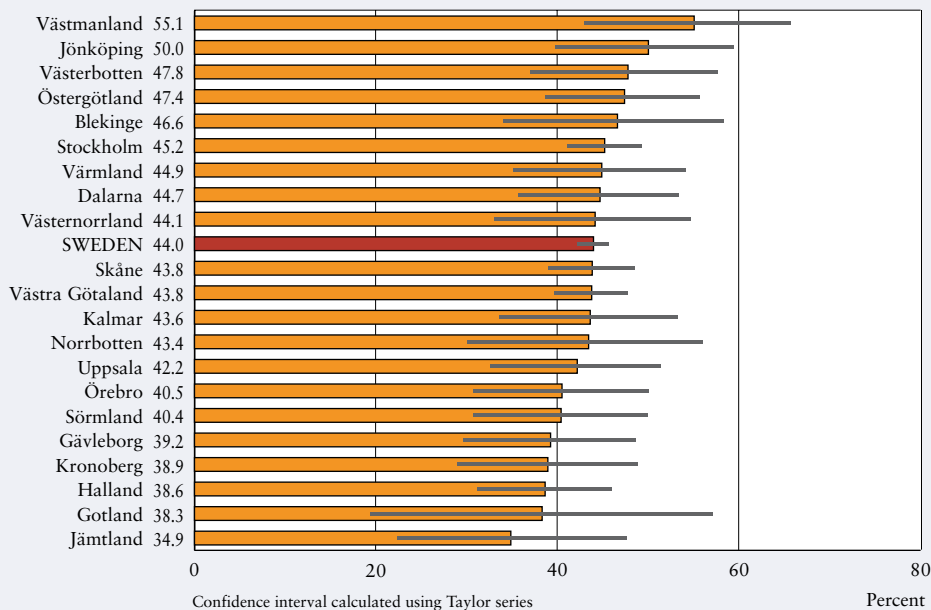
## OVARIAN CANCER

Statistics for 2009	Women
Number of diagnoses	780
Percentage of all cancer cases	3%
Prevalence, total	8 752
Relative five-year survival rate	44.0%
Number of deaths	675

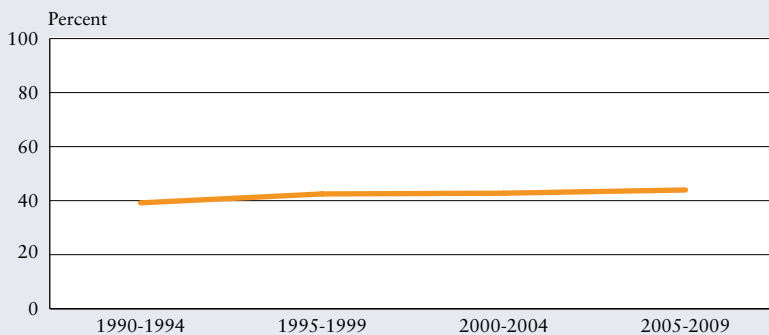
Approximately 800 women develop ovarian cancer every year. The prognosis is fairly poor and the relative five-year survival rate is 44 per cent. A total of 675 Swedes died of ovarian cancer in 2009. Due partially to the protective effect of oral contraceptives, the incidence has declined since 1975.

Many forms of cancer are broken down into four stages according to how far the tumour has spread. In this case, malignancy is limited to the ovaries during the first stage and has metastasised outside the abdominal cavity by the fourth stage. The disease has an insidious course and is often diagnosed late because it does not cause any symptoms early on. Approximately 60 per cent of cases are in the third or fourth stage when diagnosed.

This report presents four indicators: one for survival rate, one for the care process, and two for waiting time. Five-year survival rates by county are based on data from the Swedish Cancer Register. The other indicators are taken from the National Quality Register for Gynecological Onkology and presented at the regional level. The register started in 2008. This report generally presents indicators at the county level, but representatives of the quality register believe that this data cannot yet be accounted for other than at the regional level.



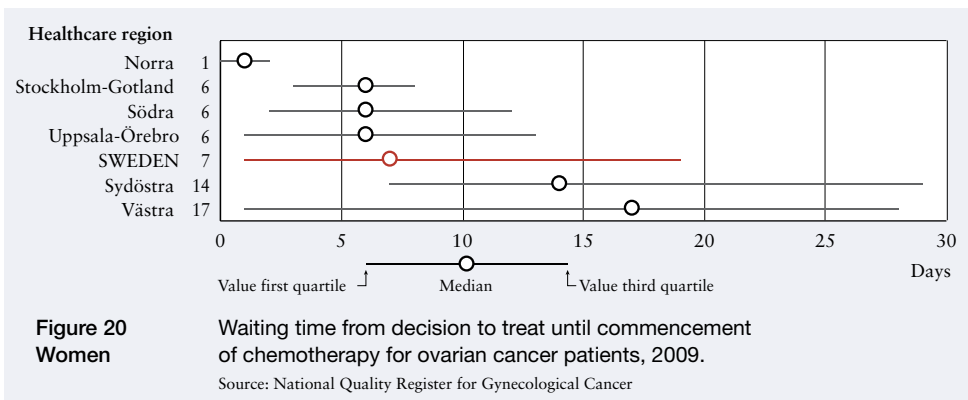
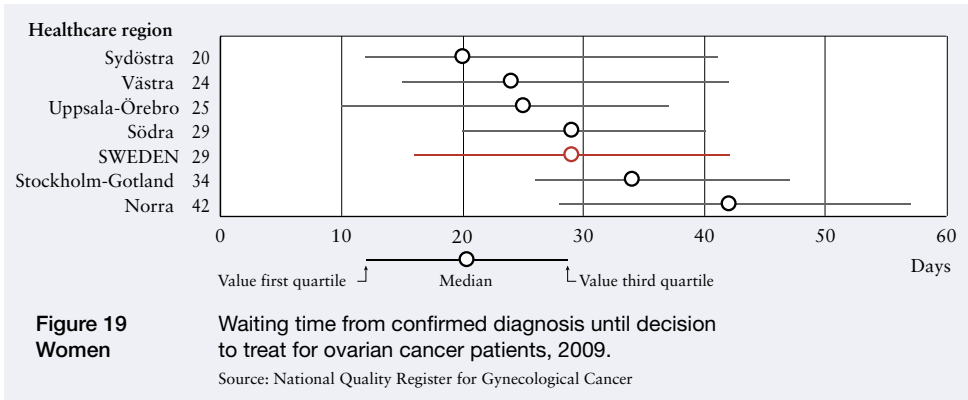
**Figure 18 Women** Ovarian cancer – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values. Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



**Figure 18 Sweden** Ovarian cancer – relative five-year survival rates. Trend, 1990–2009. Age-standardised values. Source: Swedish Cancer Register, Swedish National Board of Health and Welfare

## 18 Survival rate for ovarian cancer

Survival rates, particularly for one or two years, among ovarian cancer patients have risen since 1990. The five-year survival rate also increased somewhat to 44 per cent in 2005–2009 (see Figure 18). Some regional differences exist, but the confidence intervals are broad and the role of chance cannot be ruled out.



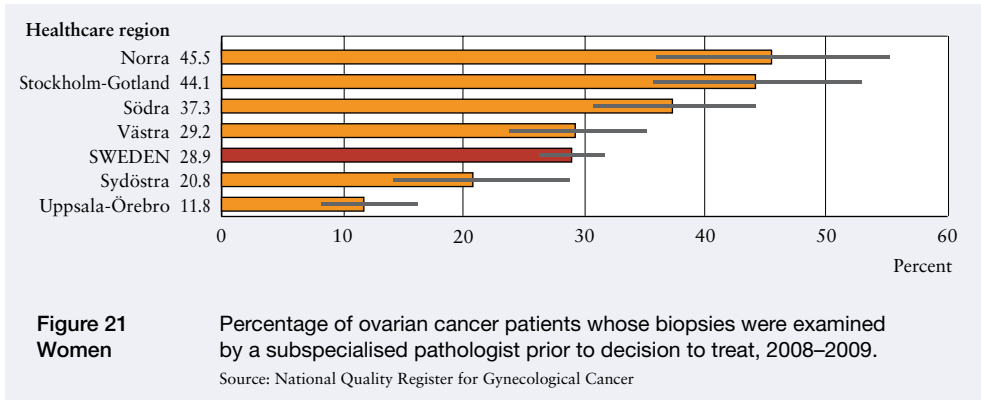
## 19 Waiting time from diagnosis until decision to treat

Ovarian cancer is often detected late when it has already reached a serious stage. Thus, minimising the waiting time from diagnosis until decision to treat is particularly important.

## 20 Waiting time from decision to treat until commencement of chemotherapy

Approximately 80 per cent of all ovarian cancer cases should be treated with chemotherapy – as soon as possible, considering the course of the disease. According to the national healthcare guarantee, treatment is to commence within 90 days after the decision.

Based on data for 452 patients, Figure 20 shows the number of days that 25, 50 and 75 per cent of patients waited between the decision to treat and commencement of chemotherapy. Fifty per cent of patients nationwide began chemotherapy within a week and 75 per cent within 19 days. Seventy-five per cent of patients in the northern region started within two days.



The National Quality Register for Gynecological Onkology contains waiting time data for 60 per cent of patients who were entered based on a decision to treat in accordance with Indicator 19 above. The relatively large percentage of unreported cases affects the outcomes for this indicator.

## 21 Percentage of biopsies assessed by a subspecialised pathologist

Diagnosis and decision to treat ovarian cancer cases are based on the pathologist's assessment of the biopsy. The National Quality Register for Gynecological Onkology has performed follow-ups indicating that a fairly large number of diagnoses would be re-evaluated if the biopsy were also assessed by a subspecialised gynaecological pathologist. The assessment influences the prognosis and can be crucial to ongoing treatment.

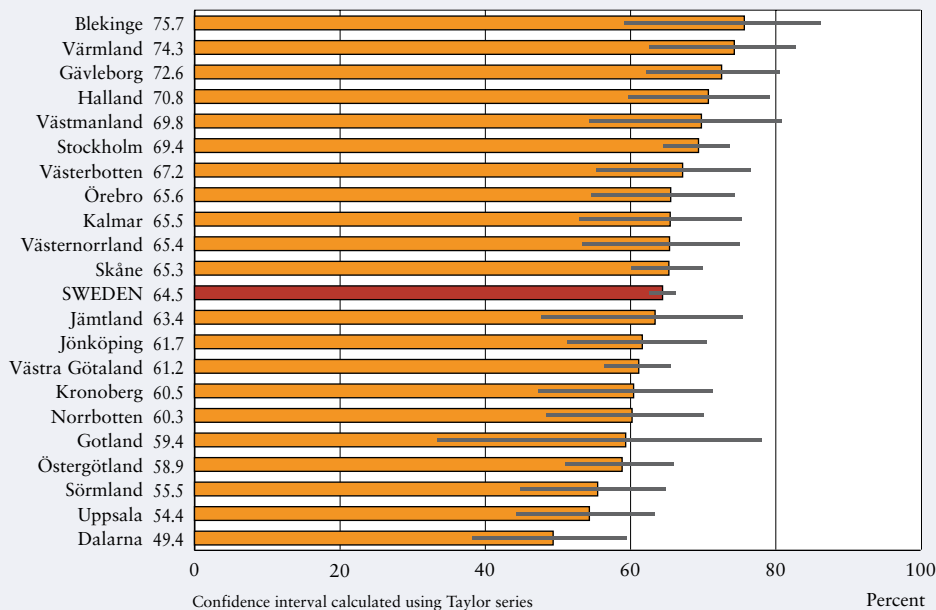
## KIDNEY CANCER

Statistics for 2009	Women	Men
Number of diagnoses	342	517
Percentage of all cancer cases	1%	2%
Prevalence, total	3 555	4 529
Relative five-year survival rate	66.1%	63.7%
Number of deaths	198	344

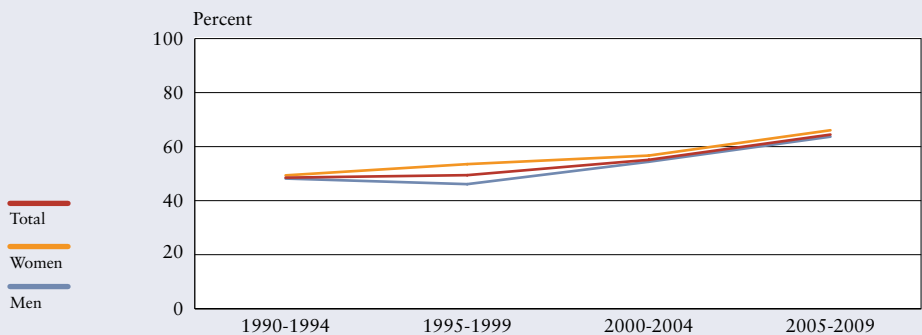
Approximately 2 per cent of all cancer cases among Swedish adults are of the kidney. Men account for approximately 60 per cent of the diagnoses. Incidence has declined over the past two decades, and no major differences between healthcare counties have been reported. Almost 900 people, most of them over 65, are diagnosed with kidney cancer every year. The causes have not been fully determined, but smoking and renal failure are two known risk factors.

The prognosis has improved over the past decade. The five-year survival rate is 90-95 per cent for patients with small tumours that do not yet extend through the renal capsule. The overall five-year survival rate for both sexes is better than 60 per cent.

The report presents outcomes for four indicators, three of which are based on data from the National Swedish Kidney Cancer Register. One indicator concerns survival rates in accordance with data from the Swedish Cancer Register, and two reflect waiting times at various links in the care chain. The fourth indicator presents the percentage of patients who have been assessed on the basis of thoracic CT scans as recommended by the clinical practice guidelines.



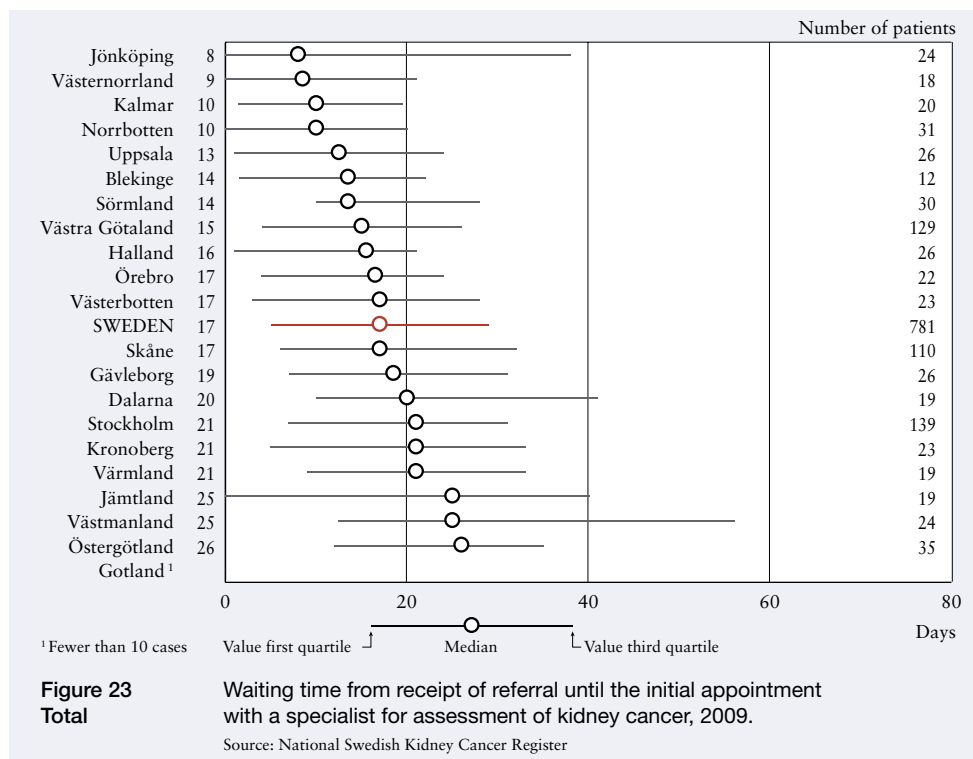
**Figure 22** Kidney cancer – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values. Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



**Figure 22** Kidney cancer – relative five-year survival rates. Trend, 1990–2009. Age-standardised values. Source: Swedish Cancer Register, Swedish National Board of Health and Welfare

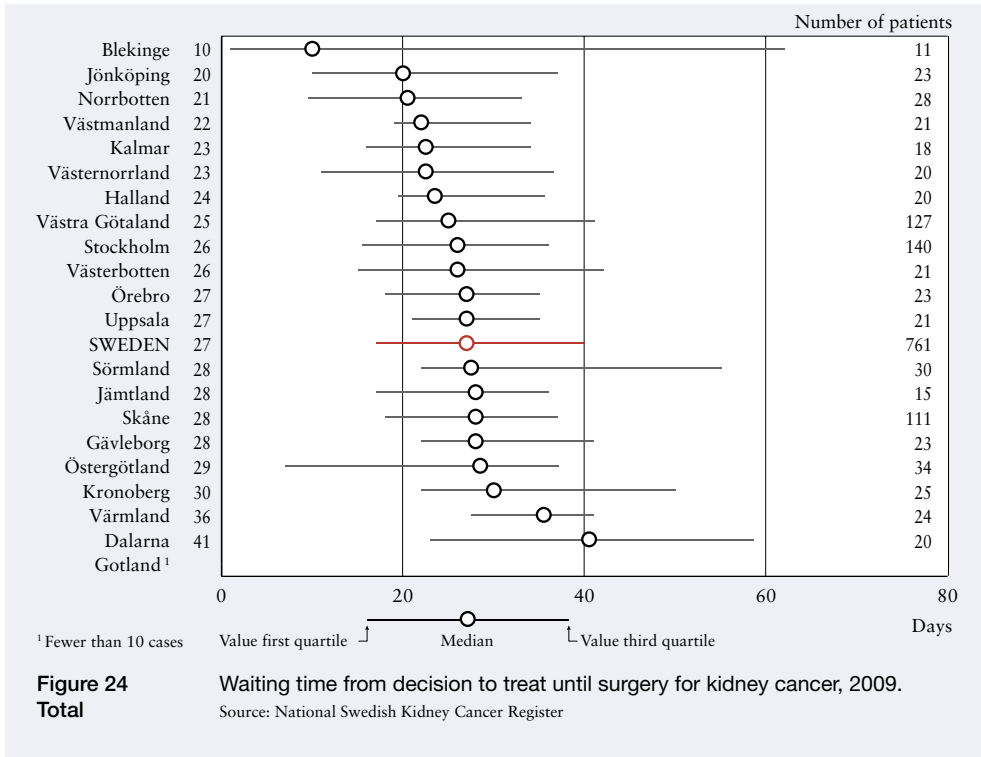
## 22 Kidney cancer – survival rates

After having held steady in the 1990s, the relative five-year survival rate increased for both women and men in the early 2000s. Figure 22 shows that the rate was higher than 66 per cent for women and almost 64 per cent for men in 2005–2009. The various counties range from 49.4 to 75.7 per cent.



## 23 Waiting time from referral to the initial appointment with a specialist

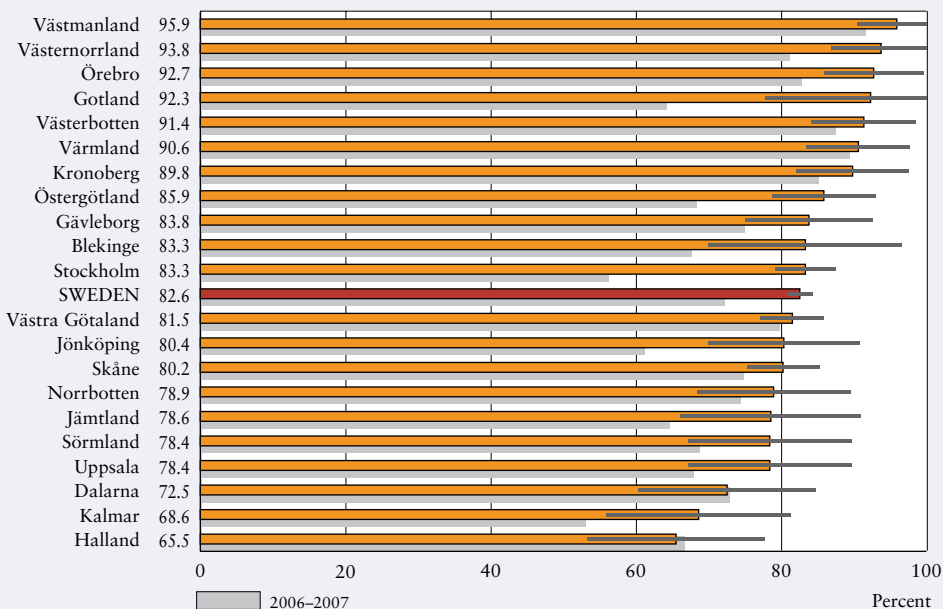
The goal is to minimise the waiting time from a referral due to suspicion of cancer until an appointment with a specialist. The waiting time has been reported to the register since 2009.



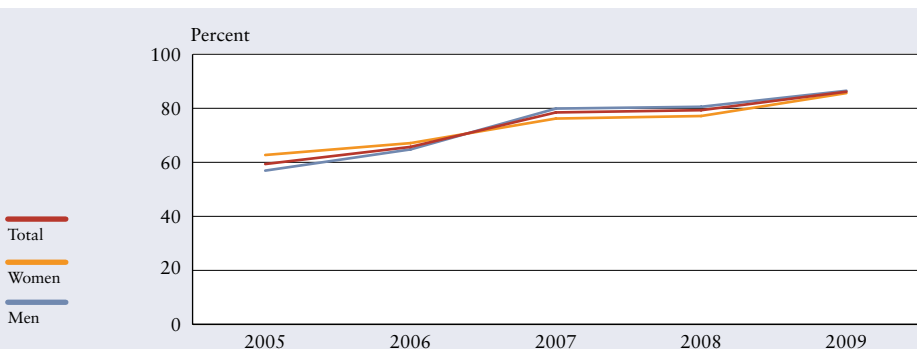
## 24 Waiting time from decision to treat until surgery

The waiting time from decision to treat until surgery should be as short as possible. The indicator reflects the healthcare system’s resources and organisational capacity. The waiting time has been reported to the register since 2009.





**Figure 25** Percentage of patients who underwent thoracic CT scan prior to kidney cancer surgery, 2008-2009. **Total**  
 Source: National Swedish Kidney Cancer Register



**Figure 25** Percentage of patients who underwent thoracic CT scan prior to kidney cancer surgery. Trend, 2005-2009. **Sweden**  
 Source: National Swedish Kidney Cancer Register

## 25 Primary assessment based on preoperative thoracic CT scan

Distant metastases from kidney cancer are often located in the lungs. A decisive preoperative assessment, best performed on the basis of a thoracic CT scan, is whether the malignancy has metastasised to the lungs. According to the clinical practice guidelines, 85 per cent of all cases should be assessed on the basis of thoracic CT scans.

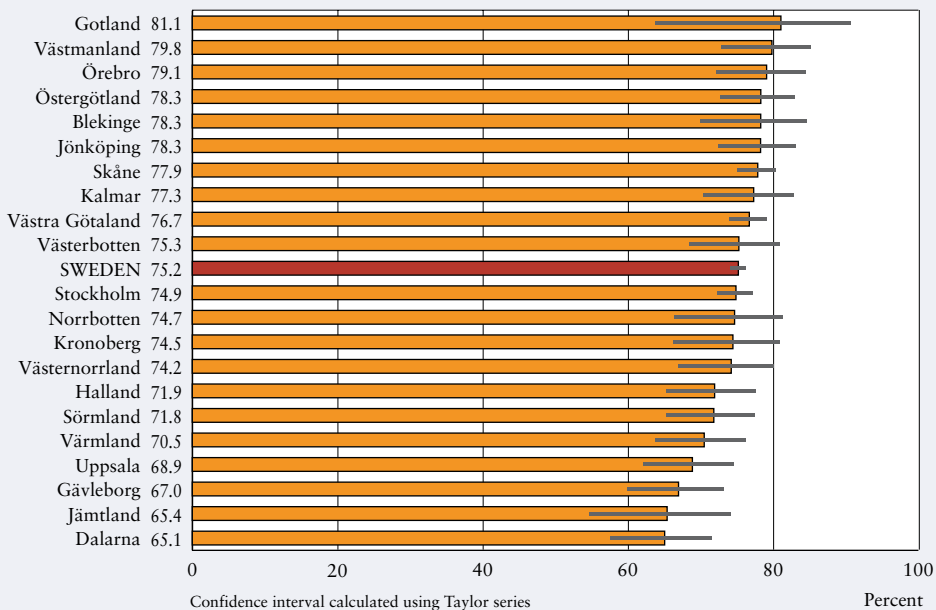
## BLADDER CANCER

Statistics for 2009	Women	Men
Number of diagnoses	587	1 667
Percentage of all cancer cases	2%	6%
Prevalence, total	5 397	15 119
Relative five-year survival rate	73.0%	76.0%
Number of deaths	214	473

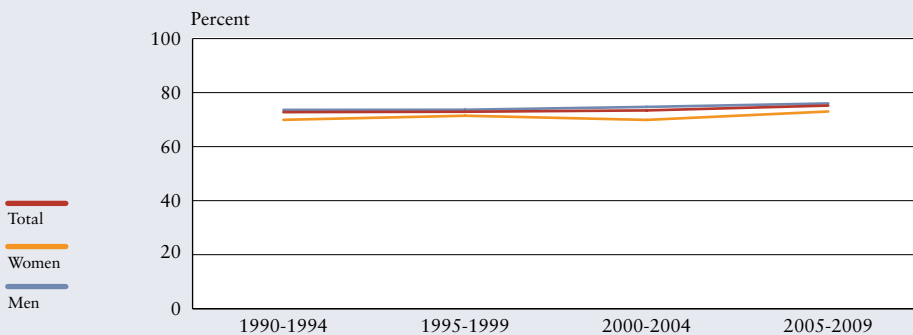
More than 2 000 Swedes, three-quarters of whom are men, develop bladder cancer every year. Many patients see their doctor for presumed urinary tract infection due to blood in the urine. The number of cases started to rise significantly in the 1960s but appears to have levelled off in the 2000s. The average age at diagnosis is approximately 70; smoking is the most important known risk factor.

Bladder cancers are broken down into three different groups: Tis, Ta and T1–T4; Tis, Ta and T1 are non-muscle invasive. Approximately three-quarters of all cases are non-muscle invasive although there is some variation among the healthcare counties.

The report presents outcomes for five indicators. The first indicator concerns survival rates. Two indicators reflect waiting times. The last two indicators show the percentage of patients who received one or more of the treatments in question depending on the stage of the tumour. With the exception of the survival indicator, which is based on the the Swedish Cancer Register, the data were taken from the Swedish Bladder Cancer Register.



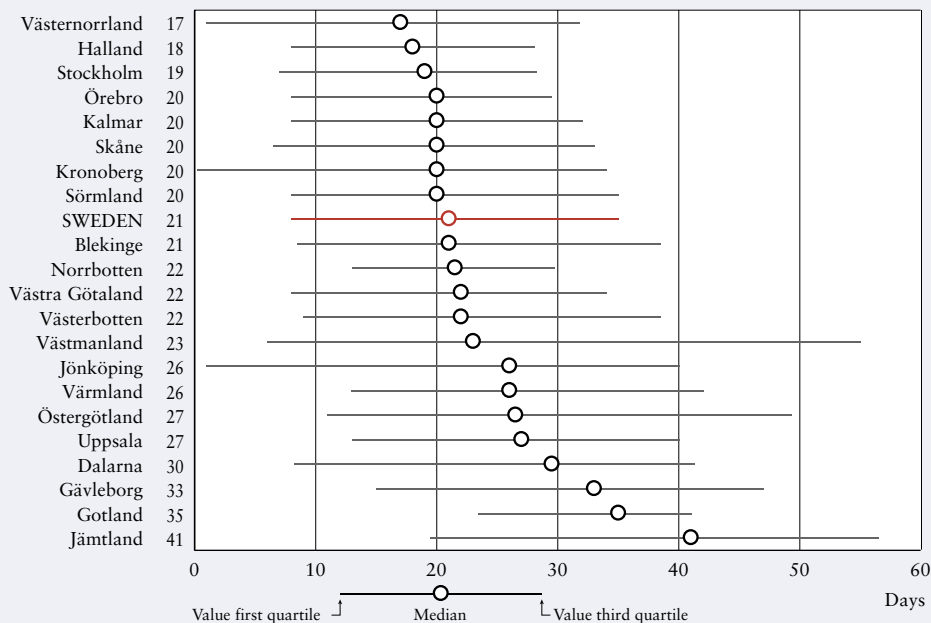
**Figure 26 Total** Bladder cancer – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values. Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



**Figure 26 Sweden** Bladder cancer – relative five-year survival rates. Trend, 1990–2009. Age-standardised values. Source: Swedish Cancer Register, Swedish National Board of Health and Welfare

## 26 Bladder cancer – survival rates

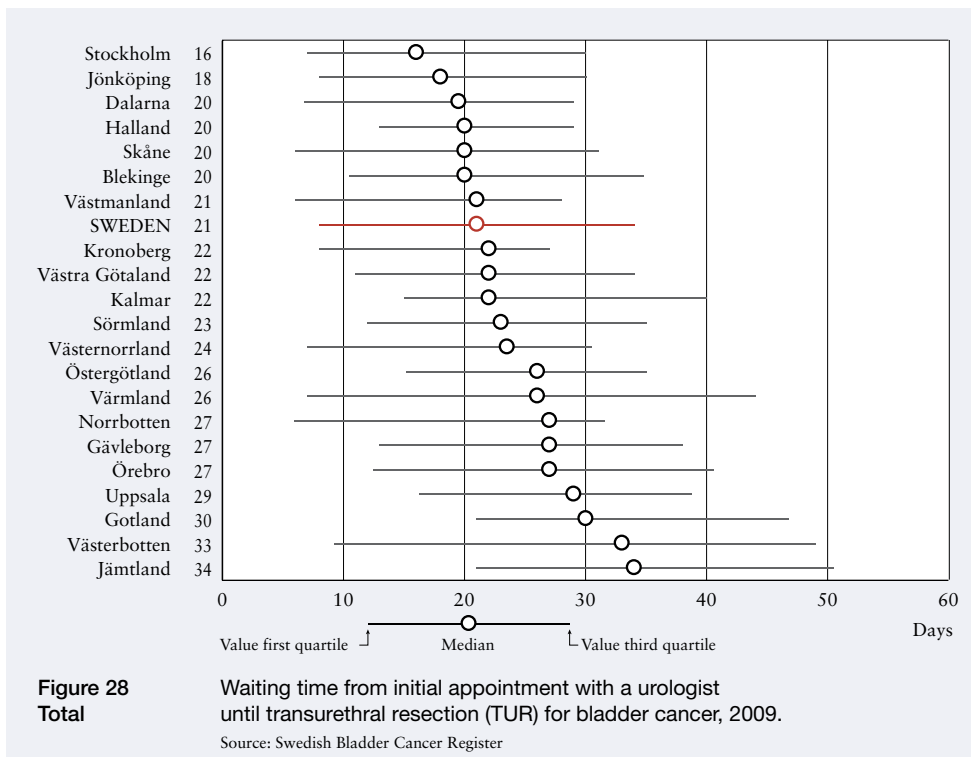
Figure 26 shows the relative five-year survival rate for bladder cancer patients. The national average for 2005–2009 was 75.2 per cent, with a regional variation of 65.1–81.1 per cent. The higher the age at the time of diagnosis, the lower the survival rate.



**Figure 27** Waiting time from receipt of the referral until the initial appointment with a urologist for bladder cancer, 2009.  
**Total** Source: Swedish Bladder Cancer Register

## 27 Waiting time from receipt of the referral to the initial appointment with a urologist

When bladder cancer is suspected, the urologist usually performs a cystoscopy of the urethra and bladder at the first appointment. In most cases, the examination suffices for detecting a tumour and making a decision to treat. The indicator concerns waiting time from receipt of a referral until the first appointment with a urologist.

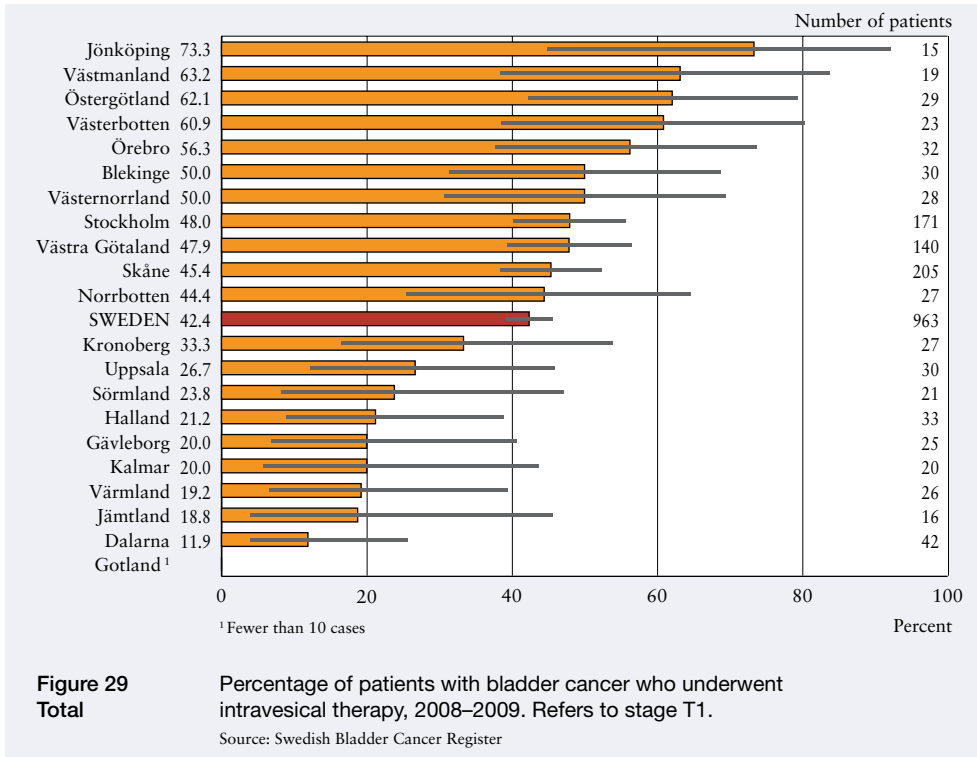


## 28 Waiting time from initial appointment with a urologist until transurethral resection

Based on the cystoscopy, the urologist determines whether a transurethral resection – which often serves as both a diagnostic tool and surgical procedure – is called for. The indicator presents waiting times from the initial appointment with a urologist until a transurethral resection is performed.

Thus the two waiting times in tandem reflect how long it takes from the point at which the patient is given a referral until actual treatment. However, it says nothing about the total waiting time that starts when the patient first schedules an appointment for primary care.

