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**SWEDISH CANCER  
SOCIETY REPORT**

SEGREGATED SCREENING



CANCERFONDEN

# 194

If all three screening programmes reached the same participation rate as the municipalities with the highest participation rate for each programme, 194 more lives could be saved each year.

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# Major differences in screening participation cost lives

Screening is an important tool for the early detection of cancer. Cancer screening involves examining large groups of people for cancer at an early stage, often before the disease causes symptoms. Thanks to screening, it is also possible to detect early stages of cancer that has not yet developed. It is a key to increased survival and more gentle treatment, with better quality of life both during and after the cancer.

In Sweden, we have three evaluated and nationally recommended screening programmes to detect cancer early. These are screening for cervical, breast and colorectal cancer. There are significant health benefits from each, both for the individual and society. It is deeply problematic that not everyone covered by the programmes is reached.

The average participation rate in cervical cancer screening is 71%, and in breast cancer screening it is 81%. In addition, participation in colorectal cancer screening in the Stockholm and Gotland regions was 71%, which translated to a national average of 14%. The low rate is due to the fact that, although the recommendation was made in 2014, the programme has not been widely implemented. Participation levels are too low.

There are also clear socio-economic differences in screening participation. This is shown in unique new figures on participation at district level in metropolitan regions. Women with higher incomes and higher education are more likely to participate in cervical and

breast cancer screening than women with lower incomes and less education. The same is true for colorectal cancer screening. In addition, the implementation of new and modified screening programmes takes far too long, and there are clear differences in participation rate success among regions.

If all three screening programmes reached the same participation rate as the municipalities with the highest participation rate for each programme, 194 more lives could be saved each year.

The regions bear the main responsibility for implementing the screening programmes, but the government also has a responsibility. The Swedish Cancer Society wants to see clearer political accountability, both nationally and regionally. Early detection is key to beating cancer. Better implementation of screening programmes is needed. Screening must reach more people. Screening saves lives. Priority needs to be given to measures to increase screening participation.

# The Swedish Cancer Society believes

## Regional

**The Swedish Cancer Society believes** that all regions need to move forward in their efforts to detect cancer diseases in time. The Swedish Cancer Society therefore considers it a priority that the regions:

- Do more to reach people in groups with low participation in screening programmes.
- Mandate the relevant administrations to ensure the region's compliance with existing cervical, breast and colorectal cancer screening programmes and recommendations. With a particular focus on increasing participation in areas where it is lowest.
- Are prepared for the rapid introduction of new screening programmes and recommendations. All regions need to fully implement the nationally recommended screening programmes and there needs to be predictability.

## National

**The Swedish Cancer Society also believes** that a clear national ambition, stronger national coordination and better national support are needed to ensure that screening programmes really do reach everyone in the target groups across the country. Equitable cancer care is a national responsibility that the government needs to shoulder. The Swedish Cancer Society therefore believes that the government should:

- Give the National Board of Health and Welfare a broader mandate in cancer screening, to speed up the introduction of new and modified screening programmes in the regions.
- Commission the National Board of Health and Welfare and the Confederation of Regional Cancer Centres in Sweden to identify and evaluate methods for reaching people in groups with low participation in screening programmes and to contribute to the dissemination of the knowledge developed on the basis of such knowledge.
- Strengthen the regions' efforts to ensure that health services are able to ensure that all those who have not been invited or have not been able to participate in screening due to the Covid pandemic are given the opportunity to do so.

# Participation in the national screening programmes

Participation in cervical, breast and colorectal cancer screening has the common feature of being unequal. Socio-economic differences are evident and mean that people living in neighbourhoods in metropolitan areas with higher median incomes and educational levels are also more likely to participate in screening. Likewise, lower median incomes and less education mean lower participation in screening. A short education coincides with a foreign background, especially in big cities, and seems to further reduce screening participation.

Inequalities also appear to arise from the fact that regions seem to have varying levels of success in reaching target groups for screening. There are large differences in participation among and within regions: screening participation is higher in socio-economically strong municipalities compared to weaker ones. There are also socio-economic differences within regions, particularly in cervical cancer screening. Participation in breast cancer screening is both higher and more consistent. Screening for colorectal cancer is still only fully underway in the Stockholm and Gotland regions.

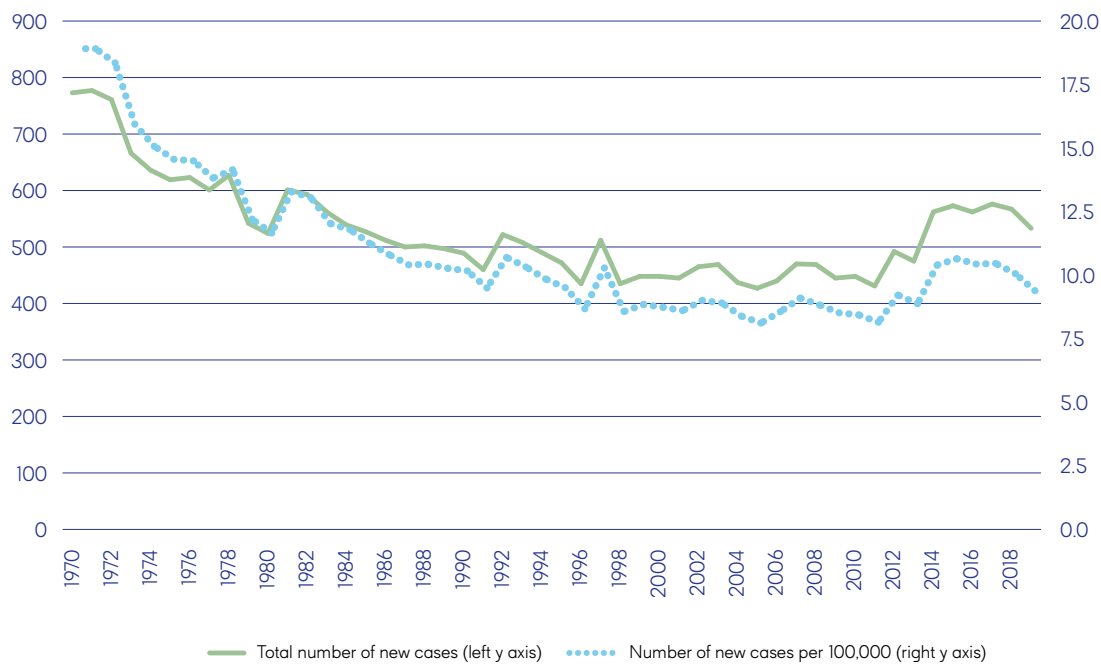
Significantly more people need to participate in screening for cervical, breast and colorectal cancer so that more cancers are detected early, giving more people the chance of curative treatment and survival. The regions therefore need to continue their efforts to facilitate and encourage regular participation by all in the target groups of the screening programmes. More proactive work is needed by the regions to achieve more equal and even higher participation in screening programmes.

