Save lives – increase uptake

A guide containing tools to increase uptake of cancer screening and catch-up HPV vaccination

CANCER FONDEN

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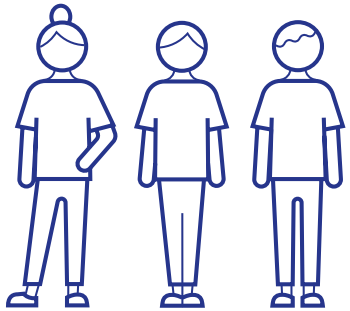
Hello,

We have gathered together evidence-based tools that can be used to increase uptake of cancer screening and catch-up HPV vaccination in this clear and easily accessible guide. Although cancer screening uptake rates in Sweden are relatively high compared with other European countries, coverage differs in different parts of Sweden and some groups attend screening less than others. We therefore hope this guide can be a source of inspiration for other countries looking to increase their cancer screening and HPV vaccination coverage.

In Sweden, healthcare is run by regions. This guide is therefore geared towards people who organise, plan and decide on regional healthcare provision, including cancer screening and catch-up HPV vaccination. In Sweden, these may be regional politicians and regional healthcare managers.

People who are responsible for cancer screening or catch-up HPV vaccination programmes can use one or more of the tools shown here to detect more cancer cases earlier and protect more people from cancer.

Together we can beat cancer.



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The Swedish Cancer Society's vision

The Swedish Cancer Society's vision is to beat cancer. We are working to ensure that fewer people get cancer and more people survive cancer by funding cutting-edge research, spreading awareness of cancer and influencing decision-makers.

We have come a long way in beating cancer but there is a lot more to do. Our vision is a society in which fewer people get cancer and more people are cured or are able to lead a long life, with a good quality of life. Focusing on progress in four areas, we are working towards the next advance, with clear targets for Sweden to reach by 2030. We will:

- **Prevent cancer so fewer people get cancer.** We know that a large proportion of all cancer cases could be prevented by healthier lifestyles. Therefore, we are working to encourage more actors in society to put measures and initiatives in place that make it easier for more people to make healthy decisions.
  Target 2030: A 30 percent reduction in preventable cancer.

- **Detect cancer early.** Detecting cancer at an early stage increases the chance of gentler cancer treatment and of survival. To increase survival rates, we need to be even better at detecting cancer early. Therefore, we are working to encourage more people to participate in screening programmes, as well as financing research into early detection of cancer. We are also working to improve the situation in primary care, where the majority of all cases of cancer are detected.
  Target 2030: A third of all cancer detected at an earlier stage.

- **Cure more people.** Research has dramatically improved people's chances of surviving cancer. Examples of research fields that will lead to even more people surviving cancer are individualised treatments, more types of immunotherapy, better diagnostic imaging and new combinations of treatments. We will continue to finance the best cancer research in Sweden, work to ensure that the results of research reach patients faster, and work for health equity nationwide.
  Target 2030: 80 percent surviving a cancer diagnosis.

- **Ensure that more people can live well.** In Sweden, one in three people will receive a cancer diagnosis during their lifetime. Thanks to research advancements, more and more people are surviving or living with cancer for a long time. We are working to ensure that everyone enjoys a good quality of life, during and after cancer. For example, we finance research into new, gentler forms of treatment. We provide advice and support to people with cancer and their families via our Cancer Helpline, and support patient organisations.
  Target 2030: Everyone living with and after a cancer diagnosis enjoys a good quality of life.

Increased uptake saves lives

Detecting cancer at an early stage increases the patient's chances of survival and of gentler cancer treatment. Screening is an important factor in the early detection of cancer. Cancer screening rates in Sweden are comparatively high but there are unwarranted inequalities between and within Sweden's regions, and between different groups in society. The same is true of rates for catch-up HPV vaccination.

In Sweden, there are three national cancer screening programmes: for breast cancer, cervical cancer and colorectal cancer. In 2021, the Swedish Cancer Society carried out a review of cancer screening coverage using data from 2019, which showed serious shortcomings in the way that Sweden's regions were carrying out the screening programmes. The review showed a clear link between socioeconomic status and uptake. For example, uptake was lower in people with lower median incomes and lower levels of education.

Screening uptake rates are still unequal

The Swedish Cancer Society has re-examined participation in screening programmes and found that uptake has not improved since the previous review. In 2023, approximately 3 out of 10 women failed to attend cervical cancer screening and 1 in 5 women did not attend their mammogram. According to this latest review, the uptake rate for colorectal cancer screening was only 64 percent. The results also show that uptake continues to vary significantly between the regions.

More people need to be vaccinated against HPV

Today we know that if enough people are vaccinated against HPV and attend regular cervical cancer screening, we can eradicate cervical cancer. In Sweden, all women born in 1994–1999 are currently offered catch-up HPV vaccination. If 70 percent of them have been vaccinated by the end of 2024, Sweden will be able to eradicate cervical cancer by 2027. However, in early 2024 only 30 percent of the target group had been vaccinated and there was a high degree of variation in vaccination coverage between different regions.