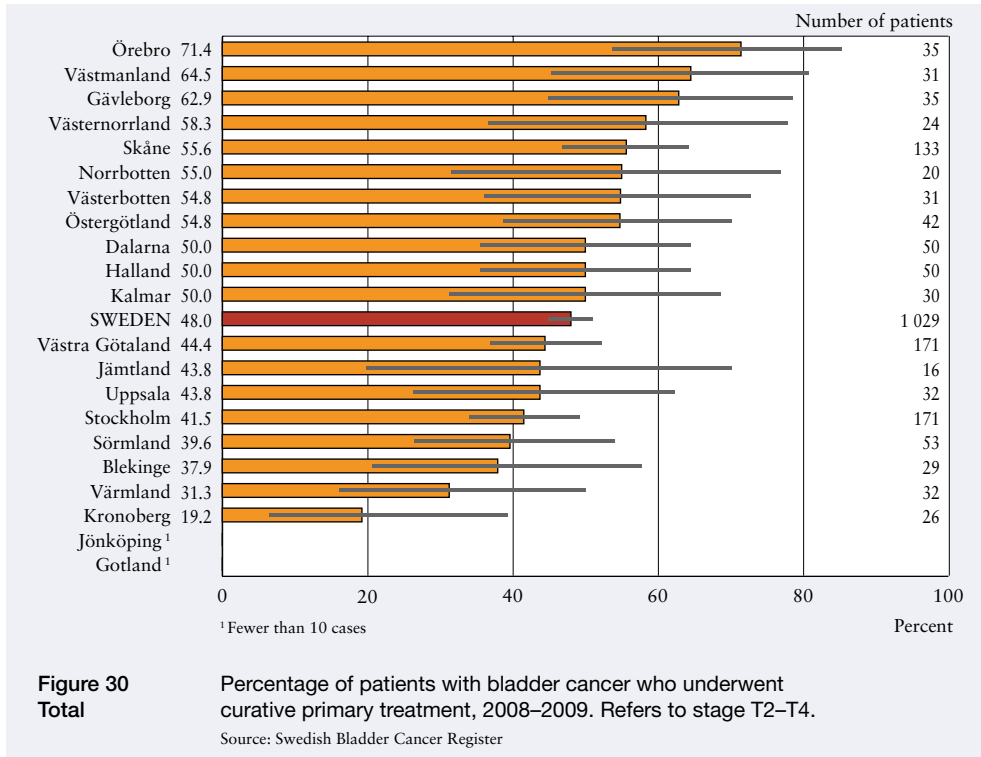
Much of the data used by the indicator have been reported to the Swedish Bladder Cancer Register. This indicator is not based on exactly the same data as the previous indicator and is more representative.



## 29 Intravesical therapy for T1 tumours of the bladder

Nearly all tumours of the bladder are treated with a transurethral resection. Though non-invasive, T1 tumours belong to a high-risk category. According to the guidelines of the European Association of Urology, most patients with a T1 tumour should also be offered intravesical chemotherapy or immunotherapy to prevent recurrence and progression. Possible exceptions are patients with comorbidity and very advanced age.

The data for the indicator in Figure 29 cover two years in order to ensure more reliable outcomes at the regional level. Some counties have so few cases that the outcomes are uncertain nonetheless. However, the figures point to notable regional differences.



**Figure 30** Percentage of patients with bladder cancer who underwent curative primary treatment, 2008–2009. Refers to stage T2–T4. **Total**  
 Source: Swedish Bladder Cancer Register

### 30 Curative treatment of T2–T4 tumours

A T2-T4 tumour has invaded the muscle and the options for curative treatment are cystectomy (removal of the bladder), with or without systemic chemotherapy, or radiotherapy. Due to comorbidity, advanced age or certain other factors, a decision may be made not to attempt a cure.

Approximately 500 Swedes are diagnosed with T2-T4 tumours of the bladder every year. The percentage of patients who receive curative treatment varies considerably from county to county. Given the low incidence, the indicator is not broken down by gender. The diagram contains data for two years in order to ensure more reliable outcomes. Nevertheless, some counties have so few cases that uncertainty remains.

## PROSTATE CANCER

Statistics for 2009	Men
Number of diagnoses	10 317
Percentage of all cancer cases	36%
Prevalence, total	75 753
Relative five-year survival rate	86.5%
Number of deaths	2 424

Prostate cancer is the most common form of the disease in Sweden and accounts for more than 36 per cent of cases in men. A total of 10 317 patients were diagnosed with prostate cancer in 2009, and Sweden currently has approximately 75 700 prevalent cases. The disease is rare before the age of 50. The median age at diagnosis has decreased to 70.

The number of new cases was stable in 1990–1995, rising substantially through 2005 and then levelling off for several years. There was a spike again in 2009, largely due to the growing number of symptom-free men who take a prostate-specific antigen (PSA) blood test and the fact that patients with elevated PSA levels (about 10 per cent of those who are symptom-free) undergo a biopsy. The greater use of the test explains why prostate cancer is detected at earlier stages and why the age at diagnosis has decreased.

The risk of death depends on the stage and degree of the tumour. Because men are increasingly diagnosed with small, well-differentiated tumours, the relative five-year survival rate has risen to 86.5 per cent. A total of 2 424 Swedes died of prostate cancer in 2009.

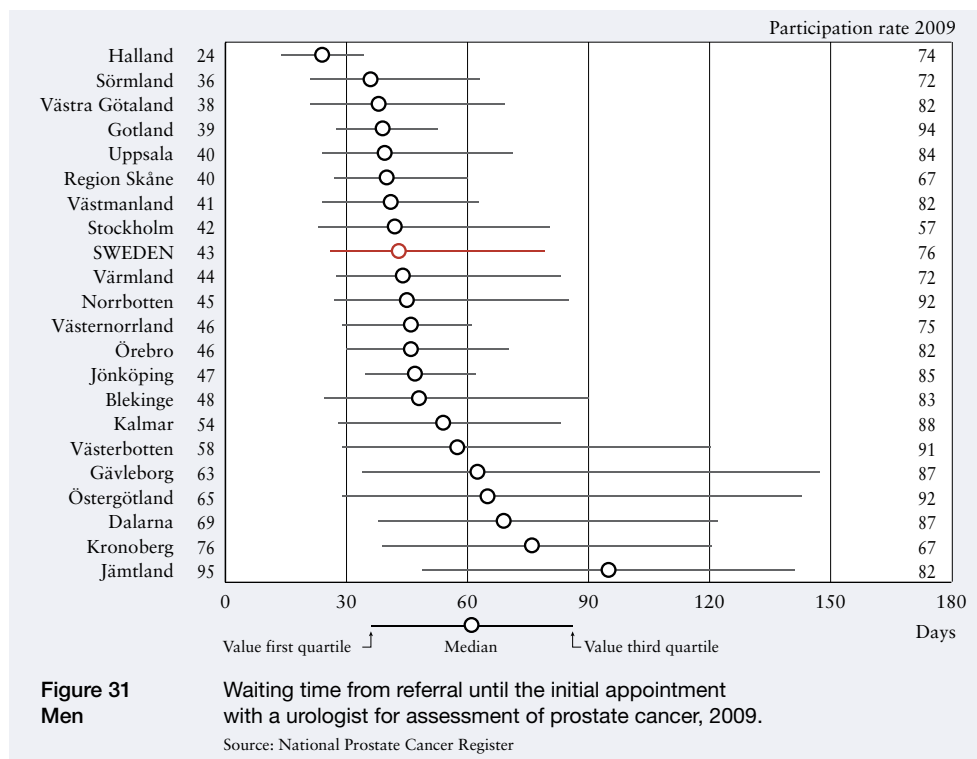
This report presents outcomes for five indicators. Four of the indicators reflect interventions at various stages and grades of prostate cancer – from tumours with low risk of metastasis to those with high risk, which often grow rapidly and aggressively. The fifth indicator concerns waiting times. The data have been taken from the National Prostate Cancer Register.

### 31 Waiting time for the initial appointment with a urologist

Usually a general practitioner makes an assessment or, at the patient's request, a PSA test is performed as part of a routine check-up. If the GP suspects cancer, the patient is referred to a urologist.

According to the national healthcare guarantee, the initial appointment with a specialist is to take place within 90 days after the referral is sent. Since tumours of the prostate tend to grow slowly, waiting time is rarely decisive to treatment outcome. The PSA level, which reflects proliferation of the tumour, is useful in determining





the need for rapid assessment. Be that as it may, a long waiting time causes unnecessary anxiety and should be avoided.

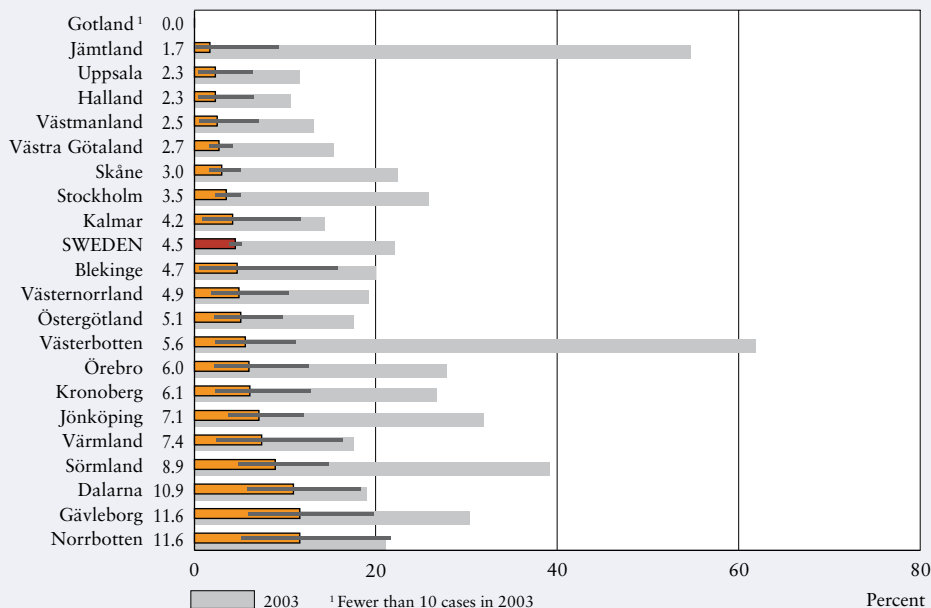
The comparison is based on how long it takes from the time that the clinic receives a referral or is contacted by the patient until the initial appointment with a urologist.

There were major regional variations. Halland, for example, had the shortest median waiting time and only 25 per cent of patients waited for more than 34 days. Because no waiting time had been reported for 26 per cent of the cases, the data are inconclusive.

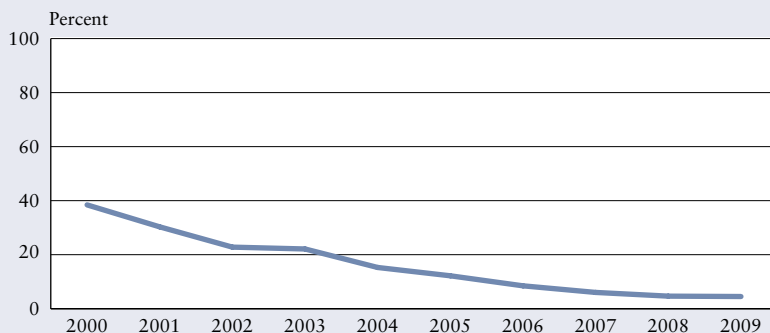
In seven counties, at least 25 per cent of patients waited longer than three months. Thus it would appear that many counties lacked the capacity in 2009 to meet the national care guarantee's 90-day deadline.

This report does not consider the possibility that a patient was offered an appointment at a second urology clinic during the waiting period but turned it down.

The column on the right side of the diagram indicates the percentage of patients included in the comparison. The counties exhibited large variations; a high percentage of unreported cases can affect the waiting time data.



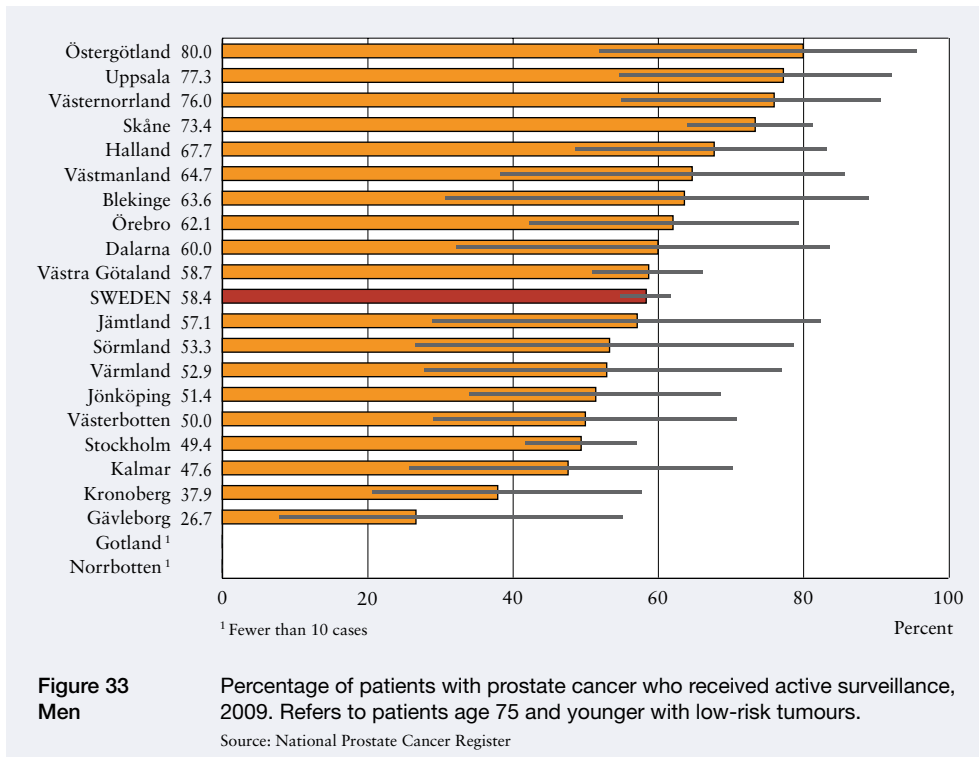
**Figure 32 Men** Percentage of patients with localised prostate cancer who underwent skeletal scintigraphy, 2009. Refers to low-risk tumours. Source: National Prostate Cancer Register



**Figure 32 Sweden** Percentage of patients with localised prostate cancer who underwent skeletal scintigraphy. Refers to low-risk tumours. Trend, 2000–2009. Source: National Prostate Cancer Register

### 32 Bone scintigraphy for low-risk prostate cancer

Bone scintigraphy involves the injection of a radioisotope in order to detect bone changes, including metastases from prostate cancer. The examination can be used to determine whether prostate cancer has spread to the skeletal system, ordinarily the spinal column or pelvis. Low-risk localised tumours rarely require bone scintigraphy. Thus, the NBHW national guidelines for prostate cancer care and the clini-



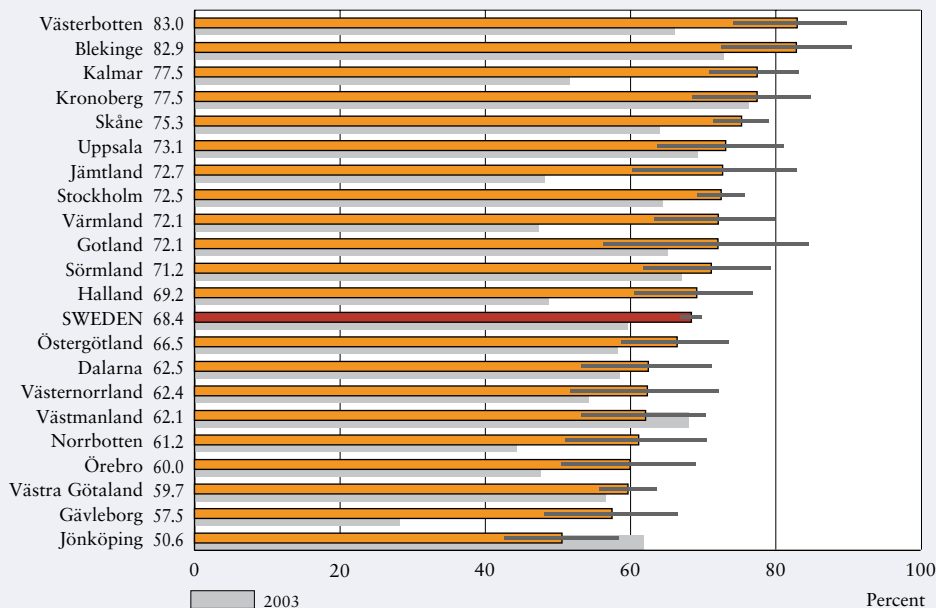
cal practice guidelines of every region specify that patients with low-risk tumours should not be given bone scintigraphy. However, a few patients may experience symptoms in the skeletal system that call for the examination to be used.

### 33 Active surveillance of low-risk prostate cancer

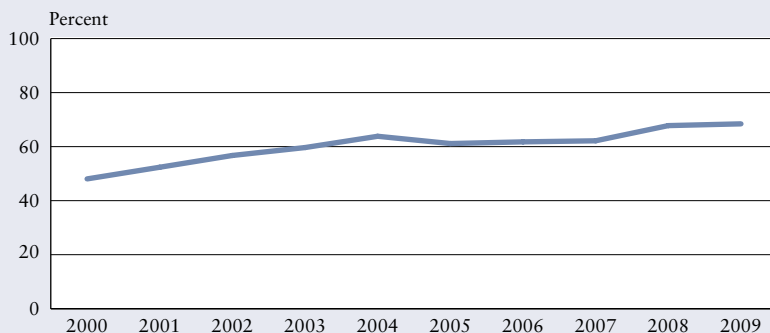
Only 3 per cent of low-risk prostate cancer patients die of the disease within 10 years. The first-line treatment strategy recommended by the NBHW national guidelines is active surveillance for patients with a remaining life expectancy of 10–20 years and prostatectomy or radiotherapy for those with a remaining life expectancy of more than 20 years. Active surveillance involves frequent PSA tests and occasional biopsies. Any indication that the tumour is growing triggers prostatectomy or radiotherapy. Since the guidelines were drawn up, the quality register has further narrowed the criteria for low-risk cancer for which active surveillance is indicated; thus fewer patients are now included in this population.

Swedish urologists disagree about the optimum treatment for low-risk prostate cancer. Active surveillance reduces the number of patients who are overtreated, but at the risk of treating some too late.

Because the quality register revised its reporting methods in 2009, no comparison with previous outcomes is possible.



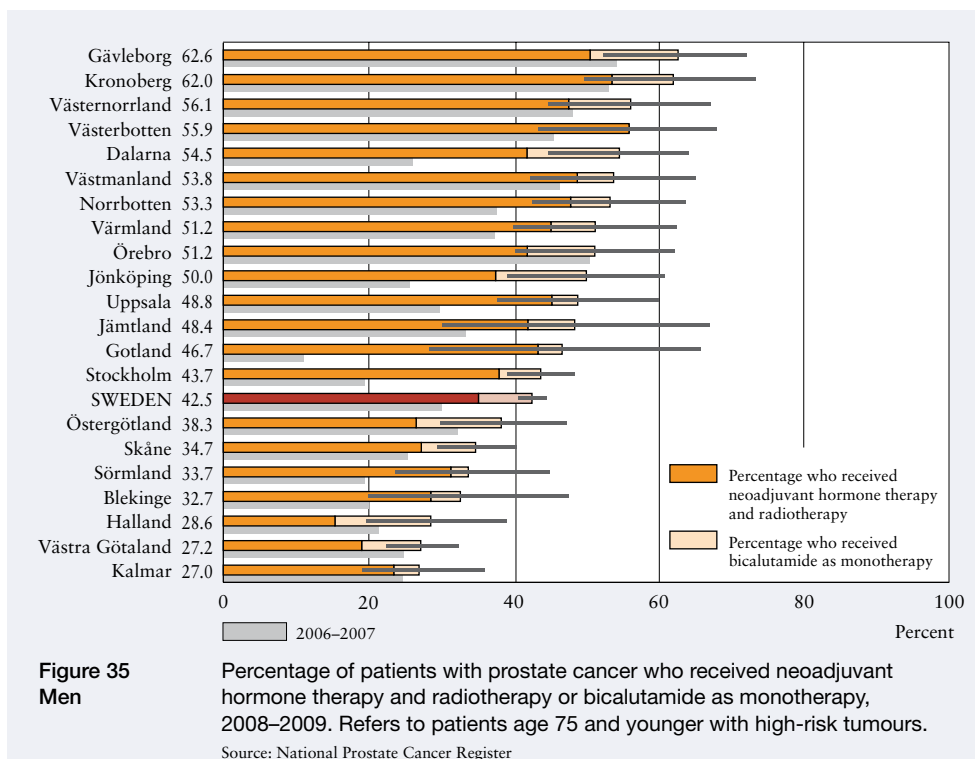
**Figure 34 Men** Percentage of patients with prostate cancer who received curative treatment, 2009. Refers to patients age 75 and younger medium and high-risk tumours. Source: National Prostate Cancer Register



**Figure 34 Sweden** Percentage of patients with prostate cancer who received curative treatment. Refers to patients age 75 and younger medium and high-risk tumours. Trend, 2000–2009. Source: National Prostate Cancer Register

### 34 Curative treatment for medium and high-risk prostate cancer

Given that medium and high-risk prostate cancer poses a significantly higher risk of death, patients are normally offered the possibility of curative treatment, which involves one of various prostatectomy or radiotherapy techniques. Such treatment is indicated only if the tumour is localised, i.e., has not metastasised beyond the



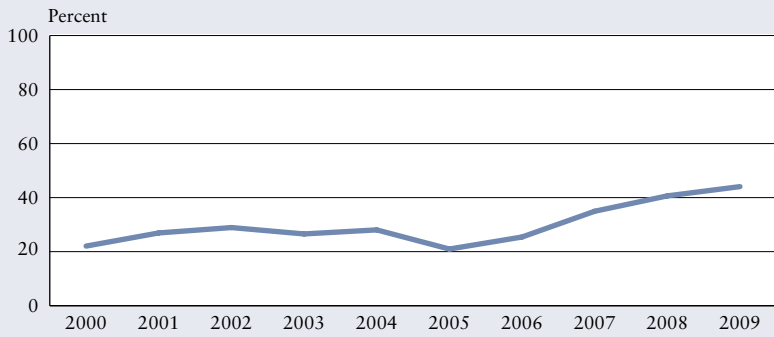
prostate. This report presents a follow-up of patients under age 75, since they usually have a remaining life expectancy of more than ten years.

Some counties are almost 70 per cent below the national average, suggesting undertreatment of this patient population.

### 35 Treatment of locally advanced prostate cancer

Locally advanced prostate cancer grows aggressively and can metastasise. The condition poses a large risk of premature death within five years of the diagnosis.

Various curative treatment methods are available to these patients. The NBHW national guidelines for prostate cancer care assign top priority to neoadjuvant hormone therapy followed by external radiotherapy. The combined treatment is recommended for patients with remaining life expectancy of more than five years. Patients with limited remaining life expectancy may instead be prescribed medication to delay progression of the disease; the guidelines favour antiandrogen therapy with bicalutamide to block the stimulating effect of testosterone on cancer cells.



**Figure 35**  
**Sweden**

Percentage of patients with prostate cancer who received neoadjuvant hormone therapy and radiotherapy or bicalutamide as monotherapy. Refers to patients age 75 and younger with high-risk tumours. Trend, 2000–2009.

Source: National Prostate Cancer Register

## COLON CANCER

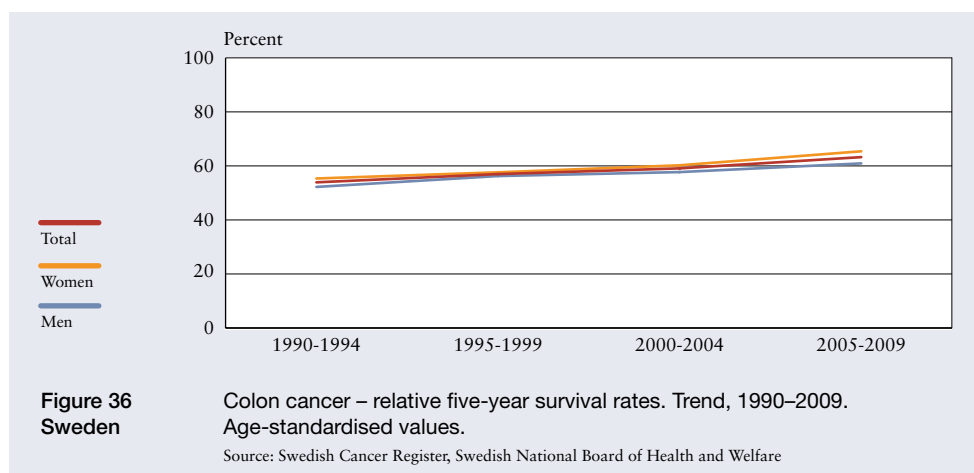
Statistics for 2009	Women	Men
Number of diagnoses	2 036	2 023
Percentage of all cancer cases	8%	7%
Prevalence, total	15 745	12 594
Relative five-year survival rate	65.4%	60.9%
Number of deaths	907	886

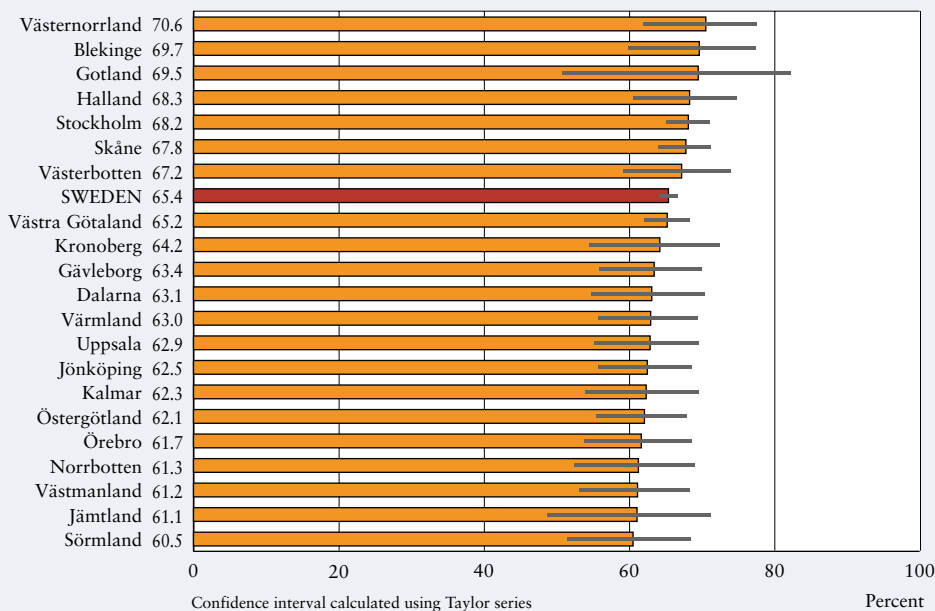
Colon cancer is the third most common form of the disease in both women and men. A total of 4 059 Swedes – 2 036 women and 2 023 men – developed colon cancer in 2009. More than 28 000 Swedes now alive have had the disease. Colon cancer is uncommon before the age of 49 and approximately 75 per cent of patients are over 65 at the time of diagnosis. The number of new cases has been stable since 1990, with a small upward trend. One reason is that the population has aged.

This report presents outcomes for eight indicators. Considering that most patients undergo surgery, five of the indicators reflect outcomes during and after the operation. One indicator concerns survival rates and two concern multidisciplinary team meetings. Seven of the indicators are based on data from the National Colon Cancer Register, which started in 2007, and the eighth indicator is based on data from the Swedish Cancer Register. The comparison period covers 2–3 years, nearly the entire lifetime of the national quality register. Thus, comparison with outcomes from previous years is out of the question.

### 36 Colon cancer – relative five-year survival rates

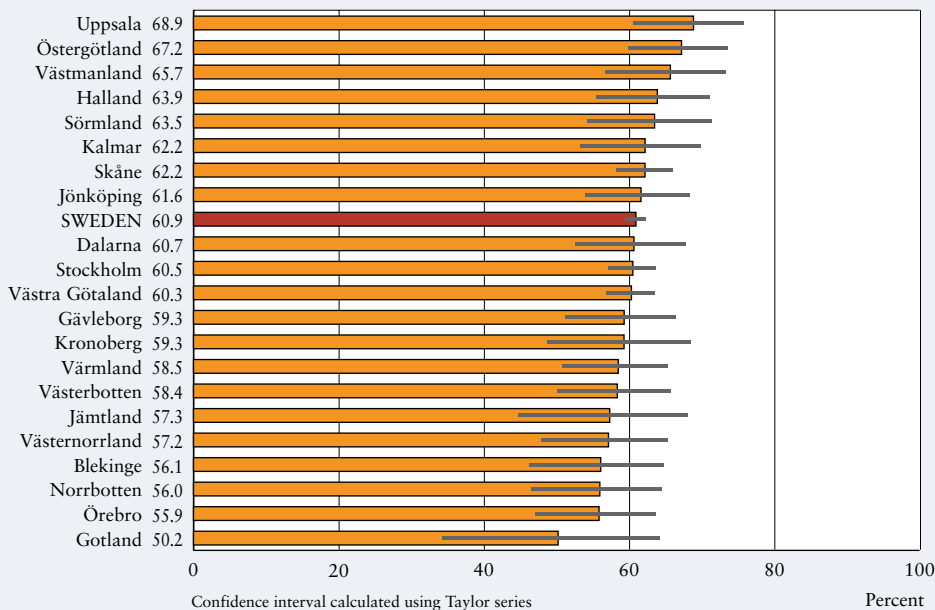
The relative five-year survival rate among colon cancer patients rose to 65.4 per cent for women and 60.9 per cent for men in 2005–2009. Figure 36 reveals that there are





**Figure 36**  
**Women**

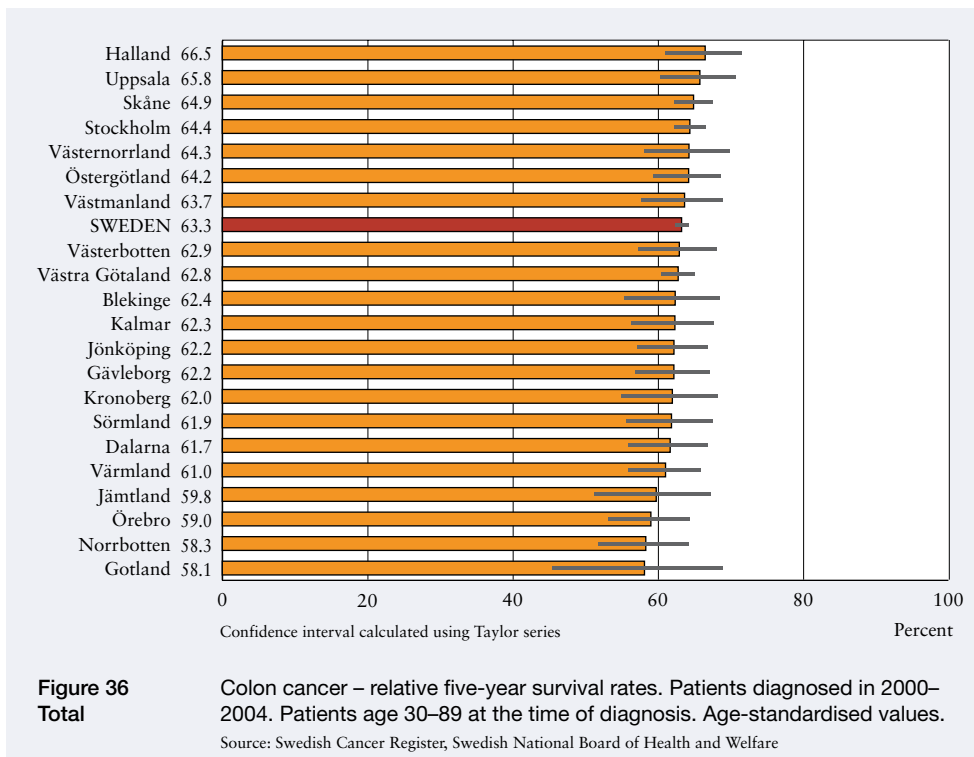
Colon cancer – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values.  
Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



**Figure 36**  
**Men**

Colon cancer – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values.  
Source: Swedish Cancer Register, Swedish National Board of Health and Welfare





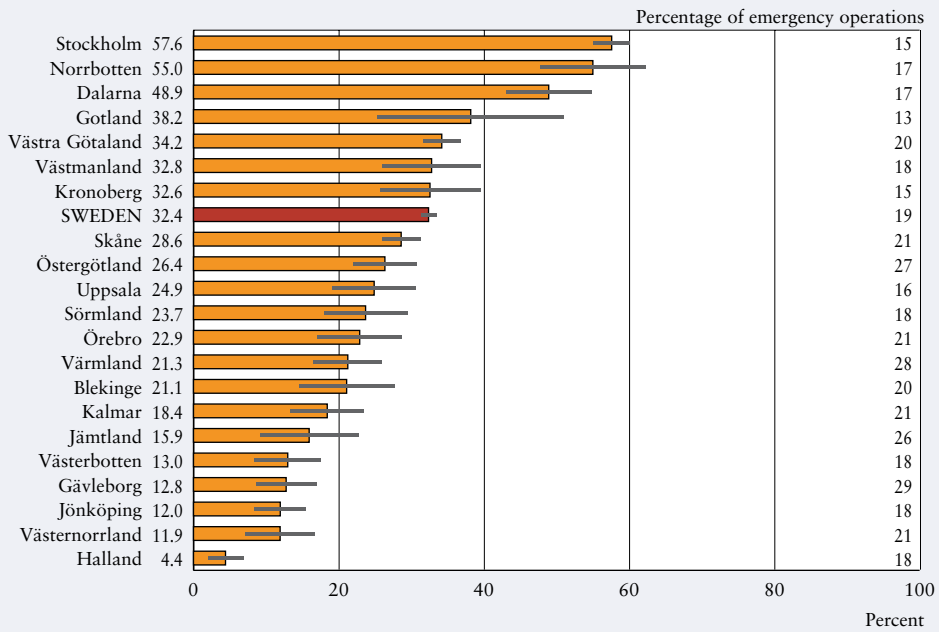
large regional differences for men: 50.2–68.9 per cent, as opposed to 60.5–70.6 per cent for women.

### 37–38 Multidisciplinary team meetings

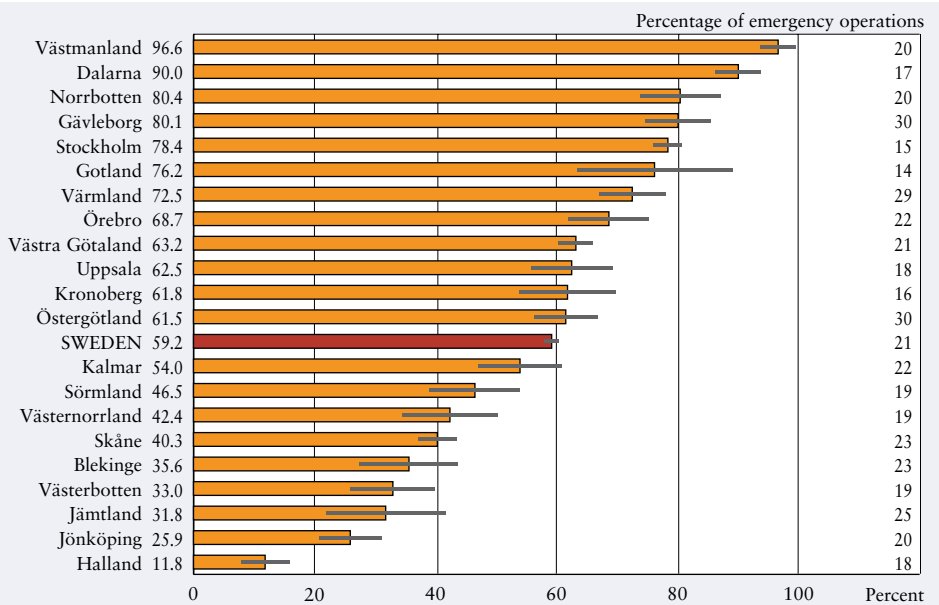
Primary colon cancer treatment may be preceded by a multidisciplinary team meeting, a comprehensive assessment for the purpose of optimising the intervention. Surgery, oncology, radiology, pathology and other specialists, as well as nurses, may participate. A postoperative multidisciplinary team meeting looks at the pathological anatomical data (PAD) and plans ongoing treatment. The NBHW national guidelines for colon cancer care recommend a multidisciplinary team meeting both before commencement of treatment for newly diagnosed cases and postoperatively.

The National Colon Cancer Register targets multidisciplinary assessments for at least 90 per cent of patients, both at commencement of treatment and postoperatively.