## Screening for cervical cancer

Screening for cervical cancer was the first national screening programme to be recommended in Sweden. It was introduced in the then county councils over a ten-year period from 1967 to 1977 (National Board of Health and Welfare, 2020a). The screening programme introduced regular gynaecological smear tests with the aim of detecting cellular changes and precursors of cervical cancer as early as possible. Screening has significantly reduced the number of new cases of cervical cancer (see Figure 1).<sup>1</sup>

Research shows that women who regularly participate in screening reduce their risk of cervical cancer by around 90%. Not participating in cervical cancer screening is the main risk factor for cervical cancer (National Board of Health and Welfare, 2020a). Screening is crucial to preventing cervical cancer incidence and death.

**Figure 1.** New cases of cervical cancer 1970–2019. Total number of new cases and number of new cases, age-standardised incidence per 100,000 women. All ages.



Source: The National Board of Health and Welfare

<sup>1</sup> The chart also shows that the number of cervical cancer cases increased between 2014 and 2018, before declining again in 2019. The reason for the increase is not fully understood (National Board of Health and Welfare, 2019; 2020a).

### Partially new screening programme from 2015

Screening for cervical cancer is based on gynaecological smear tests. Over time, new research and new knowledge have shown that the most important cause of cell changes is infection with the human papillomavirus, HPV (National Board of Health and Welfare, 2020a).<sup>2</sup> This has led to partial changes in the recommendations of the 2015 national cervical cancer screening programme.

Under the current programme, health services will primarily offer cervical cancer screening by smear test, but with HPV analysis. The target group for screening was also expanded, from ages 23–59 to ages 23–64 (National Board of Health and Welfare, 2015a). To support the regions' work in implementing the partly new programme, a national cervical cancer prevention healthcare programme was introduced in 2017, and a new regulation came into force in July 2020 (National Board of Health and Welfare, 2019a; Rognes et al, 2020).



**Research shows that women who regularly participate in screening reduce their risk of cervical cancer by around 90%.**

### THE NATIONAL CERVICAL CANCER SCREENING PROGRAMME

The national cervical cancer screening programme requires regions to offer free screening to people who are assigned the legal gender of female at birth.

**From 1 July 2020, health services will offer screening with:<sup>3</sup>**

- Cytology testing every three years for women aged 23–29.
- Smear tests with analysis for HPV every three years for women aged 30–49 and a complementary analysis also for cytology for women aged around 41.
- Smear tests with HPV analysis every seven years for women aged 50–64.

Source: The National Board of Health and Welfare

The National Board of Health and Welfare's assessment is that the updated screening programme provides even better cancer prevention. This is because testing for both cytology and HPV allows more precursors to cancer to be detected. The new programme is therefore expected to further reduce both morbidity and premature mortality from cervical cancer. The health benefits of cervical cancer screening are thus expected to increase (National Board of Health and Welfare, 2015a; 2015b).

2 Cervical cancer is also prevented by HPV vaccination. All children in grade 5 will be offered the HPV vaccine as part of the universal childhood vaccination programme from August 2020. (In August 2020, boys were also included.) (National Board of Health).

3 The Corona pandemic has temporarily given regions the option of primarily screening for cervical cancer using HPV self-testing if it is not possible to invite eligible participants to cervical cancer screening as normal. The temporary period runs from mid-July 2020 to 30 June 2022 (HSLF-FS, 2021:42).



### The transition to the partially new programme has taken time

The National Board of Health and Welfare assessed that there were good conditions for a smooth transition to the partly new cervical cancer screening programme (National Board of Health and Welfare, 2015a). This was not the case.

Instead, the National Board of Health and Welfare (2020) notes an uneven and protracted transition, with problems related to “the invitation system, lack of coordination, procurement of own regional IT systems, uncertainties about funding and uneven

availability of staff”.

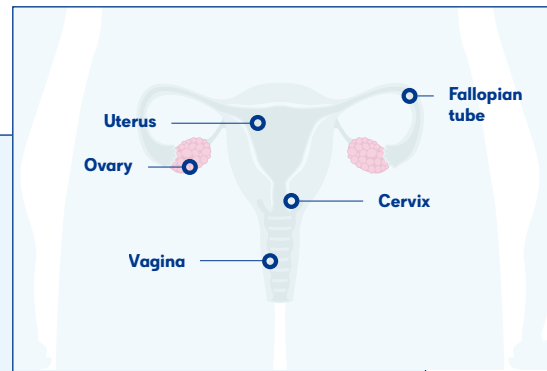
The key element of the new programme was the move to screening with HPV analysis. Rognes et al (2020) argue that the uneven uptake of this particular component is due to varied implementation of both the new screening programme and the cervical cancer prevention care programme, both among regions and activities.

### THE CERVICAL CANCER PREVENTION PROGRAMME

The Cervical Cancer Prevention Programme focuses, in particular, on what is important for achieving high and equal screening participation. Measures specified to facilitate and encourage participation include:

- Women should be invited based on population registers, and the regions should coordinate invitations or share information on the basis for invitations.
- The invitation should include a pre-arranged time and place that can be easily rescheduled online and by telephone. A wide variety of rebooking times should be available. Text message reminders should be offered.
- Additional screening should be offered at visits to the midwife and gynaecologist for other reasons.
- Women who fail to attend should receive annual reminders (invitations).
- Women who have not participated for a long time should be contacted by phone and offered help to make an appointment and offered self-testing for HPV by letter.
- Areas of low participation within each region should be identified. Barriers to participation should be analysed and targeted actions implemented and evaluated.

Source: RCC (2021a).



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more lives could be saved each year if participation in cervical cancer screening were as high nationwide as for the municipality with the highest participation (IHE, 2021).

Rognes et al (2020) show in their report that there is broad acceptance of the care programme, but also that it is perceived as too complex and detailed and that it requires more resources. They write:

*As a result, a choice is made locally to ignore some elements. For example, in-person follow-up of women who have not been screened in a number of years is seen as too resource-intensive in some regions (Rognes et al, 2020, p. 4).*

When the Confederation of Regional Cancer Centres in Sweden, RCC<sup>4</sup>, surveyed the status of implementation in the regions in September 2020, 16 out of 21 regions had introduced screening with HPV analysis. Just as many regions had raised the age limit. Only two regions, Västra Götaland and Halland, had introduced telephone calls to women who had not been screened for a long time.<sup>5</sup>

Cervical cancer screening is not carried out in an equal way across the country. The invitation system is highlighted both as a major problem and as a key to effective implementation of cervical cancer screening in the regions (National Board of Health and Welfare, 2020a; Rognes et al, 2020).

It is also important to make additional efforts to reach women who have not participated in screening for a long time, to identify geographical areas with lower participation rates and to work systematically to increase participation rates. That is, things that involve more proactive work on the part of the regions.<sup>6</sup>

## SMEAR TEST WEEK

Good and accessible information about the importance of screening in preventing cervical cancer is key to increasing participation. One example highlighted as successful is the Smear Test Week.

The Smear Test Week was first held in the regions of Västra Götaland and Halland in 2013. Since then, it has taken place in several parts of the country one week a year in April or May.

For example, participating regions provide information on the importance of regular smear screening. It may also be possible to easily find out when you last submitted a smear test and to submit smear tests via drop-in.

Source: RCC West

4 In the report, the Confederation of Regional Cancer Centres in Sweden is abbreviated simply as RCC, and the Regional Cancer Centres are abbreviated as RCC followed by the region's name.