Tools for increasing uptake

To prevent more cases of cancer and detect cancer at an earlier stage, we need to increase uptake of screening and catch-up HPV vaccination. To this end, in 2023, the Swedish Cancer Society met policymakers in nearly every region to engage in dialogue on how we can work together to increase uptake rates. The message is clear: we need targeted interventions and new approaches. We have also seen that the level of knowledge about cancer screening varies and that there is a demand from many regional politicians for more knowledge to be shared between the regions. As a result, we produced this guide to support Sweden's regions.

Programme	Introduced	Target group	Impacts
Breast cancer screening	1980–1997	Mammograms are offered to women aged between 40 and 74 every two years.	Regular mammograms lead to the detection of 60 to 70 percent of cases and screening is estimated to reduce mortality by approximately 30 percent.[16]
Colorectal cancer screening	2008–2026	Women and men aged between 60 and 74 are invited for screening every two years.	The Swedish National Board of Health and Welfare estimates that the programme will reduce mortality by 15 percent.[17] Early detection usually means that the cancer can be cured.[18]
Cervical screening	1966–1977	Offered to women aged between 23 and 49 every three years, and women aged between 50 and 64 every seven years.	Regular screening reduces the risk of cervical cancer by approximately 90 percent.[14] The biggest risk factor is not attending screening.[15]
Catch-up HPV vaccination	2021–2023	Free catch-up HPV vaccination for women born in 1994–1999. Many in the target group do not already have full protection.	Vaccination provides 70–90 percent protection against cervical cancer.[19]

National early detection and vaccination initiatives

Attending screening increases the chance of detecting cancer early, which means that more people can survive and experience gentler cancer treatment. Vaccination against HPV protects against cervical cancer. Here we outline Sweden's three national cancer screening programmes and the initiative to encourage women born in 1994–1999 to catch up on their HPV vaccination.

Breast cancer screening

- Breast cancer screening is carried out using mammography to detect and treat breast cancer at as early a stage as possible.
- Mammograms are voluntary and are offered free of charge by Sweden's regions to women aged between 40 and 74. Women are invited for a mammogram every 18–24 months. The frequency varies in different parts of Sweden.
- Mammography is an examination of the breasts carried out in a clinic using an X-ray machine.
- Regular breast cancer screening means that 60–70 percent of all breast cancer cases are detected by mammography. Screening is estimated to reduce mortality by approximately 30 percent.
- Every year, about 8,500 people are diagnosed with breast cancer in Sweden.

Read more at **cf.se/mammografi**

Screening for bowel cancer

- Bowel cancer screening is offered to men and women to detect and treat colorectal cancer at as early a stage as possible.
- The Swedish National Board of Health and Welfare recommends colorectal (bowel) cancer screening for everyone in Sweden aged between 60 and 74. Everyone offered screening receives a letter in the post containing a stool sample tube, instructions and a return envelope.
- All regions offer screening for colorectal cancer today, but the screening programme has not been fully rolled out and is expected to be fully operational in 2026. Once it is, everyone aged between 60 and 74 will be invited for screening every two years.
- The Swedish National Board of Health and Welfare estimates that the national colorectal cancer screening programme will reduce mortality from colorectal cancer by 15 percent.
- Every year about 5,000 people get colon cancer and 2,200 get rectal cancer.

Read more at **cf.se/tarmcancerscreening**

Screening and HPV vaccination give us an opportunity to entirely eradicate cervical cancer.

Cervical cancer screening

- A gynaecological cell test, also known as an HPV test, smear test or Pap test, is carried out on women to detect cell changes that could lead to cancer of the cervix. In Sweden, all women aged between 23 and 49 are invited for a smear test every five years and women aged between 50 and 64 are invited every seven years.
- The sample is taken during a gynaecological examination, where a midwife, for example, takes cells from the cervix with a small spatula or brush. The cells are then examined. The invitation to cervical cancer screening can also involve women carrying out a home HPV test.
- Since the smear test was introduced in the mid-1960s, the number of cases of cervical cancer has more than halved. Regularly attending smear tests reduces the risk of getting cervical cancer by approximately 90 percent.
- About 550 women get cervical cancer every year. The biggest risk factor for cervical cancer is not attending screening.

Read more at **cf.se/cellprov**

Catch-up HPV vaccination

- Catch-up human papillomavirus (HPV) vaccination is offered to women born between 1994 and 1999. Many women in this target group are not fully protected against HPV.
- Practically all cases of cervical cancer are caused by cell changes due to HPV. Vaccination against HPV can reduce the risk of cervical cancer by 70 percent. Today we know that if enough people are vaccinated against HPV and regularly attend cervical cancer screening, we can eradicate cervical cancer.
- If 70 percent of women born between 1994 and 1999 are vaccinated by the end of 2024, Sweden will be able to eradicate cervical cancer by 2027. We will also be able to reduce other cases of cancer caused by HPV.
- However, in early 2024, only 30 percent of the target group had been vaccinated and there was a high degree of variation in vaccination coverage between different regions.