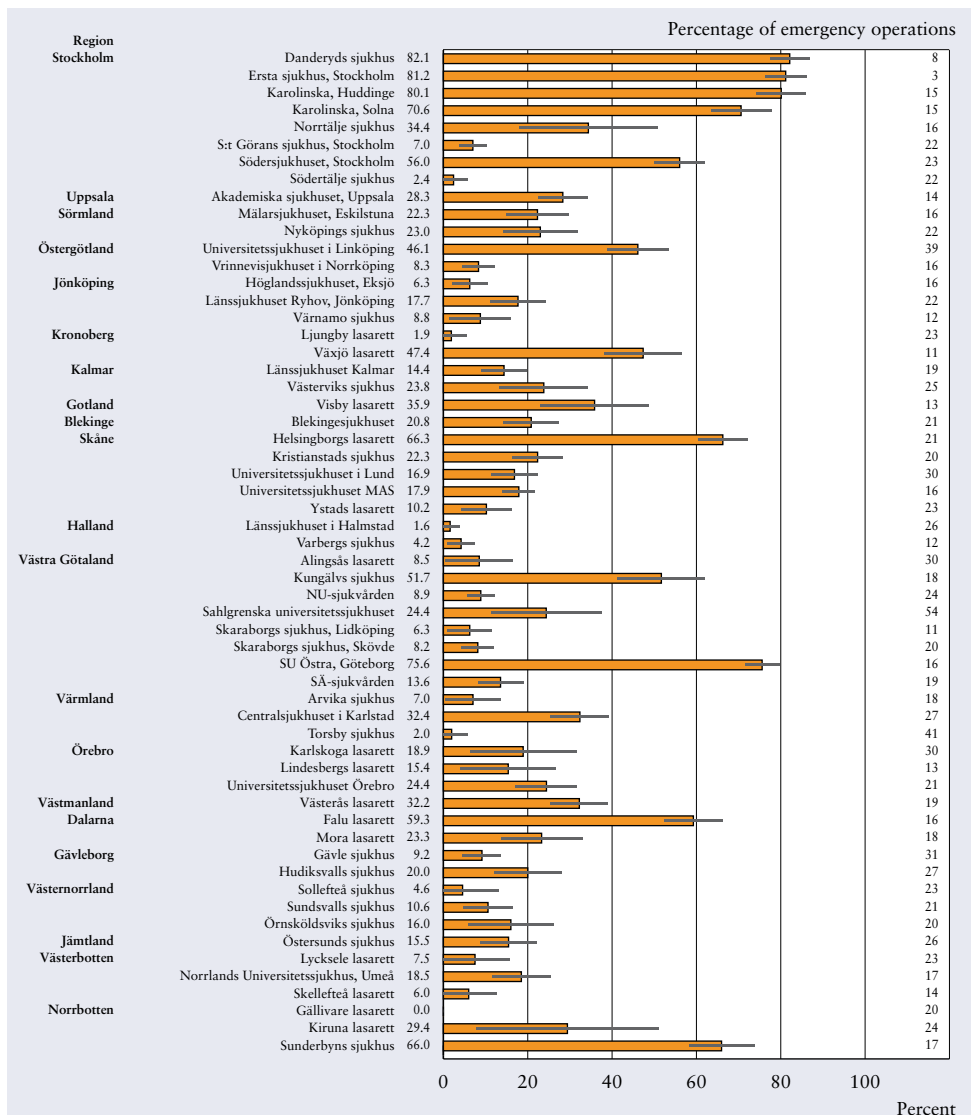
Certain regional differences in reporting of multidisciplinary team meetings affect the outcomes in the diagram. In the first place, there is no uniform definition of the specialists who need to participate in order for a multidisciplinary team meeting to take place. Some counties report only meetings attended by all of the various types of specialists and are thereby underrepresented in the register. In the second place,



**Figure 37** Percentage of patients who had a multidisciplinary team meeting prior to treatment for colon cancer, 2008–2009.  
**Total**  
 Source: National Colon Cancer Register



**Figure 38** Percentage of patients who had a multidisciplinary team meeting after colon cancer surgery, 2008–2009.  
**Total**  
 Source: National Colon Cancer Register



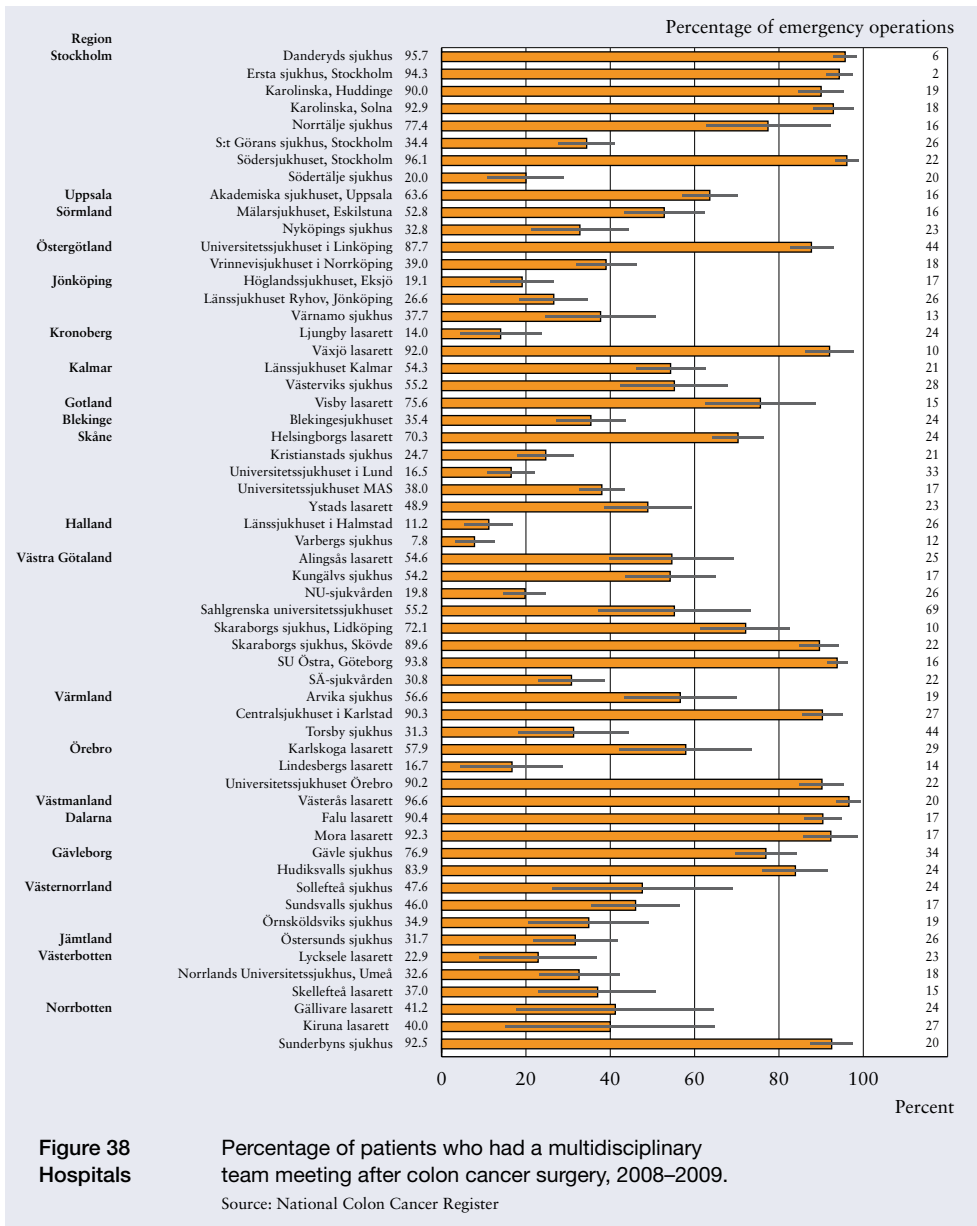
**Figure 37  
Hospitals**

Percentage of patients who had a multidisciplinary team meeting prior to treatment for colon cancer, 2008–2009.

Source: National Colon Cancer Register

the patient populations that need a multidisciplinary team meeting are identified differently from county to county.

The column of figures on the right side of the diagram shows the percentage of emergency operations per county. Because multidisciplinary team meetings are not feasible when the patient's condition is acute, the two variables are related. However, the percentage of postoperative multidisciplinary team meetings should not be affected by whether the operation was scheduled or emergency.



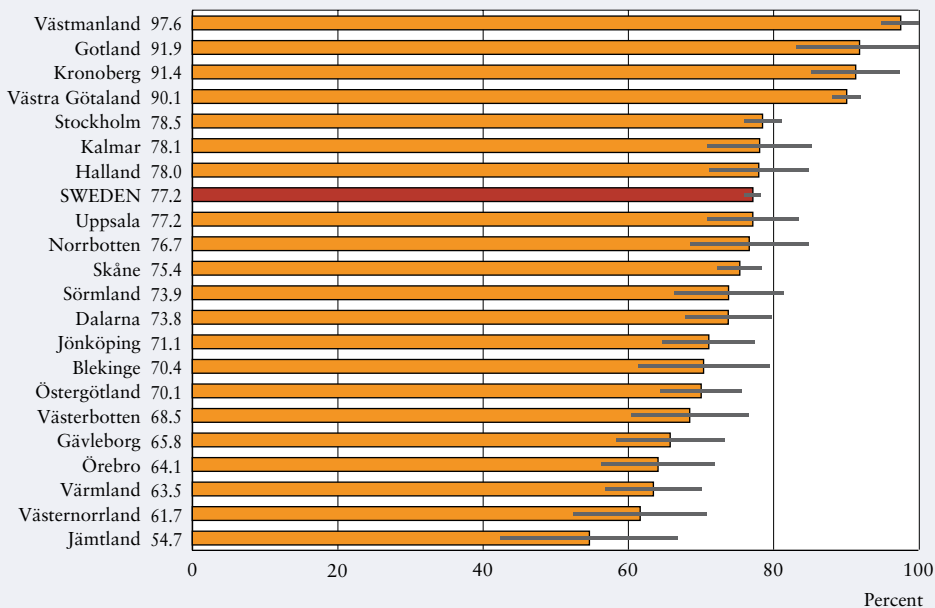
**Figure 38**  
**Hospitals**

Percentage of patients who had a multidisciplinary team meeting after colon cancer surgery, 2008–2009.

Source: National Colon Cancer Register

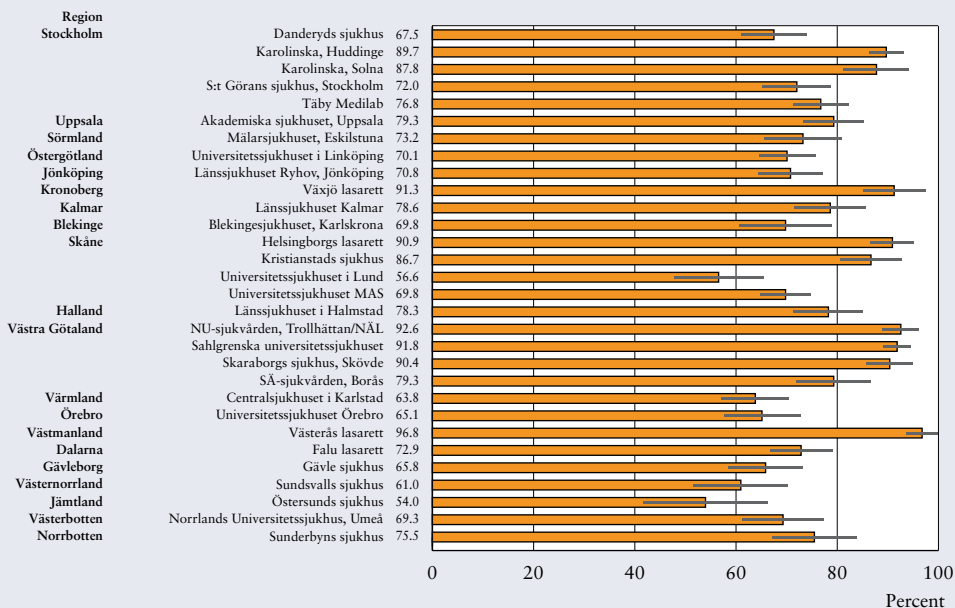
### 39 At least twelve lymph nodes examined in the tumour sample

After primary surgery for colon cancer, the intestinal tissue and tumour that have been removed are sent to a pathology lab for microscopic and macroscopic examination. The purpose of the examinations is to offer a definitive assessment of the type and stage of the tumour. Correctly classifying the malignancy is integral to predicting progression of the disease and prescribing proper treatment. Scientific studies indicate that acceptable diagnostic quality requires examination of at least twelve



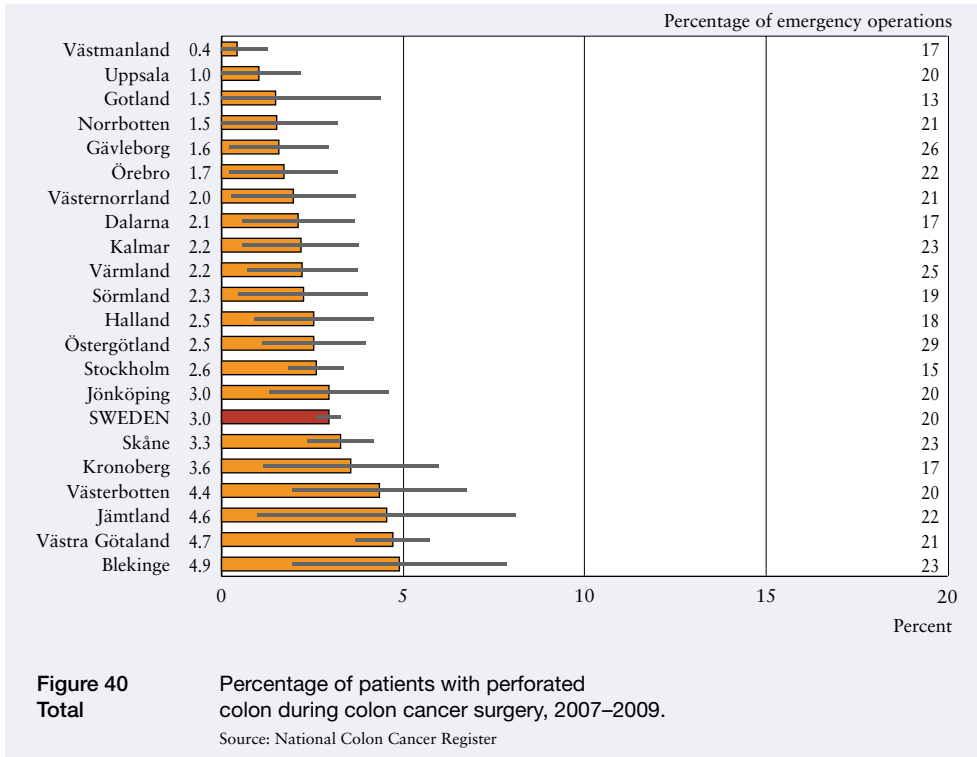
**Figure 39** Total Percentage of patients who had at least twelve lymph nodes examined after colon cancer surgery, 2008–2009.

Source: National Colon Cancer Register



**Figure 39** Pathology lab Percentage of patients who had at least twelve lymph nodes examined after colon cancer surgery, 2008–2009.

Source: National Colon Cancer Register



lymph nodes. The quality of the examinations is affected by whether the surgeon removes sufficient tissue, as well as the pathologist’s analytical skills.

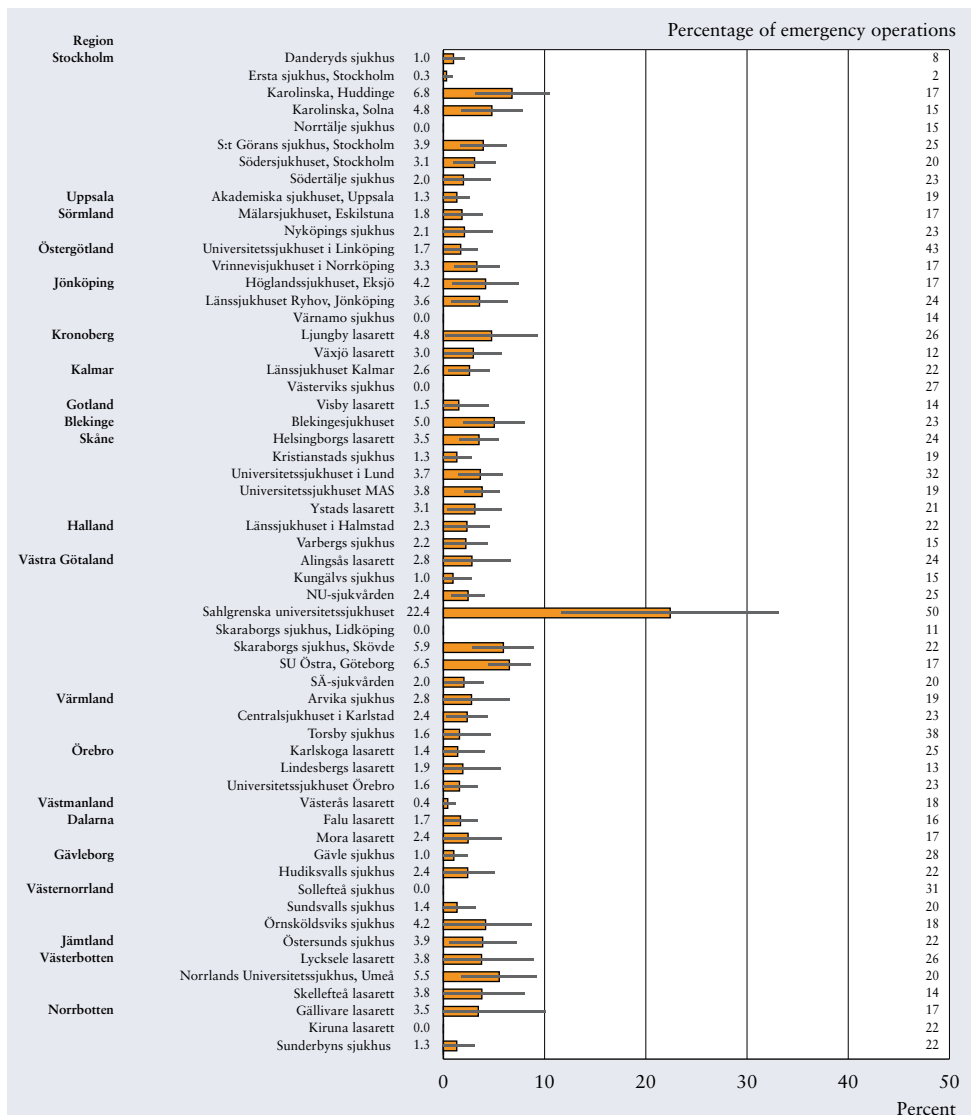
According to an analysis of 2008 data by the National Colon Cancer Register, the number of lymph nodes examined was not related to whether surgery had been performed on a scheduled or emergency basis. Given that surgery is fairly standardised, the quality of the results appeared to depend more on the ability of the pathologist to analyse at least twelve nodes than on the size of the sample.

The comparison covers a two-year period. With the exception of the large counties, however, the quality register contained few cases – as reflected in the broad confidence intervals.

Counties that were below 95 per cent should review their resources, particularly when it comes to pathologists.

#### 40 Perforation of the colon during surgery

One important complication that can occur during surgery is perforation of the colon. Such a development increases the risk of tumour recurrence and therefore suffering on the part of the patient. The risk of perforation is greater when surgery is performed on an emergency basis.

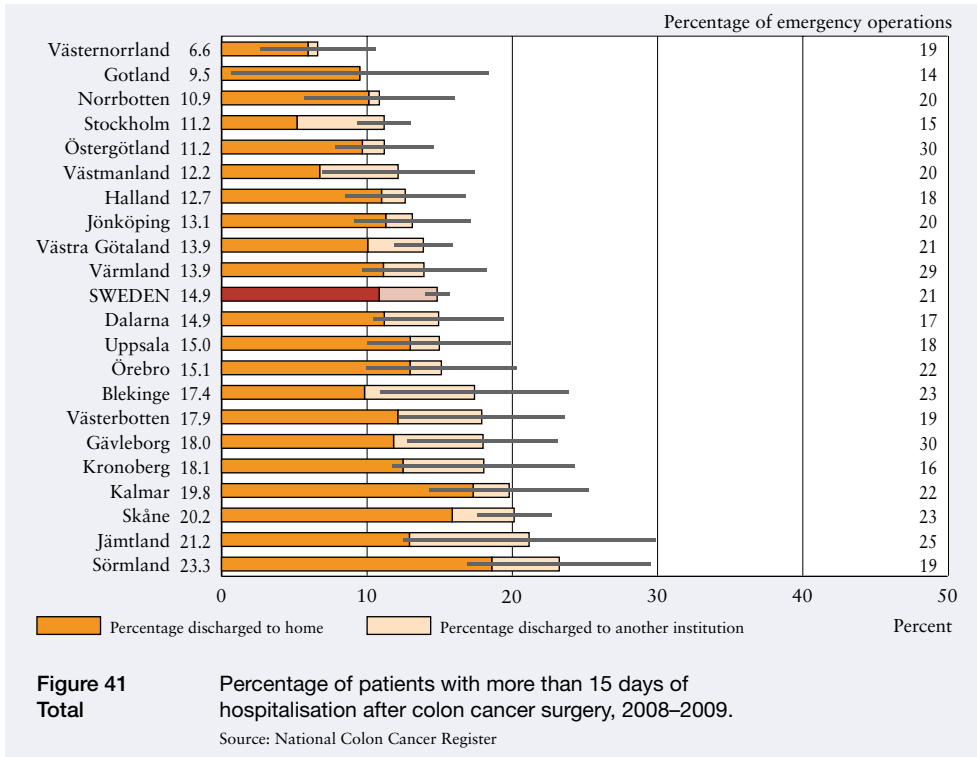


**Figure 40  
Hospitals**

Percentage of patients with perforated colon during colon cancer surgery, 2007–2009.

Source: National Colon Cancer Register

One goal is to minimise the number of complications that are due to healthcare interventions, in this case injury during the course of an operation. Perforations during surgery cannot be wholly eliminated given that they can also be caused by acute volvulus and other conditions.

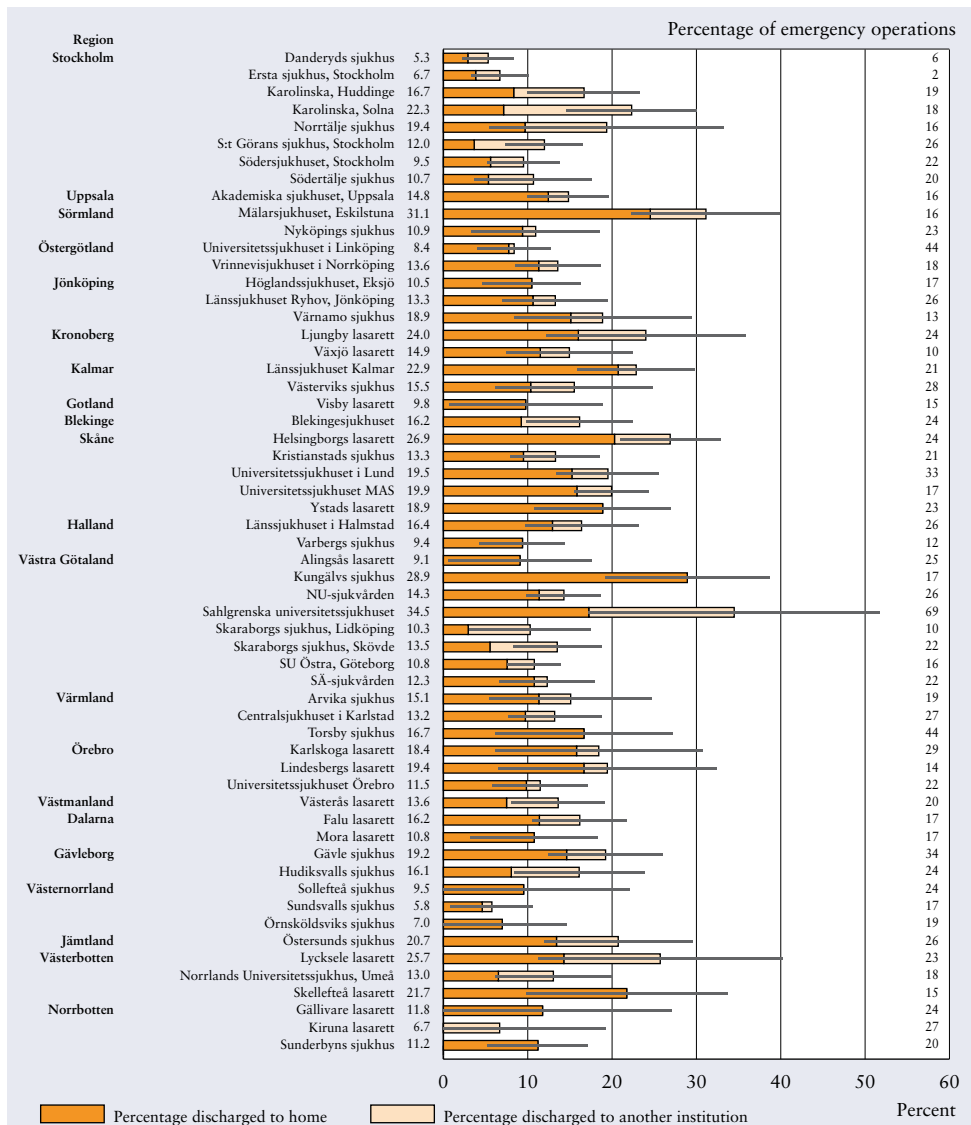


## 41 More than 15 days of hospitalisation after surgery

Assuming no complications occur, hospitalisation after surgery should not exceed 15 days. The goal is based on a 2008 follow-up by the National Colon Cancer Register showing that the median hospitalisation period following surgery was 7 days for patients discharged to home and 14 days for those who were discharged to another institution.

The comparison does not take the possible effects of comorbidity or the patient's preoperative condition into consideration.

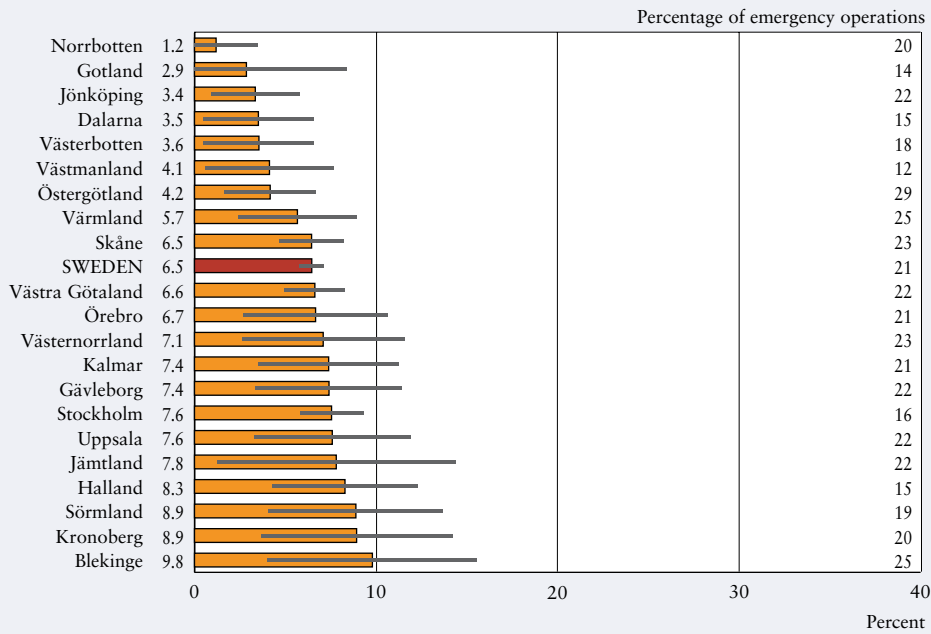




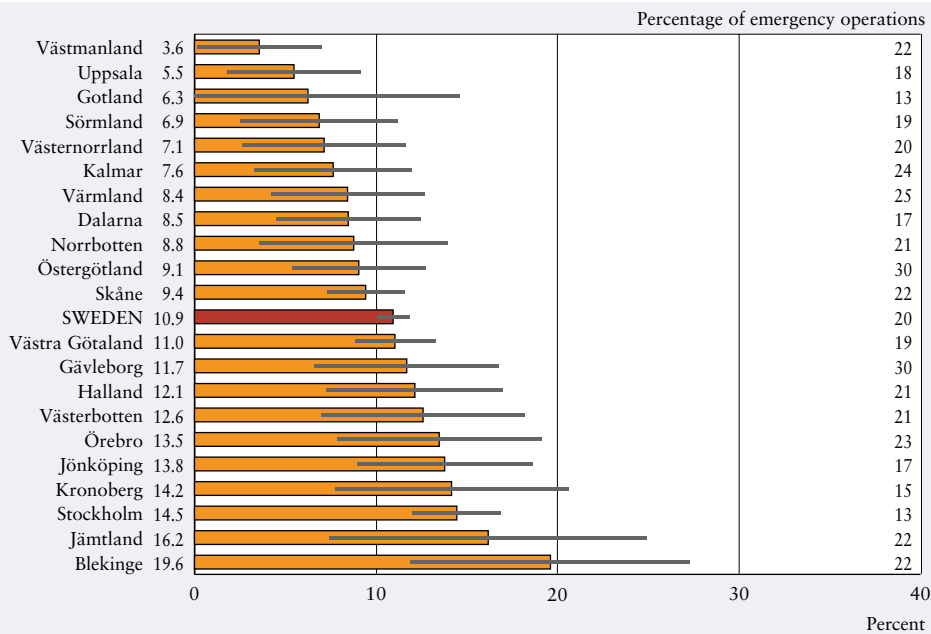
**Figure 41**  
**Hospitals**

Percentage of patients with more than 15 days of hospitalisation after colon cancer surgery, 2008–2009.

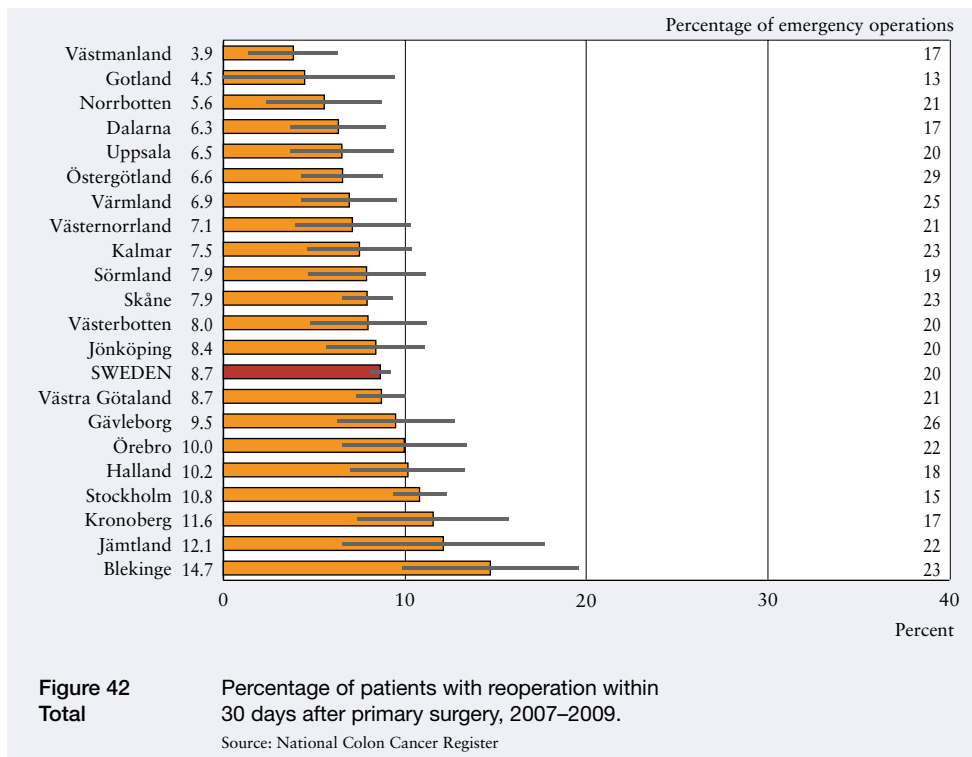
Source: National Colon Cancer Register



**Figure 42** Percentage of patients with reoperation within 30 days after primary surgery, 2007–2009.  
**Women**  
 Source: National Colon Cancer Register



**Figure 42** Percentage of patients with reoperation within 30 days after primary surgery, 2007–2009.  
**Men**  
 Source: National Colon Cancer Register

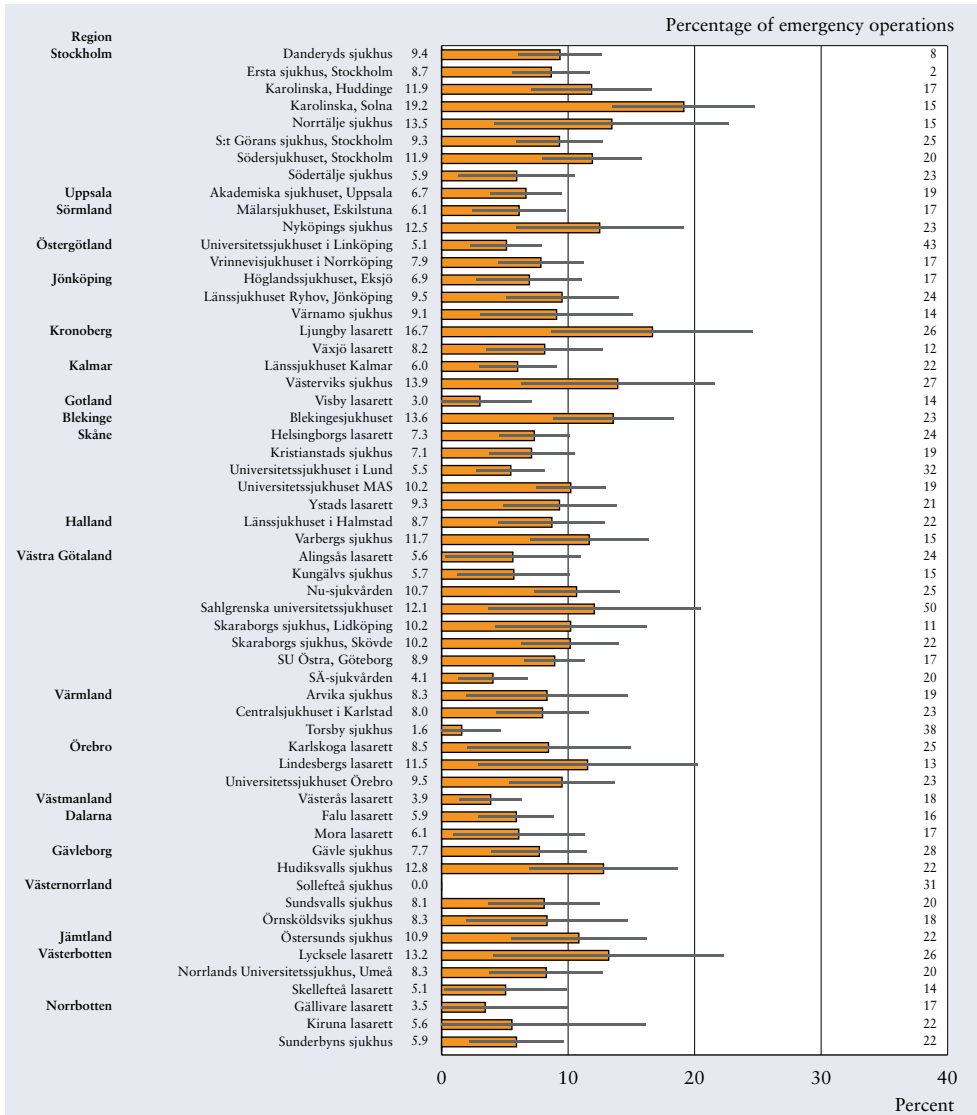


## 42 Reoperation due to complications within 30 days of primary surgery

Approximately 95 per cent of all colon cancer patients undergo surgery. The location and size of the tumour, as well as the patient's general condition, affect the scope and riskiness of the operation. Bleeding, infection, leakage or another complication may require relatively prompt reoperation, which entails additional suffering for the patient and increases the risk of further complications.