5 <https://cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/gynekologisk-cellprovskontroll/vardprogram/status-for-inforandet/>

6 It is particularly important that regions monitor and evaluate the impact of the temporary possibility to use self-testing during the Covid pandemic on screening uptake.

### Unequal participation in cervical cancer screening

According to new data collected by the Institute for Health Economics (IHE) on behalf of the Swedish Cancer Society, the average participation rate in cervical cancer screening is 71%. Regional differences in screening participation are relatively large. The highest participation rate was in Dalarna, where 86% of all invited women participated. In Västmanland, the participation rate was clearly the lowest, with only 52% of the women who were invited to screening participating.

In total, six regions reached a cervical cancer screening participation rate of over 80%, while four regions did not even reach 60% participation. See further in Figure 2.

There are also differences in screening participation across regions. The differences are often strikingly large. This is shown in Table 1.

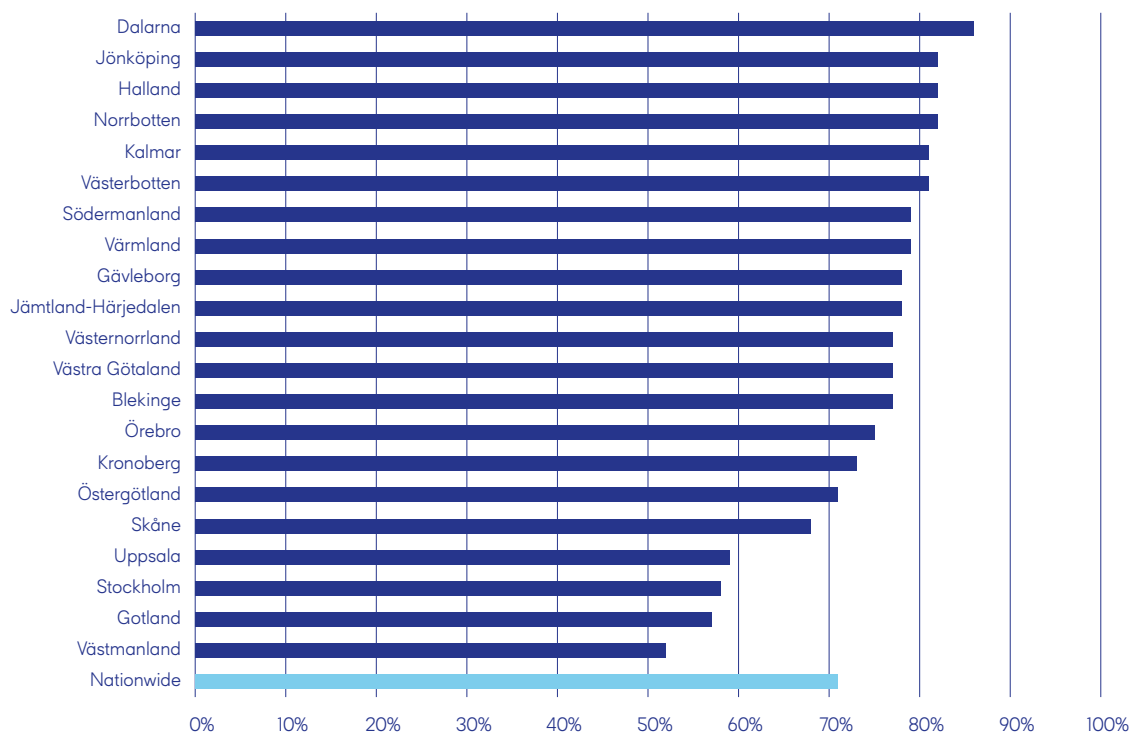
The biggest differences between the best and worst municipalities are found in the regions of Östergötland, Västmanland, Kalmar, Skåne and Stockholm. The smallest differences between municipalities are found in the Uppsala region, followed by the regions of Södermanland and Blekinge.

At the national level, the difference between the best and the worst municipality is as high as 51 percentage points. The municipality with the highest participation rate in cervical cancer screening in 2018 was Säter at 91%. The municipality with the lowest participation rate was Fagersta, with only 40% participation. Region Västmanland has the lowest average participation in cervical cancer screening, which is an important explanation for the similarly low participation in Fagersta. Instead, the Dalarna region has the highest participation rate, and within the region, Säter is the best performer.



**The Dalarna region has the highest participation rate in cervical cancer screening, and within the region, Säter is the best performer.**

**Figure 2.** Cervical cancer screening participation in the regions and the country, 2018. Percentage of participants of the number of invitations in one year.



Source: IHE

**Table 1.** Municipalities with the highest and lowest participation in cervical cancer screening by region, 2018. Percentage of participants of the number called within one year, as well as the median monthly income of women aged 20-64 and the percentage of women aged 25-64 with a lower secondary education.

Region	HIGHEST PARTICIPATION					LOWEST PARTICIPATION			
	Average participation	Municipality	Average participation	Median income per month	Share of those with lower secondary education	Municipality	Average participation	Median income per month	Share of those with lower secondary education
Dalarna	86%	Säter	91%	SEK 25,878	10%	Leksand	80%	SEK 24,751	7%
Jönköping	82%	Habo	89%	SEK 26,561	7%	Mullsjö	77%	SEK 24,344	10%
Halland	82%	Kungsbacka	84%	SEK 28,793	6%	Laholm	74%	SEK 22,875	10%
Norrbottn	82%	Gällivare	87%	SEK 28,858	9%	Pajala	71%	SEK 24,674	9%
Kalmar	81%	Vimmerby	86%	SEK 24,602	10%	Högsby	63%	SEK 21,268	15%
Västerbotten	81%	Robertsfors	87%	SEK 24,173	10%	Malå	76%	SEK 24,952	10%
Södermanland	79%	Katrineholm	83%	SEK 23,450	15%	Trosa	74%	SEK 26,878	10%
Värmland	79%	Hammarö	87%	SEK 28,636	5%	Munkfors	70%	SEK 23,905	11%
Gävleborg	78%	Ovanåker	83%	SEK 24,172	12%	Nordanstig	68%	SEK 22,517	13%
Jämtland-Härjedalen	78%	Strömsund	83%	SEK 23,330	10%	Bräcke	71%	SEK 22,983	9%
Västernorrland	77%	Härnösand	82%	SEK 24,531	11%	Sollefteå	73%	SEK 24,161	12%
Västra Götaland	77%	Götene	86%	SEK 25,086	10%	Bengtstorfors	70%	SEK 22,793	16%
Blekinge	77%	Olofström	78%	SEK 23,805	12%	Sölvesborg	69%	SEK 24,183	10%
Örebro	75%	Askersund	80%	SEK 24,571	11%	Ljusnarsberg	63%	SEK 20,683	17%
Kronoberg	73%	Växjö	76%	SEK 24,857	8%	Uppvidinge	62%	SEK 22,991	14%
Östergötland	71%	Mjölby	76%	SEK 25,055	10%	Ydre	52%	SEK 24,100	7%
Skåne	68%	Kävlinge	82%	SEK 27,489	7%	Åstorp	61%	SEK 22,402	16%
Uppsala	59%	Knivsta	63%	SEK 28,841	6%	Tierp	57%	SEK 22,722	12%
Stockholm	58%	Vallentuna	68%	SEK 29,063	7%	Södertälje	48%	SEK 22,608	16%
Gotland	57%	—	—	SEK 24,231	9%	—	—	SEK 24,231	9%
Västmanland	52%	Norberg	63%	SEK 24,040	14%	Fagersta	40%	SEK 24,177	16%
<b>Nationwide</b>	<b>71%</b>	<b>Säter</b>	<b>91%</b>	<b>SEK 25,878</b>	<b>10%</b>	<b>Fagersta</b>	<b>40%</b>	<b>SEK 24,177</b>	<b>16%</b>

Source: IHE, Kolada and SCB.