Read more at **cf.se/catchup**

Increasing uptake – factors and tools

This guide can provide support in working proactively to encourage more people in Sweden's regions to attend cancer screening and catch-up HPV vaccination. It is divided into two parts: a description of the organisational factors needed in the region, and tools geared towards different target groups.

The guide is based on analysing interviews with experts including representatives from the regions, regional cancer centres, researchers, patient organisations, charities and international cancer organisations, as well as reviewing the literature in the form of scientific studies, guidelines and other reports, and supporting expertise.

Based on this analysis, we identified target groups with lower screening and catch-up HPV vaccination rates. Tools were then mapped to increase the engagement of each target group, with evidence for each tool.

- This guide uses the accepted term "catch up-vaccination" for what in Swedish is sometimes also called "ikappvaccination".
- The guide does not contain methods to increase uptake of the public childhood vaccination programme.

Method identification and validation process

Identifying target groups

Target groups with lower uptake of screening and catch-up HPV vaccination were identified and categorised based on shared underlying factors.

Identifying tools

Tools to increase uptake and evidence for the respective method were mapped for each target group.

Analysing and synthesising tools

Target groups were selected for further analysis and individual packages of tools were produced for these.

A region can work on **organisational factors** and concrete **tools** to increase uptake.

How can regions increase cancer screening and catch-up HPV vaccination uptake?

Organisational factors

What does the region need to make sure is in place organisationally to get local people to engage?

Read more on page 10.

Put everything in place for the healthcare staff carrying out screening and vaccination

- Remits and financing
  Clear targets, remits and incentives
- Infrastructure
  IT system for invitations and referrals
- Skills
  Training to ensure skills

Improve follow-up and develop methods
Capacity to identify target groups and measure the results of interventions

- Access to data
- Analysis capacity
- Feedback on results

Tools

What tools are there to get local people to engage?

Read more on page 15.

Increase incentives

- Tangible
- Intangible

Lower barriers

- Time-related
- Geographical
- Cost-related
- Knowledge-based
- Social

Organisational factors to increase uptake

A number of organisational factors need to be in place to enable the tools to be used appropriately and to have the intended impact.

The tools chosen by a region need to reflect the situation in terms of organisation in that particular region. For example, starting work on a strategy for sending reminders to people who have not attended screening will not be effective if the providers do not have access to an invitation system capable of showing which people have not attended their appointments. In the same way, healthcare staff need to be familiar with different cancer screening programmes and catch-up vaccination in order to provide information and answer questions about the programmes, for example at routine appointments in primary care or maternity care.

The factors described here are generally applicable in a Swedish context. Two important interventions are needed to eradicate cervical cancer: high vaccination rates and equitable screening. This has consequences both for the factors already in place in the respective region and the tools that are best suited to increase cancer screening and catch-up HPV vaccination uptake rates.

The description of the organisational factors is intended primarily to highlight areas that need to be taken into account.

The most important organisational factors are based on two fundamental areas:

- putting everything in place for the healthcare staff carrying out screening and vaccination
- improving follow-up and developing methods

From these fundamental areas, four areas have been identified:

1. Clear targets, remits and incentives.
2. IT system for invitations and referrals.
3. Training to ensure skills.
4. Capacity to identify target groups and measure the results of interventions.

Breast cancer screening using mammography detects 60–70 percent of all breast cancer cases in Sweden.

Organisational factors to increase uptake

1 Remits and financing: Clear targets, remits and incentives

The problem

- Screening can be an organisationally complex service to provide, which often involves several providers. Because each of these providers has different targets and incentives, it can be difficult to get everyone pulling in the same direction. Sometimes there is also no shared vision at regional level for achieving a specific uptake rate for different screening programmes or catch-up HPV vaccination, either overall or for specific target groups. There is often no specific person/role with overarching responsibility for achieving a particular uptake rate in the region.
- The economic benefits of higher uptake often accrue to a provider other than the provider with the greatest opportunity to influence uptake rates. For example, the providers that carry out screening often have no economic incentives to ensure that people invited for screening actually turn up. Several regions raise the problem of a lack of long-term funding for efforts to increase uptake (for example targeting selected target groups). Instead efforts are carried out in project form. The impacts of the projects then often tail off once the project has finished. In addition, there is sometimes only a weak link at regional level with the healthcare work being done by the respective Regional Cancer Centre (RCC).

Potential solutions

The solutions mainly rest with the region's politicians and healthcare management.