The NBHW national guidelines for colon cancer care identify reoperation after 30 days of primary surgery as an important indicator to monitor.

One source of error in comparing data is that some hospitals report minor interventions as reoperations and some do not. The percentage of reoperations is also related to the way that primary surgery was performed and the patient's condition at the time.



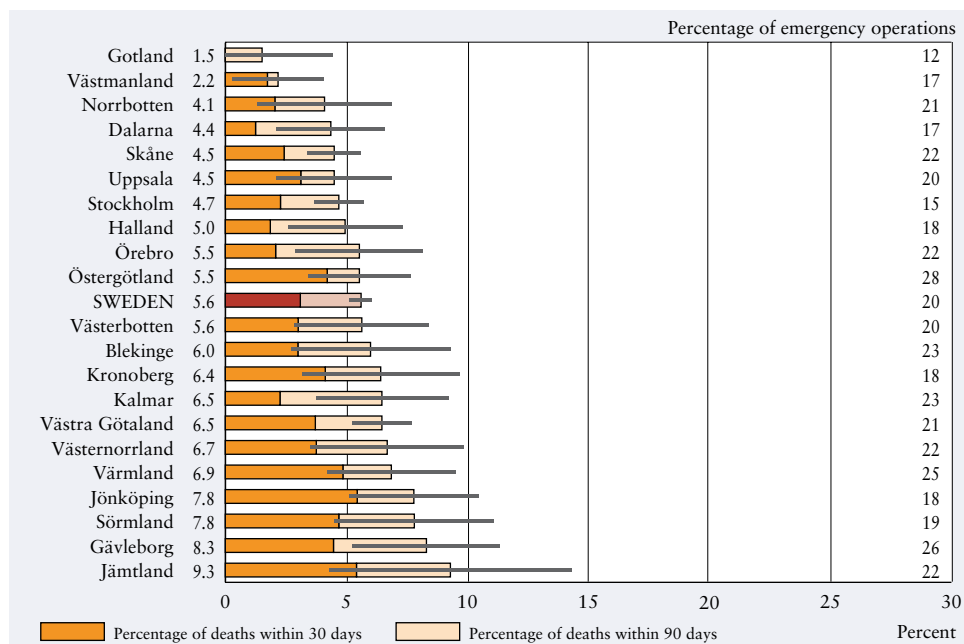
**Figure 42** Percentage of patients with reoperation within 30 days after primary surgery, 2007–2009.

Source: National Colon Cancer Register

### 43 Deaths within 30 and 90 days of surgery

The NBHW national guidelines for colon cancer care identify the percentage of deaths within 30 and 90 days of surgery as an important indicator for monitoring healthcare quality. The indicator reflects the selection of patients for surgery, as well as the care they receive before, during and after the operation.

Age, gender, and severity of the malignancy also affect the percentage of deaths. Table 1 presents the odds ratio by county, adjusted for age, gender and tumour stage.



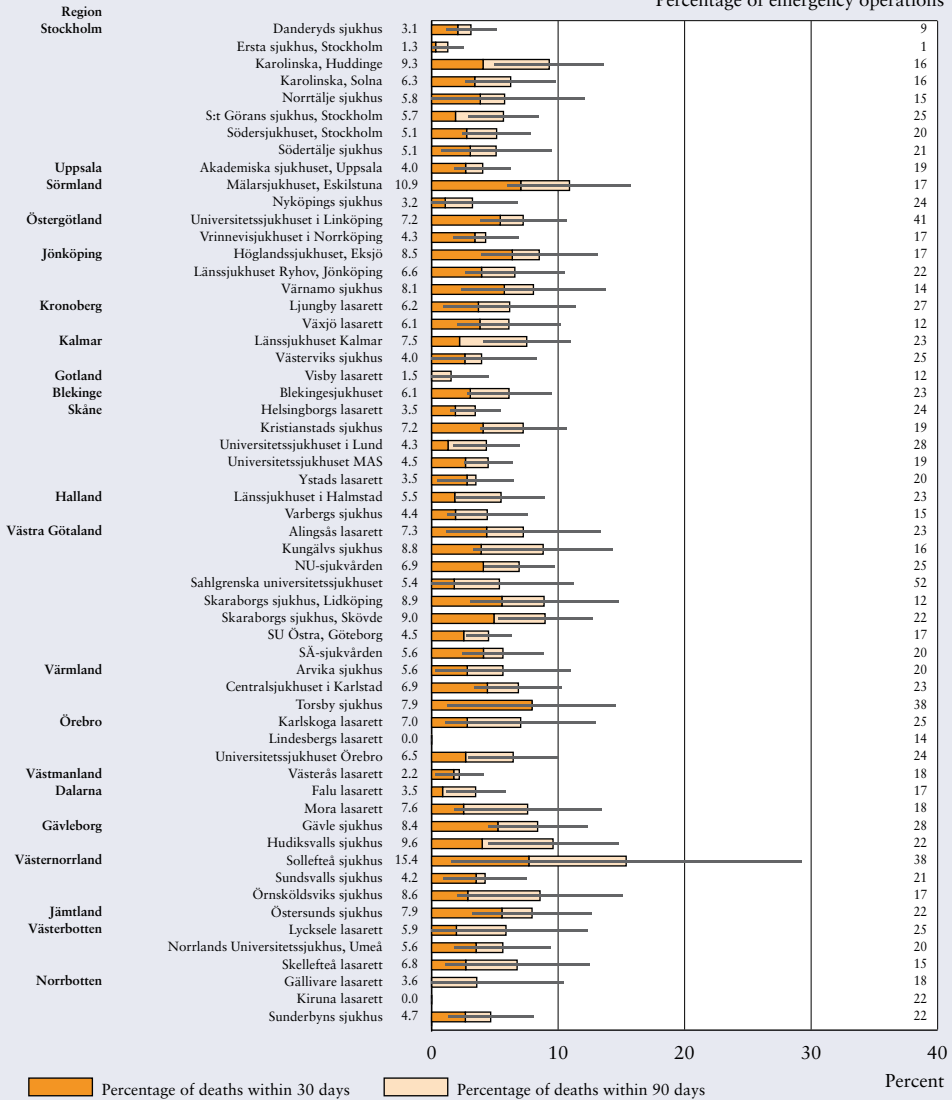
**Figure 43** Percentage of deaths within 30 and 90 days after colon cancer surgery, 2007–2009.

Source: National Colon Cancer Register

Table 1					
County council	Odds ratio	95 % confidence interval	County council	Odds ratio	95 % confidence interval
Stockholm	0.96	0.74–1.23	V. Götaland	1.11	0.88–1.40
Uppsala	0.91	0.51–1.62	Värmland	1.29	0.83–2.00
Sörmland	1.26	0.77–2.06	Örebro	1.01	0.60–1.72
Östergötland	0.94	0.61–1.43	Västmanland	0.41	0.17–1.03
Jönköping	1.23	0.83–1.84	Dalarna	0.92	0.53–1.61
Kronoberg	0.95	0.54–1.67	Gävleborg	1.46	0.94–2.25
Kalmar	0.96	0.60–1.55	Västernorrland	1.27	0.75–2.16
Gotland	0.30	0.04–2.21	Jämtland	1.78	0.95–3.33
Blekinge	1.07	0.58–1.96	Västerbotten	1.05	0.61–1.81
Region Skåne	0.79	0.60–1.05	Norrbottn	0.70	0.34–1.45
Halland	0.76	0.45–1.29			

A value of 1 is assigned to the national average of patients who die within 90 days of surgery. A value less than 1 represents a percentage below the national average and a value greater than 1 represents a percentage above the national average.

Percentage of emergency operations



**Figure 43** Percentage of deaths within 30 and 90 days after colon cancer surgery, 2007–2009.

Source: National Colon Cancer Register

## RECTAL CANCER

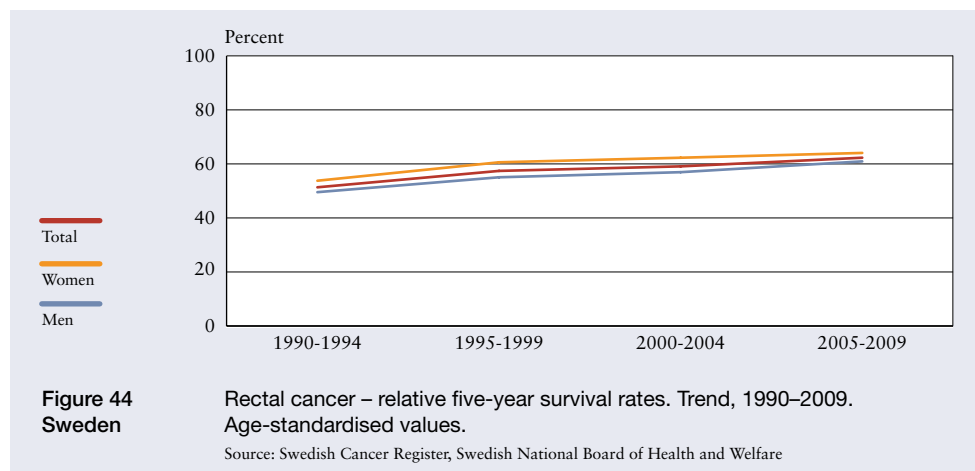
Statistics for 2009	Women	Men
Number of diagnoses	888	1 233
Percentage of all cancer cases	3%	4%
Prevalence, total	7 991	8 426
Relative five-year survival rate	64.1%	60.9%
Number of deaths	344	451

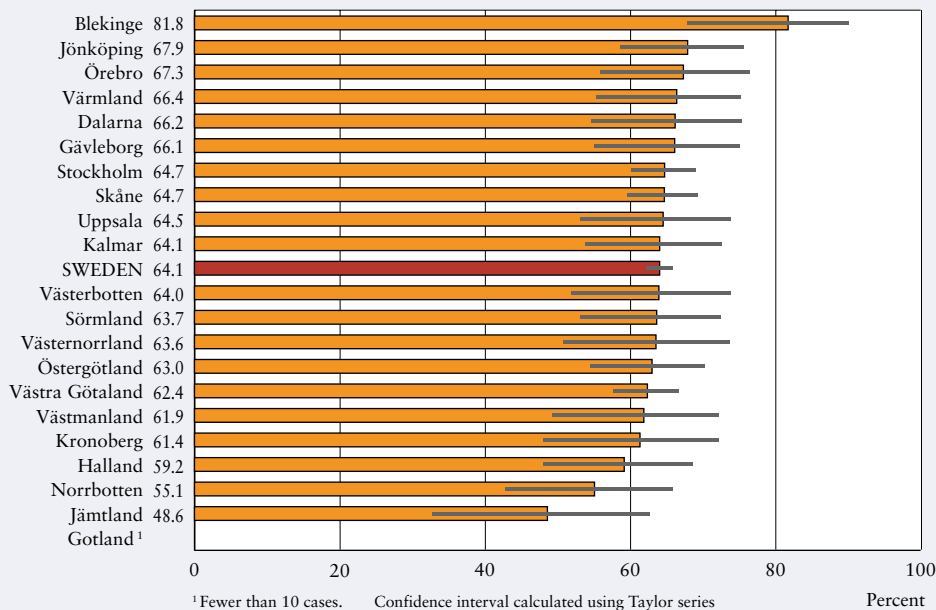
Rectal cancer is more common among men than women. A total of 888 women and 2 121 men were diagnosed with the disease in 2009. More than 16 400 Swedes now alive have had the disease. Rectal cancer is fairly uncommon before the age of 50.

This report presents outcomes for eleven indicators. Seven of them reflect outcomes during and after surgery. Given that most rectal cancer patients undergo surgery, the selection of indicators sheds a great deal of light on the quality of the operations. The other four indicators concern survival rates, frequency of recurrence within five years of surgery, and the use of multidisciplinary team meetings. Two of the indicators are based on the National Rectal Cancer Register, which started in 1995. One indicator contains data from the Swedish Cancer Register.

### 44 Rectal cancer – relative five-year survival rates

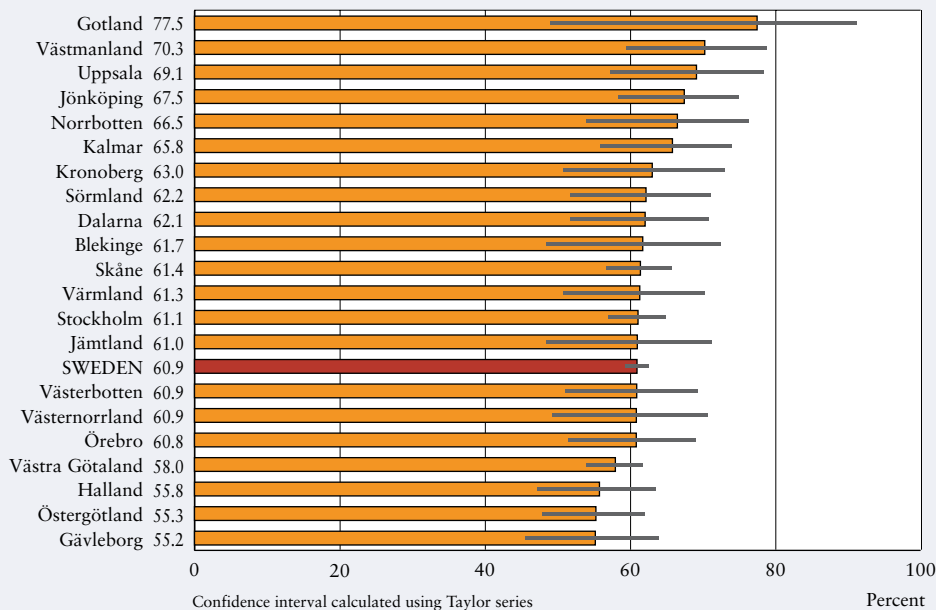
The relative five-year survival rate has increased among both female and male rectal cancer patients since the early 1990s. Figure 44 shows that the rate was 64.1 per cent for women and 60.9 per cent for men in 2005–2009. However, there were large regional differences: the figure ranged from 48.6 to 81.8 per cent for women and from 55.2 to 77.5 per cent for men.





**Figure 44**  
**Women**

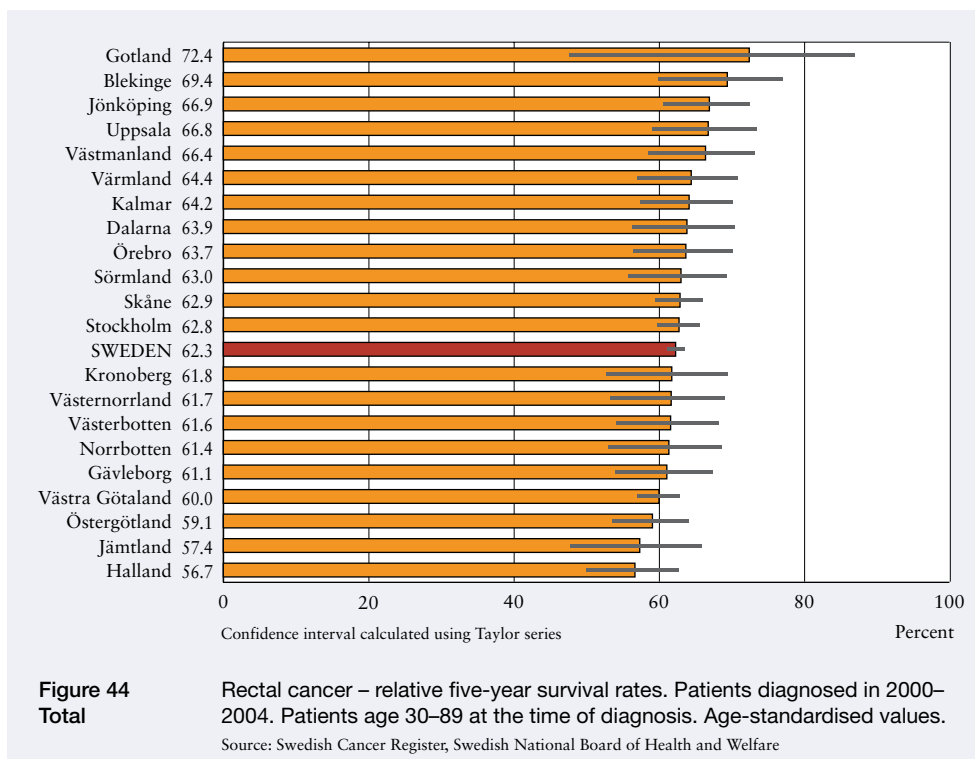
Rectal cancer – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values.  
Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



**Figure 44**  
**Men**

Rectal cancer – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values.  
Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



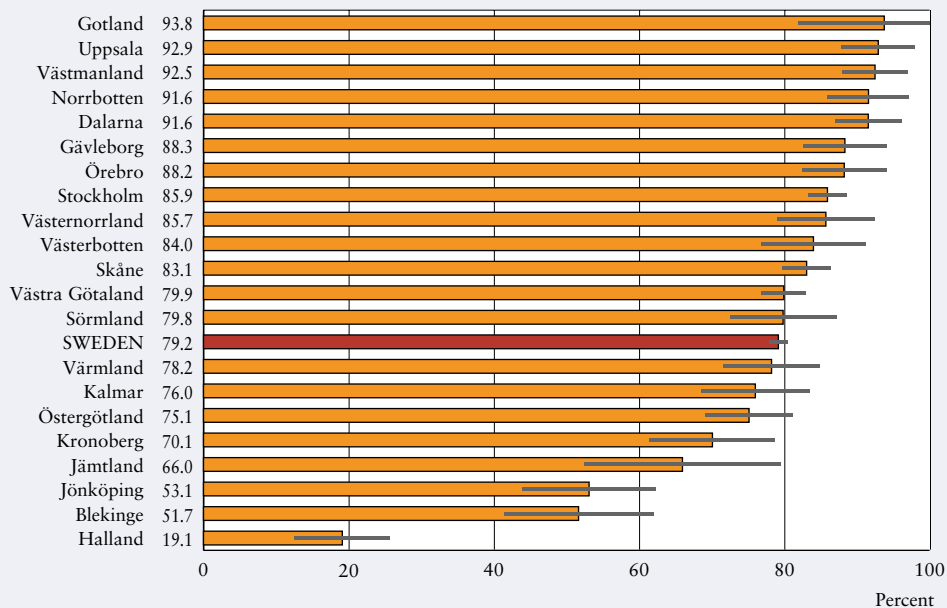


## 45–46 Multidisciplinary team meetings

Primary rectal cancer treatment may be preceded by a multidisciplinary team meeting, a comprehensive assessment for the purpose of optimising the intervention. Surgical, oncology, radiology, pathology and other specialists, as well as nurses, may participate. A postoperative multidisciplinary team meeting looks at the pathological anatomical data (PAD) and plans ongoing treatment. The NBHW national guidelines for rectal cancer care recommend a multidisciplinary team meeting both before commencement of treatment for newly diagnosed cases and postoperatively.

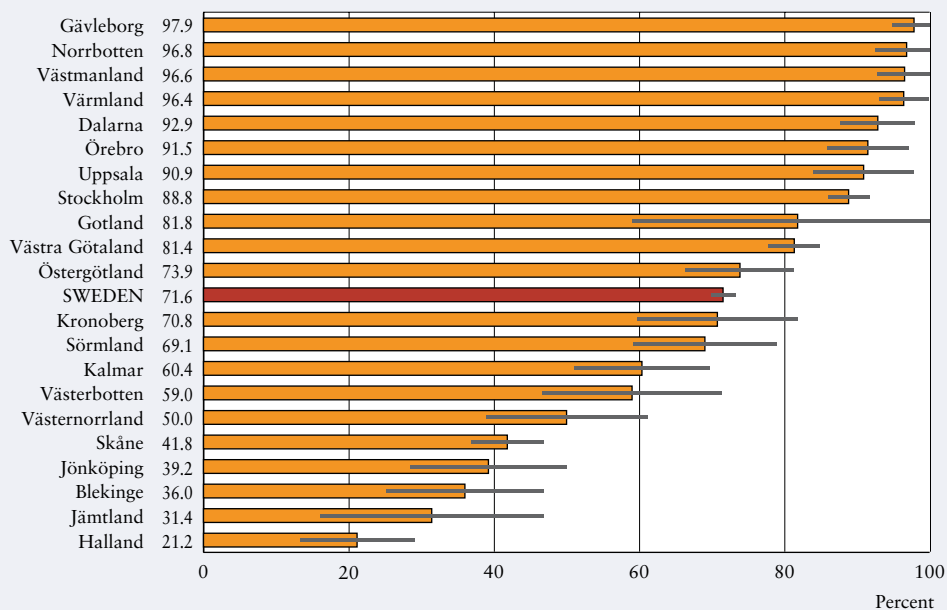
The long-term target of the National Rectal Cancer Register is that at least 90 per cent of patients receive a multidisciplinary assessment, both at commencement of treatment and postoperatively.

A follow-up performed by the register in 2009 found that only 58 per cent of patients age 85 and older were given a multidisciplinary assessment before commencement of treatment for a newly diagnosed malignancy.



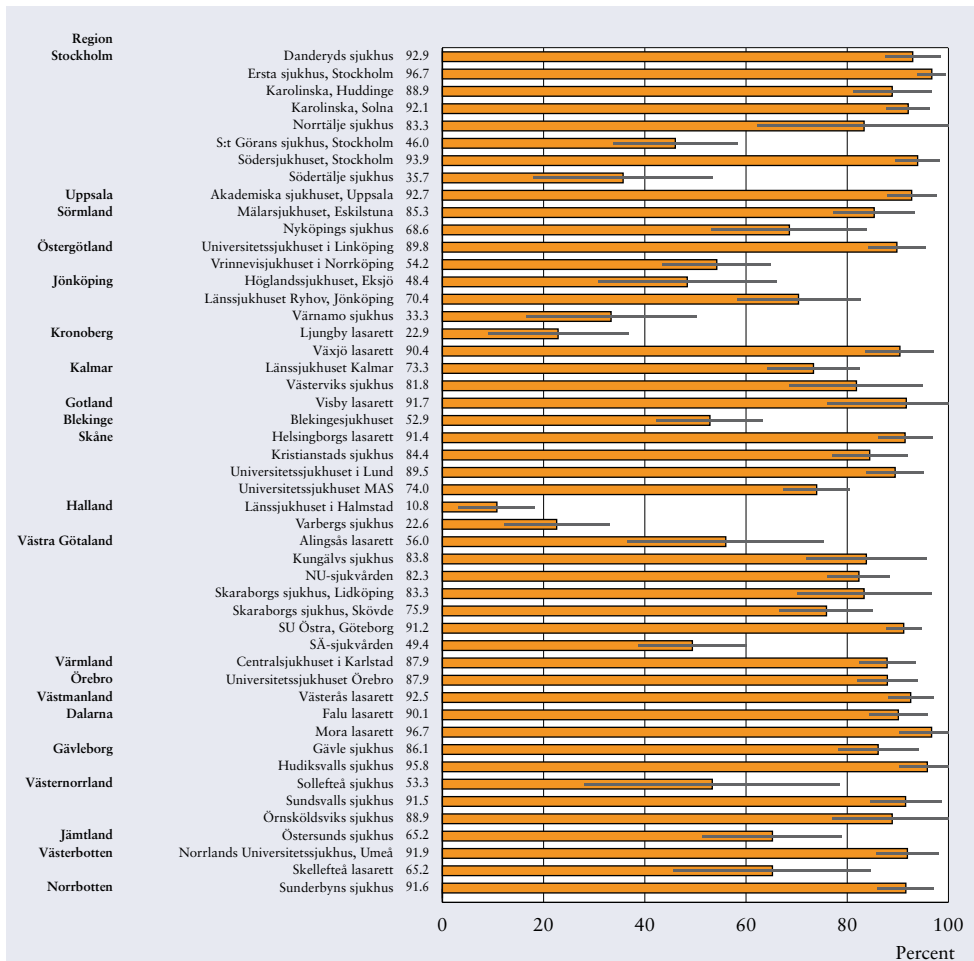
**Figure 45** Total Percentage of patients who had a multidisciplinary team meeting prior to treatment for rectal cancer, 2008–2009.

Source: National Rectal Cancer Register



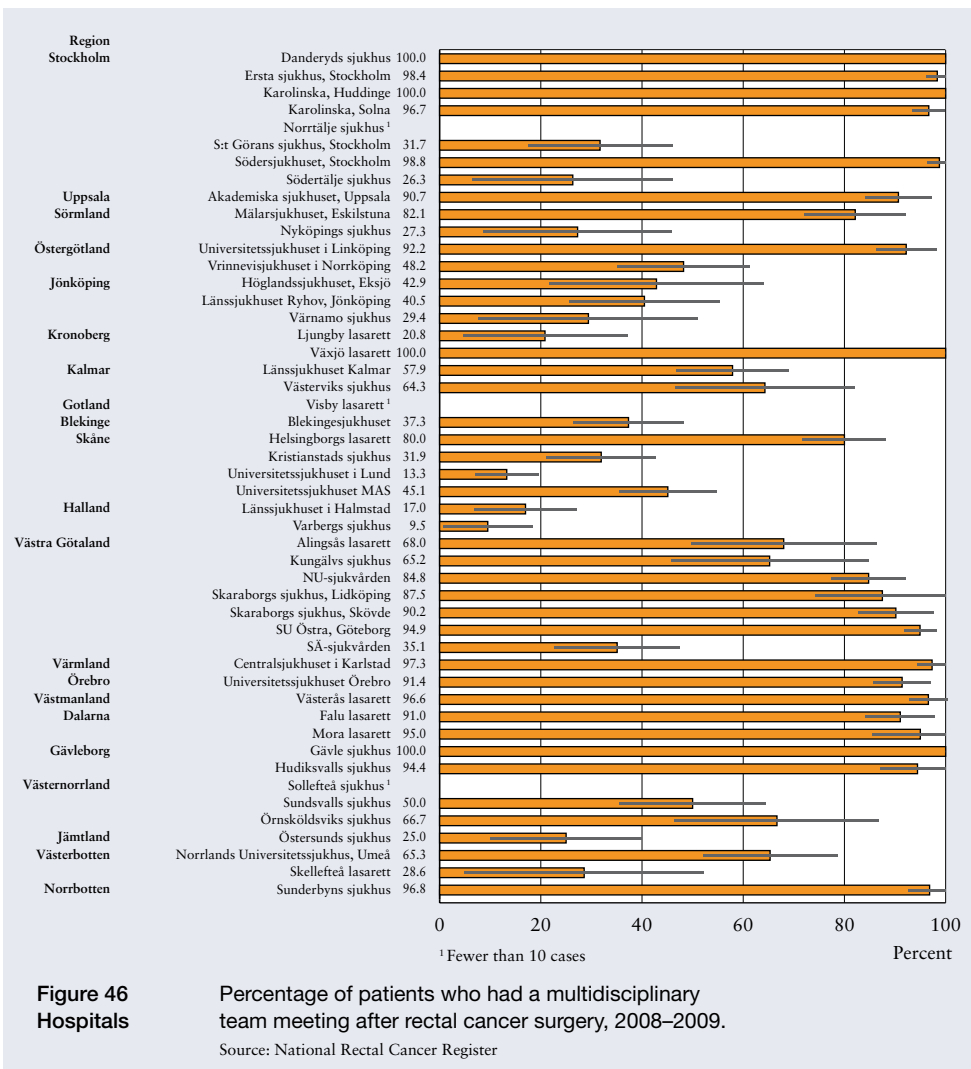
**Figure 46** Total Percentage of patients who had a multidisciplinary team meeting after rectal cancer surgery, 2008–2009.

Source: National Rectal Cancer Register



**Figure 45** Percentage of patients who had a multidisciplinary team meeting prior to treatment for rectal cancer, 2008–2009.  
**Hospitals** Source: National Rectal Cancer Register

Certain regional differences in reporting of multidisciplinary team meetings affect the outcomes in the diagram. In the first place, there is no uniform definition of the specialists who need to participate in order for a multidisciplinary team meeting to take place. Some counties report only meetings attended by all of the various types of specialists and are thereby underrepresented in the register. In the second place, the patient populations for whom a multidisciplinary team meeting is indicated are identified differently from region to region.

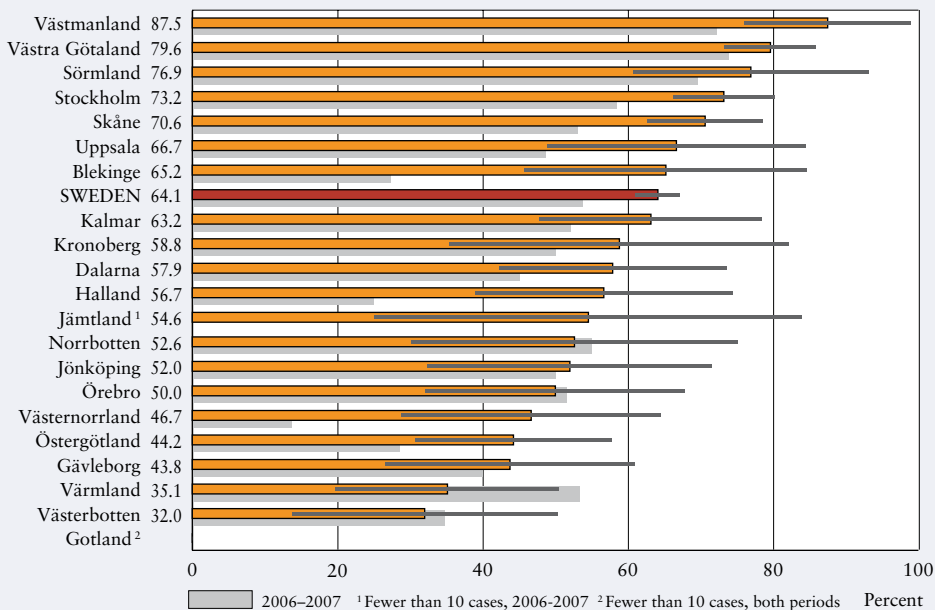


**Figure 46 Hospitals** Percentage of patients who had a multidisciplinary team meeting after rectal cancer surgery, 2008–2009.

Source: National Rectal Cancer Register

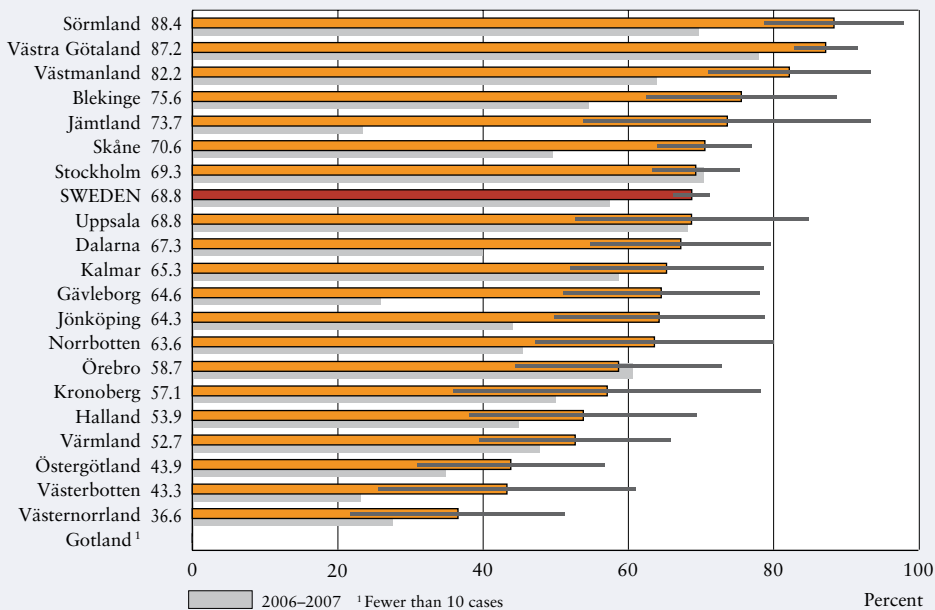
## 47 At least twelve lymph nodes examined in the tumour sample

After primary surgery for rectal cancer, the intestinal tissue and tumour that have been removed are sent to a pathology lab for microscopic and macroscopic examination. The purpose of the examinations is to offer a definitive assessment of the type and stage of the tumour. Correctly classifying the malignancy is integral to predicting progression of the disease and prescribing proper treatment. Scientific studies indicate that acceptable diagnostic quality requires examination of at least twelve lymph nodes. The quality of the examinations is affected by whether the surgeon removes sufficient tissue, as well as the pathologist’s analytical skills.



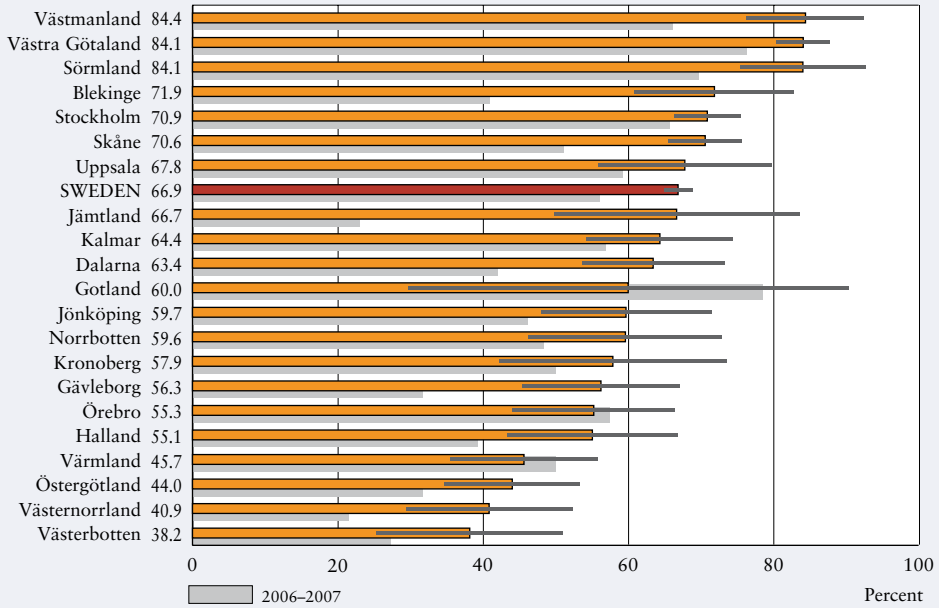
**Figure 47 Women** Percentage of patients who had at least twelve lymph nodes examined after rectal cancer surgery, 2008-2009.

Source: National Rectal Cancer Register

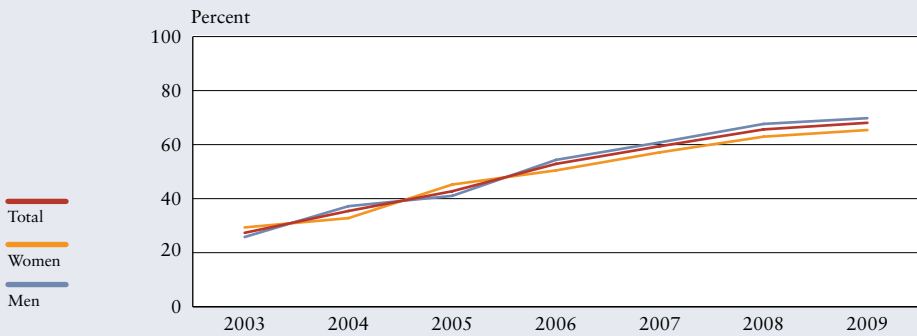


**Figure 47 Men** Percentage of patients who had at least twelve lymph nodes examined after rectal cancer surgery, 2008-2009.