Socio-economic factors appear to underlie some of the differences within regions. It is common for median incomes (earned income) to be higher in municipalities with high participation and for economically weaker municipalities to have lower participation. The municipalities with the lowest participation within the regions also have more women with lower secondary education than the municipalities with the highest participation. However, there are also other factors that influence the differences in participation. Factors that have been highlighted in relation to breast cancer screening are the importance of good and equal access geographically, but also that family situation, attitudes and perceptions, and mental health can affect participation (Swedish Agency for Health and Care Services Analysis, 2020). It could be influenced by your work situation and how easy it is to take time

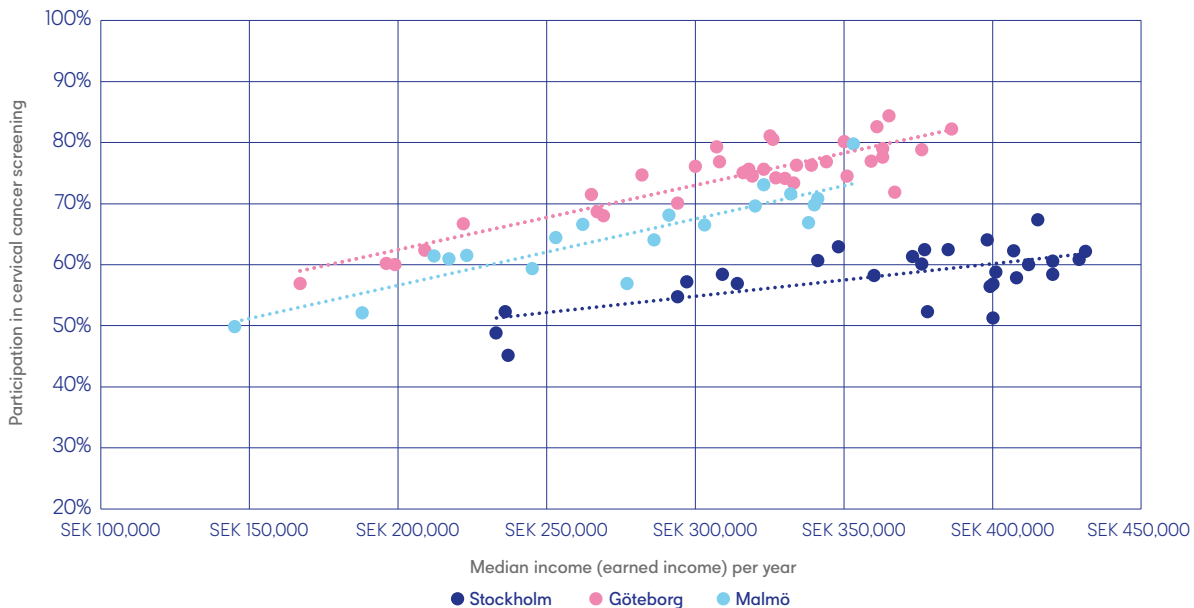
off work to go for a screening.

The systematic impact of socio-economic factors becomes even clearer in the metropolitan municipalities of Stockholm, Göteborg and Malmö.

In Figure 3, participation in screening is paired with median income within different districts (civil registration districts). Metropolitan municipalities have varying levels of success in screening participation and there are consistent socio-economic differences. In Stockholm, the average participation rate is 59%, in Göteborg 74%, and in Malmö 64%. The socio-economic correlation is that the lower the median income, the lower the participation, and vice versa: the higher the median income, the higher the participation.

**Figure 3.** Income inequality and participation in cervical cancer screening, 2018. Proportion of participants of the number invited in relation to median income in the age group 25–69 in different districts in the metropolitan municipalities of Stockholm, Malmö and Göteborg.<sup>7</sup>

Source: IHE and SCB, as well as calculations.



<sup>7</sup> The assumption of socio-economic differences in screening participation is more about the “socio-economic position” of the geographical area influencing screening participation (cf. RCC, 2021b). This is also the assumption in Table 1. However, the median income used in the chart is the one closest to the target group for cervical cancer screening according to data from SCB extracted from IHE (2021). This is to mimic the analysis of IHE (2021).

The relationship between higher median income and higher participation in cervical cancer screening could also be expressed as the higher the education, the higher the participation. This is due to the strong correlation between income level and education level.

In terms of primary education, there is also a link to foreign background: among adult women, foreign-born women, in particular, most often have primary education as their highest level of education. It seems to reinforce the already existing socio-economic patterns (cf. IHE, 2021). This could be explained, among other things, by language barriers and poorer establishment in the labour market (and in society) among foreign-born women with a low level of education and that this could push down screening participation even further.

There are also some age differences in screening participation. These mean that both the youngest (up to 30 years) and the oldest (over 60 years) women in the target group for cervical cancer screening participate at lower rates than other age groups (IHE, 2021). Using the same scenario analysis as in the National Board of Health and Welfare's health economic assessments, 55 more lives could be saved each year if participation in cervical cancer screening were as high nationwide as for the municipality with the highest participation (IHE, 2021). Low and unequal participation in cervical cancer screening costs lives.

## Screening for breast cancer

Screening for breast cancer with mammography became the second national screening programme in Sweden. It was introduced gradually during the 1980s and 1990s and was fully implemented in all the then county councils by 1997 (National Board of Health and Welfare, 2019a).

Among women who attend breast cancer screening regularly, between 60 and 70% of all breast cancer cases are detected through screening. Screening contributes to a reduction in mortality from breast cancer of between 16 and 25% (National Board of Health and Welfare, 2014a; 2019b). For women who regularly participate in breast cancer screening, the reduction is even greater (RCC, 2020).