- Set region-wide targets for cancer screening and catch-up HPV vaccination rates.
- Make sure that remits, mandates and incentives support the uptake rate target. This includes fostering collaboration between the providers involved, ensuring that decision paths are clear and that there is a person/function with overall responsibility for screening.
- Long-term funding for efforts to increase uptake.
- Coordinate efforts to increase uptake with different providers who all share the aim of reaching identified target groups.
- Create a structure for commissioning/contracts that enables the involvement of providers other than those that normally carry out screening and vaccination. This can include collaboration with the municipalities in the region or key civil society actors. Vaccination in particular can often be carried out by several different providers in and outside the healthcare organisation.[53]

In each region, there should be a clear description of the organisation with clearly allocated responsibilities and defined remits and mandates, backed by the regional leadership.

National Clinical Cancer Care Guidelines for Cervical Cancer Prevention

Organisational factors to increase uptake

2 Infrastructure: IT system for invitations and referrals

The problem

- A functional invitation and referral system is essential for effective cancer screening and HPV vaccination.[17] Failures in an invitation system can, for example, lead to invitations not being sent out to the right people at the right time, or people finding it difficult to change appointment times or get in touch with the health service to book an appointment if they have not received an invitation despite being in the target group. This creates a risk that people who would otherwise have attended screening or been vaccinated will not attend.
- In some regions, invitations are not logged so there is no way of identifying people who received an invitation but did not attend. In such cases, it is also not possible to see when an invitation was sent in order to send a reminder after a set period of time. In some regions, the target groups find booking or changing a screening appointment a complicated process. Sometimes there is no option to change an appointment online or strong authentication is needed to be able to change an appointment. This might involve needing a Bank-ID, which not everyone has. This kind of solution then ends up excluding people.
- Awareness of individual circumstances is needed so that processes can be tailored to certain target groups. Here, the invitation system needs access to more information about people than their address, sex and age. Where someone with a disability needs a longer appointment, for example, information about their disability needs to be in the system.

Potential solutions

The solutions mainly rest with the region's politicians and healthcare management and with those responsible for IT.

- Connect to the generic invitation and follow-up system developed by RCC West to support the regions in introducing the National Clinical Cancer Care Guidelines for Cervical Cancer Prevention. The system manages screening invitations and follow-up.[8]
- Offer an opportunity to change appointments online but without requiring strong authentication. Another option is to send invitations via the online healthcare service 1177.[8]
- If possible – integrate the invitation system with systems containing information on health conditions that require tailored invitations. However, there are legal obstacles here if that data is held by another data holder, such as a municipality.[48]

To carry out cervical cancer prevention in line with the National Clinical Cancer Care Guidelines, a tailored IS (information system) is needed, or IT support that incorporates an invitation system and a laboratory information system (LIS) as well as data transfer between these and to a quality registry.

National Clinical Cancer Care Guidelines for Cervical Cancer Prevention

Organisational factors to increase uptake

3 Skills: Training to ensure skills

The problem

- A lack of awareness of why screening and vaccination are important can lead to people not attending when they are invited to do so. A lack of knowledge among healthcare staff can similarly pose a barrier to uptake.[54] It is important that people in the target groups of the screening and vaccination programmes are able to obtain the right information when they are in contact with the health service in other contexts. Certain key healthcare groups thus need to be familiar with the screening and vaccination programmes. One example is that midwives need basic knowledge about cervical cancer screening and catch-up HPV vaccination so that they can identify those who have not been screened or vaccinated (non-attendees) and answer questions.[8, 53]
- In primary care, a GP can fulfil the same role for bowel cancer screening (and probably other screening programmes too). Doctors should be familiar with the screening process whether or not they are involved in it themselves. Their awareness of and attitude to the screening programmes can affect uptake among the patients they see.[55]
- It is also important that healthcare staff who see people from low-uptake groups are skilled in engaging with them in a way that inspires trust. This is true both for healthcare in general and the screening and vaccination programmes in particular. For example, staff who see migrants need cross-cultural skills.[53]

Potential solutions

The solutions mainly rest with the region's politicians and healthcare management and with those responsible for training.

- Prepare and coordinate training initiatives for key groups in the different screening and vaccination programmes. This equips them and motivates them to inform and build trust in the programmes among non-attendees.
- Use nationally produced training material. National online training on cervical cancer prevention and HPV-based screening is one example.[8]
- Attend training run by RCCs. This is often carried out jointly with those responsible for screening in the regions.

There may be a need for information material geared towards healthcare staff, as colorectal cancer screening is introduced, so that they in turn can provide adequate information about this form of cancer and about screening.

National Clinical Cancer Care Guidelines for Colorectal Cancer Screening

Health training improved uptake of the HPV vaccine when it came from healthcare staff and/or school nurses in long-form information events about the nature of the disease and the advantages and disadvantages of the vaccine.