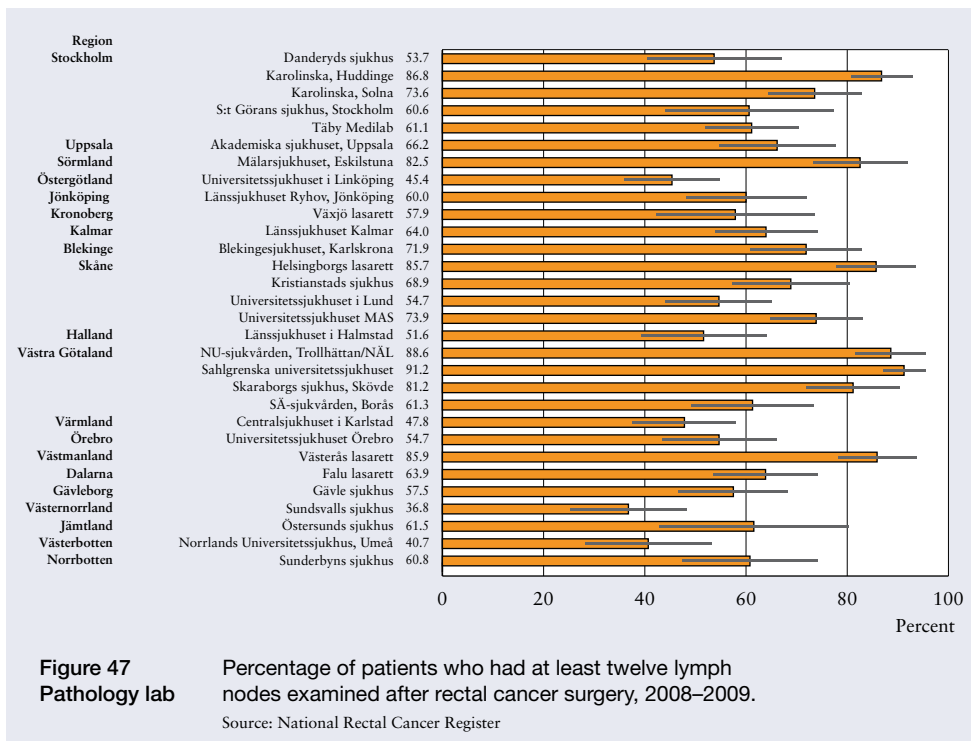
Source: National Rectal Cancer Register



**Figure 47 Total** Percentage of patients who had at least twelve lymph nodes examined after rectal cancer surgery, 2008–2009.  
Source: National Rectal Cancer Register

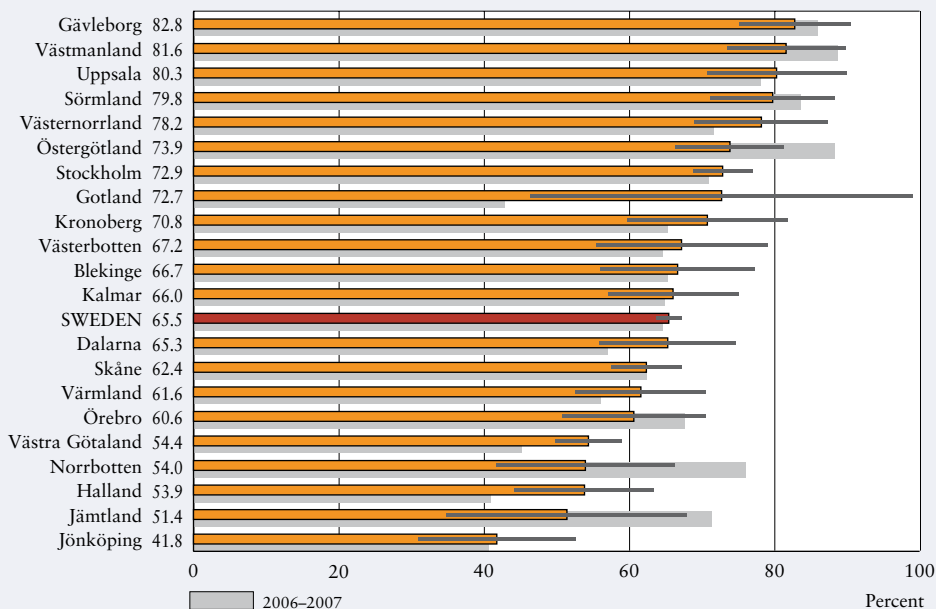


**Figure 47 Sweden** Percentage of patients who have at least twelve lymph nodes examined after rectal cancer surgery. Trend, 2003–2009.  
Source: National Rectal Cancer Register



**Figure 47** Pathology lab Percentage of patients who had at least twelve lymph nodes examined after rectal cancer surgery, 2008–2009. Source: National Rectal Cancer Register

The comparison covers a two-year period. With the exception of the large counties, however, the quality register contained few cases – as reflected in the broad confidence intervals.



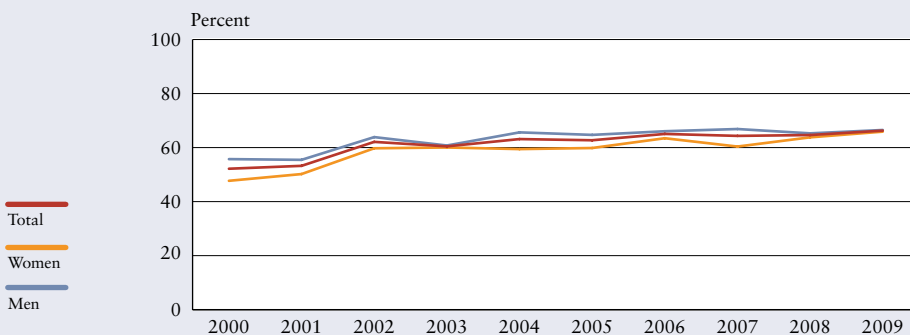
**Figure 48** Percentage of patients who received radiotherapy prior to rectal cancer surgery, 2008-2009.  
**Total** Source: National Rectal Cancer Register

## 48 Preoperative radiotherapy

Preoperative radiotherapy may be indicated to reduce the risk of local recurrence and occasionally to limit tumour extension as well. The NBHW national guidelines for rectal cancer care assign relatively high priority to the intervention, particularly if the tumour is difficult to remove. If the malignancy is small enough, however, the risk of recurrence is smaller than the risks associated with radiotherapy.

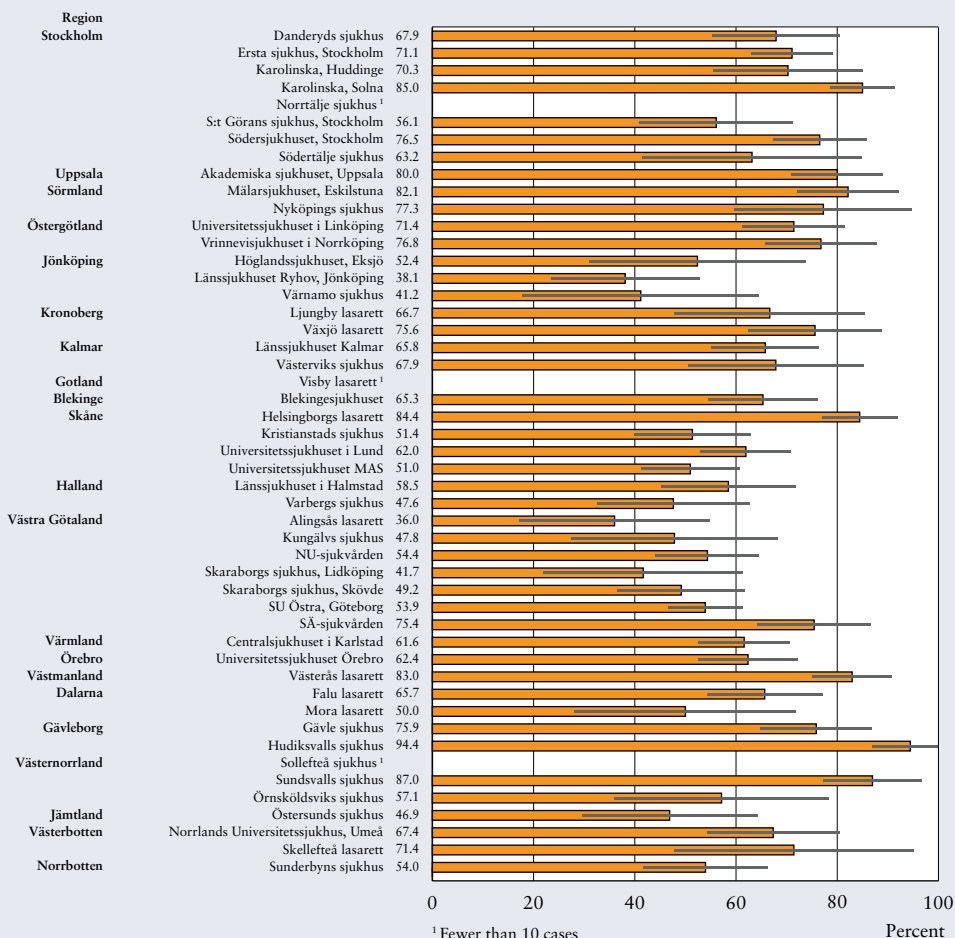
A follow-up by the rectal cancer register in 2009 showed that fewer patients over 80 were receiving preoperative radiotherapy.





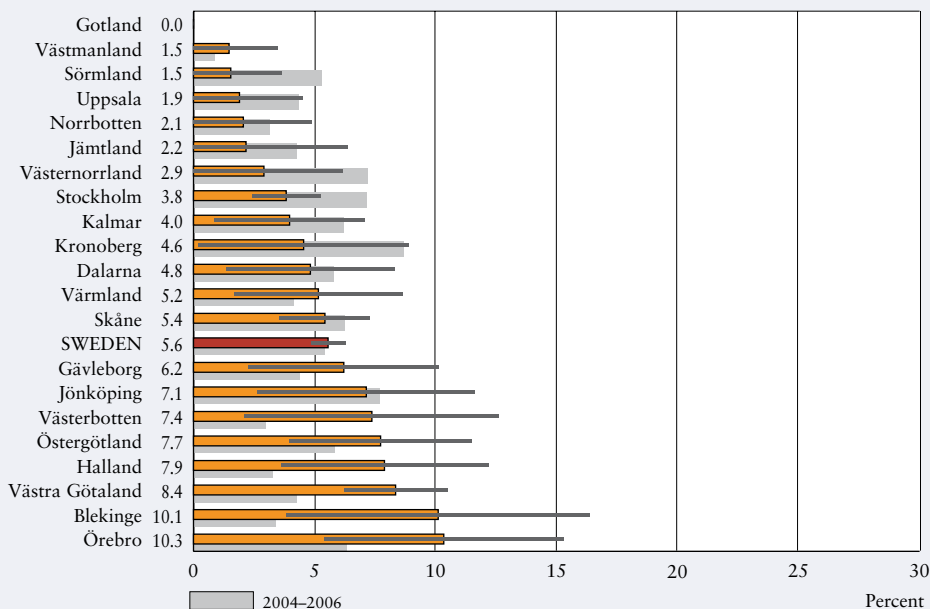
**Figure 48** Percentage of patients who received radiotherapy prior to rectal cancer surgery. Trend, 2000–2009.

Source: National Rectal Cancer Register



**Figure 48** Percentage of patients who received radiotherapy prior to rectal cancer surgery, 2008–2009.

Source: National Rectal Cancer Register



**Figure 49** Percentage of patients with perforated rectum during rectal cancer surgery, 2007–2009.

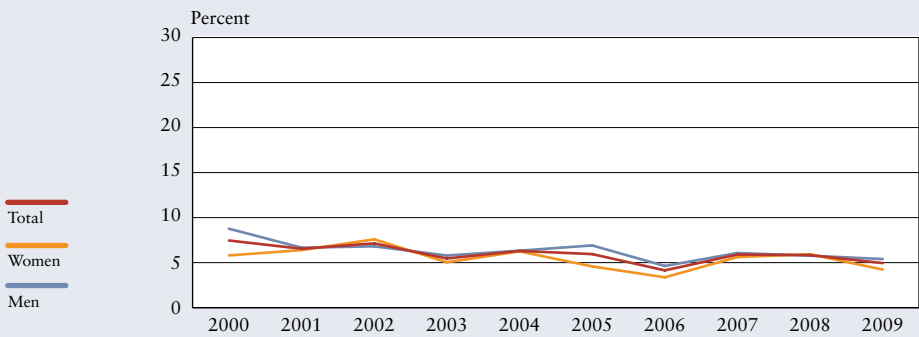
**Total**

Source: National Rectal Cancer Register

## 49 Perforation of the rectum during surgery

One important complication that can occur during surgery is perforation of the rectum. Such a development increases the risk of tumour recurrence and therefore suffering on the part of the patient.

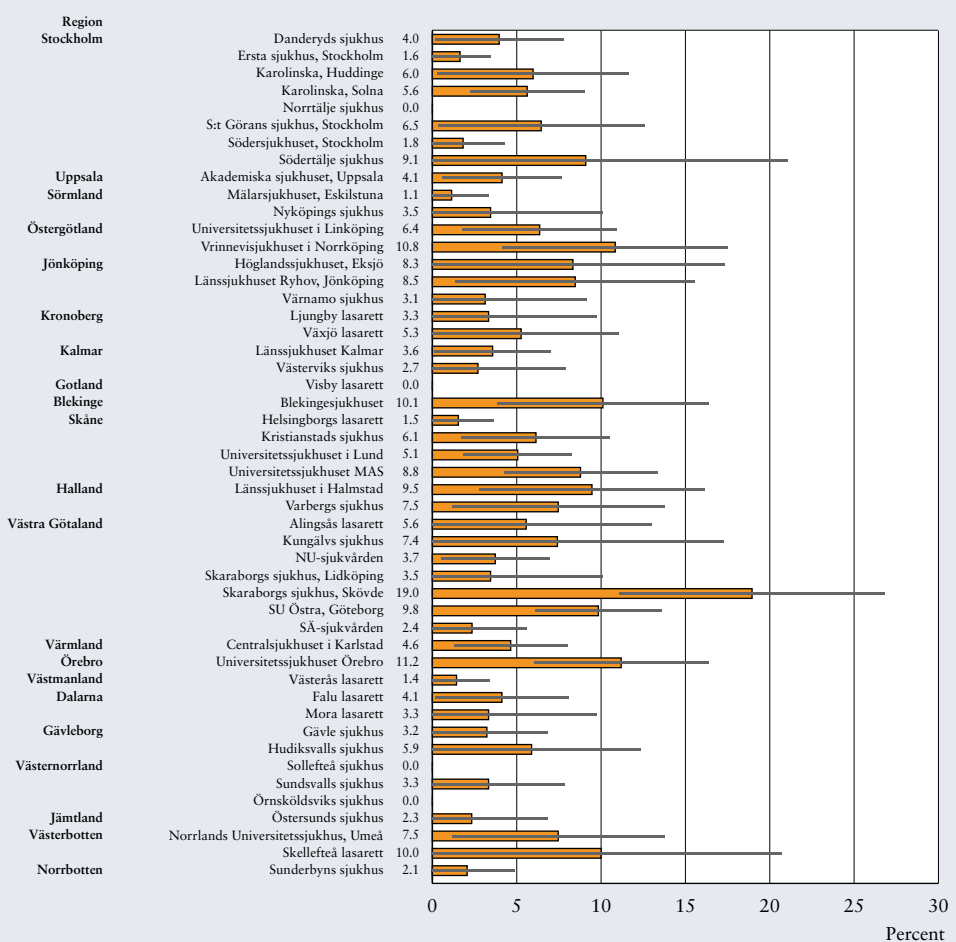
One goal is to minimise the number of complications that are due to healthcare interventions, in this case injury during the course of an operation. Perforations during surgery cannot be wholly eliminated given that they can also be caused by the patient's general condition.



**Figure 49**  
**Sweden**

**Percentage of patients with perforated rectum during rectal cancer surgery. Trend, 2000–2009.**

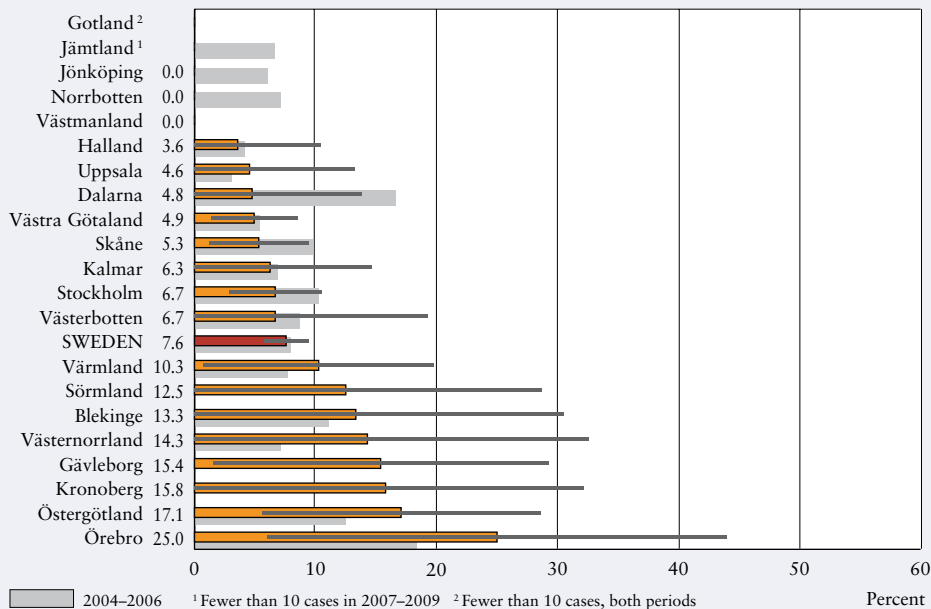
Source: National Rectal Cancer Register



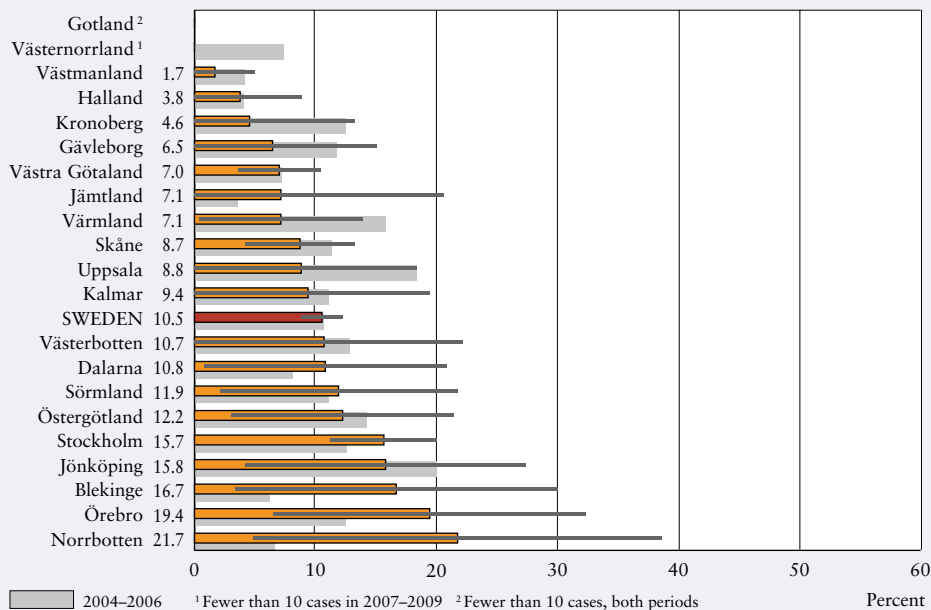
**Figure 49**  
**Hospitals**

**Percentage of patients with perforated rectum during rectal cancer surgery, 2007–2009.**

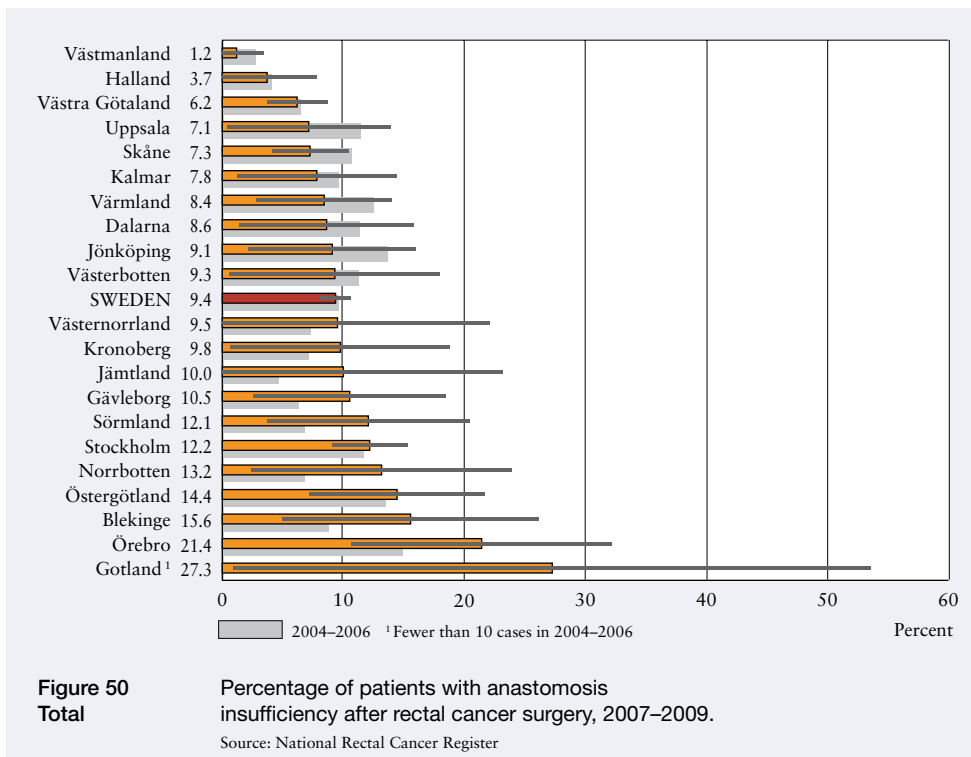
Source: National Rectal Cancer Register



**Figure 50** Percentage of patients with anastomosis insufficiency after rectal cancer surgery, 2007–2009. **Women**  
Source: National Rectal Cancer Register



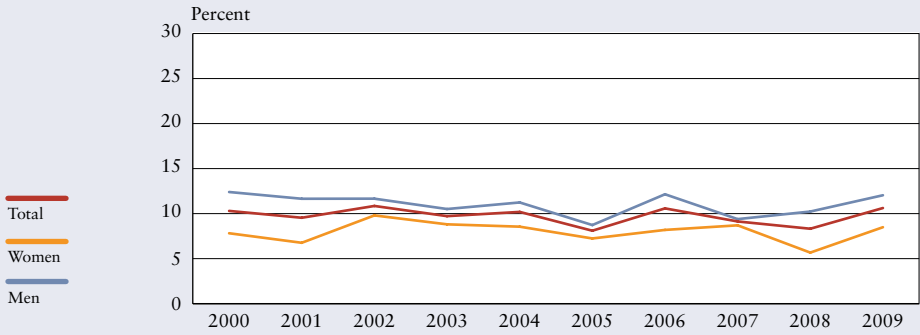
**Figure 50** Percentage of patients with anastomosis insufficiency after rectal cancer surgery, 2007–2009. **Men**  
Source: National Rectal Cancer Register



## 50 Anastomosis insufficiency after surgery

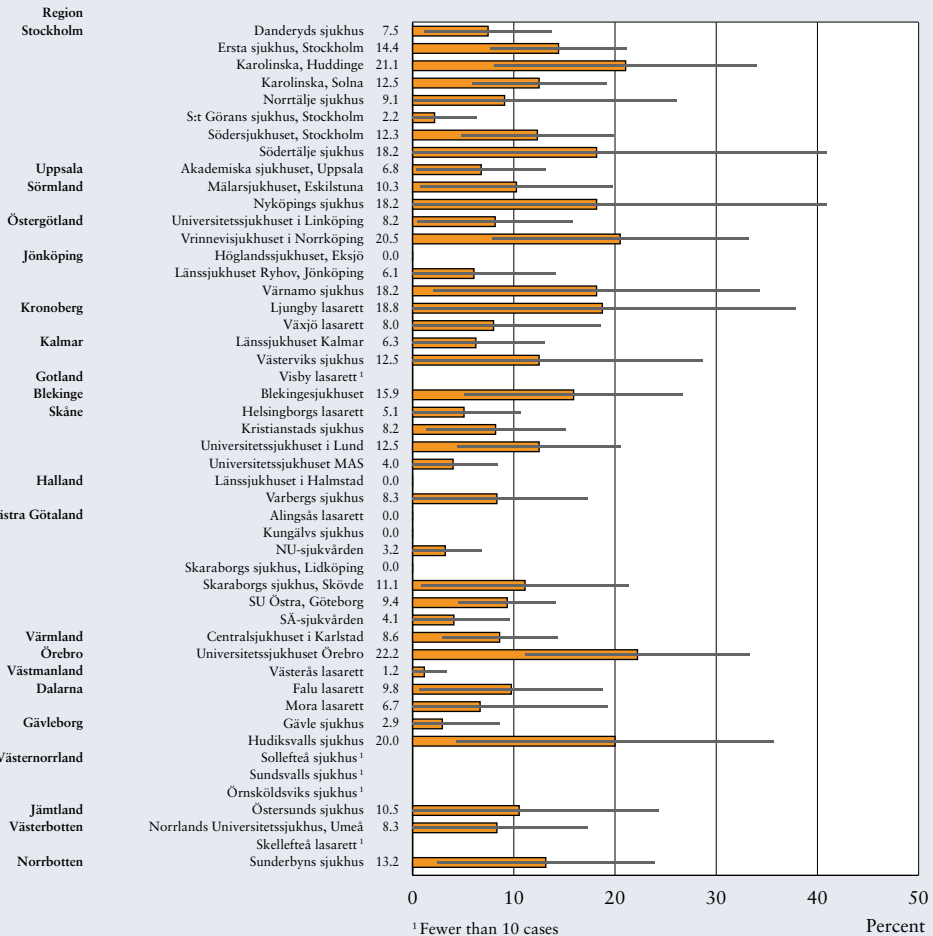
Surgery involves removal of the tumour, followed in approximately 50 per cent of cases by one of several methods to reconnect the two ends of the bowel. The area that has been reconnected is referred to as anastomosis. A serious postoperative complication is anastomosis insufficiency – leakage of faeces into the abdomen – which can cause peritonitis (inflammation) and sepsis (blood poisoning). The condition is life-threatening, requiring reoperation and posing the risk of a permanent stoma (opening). The NBHW national guidelines for rectal cancer care identify the percentage of patients who develop anastomosis insufficiency after surgery as an important indicator to monitor.

The outcome is affected to some extent by whether and when the patient received preoperative radiotherapy. The comparison does not take case mix, age, tumour stage, or the patient’s condition into consideration. Such factors can affect the occurrence of anastomosis insufficiency.



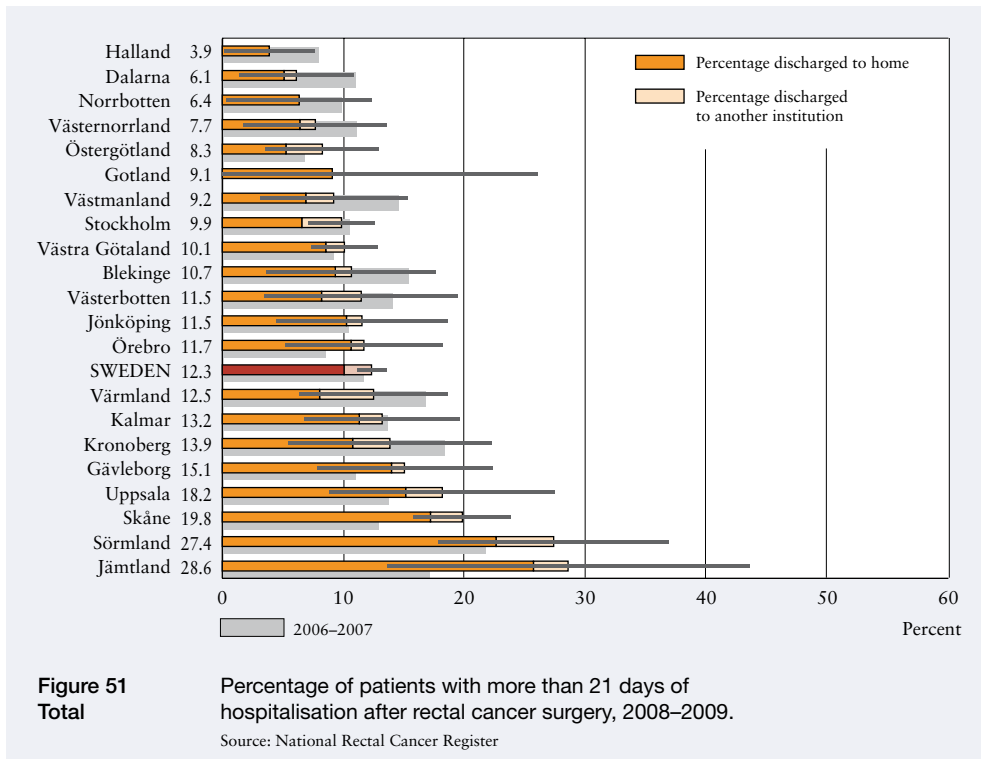
**Figure 50** Percentage of patients with anastomosis insufficiency after rectal cancer surgery. Trend, 2000–2009.

Source: National Rectal Cancer Register



**Figure 50** Percentage of patients with anastomosis insufficiency after rectal cancer surgery, 2007–2009.

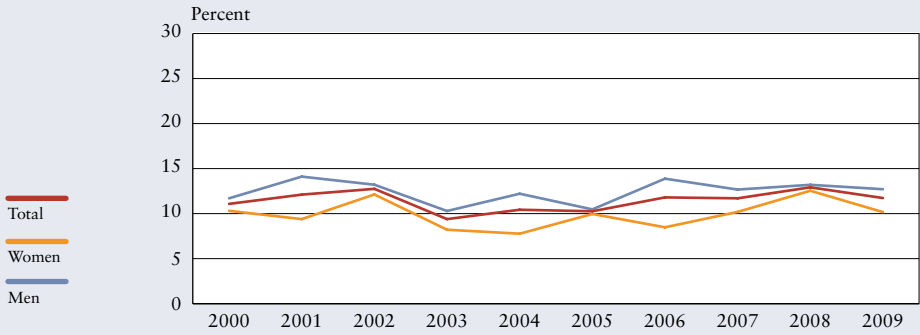
Source: National Rectal Cancer Register



## 51 More than 21 days of hospitalisation after surgery

Assuming no complications occur, hospitalisation after surgery should not exceed 21 days. The goal is based on a follow-up by the National Rectal Cancer Register for 1995-2009 showing that the median hospitalisation period following surgery was fewer than 13 days for patients discharged to home and fewer than 21 days for those who were discharged to another institution (a different department or special housing). Only a few years deviated from that pattern. Thus, patients who were discharged to another institution had generally been hospitalised longer.

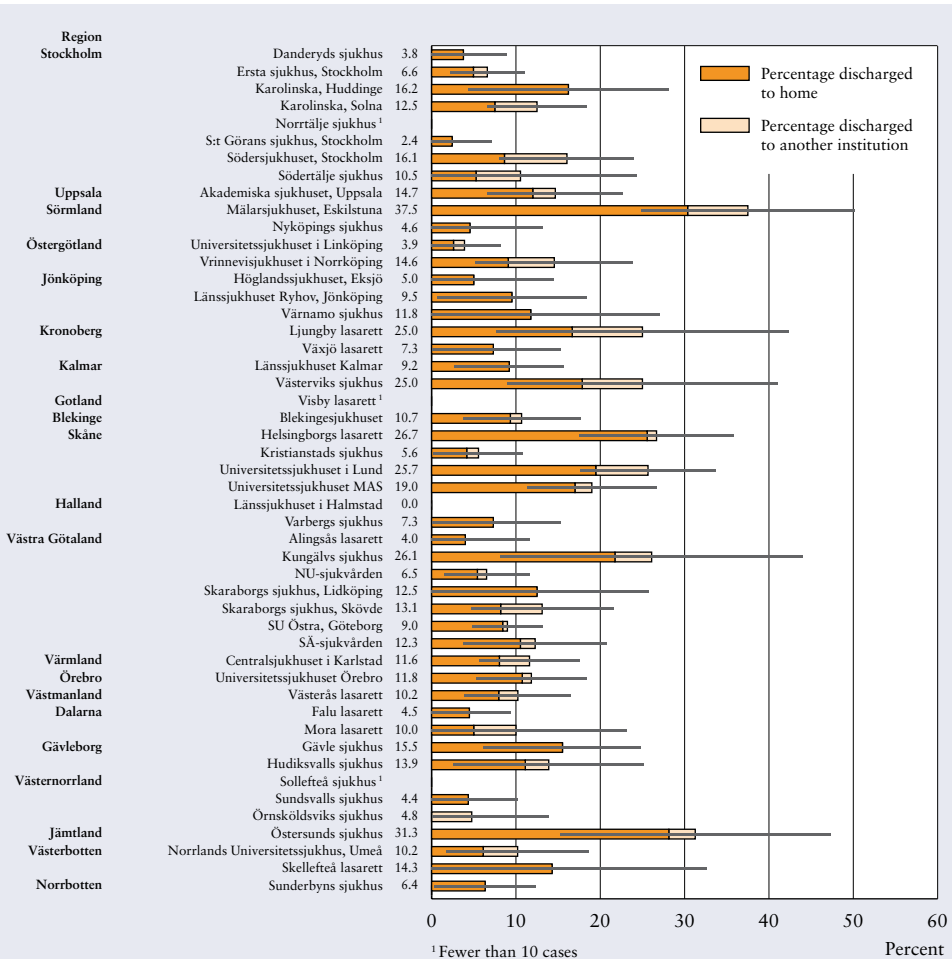
The comparison does not take the possible effects of comorbidity or the patient's preoperative condition into consideration.