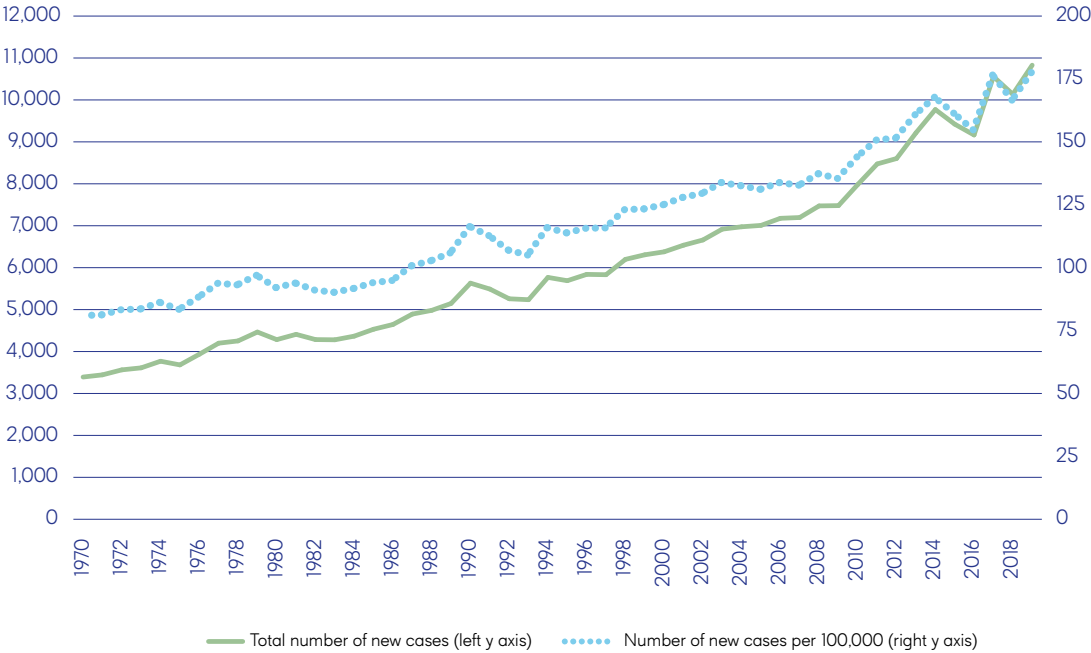
Breast cancer screening is very important for the early detection of breast cancer, and early detection reduces breast cancer mortality.

Breast cancer is the most common cancer among women in Sweden. The number of new cases is increasing over time and in recent years has been around 11,000 or up to 180 new cases per 100,000 women (see Figure 4). Every new tumour detected is counted as a new cancer case and the National Board of Health and Welfare points out that, since 2003, more tumours have been reported per woman. In 2019, a total of almost 11,000 new cancer tumours were detected in 8,290 women. This means that the women who were diagnosed with breast cancer had an average of 1.3 tumours.

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more people would have survived breast cancer annually if participation in breast cancer screening was as high in Sweden as in the municipality with the highest participation (IHE, 2021).

**Figure 4.** New cases of breast cancer 1970-2019. Total number of new cases and number of new cases, age-standardised incidence per 100,000 women. All ages.



NOTE: Since 2003, according to the National Board of Health and Welfare, there has been increasing reporting of the number of tumours per woman for breast cancer. This is important to take into account when interpreting the statistics.

Source: The National Board of Health and Welfare

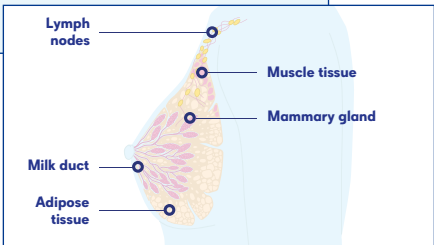
**Need for improved regional work on breast cancer screening**

In 2014, the National Board of Health and Welfare reviewed the breast cancer screening programme and concluded that the work of the programme needed to be developed. The regions were therefore tasked with “improving and developing the existing programme by clarifying information about the programme and creating the conditions for systematically measuring and following up effects” (National Board of Health and Welfare, 2014a, p. 5).

**THE NATIONAL BREAST CANCER SCREENING PROGRAMME**

The National Breast Cancer Screening Programme invites everyone who has been assigned the legal gender of female at birth and is between 40 and 74 years old to free breast cancer screening at least every two years.<sup>8</sup>

Source: The National Board of Health and Welfare



<sup>8</sup> The screening interval varies between 18 and 24 months. According to the National Board of Health and Welfare (2014a), many regions offered the shorter time interval (every 18 months) to women up to 55 years of age. The reason is that younger women usually have denser breasts, which can make it harder to detect changes. In addition, younger women often have more fast-growing cancers.

Since July 2016, breast cancer screening has been free of charge nationwide. This, along with other efforts, is important in order to increase participation in breast cancer screening. This is particularly true from a socio-economic perspective (cf. Törnberg et al, 2014; Swedish Agency for Health and Care Services Analysis, 2020). The Swedish Agency for Health and Care Services Analysis (2020) also specifically emphasizes the importance of good and equal geographical access to screening in all regions.

Otherwise, high and more equal participation is mainly linked to a development-oriented way of working in the regions: to methodical and structured improvement work through monitoring and development of how the regions work with implementation, both in terms of general measures and measures targeted at women in groups with lower participation. Regarding the general measures, there is good compliance with national recommendations at the regional level: accessibility, invitations, reminders, communication and information.<sup>9</sup> Targeting includes proactive measures. The Swedish Commission for Equity in Health, for example, argued that the regions should actively analyse who does not attend screening and develop measures to reach those who do not attend, and that it is important to draw on experiences from other regions in this work (SOU 2017:47). In particular, the Swedish Agency for Health and Care Services Analysis (2020) highlights that some regions have worked with health information officers, targeted information activities and various types of mobile and outreach activities to increase participation. For the future, the Swedish Agency for Health and Care Services Analysis (2020) also suggests that it could:

*... be motivated to focus more on factors other than socio-economic factors that influ-*

*ence participation, such as the importance of practical factors such as distance and travel time to the screening centre. Other issues that may need to be addressed in future studies and follow-up include the impact of organisational, contextual and workplace factors on participation. Screening programmes should also be examined from the perspective of certain particularly vulnerable groups, such as people with disabilities or mental health issues (Swedish Agency for Health and Care Services Analysis, 2020, p. 69).*

### Unequal participation in breast cancer screening

New figures from the IHE (2021) show that participation in breast cancer screening is both higher and more consistent across the country than for cervical cancer screening. On average, 81% of the women invited participated in breast cancer screening in 2019.

Regional differences are comparatively small (see Figure 5), with the exception of one region that stands out on the negative side. Stockholm has a participation rate of 71%. Participation in breast cancer screening in Stockholm has long been at a relatively low level and therefore attempts have been made to understand why. There are three main explanations put forward. These include possible inaccuracies in the data, breast cancer screening outside the screening programme (“wild screening”) and more people getting mammographies at private clinics (Swedish Agency for Health and Care Analysis, 2020).

Apart from the Stockholm region, the regions are relatively close to each other: ranging from 80% participation in the Kronoberg, Uppsala and Södermanland regions to 90% participation in the Blekinge region.

<sup>9</sup> For breast cancer screening, quality-assured invitation and information packages have been available for several years, developed by SKL (now SKR) as part of the work on the national cancer strategy. However, there are regions that do not use the national invitation. To ensure that all women have access to equal and quality-assured information on breast cancer screening, it is reasonable that all regions use the quality-assured national invitation and information packages.





**Figure 5.** Breast cancer screening participation in the regions and the country, 2019. Percentage of participants of the number of invitations.

Source: IHE

Differences within regions are also relatively small overall. The difference between the best and the worst municipality within the regions is generally no more than 15 percentage points. There is one exception, however, and that is the region of Västra Götaland, which has a much larger difference between the municipality with the highest and the municipality with the lowest participation (see further in Table 2).

The Halland region is almost unique and has almost no differences in screening participation between municipalities. Relatively small differences between the best and worst municipalities are

also found in the regions of Kalmar and Jämtland.