Strategies to increase vaccination coverage, Centre for Epidemiology and Community Medicine, Region Stockholm

Organisational factors to increase uptake

4 Improve follow-up and develop methods: Capacity to identify target groups and measure the results of interventions

The problem

- The ability to identify the groups whose uptake is low is crucial to carrying out targeted interventions. Capacity to conduct such an analysis differs between the regions but generally seems to be low for selection criteria other than geography and age.[48] This limits opportunities to identify groups with similar behaviour patterns, which is considered to be important in order to put strategies in place tailored to the needs of the different groups.[53] Furthermore, it is useful to be able to identify the barriers or underlying reasons for low uptake in different groups. Such an understanding should underlie the interventions chosen.[53] The interventions carried out should also be able to be evaluated to ensure that resources are channelled to where they have the greatest impact.

Potential solutions

The solutions mainly rest with the region's politicians and healthcare management.

- Ensure skills and develop processes to analyse the underlying causes of low uptake in different groups. The work can usefully be coordinated with other aspects of the region's healthcare provision, such as dental care or maternity care, as the same groups tend to fail to attend recommended appointments in other parts of the healthcare system too.
- Join the joint coordination office (GSK) for colorectal cancer screening set up by RCC Stockholm-Gotland. Regional coordination and follow-up are offered there as part of the programme.[17]
- Facilitate randomised testing with control groups when different interventions are carried out, for example, by bringing in experts in the field. This is necessary so that the effectiveness of different interventions can be better evaluated.[55] Involving researchers in some interventions could be one example.

The opportunity for rapid, recurring follow-up gives the regions an effective tool to direct their interventions to where the need is greatest, using the methods that are most effective.

Government inquiry, Evaluation of the implementation of vaccination against COVID-19

A screening register should be set up for everyone invited and those who choose to participate, mainly for ongoing quality follow-up of the whole programme.

National Clinical Cancer Care Guidelines for Colorectal Cancer Screening

Tools to increase uptake

Interventions to increase the uptake rate of cancer screening and catch-up HPV vaccination can be general or designed to target specific groups.

Different uptake in different groups

The screening and vaccination uptake rate often differs significantly between different groups. Targeted interventions aimed at the different groups can be carried out to make uptake more equitable. Before such interventions are carried out, it is important to understand which groups have lower uptake rates.

Tools suitable for everyone due to be invited

There are tools to increase uptake among everyone offered cancer screening or catch-up HPV vaccination. These types of intervention are often based on improving central processes and communication. Thus they do not require specific target group analysis.

Tools for groups with lower uptake

The groups with lower uptake may differ in different regions. However, there are some groups that frequently recur in the analyses carried out and where many methods have been tested and evaluated.

This guide presents specific tools for these groups. The tools do not cover all the possible groups and a selection has been made based on the groups:

- identified in interviews and literature reviews
- for which several tools and methods are described and evaluated in different studies
- with limited opportunities to be active and engage in their health and social care.

Prioritising tools based on the circumstances and needs of the region

Ways of comparing the different tools are needed to ensure that the regions maximise the value of the interventions carried out to increase uptake of the various screening programmes and catch-up HPV vaccination.

Impact and resources

The comparison needs to be based on the effectiveness of increasing uptake and the effort required to introduce the intervention in terms of resources – a simplified cost-benefit analysis.

Select groups to focus on

Begin by identifying the groups in which uptake is low in the region. In this way, identify the people who are most in need of targeted interventions. When the most relevant groups have been identified, tools tailored to that specific group are selected for further analysis.

Select relevant tools

When selecting tools for further analysis, it is equally important to reject those tools that are not relevant from a regional perspective. For example, this may be because there is no system support for a particular tool. Naturally, other tools and methods not presented in this guide can also be added.

Take circumstances and priorities into account

For several of the tools, the circumstances in different regions are likely to differ. This means that each region will need to conduct an individual assessment. The assessments should also take into account variables such as the size of each local target group and any priorities when it comes to increasing uptake among particular groups.

Once the expected impact and resource needs required have been assessed for the region, the relevant tools can be compared using the matrix below.

The matrix provides guidance on how to relate to the different tools but does not generally provide answers as to which interventions need to be carried out.

The tools target the following groups:

Structure of the tools

Both the general tools and the tools for groups with lower uptake begin with a brief description of the group, the barriers to their uptake, contact opportunities and the screening programmes/vaccinations that are relevant.

There is also a matrix which can be used to guide prioritisation of the tools based on expected resource needs and impacts.

Table: Tools for increasing screening or vaccination programme uptake

Identified tools

Tools relevant to particular target groups have been identified as a means to increase uptake in that target group.