**Figure 51**  
**Sweden**

**Percentage of patients with more than 21 days of hospitalisation after rectal cancer surgery. Trend, 2000–2009.**

Source: National Rectal Cancer Register

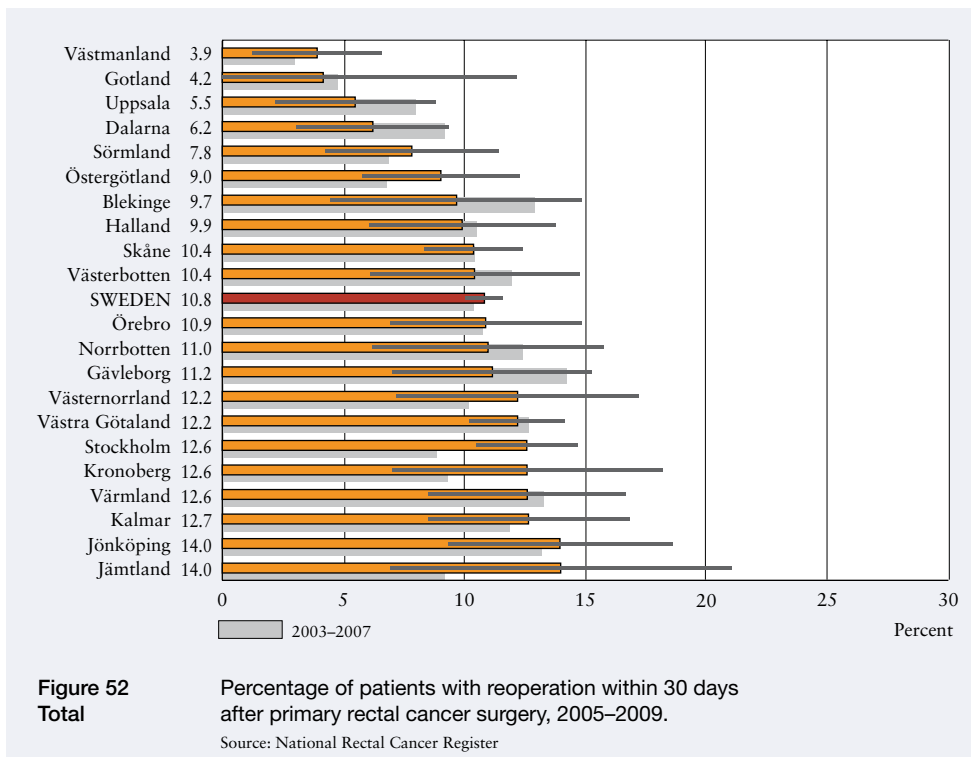


**Figure 51**  
**Hospitals**

**Percentage of patients with more than 21 days of hospitalisation after rectal cancer surgery, 2008–2009.**

Source: National Rectal Cancer Register



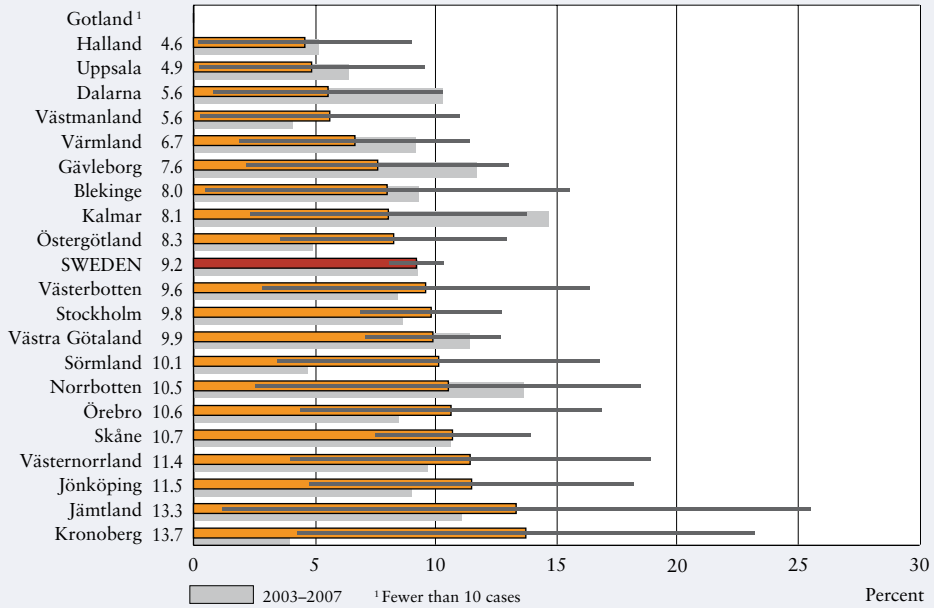


## 52 Reoperation due to complications within 30 days of primary surgery

Approximately 82 per cent of all rectal cancer surgery involves removal of the entire tumour. The location and size of the tumour, as well as the patient’s general condition, affect the scope and riskiness of the operation. Relatively prompt reoperation may be required due to bleeding, infection, leakage or another complication. Reoperation entails additional suffering for the patient and increases the risk of further complications.

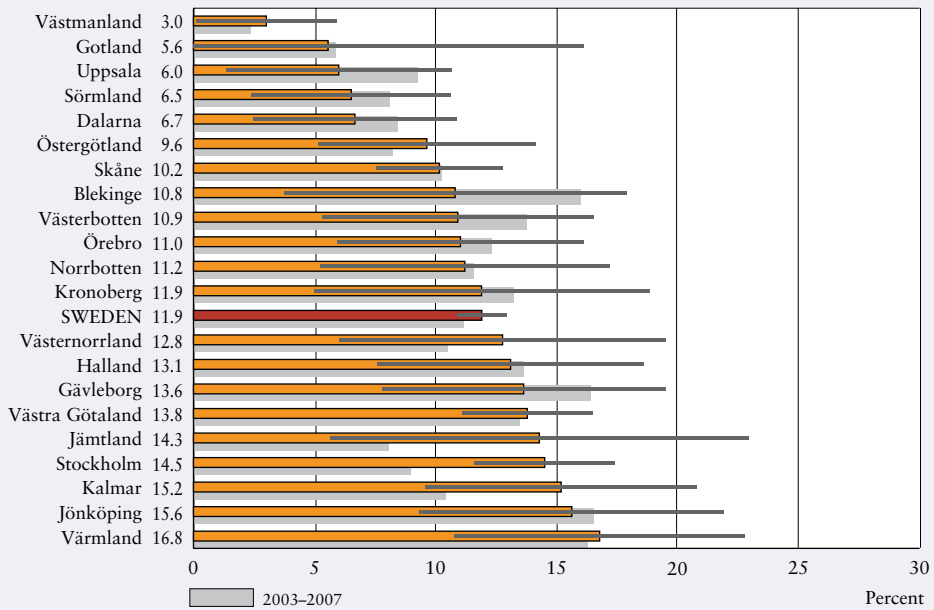
The NBHW national guidelines for rectal cancer care identify reoperation within 30 days of primary surgery as an important indicator to monitor.

One source of error in comparing data is that some hospitals report minor interventions as reoperations and some do not. The percentage of reoperations is also related to the way that primary surgery was performed and the patient’s condition at the time.



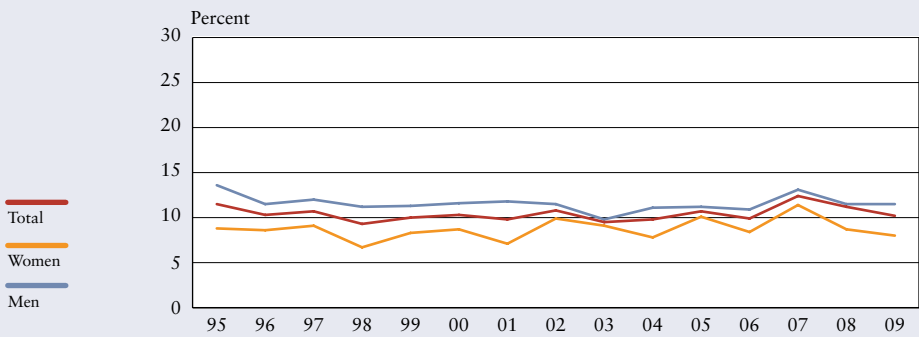
**Figure 52** Percentage of patients with reoperation within 30 days after primary rectal cancer surgery, 2005-2009. **Women**

Source: National Rectal Cancer Register



**Figure 52** Percentage of patients with reoperation within 30 days after primary rectal cancer surgery, 2005-2009. **Men**

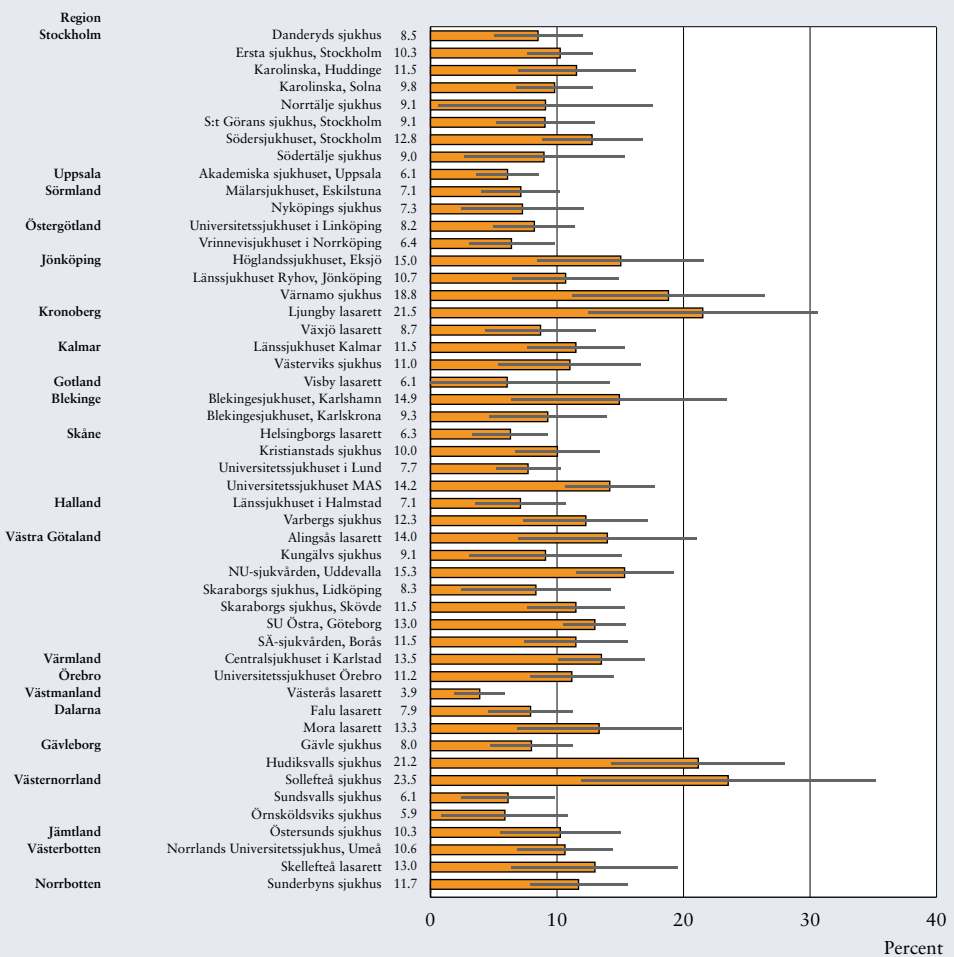
Source: National Rectal Cancer Register



**Figure 52**  
**Sweden**

**Percentage of patients with reoperation within 30 days after primary rectal cancer surgery. Trend, 1995–2009.**

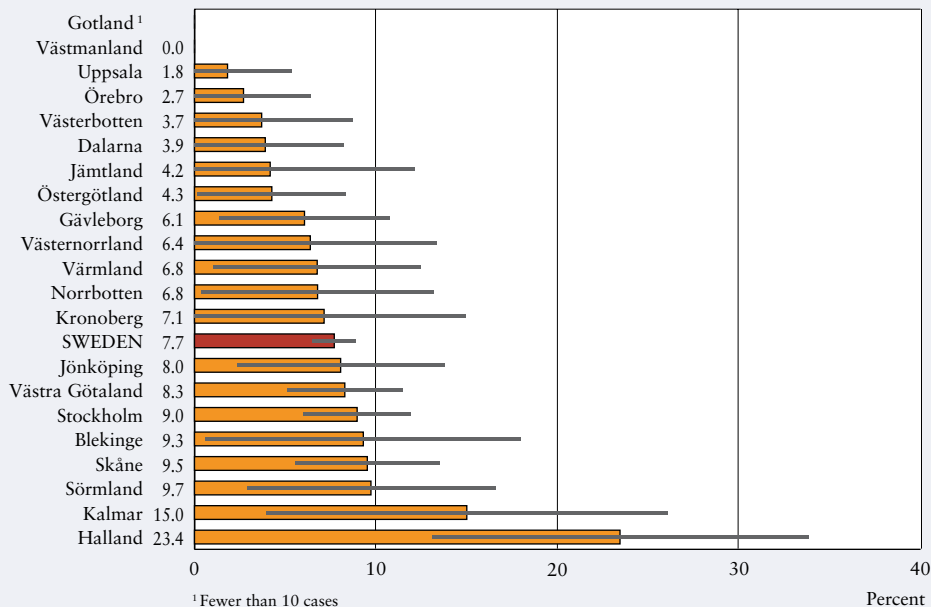
Source: National Rectal Cancer Register



**Figure 52**  
**Hospitals**

**Percentage of patients with reoperation within 30 days after primary rectal cancer surgery, 2005–2009.**

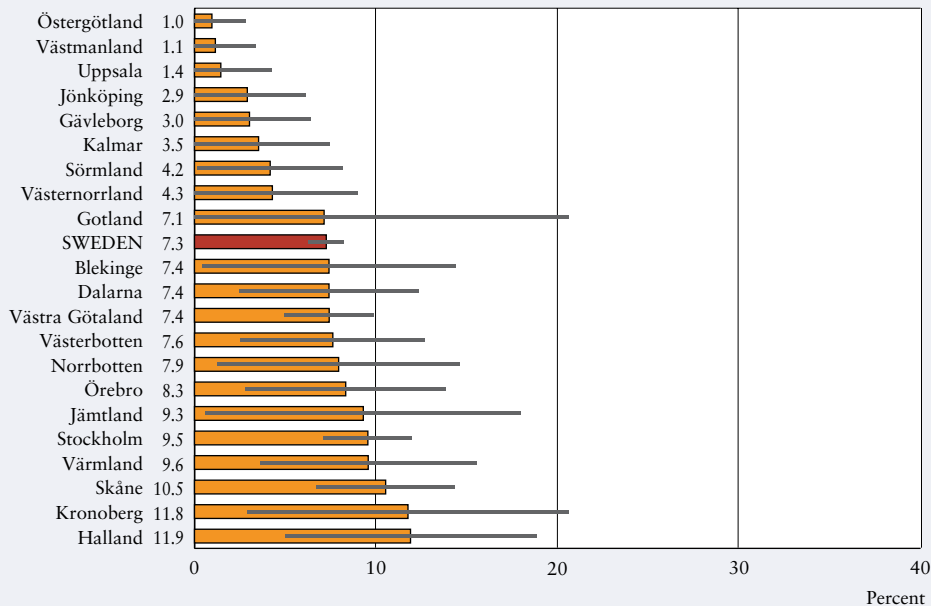
Source: National Rectal Cancer Register



**Figure 53**  
**Women**

Percentage of patients with relapse of cancer of the pelvis within five years after rectal cancer surgery. Patients who underwent surgery in 2001–2004 with follow-up through 2009.

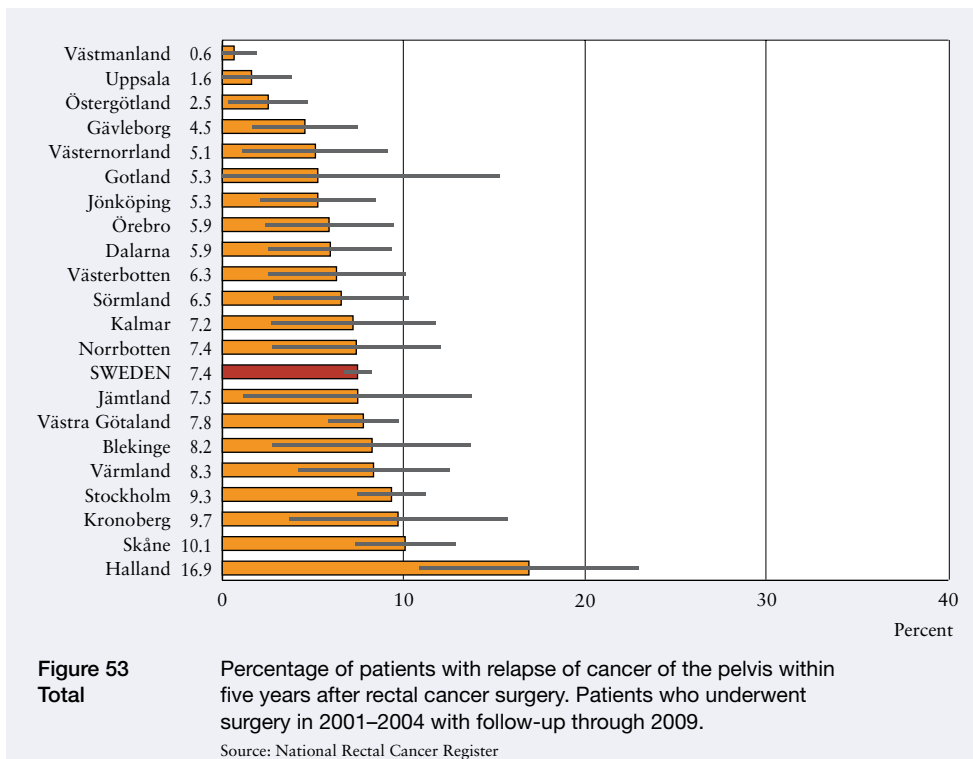
Source: National Rectal Cancer Register



**Figure 53**  
**Men**

Percentage of patients with relapse of cancer of the pelvis within five years after rectal cancer surgery. Patients who underwent surgery in 2001–2004 with follow-up through 2009.

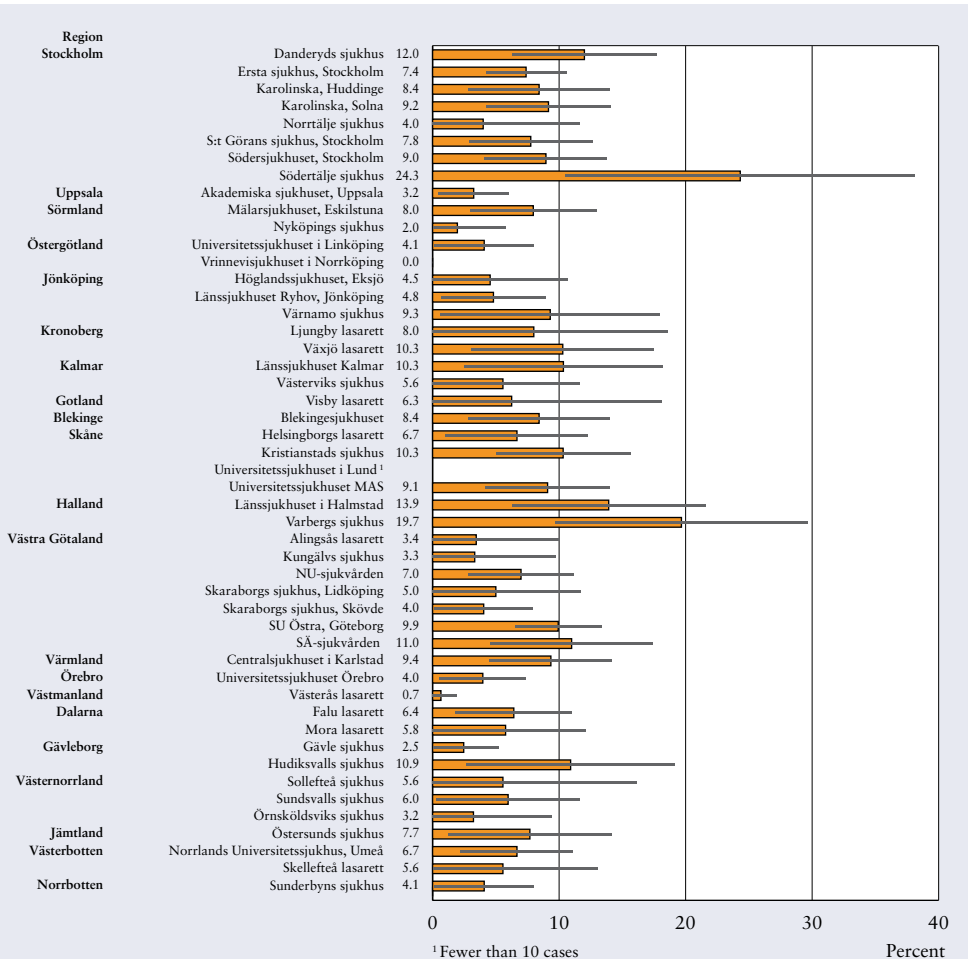
Source: National Rectal Cancer Register



### 53 New cancer of the pelvis within five years of surgery

Relapse refers to the recurrence of a malignancy in an area that was previously treated by surgery or radiotherapy. The result is a very high risk of incurable disease or extensive surgery, chemotherapy or radiotherapy. The NBHW national guidelines for rectal cancer care identify the percentage of relapses in the pelvis within two years after surgery as an important indicator to monitor. The rectal cancer register monitors tumour recurrence for five years after surgery, as presented in this comparison.

The result is affected to some extent by the patient’s preoperative condition.



**Figure 53**  
**Hospitals**

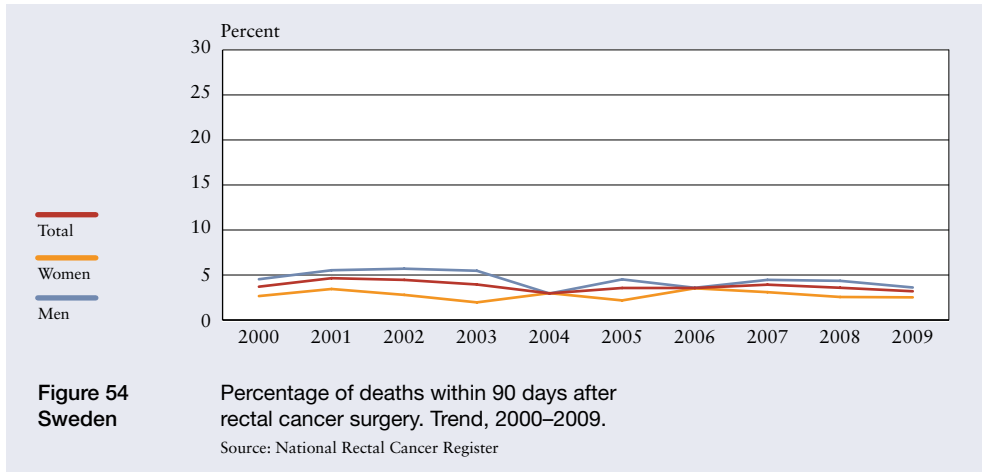
Percentage of patients with relapse of cancer of the pelvis within five years after rectal cancer surgery. Patients who underwent surgery in 2001–2004 with follow-up through 2009.

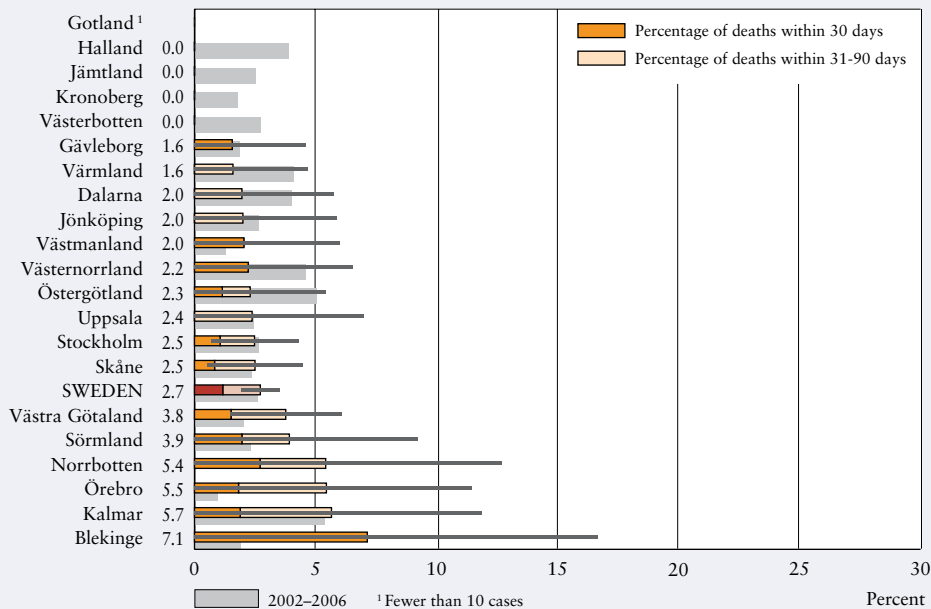
Source: National Rectal Cancer Register

## 54 Deaths within 30 and 90 days of surgery

The NBHW national guidelines for rectal cancer care identify the percentage of deaths within 30 days of surgery as an important indicator for monitoring health-care quality. The indicator reflects the selection of patients for surgery, as well as the care they receive before, during and after the operation. Given that patients who experience complications generally survive the first 30 days thanks to intensive care and other interventions, this comparison also presents those who die within 90 days.

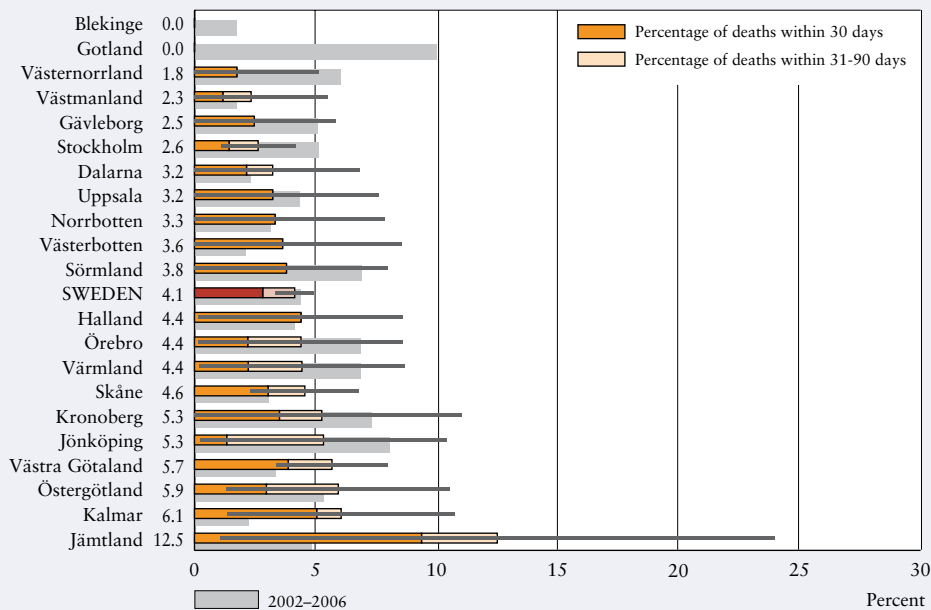
Age, gender, and severity of the malignancy also affect the percentage of deaths. Table 2 shows the odds ratio by county, adjusted for age, gender and tumour stage. A value of 1 is assigned to the national average of patients who die within 90 days of surgery. A value less than 1 represents a percentage below the national average and a value greater than 1 represents a percentage above the national average.





**Figure 54 Women** Percentage of deaths within 30 and 90 days after rectal cancer surgery, 2007–2009.

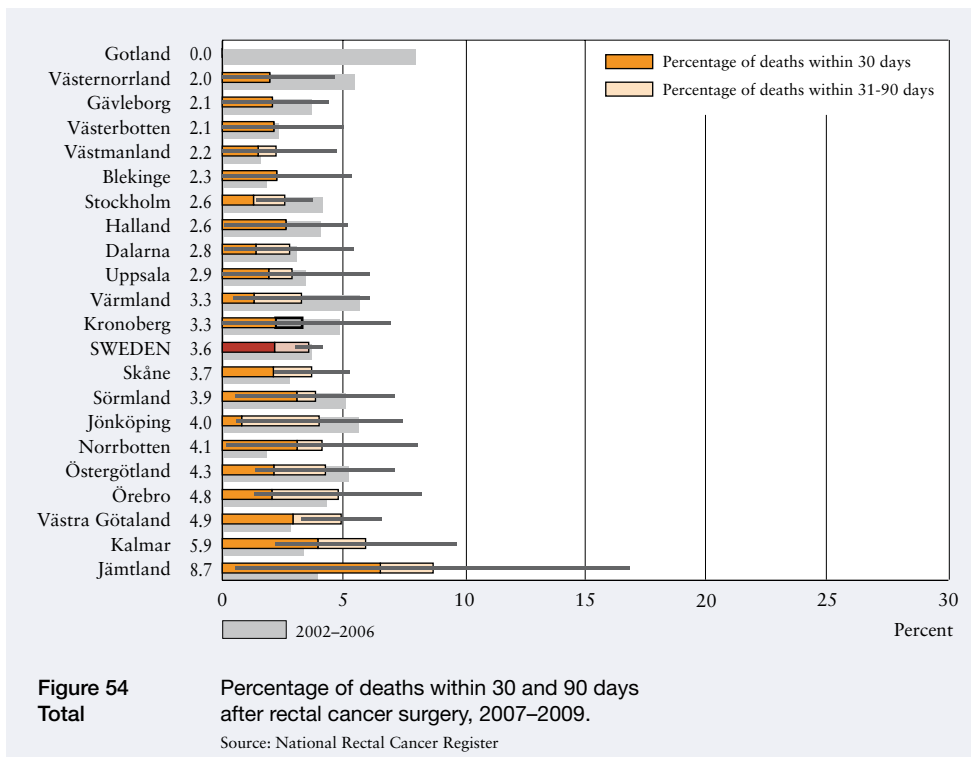
Source: National Rectal Cancer Register



**Figure 54 Men** Percentage of deaths within 30 and 90 days after rectal cancer surgery, 2007–2009.

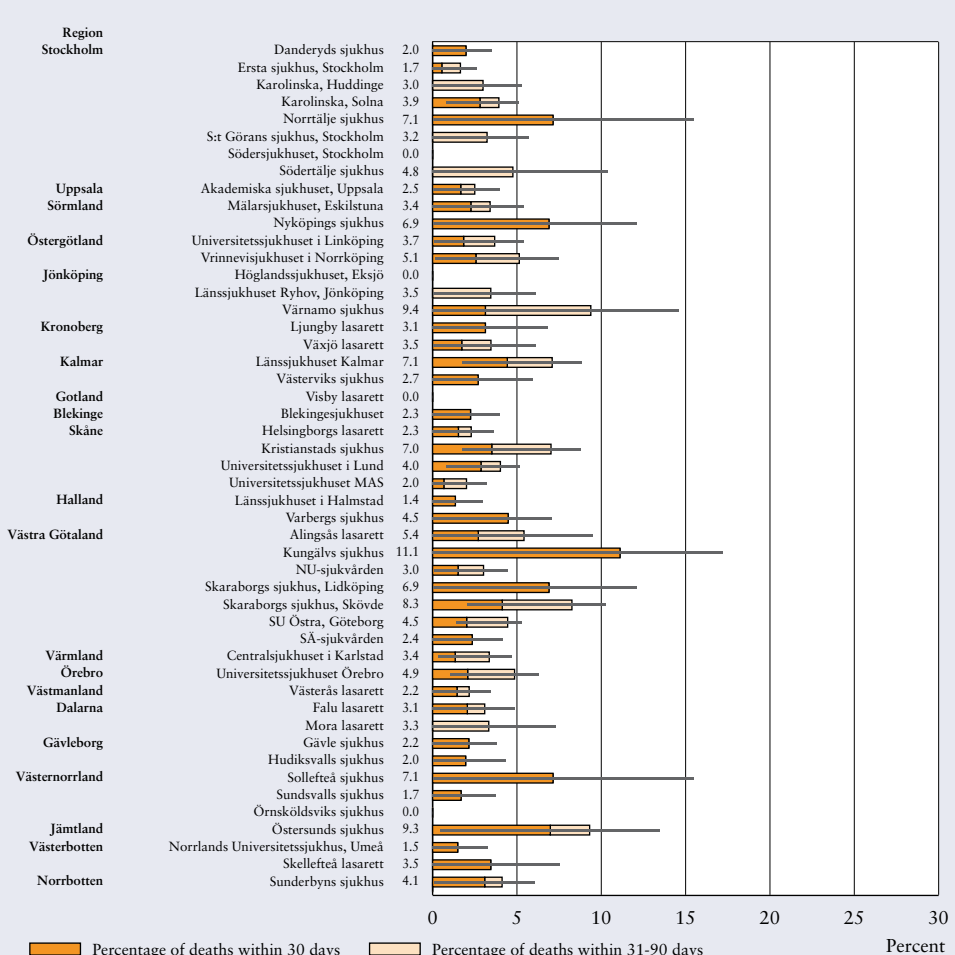
Source: National Rectal Cancer Register





**Table 2**

County council	Odds ratio	95 % Confidence interval	County council	Odds ratio	95 % Confidence interval
Stockholm	0.84	0.51-1.39	V. Götaland	1.37	0.90-2.09
Uppsala	0.58	0.14-2.41	Värmland	0.93	0.37-2.32
Sörmland	1.18	0.46-2.99	Örebro	1.25	0.56-2.81
Östergötland	1.33	0.63-2.82	Västmanland	0.74	0.23-2.38
Jönköping	1.08	0.42-2.73	Dalarna	0.74	0.27-2.08
Kronoberg	0.85	0.26-2.83	Gävleborg	0.40	0.10-1.65
Kalmar	1.57	0.77-3.23	Västernorrland	0.68	0.16-2.80
Gotland	0.00		Jämtland	2.34	0.80-6.81
Blekinge	0.69	0.17-2.88	Västerbotten	0.52	0.13-2.18
Region Skåne	1.09	0.68-1.76	Norrbottn	1.23	0.44-3.43
Halland	0.30	0.07-1.23			



**Figure 54** Percentage of deaths within 30 and 90 days after rectal cancer surgery, 2007–2009.

Source: National Rectal Cancer Register

## LUNG CANCER

Statistics for 2009	Women	Men
Number of diagnoses	1 772	1 696
Percentage of all cancer cases	7%	6%
Prevalence, total	4 248	3 419
Relative one-year survival rate	43%	37.7%
Number of deaths	1 656	1 830

As the fifth most common form of the disease, lung cancer was diagnosed in 1 772 women and 1 696 men in 2009. Approximately half of newly diagnosed patients are over 70 and fewer than 1 per cent are below 40. Lung cancer claims approximately 3 500 Swedish lives every year, more than any other form of the disease. The most frequent cause by far is smoking.

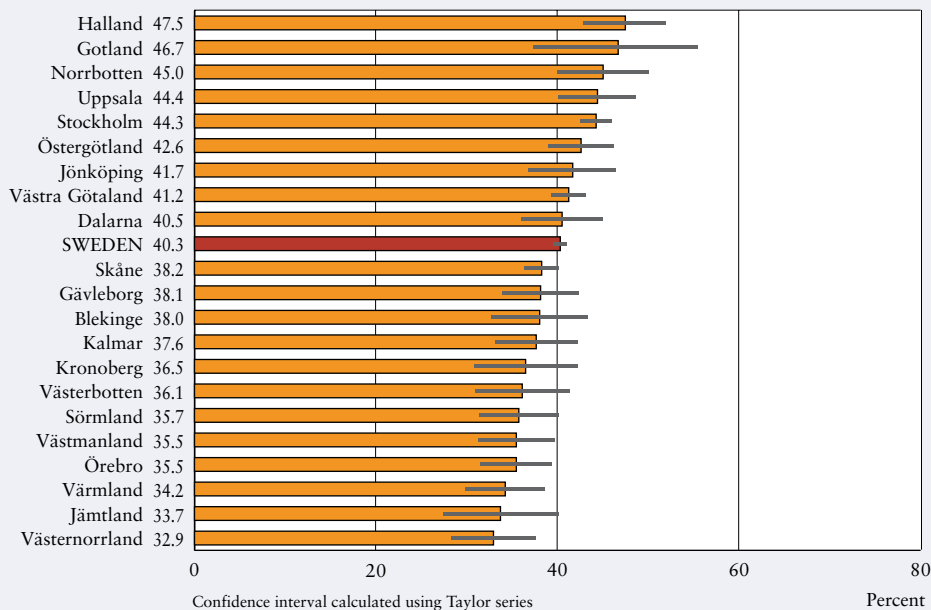
The number of cases has decreased among men since the 1980s and increased among women, most probably due to changes in women's smoking habits since the 1950s. The number of smokers has decreased in recent decades, but the steady growth of cases among women reflects their smoking habits 20 years ago and earlier.

Lung cancer is aggressive but can be cured if it has not metastasised. There are two different types of the disease: small-cell and non-small-cell. Approximately 80 per cent of all lung cancer is non-small-cell, 15 per cent small-cell and 5 per cent indeterminate. Stages I and II of non-small-cell cancer are amenable to surgery, assuming that the patient does not have reduced lung capacity, poor general health or other diseases that present obstacles. Stage III non-small-cell lung cancer is limited to the thoracic cavity and may be operable. Stage IV non-small-cell cancer has metastasised and cannot be cured through surgery.