At the national level, the difference between the municipalities with the highest and lowest participation in breast cancer screening is 42 percentage points. Bollnäs municipality in the Gävleborg region has the highest rate, with 93% participation in breast cancer screening in 2019. The lowest is Tidaholm municipality in region Västra Götaland, with 51%. Tidaholm's participation is significantly lower than that of other municipalities in the Västra Götaland region.

**Table 2.** Municipalities with the highest and lowest participation in breast cancer screening by region, 2019. Percentage of participants of the number invited, as well as the median monthly income of women aged 20–64 and the percentage of women aged 25–64 with a lower secondary education.<sup>10</sup>

Region	HIGHEST PARTICIPATION					LOWEST PARTICIPATION			
	Average participation	Municipality	Average participation	Median income per month	Share of those with lower secondary education	Municipality	Average participation	Median income per month	Share of those with lower secondary education
Blekinge*	90%	—	—	—	—	—	—	—	—
Gävleborg	89%	Bollnäs	93%	SEK 23,627	11%	Nordanstig	83%	SEK 22,517	13%
Halland	89%	Varberg	90%	SEK 25,773	8%	Laholm	89%	SEK 22,875	10%
Dalarna**	88%	Avesta	92%	SEK 23,824	13%	Mora	73%	SEK 25,782	9%
Jönköping	86%	Nässjö	90%	SEK 24,180	12%	Mullsjö	79%	SEK 24,344	10%
Västerbotten***	86%	Norsjö	92%	SEK 23,739	9%	Lycksele	80%	SEK 24,221	10%
Jämtland-Härjedalen	85%	Berg	92%	SEK 23,125	9%	Ragunda	84%	SEK 22,462	11%
Kalmar	85%	Vimmerby	88%	SEK 24,602	10%	Högsby	81%	SEK 21,268	15%
Västernorrland	85%	Ånge	87%	SEK 24,489	11%	Härnösand	75%	SEK 24,531	11%
Norrbotten	85%	Piteå	89%	SEK 25,627	6%	Boden	74%	SEK 25,576	9%
Värmland	85%	Hammarö	91%	SEK 28,636	5%	Storfors	76%	SEK 23,283	15%
Västmanland	85%	Surahammar	87%	SEK 24,399	12%	Arboga	77%	SEK 23,181	11%
Västra Götaland****	84%	Värgårda	91%	SEK 24,406	12%	Tidaholm	51%	SEK 24,641	12%
Gotland	84%	—	—	SEK 24,231	9%	—	—	SEK 24,231	9%
Örebro	83%	Lekeberg	85%	SEK 25,638	9%	Ljusnarsberg	74%	SEK 20,683	17%
Östergötland	82%	Motala	86%	SEK 24,282	13%	Ydre	70%	SEK 24,100	7%
Skåne	82%	Lomma	90%	SEK 32,677	4%	Burlöv	77%	SEK 22,874	13%
Södermanland	80%	Nyköping	83%	SEK 25,392	11%	Gnesta	68%	SEK 25,028	11%
Uppsala	80%	Knivsta	83%	SEK 28,841	6%	Ålvkarleby	65%	SEK 23,402	14%
Kronoberg*	80%	—	—	—	—	—	—	—	—
Stockholm	71%	Nykvarn	76%	SEK 30,919	7%	Botkyrka	64%	SEK 22,291	17%
Nationwide	81%	Bollnäs	93%	SEK 23,627	12%	Tidaholm	51%	SEK 24,641	12%

\* For Blekinge and Kronoberg regions, it has not been possible to obtain data for participation at municipality level.

\*\* In the Dalarna region, participation in breast cancer screening is higher in Vansbro and Malung-Sälen than in Avesta, and participation is significantly lower in Älvdalen municipality than in Mora. However, the data for Vansbro and Malung-Sälen as well as Älvdalen look incorrect. Therefore, they are not included in the comparison.

\*\*\* In the Västerbotten region, the municipalities of Nordmaling, Vindelns and Robertsfors show significantly lower participation in breast cancer screening. However, very few people were invited to screening in 2018, so the results are unlikely to be representative. Therefore, the results for these municipalities are not included.

\*\*\*\* For Västra Götaland, there is no data on participation in breast cancer screening in Tjörn and Munkedal.

Source: IHE, Kolada and SCB.

<sup>10</sup> As described earlier, the assumption of socio-economic differences in screening participation is based primarily on the "socio-economic position" of the geographic area (RCC, 2021b). This assumption is also made in Table 2. However, the median income for the age group 35–74 (IHE, 2021) is used to illustrate the socio-economic link and participation in breast cancer screening in Figure 6. This is to mimic the IHE analysis.

As with participation in cervical cancer screening, there are socio-economic explanations for differences in participation in breast cancer screening. This is partly reflected in Table 2 above, but even more so in Figure 6 below.

In metropolitan districts (Stockholm, Göteborg and Malmö) with lower median incomes,

fewer people participate in breast cancer screening than in districts with higher median incomes. The average participation rate was 71% in Stockholm, and 81% and 78% in Göteborg and Malmö.

**Figure 6.** Income inequality and participation in breast cancer screening, 2019. Proportion of participants of the number invited in relation to median income in the age group 35-74 in different districts in the metropolitan municipalities of Stockholm, Malmö and Göteborg.



Source: IHE and SCB, as well as calculations.

For breast cancer screening, participation is somewhat more uniform and is consistently at comparatively higher levels than for cervical cancer screening. For breast cancer screening, age differences in participation are not as clear, although the youngest age groups participate at a slightly lower rate than other age groups (IHE, 2021).

A more general partial explanation for the differences in participation between cervical and breast cancer screening could have to do with the different target groups of the programmes: reaching the larger age group of 23 to 64-year-olds on a regular basis is likely to be more challenging than reaching the smaller age group of 40 to 74-year-olds on a regular basis.

The question is also whether the higher participation in breast cancer screening can be linked to the fact that it is the most common cancer among women and that breast cancer, as such, is better known and recognised than cervical cancer. Further investigation by regions into why breast cancer screening is more successful than cervical cancer screening has the potential to highlight whether there are lessons that can be learned to boost participation to higher levels. At the same time, more action is needed to both increase and equalize participation in both cervical and breast cancer screening. The fact that three and two out of ten, respectively, do not attend screening is a challenge.

IHE (2021) has estimated how many more lives could be saved each year if participation in breast cancer screening were as high in Sweden as in the municipality with the highest participation. The

estimate, based on the same methodology as the National Board of Health and Welfare's health economic assessments, suggests that 33 more people would have survived breast cancer each year.

## Screening for colorectal cancer

Colorectal cancer is one of the most common cancers in both men and women. Over time, the number of new cases has increased, both

overall and as new cases per 100,000 people (see Figure 7).

**Figure 7.** New cases of colorectal cancer 1970-2019. Total number of new cases and number of new cases, age-standardised incidence per 100,000 women and men. All ages.



Source: The National Board of Health and Welfare

Colorectal cancer is a disease of which almost everyone can be cured if detected early. On the other hand, late detection of tumours and advanced disease has a much poorer prognosis and entails a high risk of premature death (RCC, 2018).

The National Board of Health and Welfare therefore recommended a national colorectal cancer screening programme as early as 2014. A key factor in the recommendation was that mortality from colorectal cancer was expected to be reduced by 15% (National Board of Health and Welfare, 2014c).