Identified barriers

There can be many reasons why people do not take up invitations for screening and/or catch-up HPV vaccination and these differ between the different target groups. However, there are a number of barriers that exist:

- Time — Shortage of time, such as waiting times or opening times that clash with work.
- Geography — Difficult to get to the clinic, for example because it is far away or because no transport is available.
- Awareness — Not being reached by information or not understanding the importance of attending, including not understanding the invitation or not being aware of the risks of not taking up the invitation.
- Social — People who are unwilling or scared to attend, for example if they feel uncomfortable or if attendance is associated with stigma.

Relevant programmes

Some tools can increase uptake of all screening programmes and catch-up HPV vaccination. Other tools are only relevant to one or more specific programmes. Each tool therefore comes with a description of relevant programmes:

- Breast cancer
- Bowel cancer
- Cervical cancer
- Catch-up HPV vaccination

Expected impact and resource needs

Each tool in the guide comes with a rough estimate of the expected impact and resources needed. The estimates are based on a general assessment of circumstances nationally and on the interviews and literature studies that underlie the guide.

Expected impact refers to the extent to which the tool can increase uptake of cancer screening or HPV vaccination programmes. The expected impact may be:

- High
- Medium
- Low

Resource need refers to an estimate of the staffing and financial resources required for a region to implement and benefit from the tool. The resource need may be:

- Low
- Medium
- High

Level of evidence

Identified tools are classified into four levels based on the amount of evidence available:

High evidence

1. Scientific evidence that the method increases uptake of cancer screening or HPV vaccination
2. Tried and tested experience of use in cancer screening or HPV vaccination or scientific evidence that the method increases uptake in similar healthcare activities
3. Tried and tested experience without structured follow-up
4. Tools that have not yet been tested or have been tested in very limited use without follow-up

Low evidence

More detail

Some tools are described in more detail. More in-depth descriptions are provided for tools that meet at least one of the following criteria:

1. Tools that studies have found to be especially important for increasing uptake
2. Tools that require deeper explanation in terms of their content or in organisational terms
3. Tools where relevant examples of their application exist, e.g. where a tool has been used and evaluated in Sweden

The description for each of these more detailed areas sets out:

- Relevant programmes
- Relevant target groups
- Examples of tried and tested experience or studies
- What is needed for the region to introduce the tool?

> To increase equity of uptake, the regions can put targeted interventions in place for currently under-represented groups.

Interventions to increase cancer screening and catch-up HPV vaccination uptake rates can be general or target specific groups.

General tools to increase uptake in cancer screening and catch-up HPV vaccination programmes

Everyone invited for cancer screening and catch-up HPV vaccination

See the explanation of the structure on page 16.

The general tools in the guide seek to increase uptake in all the groups that have access to screening or HPV vaccination. By their nature, the tools are such that they are applied to the whole population and so do not require the region to analyse the uptake rate and needs of different target groups. However, this does not necessarily mean that the general tools have the same effect on all target groups, because different groups may have different needs and so the general tools may have differing impacts.

Barriers to uptake

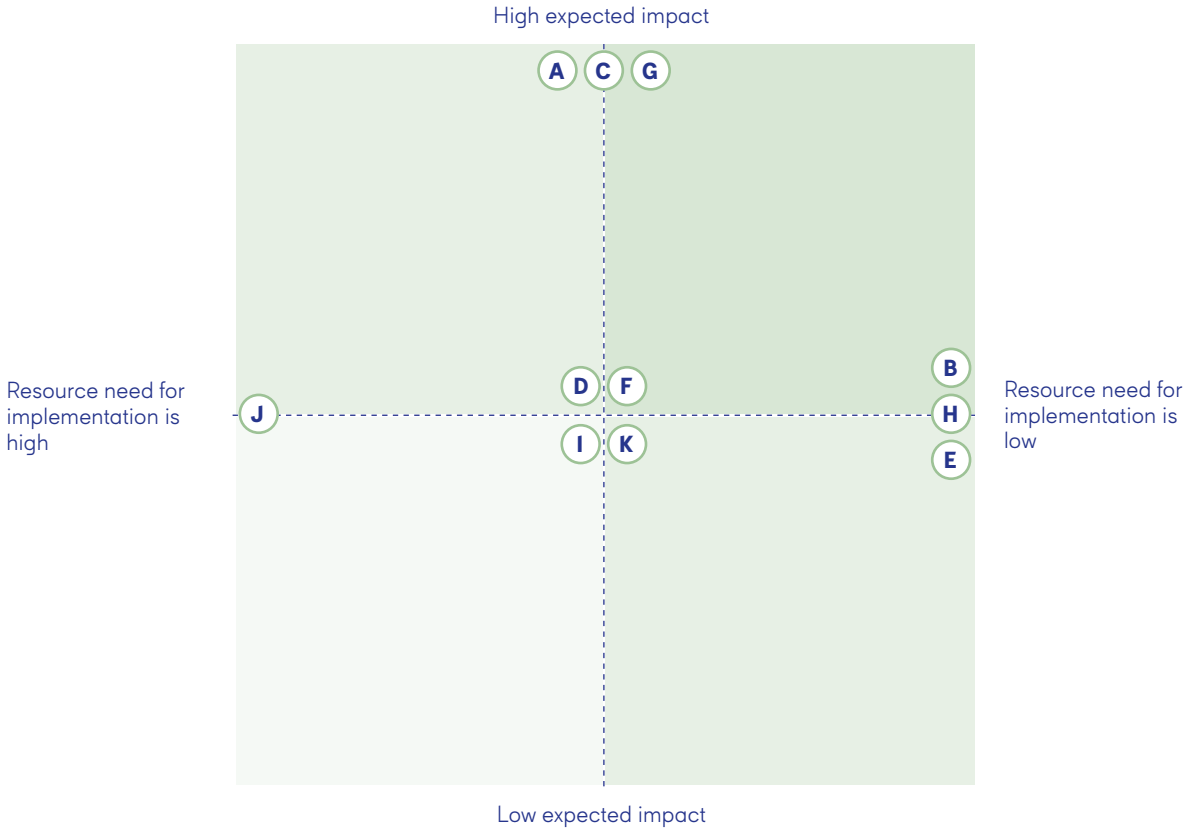
There are several reasons why people who are invited for screening or catch-up HPV vaccination do not take up the invitation. The reasons may be entirely practical; a long way to travel to the clinic, an appointment at a time that doesn't fit with working hours or it being difficult to change the appointment time. Non-attendance may also be due to a lack of knowledge about screening and catch-up HPV vaccination.