Approximately 70 per cent of patients are at stages III or IV at the time of diagnosis and usually cannot be cured. Some 75 per cent of them die within a year. The various palliative treatment methods (drug therapy, radiotherapy or other means of alleviating symptoms) all focus on improving the quality of life of these patients.

This report presents outcomes for eight indicators that reflect either curative or palliative interventions. The indicators look at survival rates, diagnosis, curative surgery, palliative treatment, multidisciplinary team meetings and waiting times. Seven of the indicators are based on data from the National Lung Cancer Register, whereas the survival indicator is taken from the Swedish Cancer Register.

The national guidelines for lung cancer care published by the NBHW in 2011 contain targets for several of the indicators. The project to formulate the targets in spring 2011 collected data from the National Lung Cancer Register on everyone who had been diagnosed in 2002–2009. The subsequent statistical method chose the



**Figure 55** Lung cancer – relative one-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values. Source: Swedish Cancer Register, Swedish National Board of Health and Welfare

90th percentile of the nationwide results as the target. Thus, the target is realistic in the sense that some counties have already attained it.

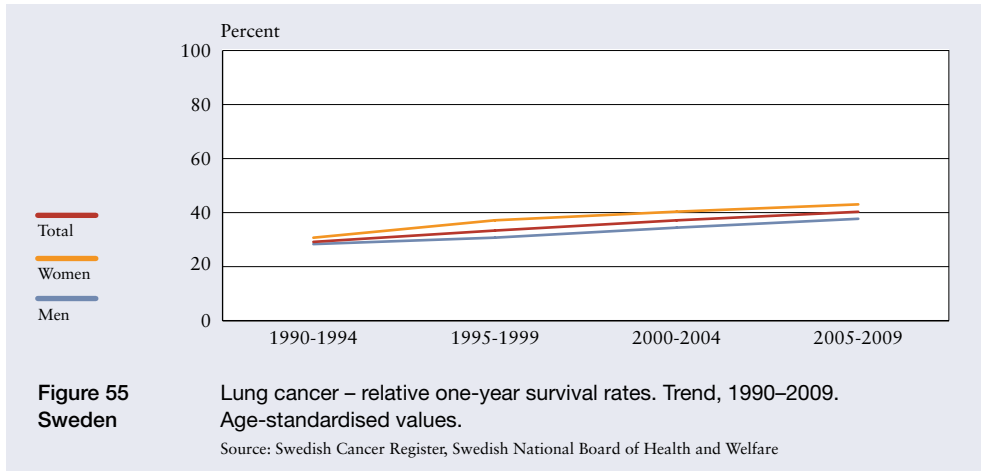
The comparisons that are presented are for 2002–2009 when no targets had yet been set. Along with the outcomes for each indicator, however, the discussion specifies the future targets that can now be used to find potential for improvement in lung cancer treatment and care.

The same sample from the National Lung Cancer Register has been used as during the project to formulate the targets. Thus, the outcomes cover a longer period than is typical for this report.

### 55 Lung cancer – relative one-year, two-year and five-year survival rates

Relative survival rates for lung cancer are low but somewhat higher among women than men. Survival rates, particularly for one or two years, have trended upwards since the early 1990s. More women develop and die of lung cancer before the age of 60, whereas the majority of older patients are men.

Figure 55 indicates that the relative one-year survival rate among men rose by almost 10 per cent from 1990-1994 to 2005–2009. The increase among women was somewhat greater. Men had a relative one-year survival rate of 37.7 per cent and a

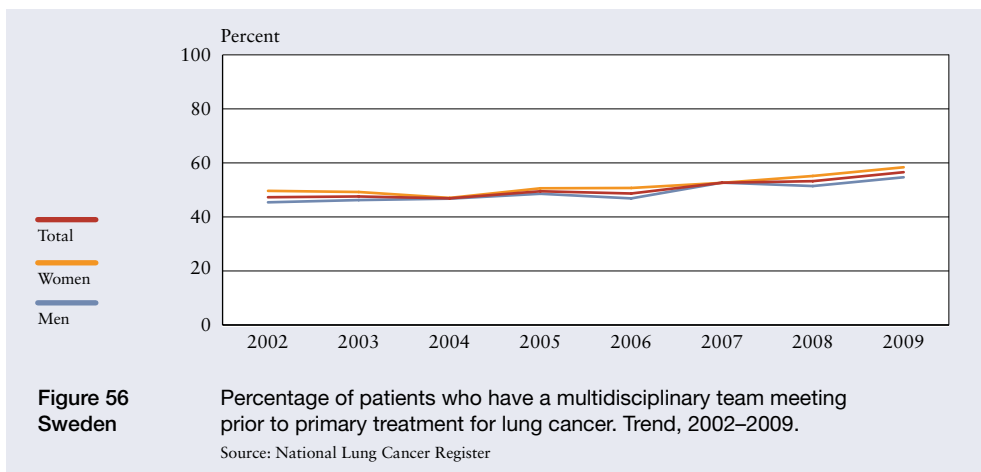


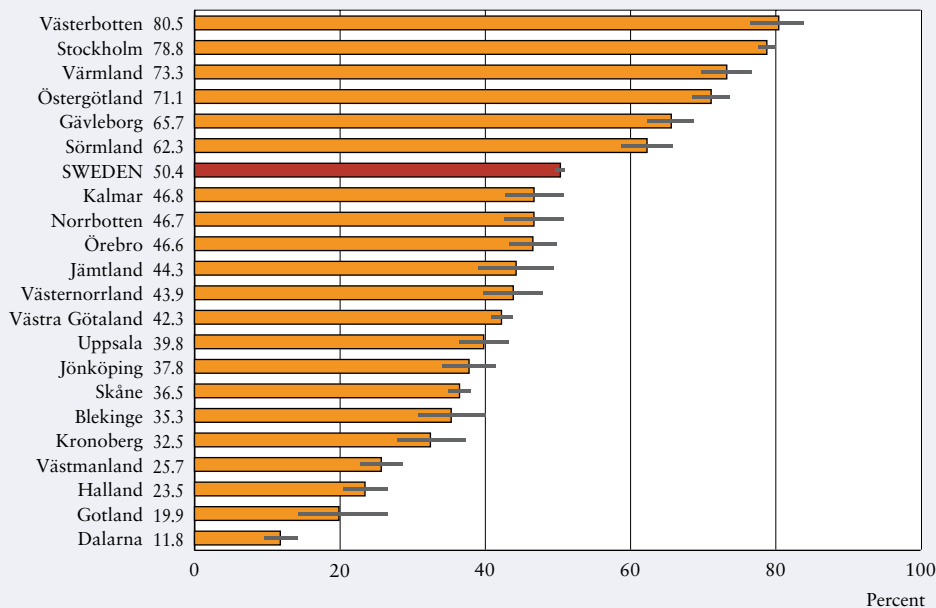
two-year rate of 20.9 per cent in 2005–2009, as opposed to 43 per cent and 27 per cent respectively for women. There were significant regional differences: anywhere from 32.9 to 47.5 per cent. The older the patient at the time of diagnosis, the lower the survival rate.

The relative five-year survival rate is approximately 12 per cent among men and 15 per cent among women.

## 56 Multidisciplinary team meeting prior to treatment

Primary lung cancer treatment may be preceded by a multidisciplinary team meeting, a comprehensive assessment for the purpose of optimising the intervention. Surgery, oncology, pulmonary, radiology, pathology and other specialists, as well as nurses, may participate. A multidisciplinary team meeting is particularly important when the benefit of surgery, radiotherapy or drug therapy is difficult to assess; multimodal treatment may be indicated. The NBHW national guidelines for lung can-





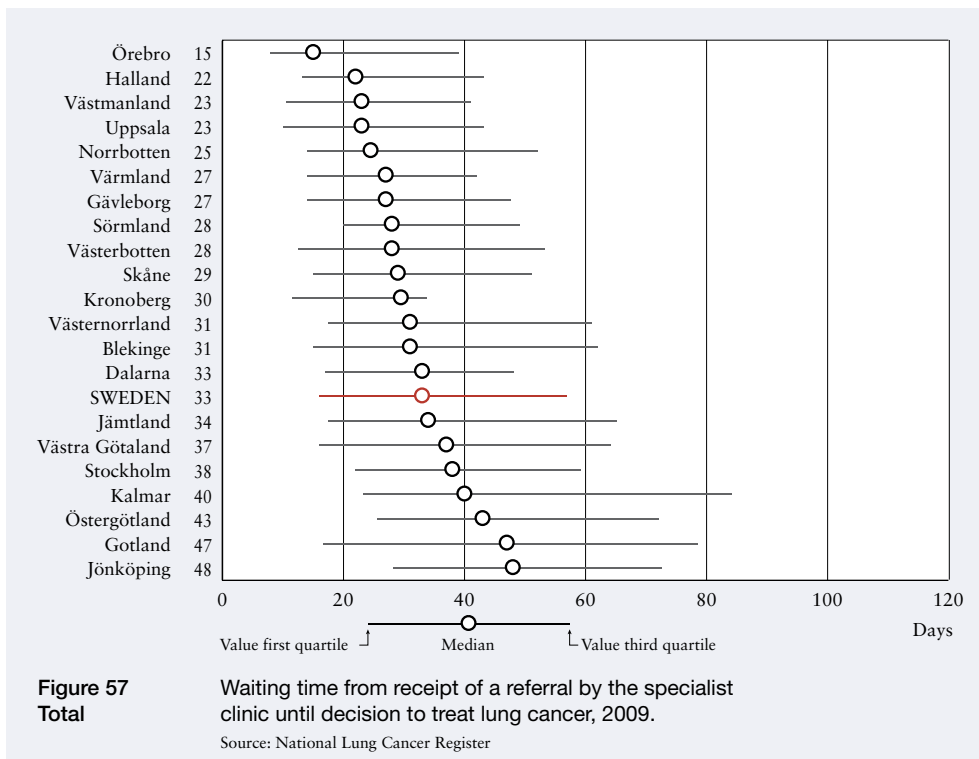
**Figure 56** Percentage of patients who had a multidisciplinary team meeting prior to primary treatment for lung cancer, 2002–2009.  
**Total** Source: National Lung Cancer Register

cer care assign high priority to a multidisciplinary team meeting before commencement of treatment of a newly diagnosed case. The guidelines target meetings in 74 per cent of the cases, but few counties reach that level. The idea is that all counties should be able to do so and that the level be even higher eventually.

Certain regional differences in reporting of multidisciplinary team meetings affect the outcomes in the diagram. For one thing, there is no uniform definition of the specialists who need to participate in order for a multidisciplinary team meeting to take place. Some counties report only meetings attended by all of the various types of specialists and are thereby underrepresented in the register.

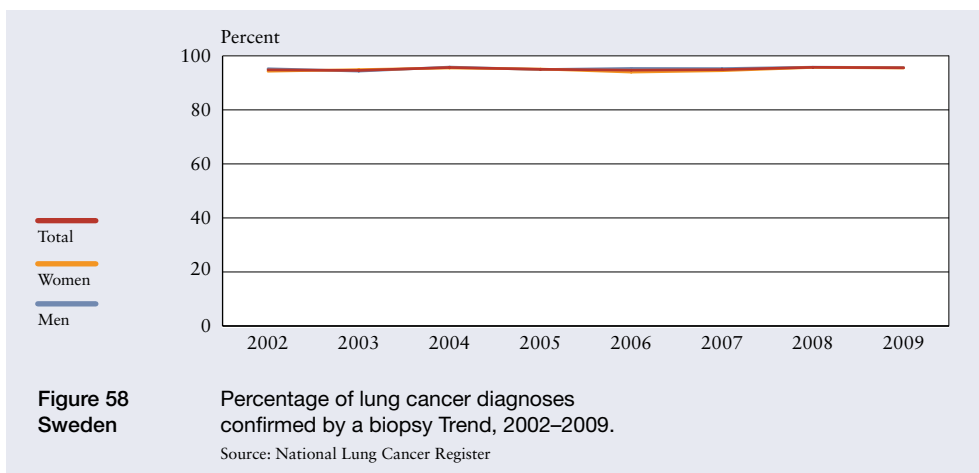
### 57 Waiting time from receipt of a referral by the specialist clinic until decision to treat

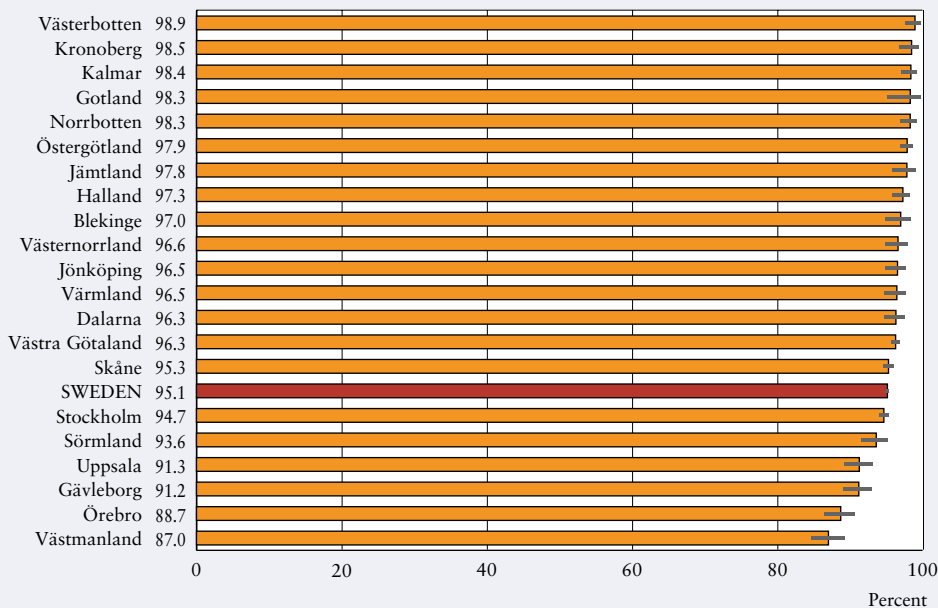
A key indicator of lung cancer care is the amount of time that transpires between the date that a specialist clinic receives a referral – or is contacted by the patient – and decision to treat. The waiting time includes assessment and diagnosis until a decision is made at a multidisciplinary team meeting or in some other manner. The clinic ordinarily specialises in either pulmonary medicine or oncology. According to the Swedish Lung Cancer Group, the waiting time should be 28 days or less for at least 80 per cent of patients.



## 58 Lung cancer confirmed by a biopsy

A biopsy is required to confirm the diagnosis of lung cancer, determine what type is involved and ensure that it is primary and not metastasis from another tumour. Such an assessment sets the stage for correct and optimum treatment and care. The NBHW national guidelines for lung cancer care assign very high priority to a biopsy.





**Figure 58** Percentage of lung cancer diagnoses confirmed by a biopsy, 2002–2009.  
**Total** Source: National Lung Cancer Register

The guidelines target biopsies in 99 per cent of cases, a level that most counties are close to attaining. The figure may be lower for some counties because they do not report all of their cases – particularly elderly patients and those with comorbidity – to the lung cancer register.

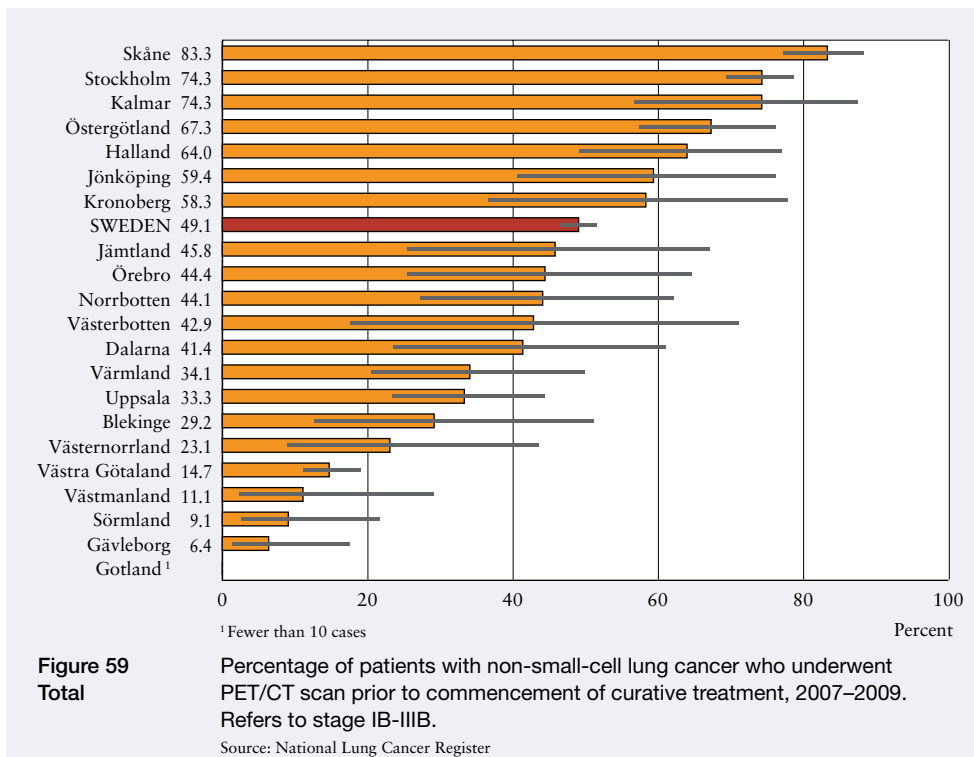
### 59 Combined PET/CT scan prior to curative treatment

Providing the best possible treatment requires as exact a determination as possible of the location of the malignancy. Lung cancer assessments include examining the upper abdomen by means of X-rays, CT scans, etc. Combined positron emission tomography (PET) and computer tomography (CT) in patients with stage IB-IIIIB non-small-cell lung cancer can help decide whether curative treatment is indicated by means of either surgery, chemotherapy or radiotherapy. The NBHW national guidelines assign very high priority to PET/CT scans for this patient population.

Because this is a new variable in the National Lung Cancer Register, data are presented for 2007–2009 only. Even though the sample is small, the guidelines indicate that at least 82 per cent of cases should be assessed with a PET/CT scan.

The benefit of the diagnostic method was not generally known during the comparison period and the counties were still in the process of adopting it.



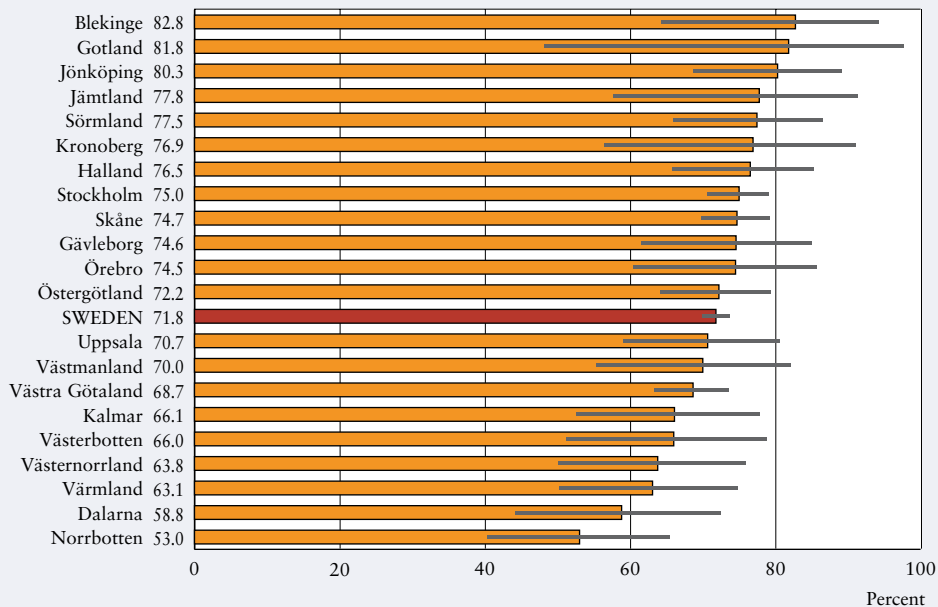


## 60 Curative surgery for stage I and II non-small-cell lung cancer

Surgery cures more cases of non-small-cell lung cancer by far than any other method. Whether the disease is operable depends on the location and size of the malignancy, as well as whether it has metastasised to other organs. Curative surgery is indicated primarily for patients in stages I or II. The NBHW national guidelines for lung cancer care identify curative surgery as an important indicator to monitor. Underutilisation of the method may reflect missed opportunities to cure the disease.

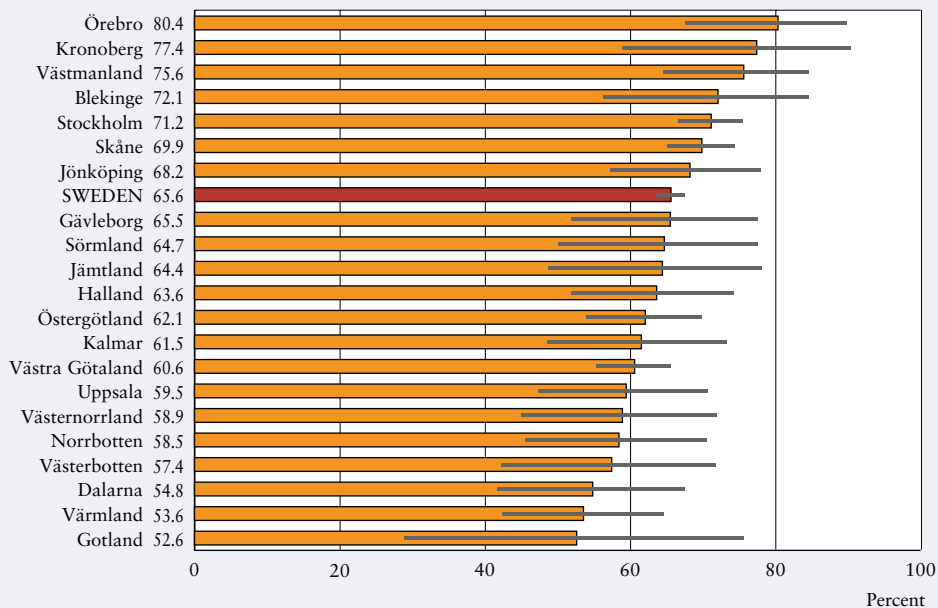
This indicator measures treatment interventions by county for people in an early stage of lung cancer. The comparison presents the percentage of patients who are scheduled for curative surgery. A follow-up by the lung cancer register showed that surgery was performed 90 per cent of the time.

The target of the NBHW national guidelines for 2011 is that 79 per cent of patients in stage I or II of non-small-cell lung cancer receive curative surgery.



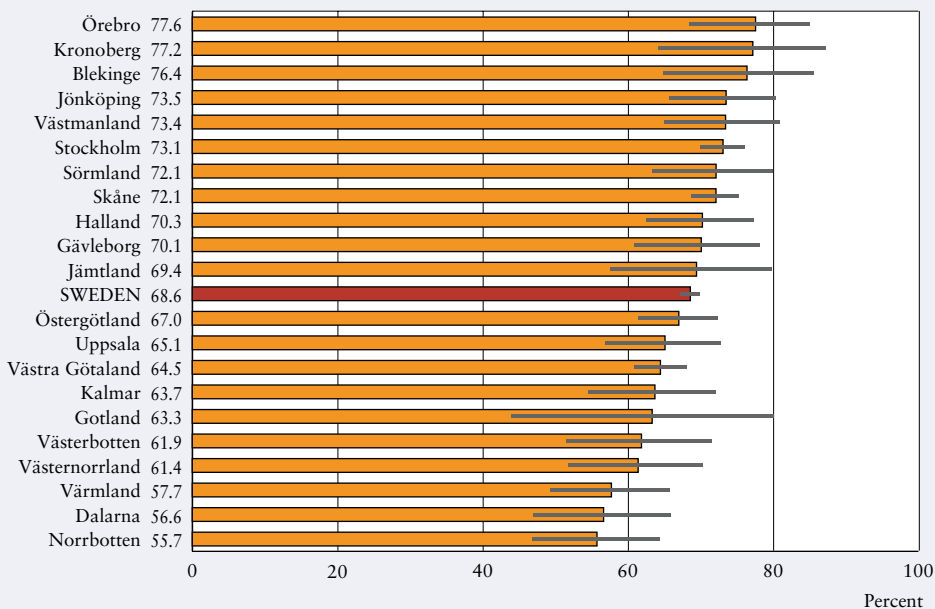
**Figure 60 Women** Percentage of patients with non-small-cell lung cancer scheduled for curative surgery, 2002–2009. Refers to stage I and II.

Source: National Lung Cancer Register

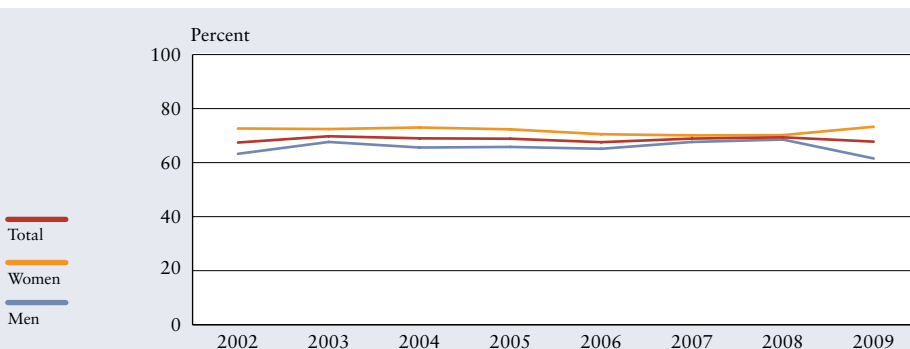


**Figure 60 Men** Percentage of patients with non-small-cell lung cancer scheduled for curative surgery, 2002–2009. Refers to stage I and II.

Source: National Lung Cancer Register



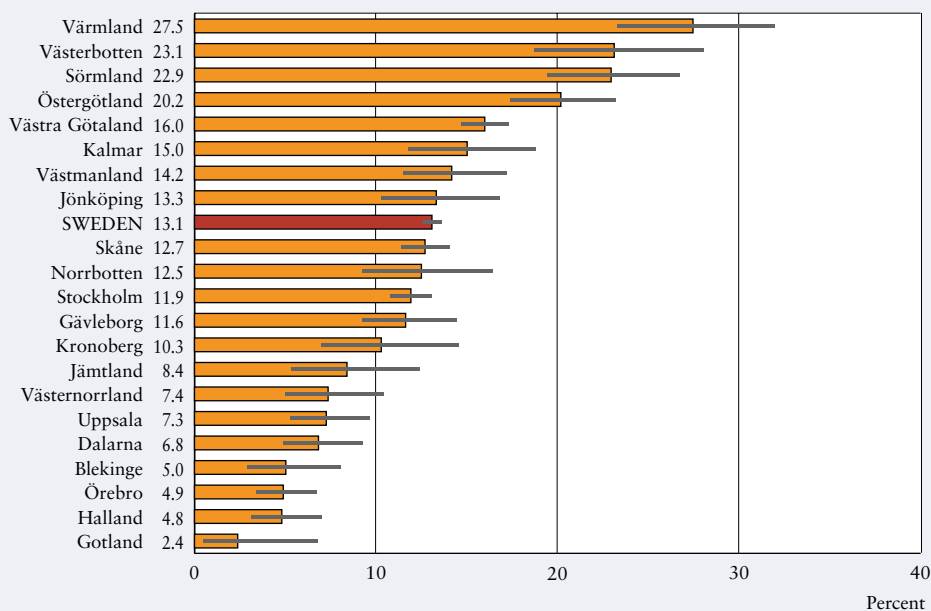
**Figure 60 Total** Percentage of patients with non-small-cell lung cancer scheduled for curative surgery, 2002–2009. Refers to stage I and II.  
Source: National Lung Cancer Register



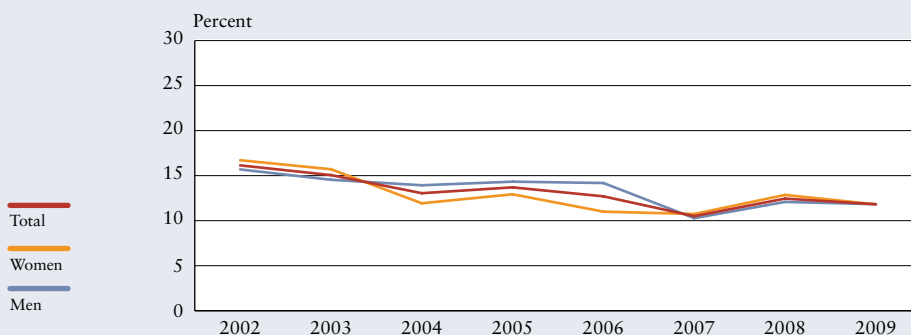
**Figure 60 Sweden** Percentage of patients with non-small-cell lung cancer scheduled for curative surgery. Refers to stage I and II. Trend, 2002–2009.  
Source: National Lung Cancer Register

## 61 Palliative radiotherapy for stage IIIB and IV lung cancer

The purpose of palliative radiotherapy is to damage the cancer cells and prevent the tumour from growing, thereby delaying or alleviating the symptoms. The NBHW national guidelines assign high priority to the method for patients in stage IIIB or IV of incurable lung cancer who are experiencing pain, coughing, haemoptysis (expectoration of blood) or dyspnoea (breathlessness) from the thoracic organs. Given



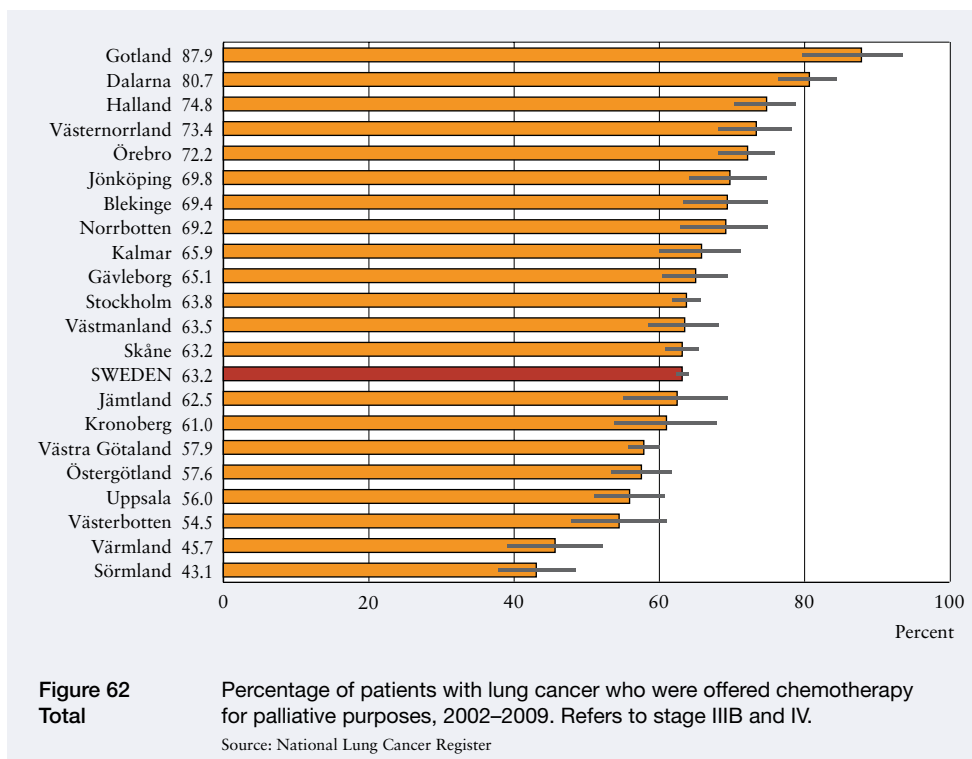
**Figure 61** Percentage of patients with incurable lung cancer who were offered radiotherapy for palliative purposes, 2002–2009. Refers to stage IIIB and IV.  
**Total** Source: National Lung Cancer Register



**Figure 61** Percentage of patients with incurable lung cancer who were offered radiotherapy for palliative purposes, 2002–2009. Refers to stage IIIB and IV.  
**Sweden** Trend 2002–2009. Source: National Lung Cancer Register

that the adverse effects of radiotherapy can cause deterioration of a patient’s general condition, it is not indicated in all cases. Some patients decline the treatment for other reasons.

The indicator reflects whether patients with incurable stage IIIB and IV lung cancer are actively offered palliative radiotherapy; large regional differences may suggest



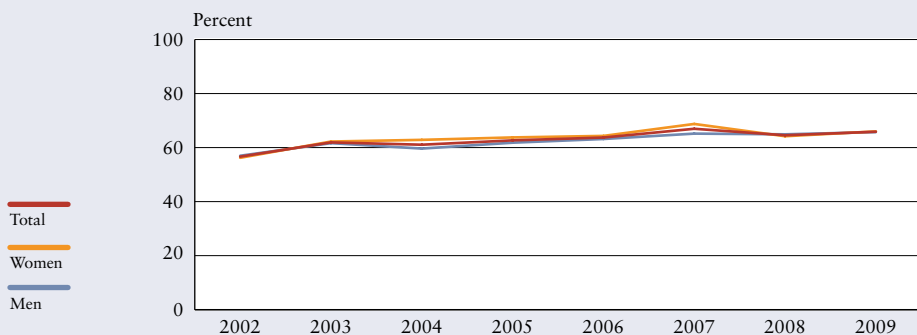
discrepancies in care quality. The counties also varied substantially, anywhere from 2.4 to 27.5 per cent.

Given that the guidelines target 22 per cent, a number of counties should consider the possibility that they are underutilising palliative radiotherapy.

## 62 Palliative chemotherapy for incurable lung cancer

Chemotherapy involves drug therapy to kill cancer cells or prevent them from multiplying. A number of different drugs can be used, often in combination, with equal efficacy. However, the adverse effects may vary somewhat. The clinical practice guidelines recommend that chemotherapy be tried for the purpose of alleviating symptoms in patients with incurable lung cancer. The NBHW national guidelines for lung cancer care identify palliative chemotherapy in stage IIIB and IV patients with a performance status of 0–2 as a key indicator to monitor. Although not all stage IV patients should receive the treatment, the indicator is relevant to a comparison of regional variations and may suggest quality differences.

Performance status (PS) grades a patient’s level of functioning on a scale of 0-4. PS 0 refers to a fully active person, while PS 2 is assigned to people who can perform normal activities and are out of bed for more than half the day, though with reduced



**Figure 62** Sweden Percentage of patients with lung cancer who were offered chemotherapy for palliative purposes. Refers to stage IIIB and IV. Trend, 2002–2009.

Source: National Lung Cancer Register

strength. PS is important for assessing whether a patient can handle and benefit from chemotherapy.

The target of the NBHW national guidelines is that 78 per cent of this patient population be offered palliative chemotherapy. The target considers the fact that curative radiotherapy or chemotherapy is indicated instead for some stage IIIB patients.

The outcomes for individual hospitals may be affected by their having recorded the stages of the disease in different ways or underreported elderly patients to the quality register. Furthermore, some hospitals may have a larger percentage of patients with performance status 3–4, i.e., unable to handle chemotherapy. While some of the regional variation may be due to these factors, the data suggest that a certain degree of undertreatment is likely.

## HEAD AND NECK CANCER

Statistics for 2009	Women	Men
Number of diagnoses	426	789
Percentage of all cancer cases	2%	3%
Prevalence, total	3 777	6 258
Relative five-year survival rate	65%	60%
Number of deaths	115	234

Head and neck cancer refers to malignancies of the lip, mouth, throat, larynx, nose, sinus cavities and salivary glands. Assessment, treatment and diagnostic methods for the various forms of the disease vary greatly. Approximately 10 000 Swedes currently alive have or have had head or neck cancer. The overall five-year survival rate is 65 per cent for women and 60 per cent for men. The disease is more common among men and people over 60 years of age.