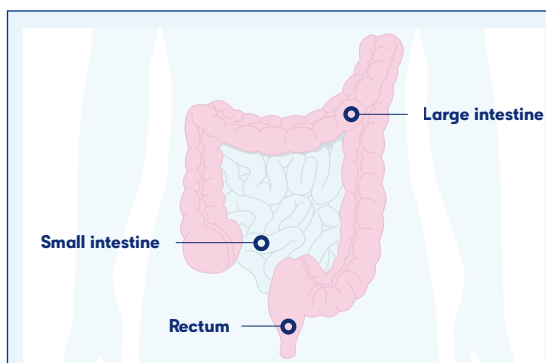
### Universal screening underway but implementation slow

The process that has characterised the implementation of colorectal cancer screening has been cumbersome and lengthy. The screening programme is still far from being fully implemented. The National Board of Health and Welfare highlighted colorectal cancer as an important area of research and development in 2011 and the screening recommendation came in 2014, but the programme will not be fully implemented until 2027. The slow implementation has caused more cancer cases

and cancer-related deaths than would have been the case if the programme had been implemented more quickly (see below).

A contributing factor to the lengthy implementation is that both the National Board of Health and Welfare and the RCC have wanted to wait for the so-called SCREESCO study. This study started in 2014 and had as an important objective to compare different screening methods. The study was also seen as an important preparation for implementation, as a total of 33 hospitals in 18 regions participated. A total of 90,000 people were also invited to screening as part of the research study,<sup>11</sup> which ended in 2019. In light of the study results, the RCC proposed that all regions should go ahead and start implementing universal colorectal cancer screening by the end of 2019 (RCC, 2018; National Board of Health and Welfare, 2019a). Since then, however, it has taken more time.

The Stockholm and Gotland regions are the only regions in Sweden to have offered screening for colorectal cancer to men and women aged 60–69 since 2009.<sup>12</sup> For all other regions, the timetable for implementation was set as late as June 2021. The regions will join gradually over the next two years. In 2021, the regions of Dalarna and Skåne have started screening activities and the regions of Örebro and Östergötland are next. Thereafter, other regions will gradually introduce screening starting in 2022. According to the RCC's timetable, universal colorectal cancer screening will be fully rolled out between 2024 and 2027.<sup>13 14</sup>



### THE NATIONAL COLORECTAL CANCER SCREENING PROGRAMME

The national screening programme for colorectal cancer requires health services to offer stool blood tests to men and women aged 60–74 every two years.

The screening involves mailing a screening offer to selected age groups containing instructions, a test tube and a response envelope. The stool sample is taken at home and then sent to the laboratory for analysis. If blood is found in the stool sample, the person is offered further colonoscopy examination in the health care system.

Source: National Board of Health and Welfare (2014c); RCC.

<sup>11</sup> Study participants will be followed for 15 years to evaluate the impact of screening on colorectal cancer incidence and mortality.

<sup>12</sup> Note, however, that the activity does not yet cover the entire age group 60–74. For those aged 70–74, services will be gradually expanded between 2021 and 2025.

<sup>13</sup> PowerPoint presentation (cancercentrum.se)

<sup>14</sup> The RCC and RCC Stockholm-Gotland offer various forms of support for the regions' introduction of universal colorectal cancer screening. A common invitation system has been developed and implemented, and a common coordination office is being established within RCC Stockholm-Gotland. The idea is to allow all regions in the country to connect to and use the common functions. The RCC's national working group on colorectal cancer screening is also tasked with developing a national care programme for colorectal cancer screening.

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more people would have survived colorectal cancer annually if participation in colorectal cancer screening were as high in Sweden as in the municipality with the highest participation (IHE, 2021).

### Major health benefits from targeted information on colorectal cancer screening

The Stockholm and Gotland regions have an established colorectal cancer screening service. The researchers in the report “Geomapping of Colorectal Cancer” (RCC, 2021b) have taken advantage of this service.

The researchers show that the population in the age group 60–79 in the Stockholm and Gotland region during the period 2015 to 2019 had a significantly lower incidence of colorectal cancer compared to the other five health regions, which had between 17 and 21% higher incidence. They also show that tumours are detected at earlier stages in Stockholm and Gotland compared to the rest of the country and believe:

*Based on these convincing results regarding the benefits of organised colorectal cancer screening in the RSG [note: Stockholm and Gotland regions], it can be expected that the introduction of organised screening in other parts of Sweden will significantly reduce the impact of colorectal cancer (RCC, 2021b, p. 1).*

In addition, the odds of early detection of tumours were significantly lower among 60 to 79-year-olds in areas with the worst economic standards compared to areas with the best economic standards (RCC, 2021b).

It is therefore important that implementation focuses on achieving both high and equal participation. The researchers (RCC, 2021b) are on

the same track as the National Cervical Cancer Prevention Care Programme (RCC, 2021a) and the Swedish Agency for Health and Care Services Analysis (2020) in terms of the feasibility of successfully implementing and executing the national cancer screening programmes:

*Our hope is that the evidence presented in this report will be used to test and evaluate targeted information campaigns aimed at promoting adherence to colorectal cancer screening in vulnerable populations. Targeted and controlled trials of information campaigns should be initiated in a coordinated manner across Sweden. In practice, this involves selecting intervention vs. control areas, conducting information campaigns, and following up on screening participation (RCC, 2021b, p. 7).*

### Unequal participation in colorectal cancer screening

Participation in colorectal cancer screening is still low in the entire population aged 60–74. This is because colorectal cancer screening is still only in place in the Stockholm and Gotland regions for the 60–69 age group.<sup>15</sup> In 2019, participation averaged 71% in the Stockholm and Gotland regions. According to the IHE (2021), this makes the participation rate for the whole country as low as 14%.

IHE (2021) also shows that there are differences in screening participation between the regions of Stockholm and Gotland and between men and women. Participation is higher in Gotland than in Stockholm, 77 and 71%,

<sup>15</sup> In the Stockholm and Gotland regions, the oldest age group 70–74 is not yet screened, but work on expanding screening has begun and is expected to be completed by 2025.

respectively. In both regions, women’s participation is higher than men’s. On average, women’s participation was 74% and men’s 68%.

Region Gotland and Gotland municipality coincide and have the highest participation in colorectal cancer screening (77%). Within the Stockholm region, there are differences between municipalities and neighbourhoods. The municipality with the lowest participation rate was Botkyrka (66%), and the municipality with the highest was Täby (76%).

The average participation rate in colorectal cancer screening in the municipality of Stockholm was also 71% in 2019. Screening participation, like cervical and breast cancer screening, shows socio-economic patterns of participation. There is higher screening participation in neighbourhoods with higher median incomes than with lower ones. As before, the relationship could just as easily be expressed as the higher the level of education, the higher the participation.

**Figure 8.** Income inequality and participation in colorectal cancer screening, 2019. Proportion of participants of the number invited by median income in the age group 55-74 in different districts in Stockholm.<sup>16</sup>



Source: IHE and SCB, as well as calculations.

Because universal screening for colorectal cancer is still so limited, the IHE (2021) estimate is that the most lives could be saved if screening participation were the same across the country

as in the municipality with the highest participation. It is estimated that 106 more people would survive colorectal cancer each year if this were the case.