Relevant programmes

- ☒ Breast cancer
- ☒ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Positioning of identified tools based on estimated impact and resources needed, across all target groups.

Tools A – K are described on the next page.



Tools for increasing screening or vaccination programme uptake

Identified tools aimed at lowering barriers		Identified barriers	Relevant programmes	Expected impact	Resource need	Level of evidence	Source
(A) Send invitation with appointment*	The likelihood that a person will attend increases if the invitation is presented as an invitation with a booked appointment time and place, rather than an offer where the person can book an appointment themselves.	Time	All	High	Medium	1	7, 8, 9
(B) Design the invitation so it is easily accessible (linguistically and visually)	Use everyday language. Explain difficult terms. Make the invitation easily accessible visually, for example using fact boxes, highlighting important sentences, and using larger fonts and wider line spacing. National templates are available from the Confederation of Regional Cancer Centres in Sweden (RCC). • Invitation for breast cancer screening: cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/brostcancerscreening/kallelser--och-svarsbrev • Invitation for cervical cancer screening: cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/gynekologisk-cellprovskontroll/kallelser-och-svarsbrev • Invitation for bowel cancer screening: cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/Screening-tjock-och-andtarmscancer	Awareness Social	All	Medium	Low	1	4, 5, 8
(C) Send reminders	Send another invitation/reminder to those who have not attended their appointment. Send an annual invitation to those who did not respond to the second invitation.	Time	All	High	Medium	1	5, 8, 10, 11
(D) Offer a simple way of changing appointments	The easier it is to book, cancel and change appointments, the higher the uptake rate. If an online invitation system is used, it is helpful if it does not require strong authentication (such as a Bank-ID) because not everyone has access to such services.	Time	All	Medium	Medium	2	8
(E) Send text reminder	A text reminder can be sent before the appointment time to reduce the number of people who forget their appointments.	Time	All	Medium	Low	1	8, 12

continued

Identified tools aimed at lowering barriers		Identified barriers	Relevant programmes	Expected impact	Resource need	Level of evidence	Source
(F) Send a home HPV test to non-attendees*	Sending a home HPV test instead of only sending a second invitation/ reminder increases uptake.	Time Geography	Cervical cancer	Medium	Medium	1	8, 13, 21, 52
(G) Send home test by post	Sending a home test in the post instead of the recipient needing to collect it from a pharmacy increases the likelihood of them completing the test.	Time Geography	Bowel cancer Cervical cancer	High	Medium	1	5, 20
(H) Provide clear instructions for the home test	Some people think home tests are hard to do. This means that clear instructions are needed, with pictures that are easy to follow. Including a link to a video showing how to do the test is also helpful.	Awareness	Bowel cancer Cervical cancer	Medium	Low	2	5
(I) Offer home HPV tests and smear tests at midwife appointments	Tests carried out in a clinic or at home differ in several ways. Some people prefer a clinic, while others prefer doing the test themselves. This means that uptake rates can increase if both methods are offered and the message that people can choose the method they prefer is clearly communicated.	Geography	Cervical cancer	Medium	Medium	1	8, 20, 12
(J) Offer a range of accessible opening times	Times in the evening and at weekends at a reasonable distance from the home address should be offered to make screening and HPV vaccination accessible for people who have difficulties taking time off work.	Time	All	Medium	High	2	8
(K) Allow screening and vaccination in paid working hours	More people can attend screening and HPV vaccination if they don't need to take time off work and are instead encouraged to attend by their employer. This is something that the regions can offer their own employees as employers themselves.	Time Geography	All	Medium	Medium	3	23

* The tool is described in more detail on the following pages.