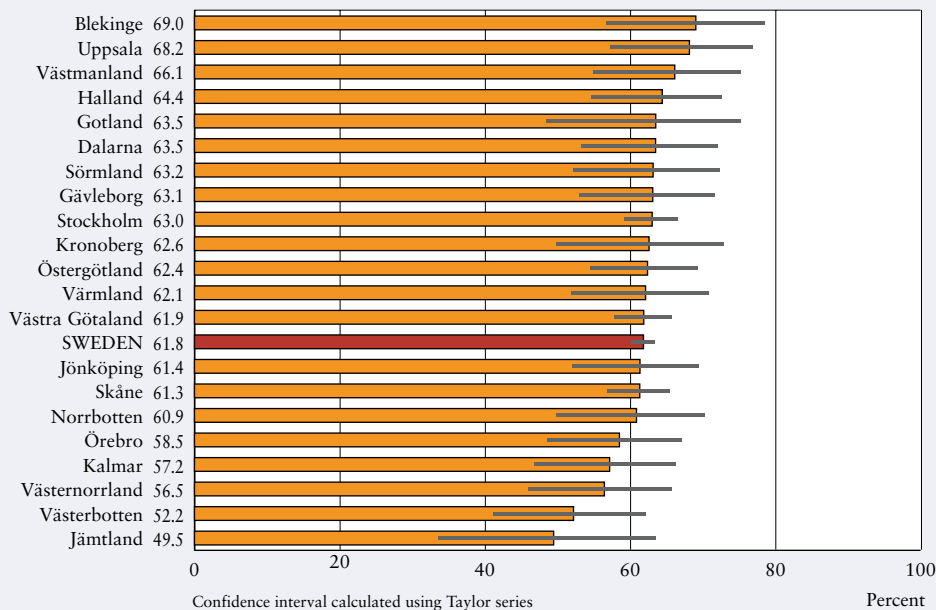
Head and neck cancer can cause a great deal of suffering by making it difficult to breathe or eat, as well as affecting speech, vision, hearing, smell and other important functions.

This report presents four indicators. The first indicator concerns survival rates, followed by one that reflects multidisciplinary team meetings and two that measure waiting times. Five-year survival rates are broken down by county and are based on data from the Swedish Cancer Register. The other data are taken from the Swedish Head and Neck Cancer Register. The register, which has been in existence since 2008, covers surgery, chemotherapy and radiotherapy alike.

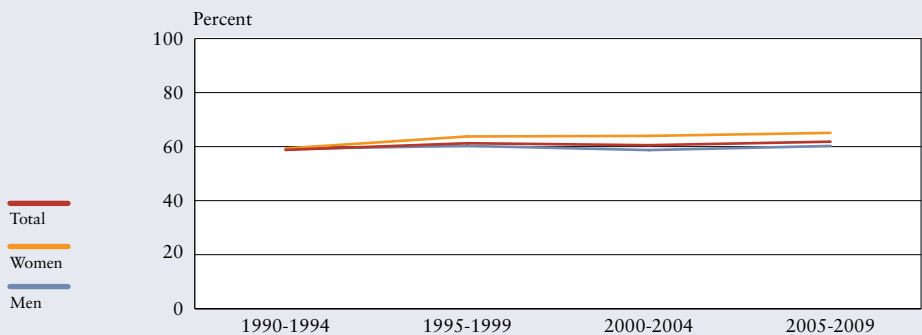
Approximately 90 per cent of treatment for head and neck cancer is provided at the regional level, whereas county hospitals perform assessments until decision to treat. Most decisions are made by a multidisciplinary team meeting at the regional level. Thus, we have chosen to present the percentage of patients assessed by means of a multidisciplinary team meeting by region and waiting times by both region and county.

### 63 Head and neck cancer – five-year survival rates

Five-year survival rates are presented collectively for all forms of head and neck cancer even though there are major differences between them. The survival rate has increased somewhat for women since 1990 but remained constant for men. Figure 63 shows that the five-year survival rate was 62 per cent in 2005–2009. Some regional differences exist, but the confidence intervals are broad and the role of chance cannot be ruled out.



**Figure 63** Head and neck cancer – five-year survival rates Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values.  
**Total** Source: Swedish Cancer Register, Swedish National Board of Health and Welfare

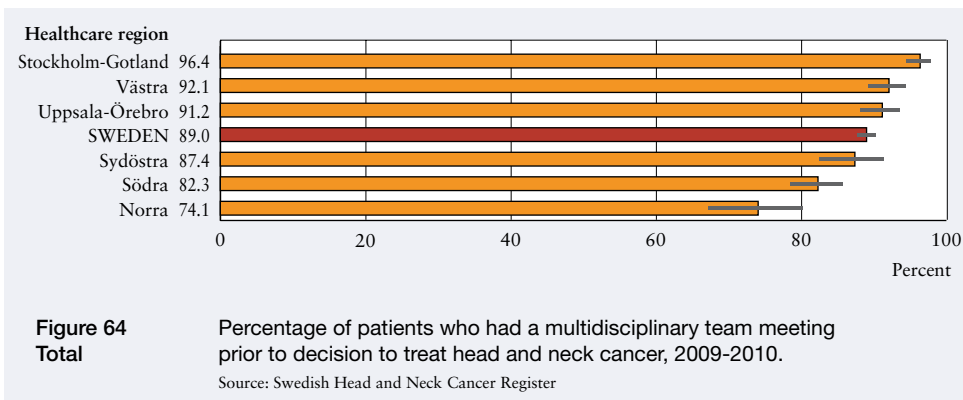


**Figure 63** Head and neck cancer – five-year survival rates Trend, 1990–2009. Age-standardised values.  
**Sweden** Source: Swedish Cancer Register, Swedish National Board of Health and Welfare

## 64 Multidisciplinary team meeting prior to treatment

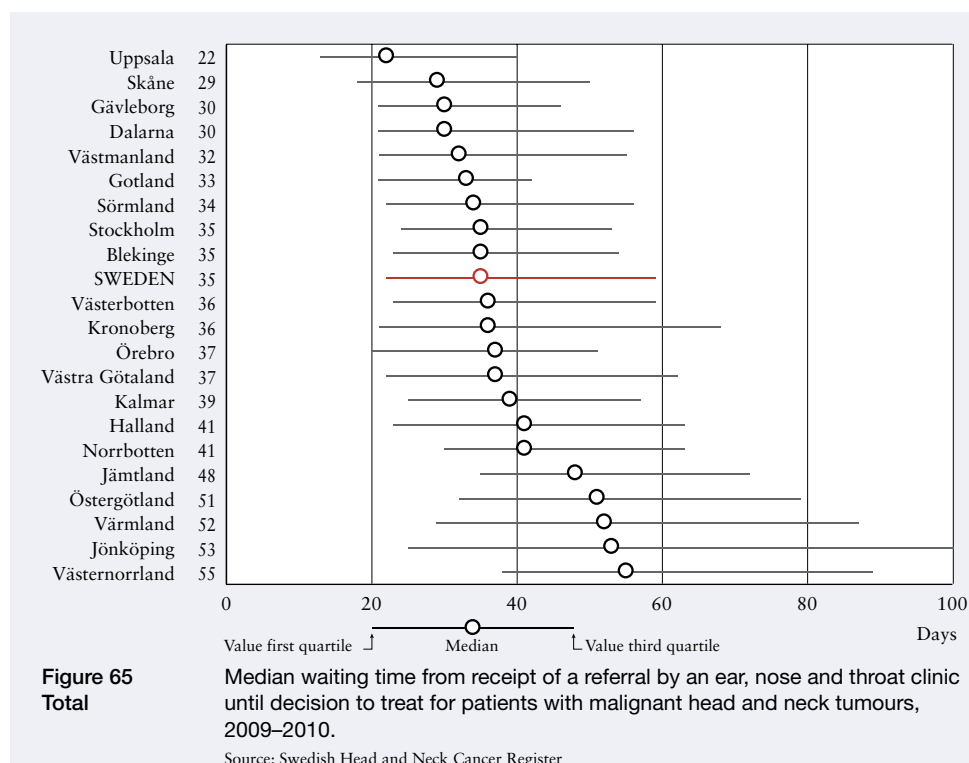
Primary treatment for head and neck cancer may be preceded by a multidisciplinary team meeting, a comprehensive assessment for the purpose of optimising the intervention. ENT surgery, oncology, radiology, pathology and other specialists may participate.

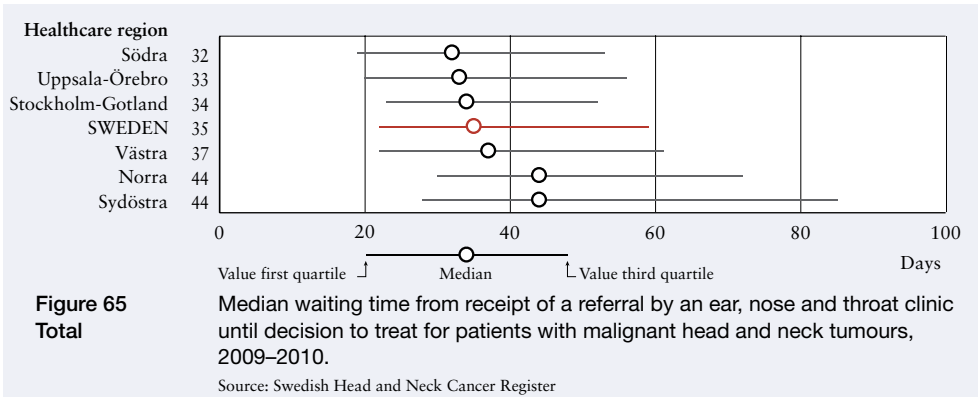




### 65 Waiting time from receipt of a referral until decision to treat

This indicator was presented in the 2010 edition of *Quality and Efficiency in Swedish Health Care – Regional Comparisons*. Assessment of suspected cancer must be completed quickly so that treatment can commence before the malignancy gets bigger or metastasises. The way that the assessment is planned and the resources that are at the disposal of the units that must be utilised determine the amount of time that passes from the day that a clinic receives a referral or is contacted by the patient until decision to treat.

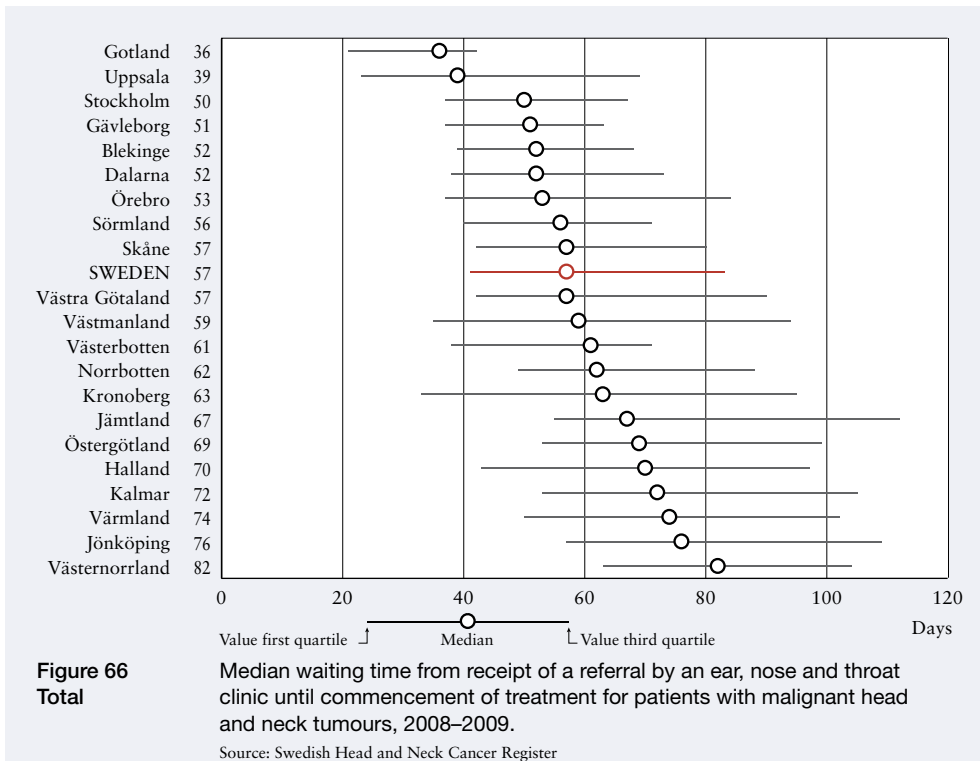


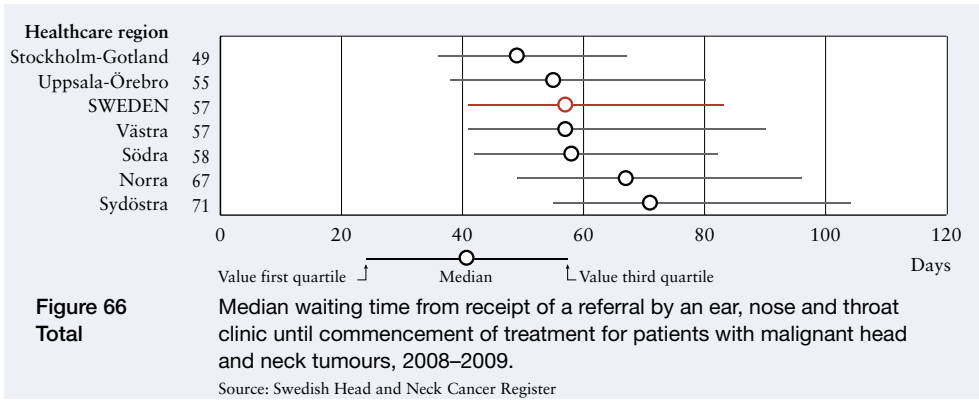


Differences both within and between the various regions are relatively large. Similarly, the northern (Norra) and south-east (Sydöstra) regions have longer waiting times than the other regions.

### 66 Waiting time from receipt of a referral until commencement of treatment

The waiting time from receipt of a referral until commencement of treatment illuminates an additional step in the process and reflects a variable that is central to the





ongoing progress of the disease. It is also important to patients that they can quickly start on prescribed treatment.

There is a large variation within and between the various counties.

The south-east (Sydöstra) and northern (Norra) regions have longer waiting times for commencement of treatment than the other regions. The difference is presumably due to the period after receipt of the referral.

## MALIGNANT MELANOMA

Statistics for 2009	Women	Men
Number of diagnoses	1 411	1 408
Percentage of all cancer cases	5%	5%
Prevalence, total	17 119	13 401
Relative five-year survival rate	92.6%	86.0%
Number of deaths	217	282

Malignant melanoma is the most serious of the three common forms of skin cancer. It accounts for 5 per cent of all cancer in both women and men. A total of 2 819 people – 1 411 women and 1 408 men – were diagnosed with malignant melanoma in 2009. More than 30 500 Swedes now alive have had the disease. After having held fairly steady in the 1990s, the incidence has risen by nearly 5 per cent every year in the 2000s. Generally speaking, however, malignant melanoma is more common in southern than northern Sweden. Mortality rates have also increased: from approximately 4 per cent to approximately 5 per cent. Excessive exposure to ultraviolet rays constitutes the biggest risk factor for the disease.

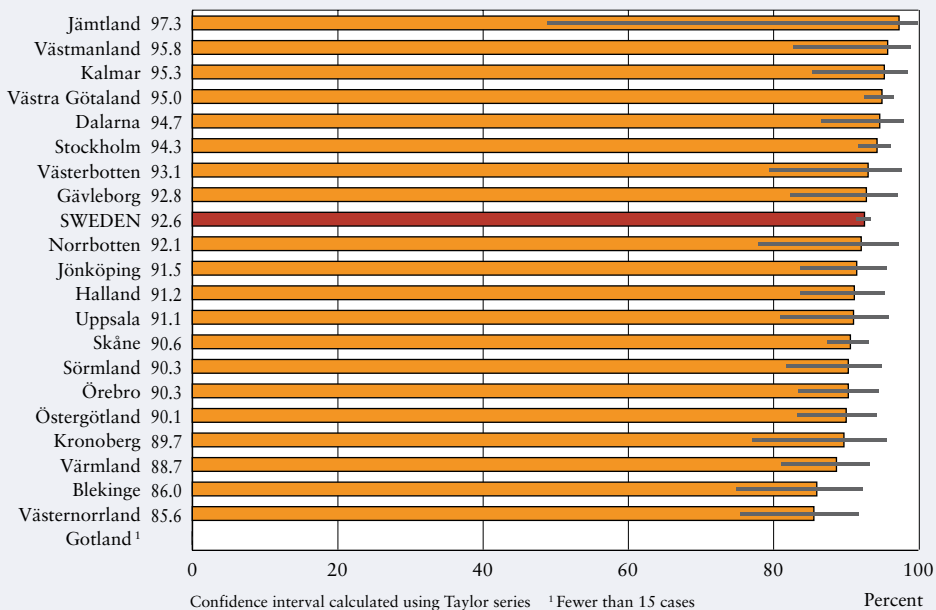
A melanoma that is detected at an early stage (1 millimetre thick or less) can usually be cured with simple surgery. However, a melanoma that is thicker than 4 millimetres carries a considerable risk of recurrence and death.

The median age at diagnosis is 64 in men and 60 in women, but young people can also develop the disease. However, it is very uncommon in children. Approximately 40 per cent of women and 30 per cent of men are younger than 55 when they are diagnosed.

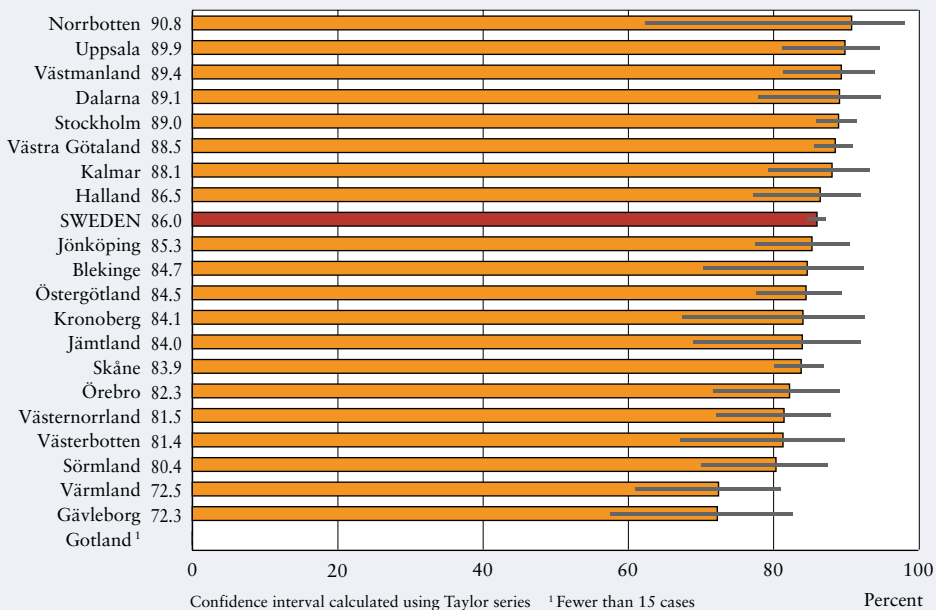
This report presents outcomes for four indicators, three of which are based on data from the Swedish Melanoma Register. Two indicators measure the waiting times that are important from the patient's point of view and one indicator measures the percentage of thin malignant melanomas (1.0 millimetre or less). The survival data have been taken from the Swedish Cancer Register.

### 67 Malignant melanoma – relative five-year survival rates

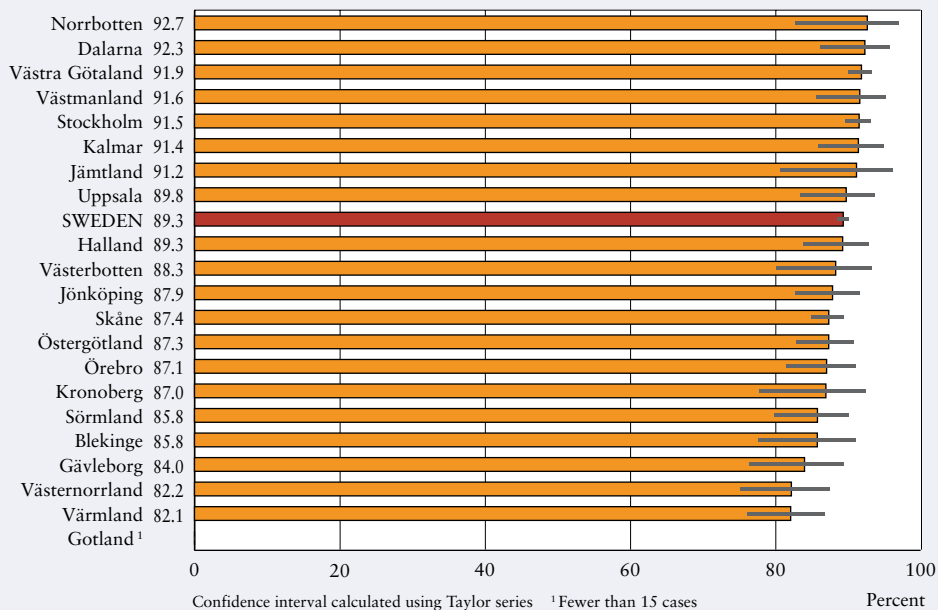
Figure 67 shows that the relative five-year survival rate for 2005–2009 was 86.0 per cent for men and 92.6 per cent for women. Men's survival rate increased in the 1990s and then retreated somewhat, whereas women's has risen modestly since the 1990s. There are certain differences between various parts of the country.



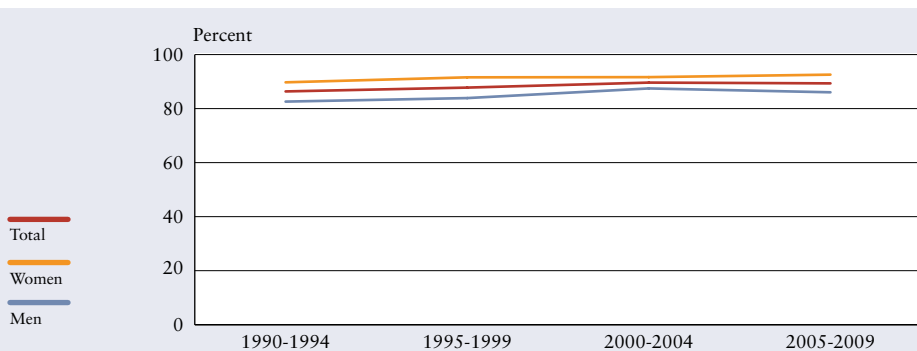
**Figure 67** Malignant melanoma – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values. Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



**Figure 67** Malignant melanoma – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values. Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



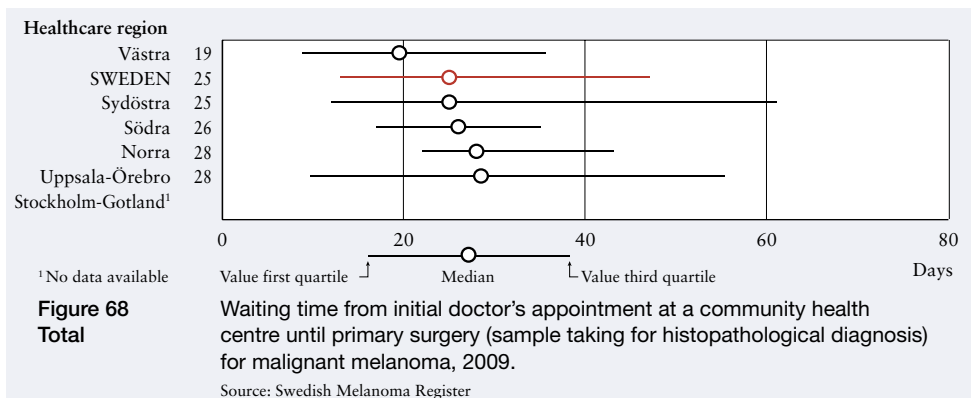
**Figure 67** Malignant melanoma – relative five-year survival rates. Patients diagnosed in 2000–2004. Patients age 30–89 at the time of diagnosis. Age-standardised values. **Total**  
Source: Swedish Cancer Register, Swedish National Board of Health and Welfare



**Figure 67** Malignant melanoma – relative five-year survival rates. **Sweden**  
Trend, 1990–2009. Age-standardised values.  
Source: Swedish Cancer Register, Swedish National Board of Health and Welfare

## 68 Waiting time from initial doctor’s appointment until primary surgery

The melanoma register has been set up for entry of waiting times since 2009. However, there is still a high percentage of nonreporting and only half of the county councils can account for waiting times from the initial doctor’s appointment until primary surgery (removal of the skin change that has been sent for histopathologi-



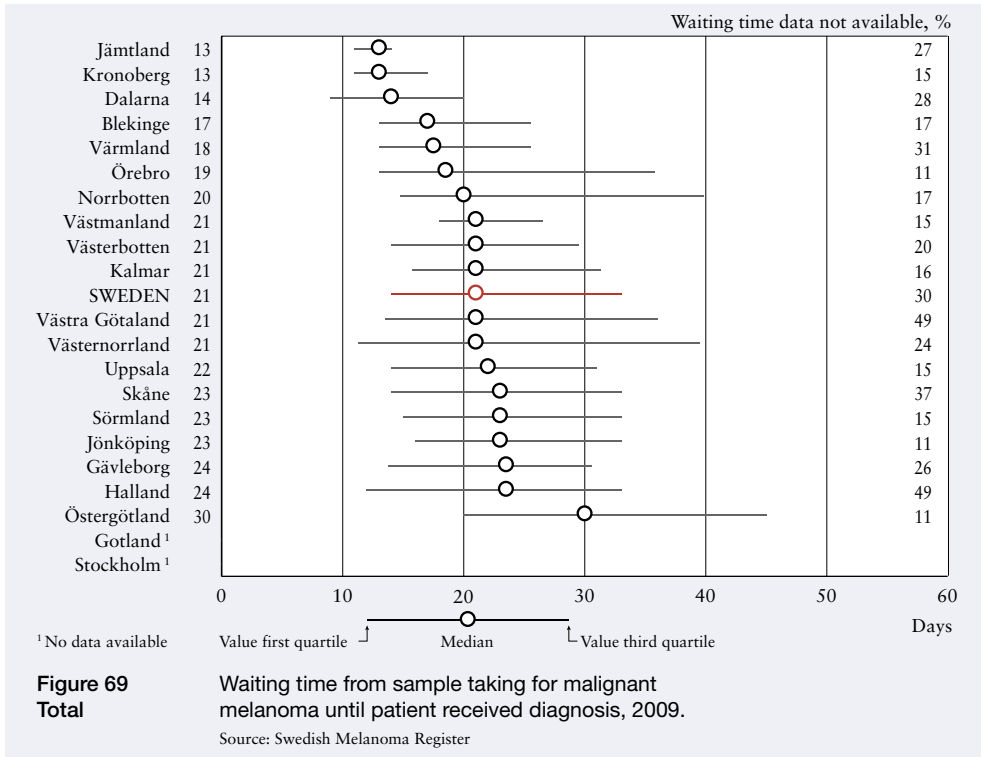
cal diagnosis). The indicator is measured on a regional basis to ensure more reliable outcomes.

A large percentage of patients undergo primary surgery during their first appointment at the community health centre. This comparison concerns only the relatively small percentage of the patient population who are referred to a specialist clinic. Figure 68 shows that their median waiting time in 2009 ranged from 19 to 28 days for the various regions. Regional routines and referral procedures can affect waiting times, not to mention the possibility that a specialist clinic will pass a referral on to another one. The national median was 25 days.

The fact that the variable was relatively new to the register rendered complete assessments that much more difficult.

## 69 Waiting time from sample taking until notification of the diagnosis

Figure 69 indicates that the median waiting time from the date that a sample was taken until the patient received a diagnosis was 21 days, with a regional variation of 13–30 days. The waiting time also covers the period from the date that the sample is taken until a histopathological diagnosis is performed and the referring doctor receives the results. As of 2011, the waiting time until the diagnosis has been completed is also analysed. Only the Stockholm and Gotland Regions, which started their registration process late, were unable to report data.

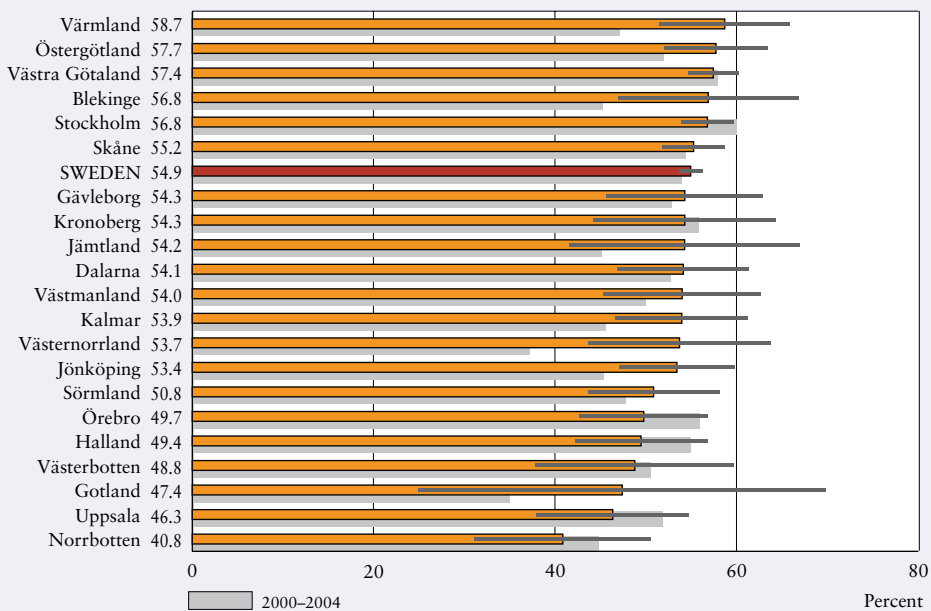


## 70 Malignant melanoma 1.0 millimetre or thinner

The indicator is a yardstick of people’s general awareness of the need to see a doctor when they suspect skin cancer. It also measures the ability of doctors to correctly assess the seriousness of a skin change. Detecting melanoma at an early stage (1 millimetre or thinner) is important; the survival rate at that point is excellent. This indicator reflects the percentage of patients with a melanoma that is no more than 1.0 millimetre thick. Five years of data have been combined to ensure greater reliability.

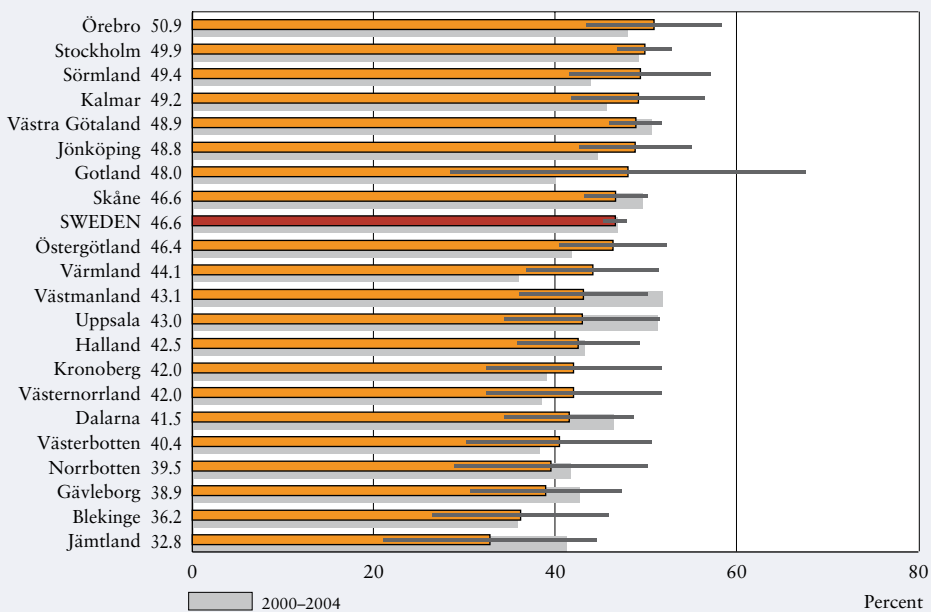
A comparison between 1990–1999 and 2000–2008 shows a decline in the percentage of melanomas that were thin at the time of diagnosis – which obviously represents a negative trend. The gap between women and men appears to be narrowing.





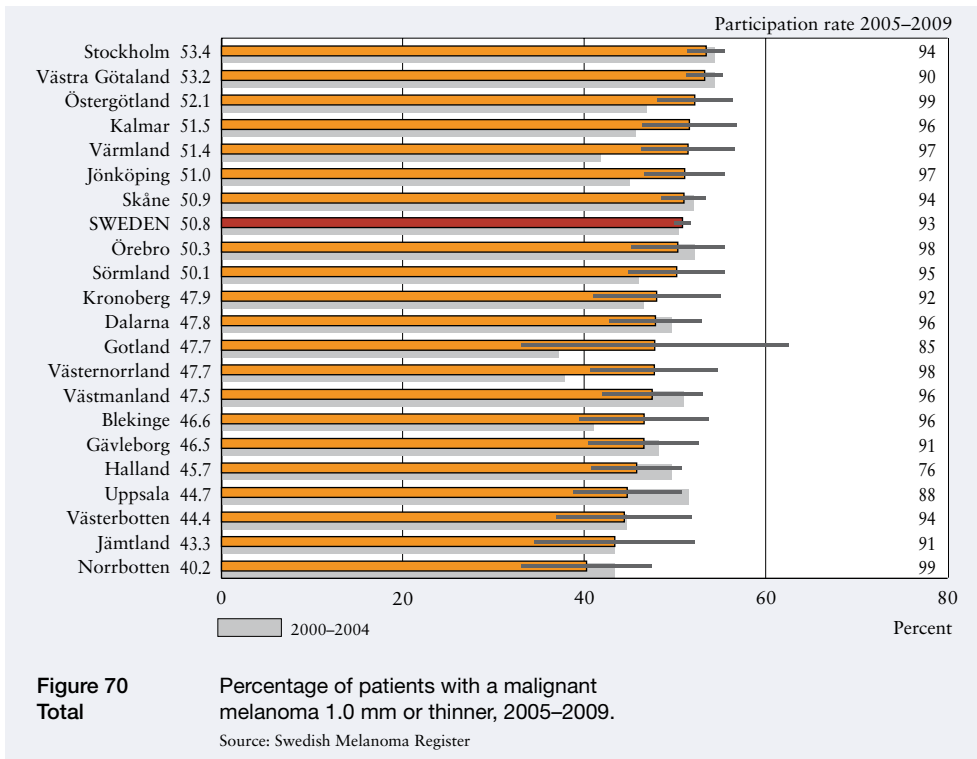
**Figure 70** Percentage of patients with a malignant melanoma 1.0 mm or thinner, 2005-2009.  
**Women**

Source: Swedish Melanoma Register



**Figure 70** Percentage of patients with a malignant melanoma 1.0 mm or thinner, 2005-2009.  
**Men**

Source: Swedish Melanoma Register



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# Quality and Efficiency in Swedish Cancer Care

This special edition of *Quality and Efficiency in Swedish Health Care – Regional Comparisons* – examines cancer care only. The report, which includes ten forms of cancer and 70 indicators, is a joint project of the Swedish National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions. The indicators reflect different aspects of cancer care, including medical outcomes, patient experience and waiting times.

The overall purpose of the report is to promote local, regional and national improvement efforts by comparing the quality of cancer care throughout the country. It is also intended to provide the general public with insight into what publicly financed cancer care is accomplishing.

While the majority of the indicators are presented at the county level, some of them are of necessity limited to a regional perspective. The indicators for certain types of cancer are also shown at the hospital level. A number of the indicators are broken down between women and men in order to capture potential gender differences.

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