<sup>16</sup> The median income for the age group 55-74 years (IHE, 2021) is used to illustrate the socio-economic link for participation in colorectal cancer screening in the municipality of Stockholm.

# Better preparedness for new screening programmes

What the three current national cancer screening programmes have in common is that they have taken a long time to implement and execute. Cervical cancer screening was implemented progressively over ten years from the late 1960s, and breast cancer screening over roughly the same period from the late 1980s. Since colorectal cancer screening was recommended in 2014, few regions have even started implementation in 2021. Full implementation in all regions is expected by 2027.

The National Board of Health and Welfare (2019b) considers two new cancer screening programmes to be relevant for introduction within five years: screening for lung cancer and screening for prostate cancer. According to the National Board of Health and Welfare, so-called liquid-based biopsies may soon be used as a screening method to detect cancer or the risk of cancer. It involves the analysis of biomarkers for cancer in blood, saliva or other body fluids. Intensive research on this type of screening is ongoing in most cancer areas (National Board of Health and Welfare, 2019b).

In the longer term, the National Board of Health and Welfare also believes that a general screening test for cancer may be appropriate. This aim is to make possible the detection of early signs of several types of cancer using blood tests. In addition to recommendations for population-based screening programmes, the National Board of Health and Welfare may also develop recommendations for screening of specific high-risk groups, and several stakeholders have identified the need to adapt screening to each person's risk of developing cancer through personalised screening. The basis for the latter is that individual cancer risks can be estimated

using risk assessment models that combine different types of information to tailor screening so that people at a higher risk are screened more often. For example, current screening for breast cancer could be made more effective in this way (Swedish National Board of Health and Welfare, 2019b).

It is also assumed that breast cancer screening could be made more efficient through better diagnostics, while cervical cancer screening could be adjusted according to year of birth, as the age groups vaccinated against HPV could start screening at an older age than the current age of 23.

In short, much will happen in cancer screening, both in the short and longer term. In the light of the protracted implementation of the three existing screening programmes, lessons need to be learned about the obstacles and difficulties that have contributed to the slow roll-out in order to avoid them. These are primarily effective referral systems, adherence to recommendations and care programmes, and methodical efforts to achieve high participation rates among people in low-participation groups.

It is not acceptable that future screening programmes should take as long to implement as the three recommended so far.



# Screening must reach more people

The common thread in this report is that the implementation of the three nationally recommended screening programmes is flawed, the programmes are simply reaching too few people. This is mainly the responsibility of the regions.

In particular, there are three systematic patterns that need to be overcome far better to enable an increase in early detection of cancer. These include socio-economic differences as well as regional and intra-regional differences. All of them need to be reduced in order to increase participation in the screening programme significantly across the country and at the same time make it more equitable. The report shows that it is important to aim higher.

High and equal participation in screening saves lives, and action to achieve this needs to be a priority. This requires more from the regions and the government.

## The regions bear the main responsibility

The Swedish Cancer Society believes that all regions need to move forward in their efforts to detect cancer diseases in time. The Swedish Cancer Society therefore considers it a priority that the regions do more to reach people in groups with low participation in screening programmes.

Initiatives are needed for new models and a systematic evaluation of what works. All regions need to analyse participation and implement targeted interventions for people in groups and geographical areas with low screening participation. This is also a clear recommendation in the "RCC's Common Focus for Swedish Cancer Care in 2020-2022".<sup>17</sup>

Two concrete examples of working methods

are the annual Smear Test Week and the health information officers in the Stockholm and Södermanland regions. There is also a general need for a more development-oriented approach and an active exchange of experience between regions to disseminate examples of what works well.

Regions also need to task the relevant administrations to ensure the region's adherence to commonly agreed care programmes and recommendations for cervical, breast and colorectal cancer screening. Also with a particular focus on increasing participation in areas where participation is lowest.

Health programmes and recommendations include important measures to increase screening participation. This ranges from the invitation design, to how appointment booking should work and whether or not reminders should be sent. It is important to prioritise actions that are more resource-intensive, such as making personal contact with women who have not participated in cervical cancer screening for a long time.

In addition, regions must be prepared for the rapid introduction of new screening programmes and recommendations. All regions need to fully implement the nationally recommended screening programmes, and there needs to be predictability. Several new screening programmes, as well as changes to existing programmes, are likely to shape the field of early detection of cancer in both the short and long term. Screening for lung cancer and prostate cancer is expected to

<sup>17</sup> See more here: <https://cancercentrum.se/globalassets/om-rcc/samverkan/vagen-framat-rcc-inriktning-svensk-cancer-var-d-2020-2022.pdf>

be the next recommendation from the National Board of Health and Welfare. It is unreasonable that the implementation of new and modified screening programmes should take as long as the cervical, breast and colorectal cancer screening programmes.

When the National Board of Health and Welfare recommends new or modified screening programmes, the ambition should be that they can be offered to all Swedish residents in the target groups covered with as little delay as possible.

### The government must take greater responsibility

Although the regions bear the main responsibility for running and organising health care, national decision-makers cannot sit back. Reducing inequality is a national responsibility. There are too many differences in participation in screening programmes within, but also between regions, not least by socio-economic status.

The tools available to national policy makers can be used to support the work of the regions. Partly to provide direction and partly to monitor, stimulate and develop the implementation of national screening programmes more effectively. A clear national ambition is needed, and the government can do more.

The Swedish Cancer Society therefore believes that the government should give the National Board of Health and Welfare a broader role in cancer screening. The introduction of new and modified screening programmes in the regions is too slow. Separate systems and processes create difficulties in cooperating across regional boundaries. Governments should take greater responsibility for national solutions where they are needed for facilitation. This could include coordination of quality registers, of IT systems for referrals and follow-up, and of the legal conditions for regions to share information to enable more coordination.

The Swedish Cancer Society also believes that the government should commission the National Board of Health and Welfare and the RCC to identify and evaluate methods for reaching people in groups with low participation in screening programmes and to contribute to the dissemination of the knowledge developed on the basis of such a knowledge base. The new assignment can be seen as a continuation of the dialogue forum that the National Board of Health and Welfare started in 2019, and where the hosting is shared between the Agency and the RCC.<sup>18</sup>

The government also needs to strengthen the regions' efforts to see to it that the health service can ensure that all those who have not been invited or have not been able to participate in screening because of the Covid pandemic are given the opportunity to do so. Equitable cancer care is a national responsibility that the government needs to shoulder.



If you have questions or concerns about cancer, you are very welcome to contact our helpline, Cancerlinjen.

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<sup>18</sup> At the end of May 2021, the Government decided to give the National Board of Health and Welfare an extended mandate to develop the screening work (Government, 21-05-27). This is in line with what The Swedish Cancer Society is calling for. This particular mission is due to be completed in June 2022. It is important that the government continues to have a clear national level of ambition for supporting the regions' efforts to achieve high and equal participation in screening programmes. A step in the right direction is the assignment given to the National Board of Health and Welfare on a coherent infrastructure for national quality registers, which will also be finalised in 2022 (October). See more here: <https://www.regeringen.se/pressmeddelanden/2021/09/nationell-digital-infrastruktur-for-nationella-kvalitetsregister-ska-utredas/>

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