More detail: **Send invitation with appointment** (A)

Description

The likelihood that a person will attend increases if the invitation is presented as an invitation with a booked appointment time and place, rather than an offer where the person can book an appointment themselves.

Offering a booked appointment risks taking up resources if a large proportion of the people invited fail to attend. However, it is judged that the cost will be offset by detecting a higher proportion of cases earlier.

Relevant programmes

- ☒ Breast cancer
- ☒ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Relevant target groups

All

Examples of tried and tested experience or studies

Study of methods for increasing uptake of breast and cervical cancer screening

A randomised study from 1998 tested the impact of different types of invitations to breast and cervical cancer screening.

The result showed that uptake was 39 percent lower in the group that were not given a booked appointment compared with the reference group who were given a specific appointment by their GP. The study proposed that the risk of gridlock due to overbooking can be counteracted by constantly monitoring the proportion who take up their invitation and adapting the overbooking rate accordingly.[7]

National Clinical Cancer Care Guidelines for Cervical Cancer Prevention

The National Clinical Cancer Care Guidelines for Cervical Cancer Prevention recommend sending an invitation with a time and place to increase uptake.[8]

What is needed for the region to introduce the tool?

Resources and organisation

- Give clinics a mandate and incentives to work to ensure that people invited actually complete their screening.
- Earmark sufficient funding to enable appointment booking.

Important to remember

- Combine appointment booking with easy ways to change or cancel an appointment, especially to avoid clinics being empty (see tool *Offer a simple way of changing appointments*).
- Send a clear invitation that enables an informed choice to be made (see tool *Design the invitation so it is easily accessible*).

More detail: **Send a home HPV test to non-attendees** (F)

Description

A second invitation or a reminder is often sent to people who did not attend screening after the first invitation, known as non-attendees. Several studies have shown that sending a home HPV test with the reminder increases screening uptake.

There is no clear answer as to how many invitations or reminders should be sent before a home test should be included. This needs to be assessed based on regional circumstances. Studies have shown good results from sending out home tests with the second reminder,[13] while the National Clinical Cancer Care Guidelines for Cervical Cancer Prevention recommend sending home tests to "Long-term non-attendees", in other words those who have not attended their screening appointments for four years or more (see the target group long-term non-attendees).[8]

Relevant programmes

- ☐ Breast cancer
- ☐ Bowel cancer
- ☒ Cervical cancer
- ☐ Catch-up HPV vaccination

Relevant target groups

All

Examples of tried and tested experience or studies

Randomised study of women in Oslo, Norway

A Norwegian study of women in Oslo in 2015 tested the effect of sending a home HPV test with the second reminder. The study included women about to receive their second reminder to attend a smear test. 800 women in this group were selected at random to be in the treatment group and were then given a home HPV test but also the option of coming in to a clinic for the test. The control group of 2,593 people were instead sent a reminder in line with the prevailing guidelines for screening in Norway. The results showed that uptake was 44 percent higher in the treatment group than in the control group and the result has a significance level of at least 5 percent.[13]

Randomised study of women in Espoo, Finland

A similar study to that in Norway was carried out on women living in Espoo, Finland in 2011. The women were randomly allocated to a treatment group and a control group. The treatment group (2,397 women) were sent a home test after failing to attend in response to the first invitation. The control group (6,302 women) were sent a reminder without a home test. Of the members of the control group who did not take up the invitation, 1,315 were sent a home test with the third invitation. For the group sent a home test with the second invitation, the chance of uptake was 21 percent higher than for the control group. Higher uptake was also seen in the group who were sent a home test with the third invitation.[52]

What is needed for the region to introduce the tool?

Resources and organisation

- An effective invitation system needs to be in place, for example to see how many invitations have been sent out and when the most recent invitation was sent.
- The National Clinical Cancer Care Guidelines for Cervical Cancer Prevention incorporate a nationally coordinated system that individual regions can join for help with invitations and reminders

Important to remember

- Each region needs to determine for itself how many invitations/reminders are required before a home test is sent out.

Tools to increase uptake in cancer screening and catch-up HPV vaccination programmes

Women born abroad, living in socioeconomically disadvantaged areas

See the explanation of the structure on page 16.

The target group often has non-existent or poor Swedish language skills, no or limited education and is often far removed from the labour market.

Many often operate in geographically restricted areas, such as moving between the home, local food shops and preschool. They rarely leave their residential area.[3]

Some in this group have a sceptical attitude towards authorities. Disinformation campaigns about social services and education have spilled over to other functions in society and it is common to mainly rely on information from people in one's own group. Some have low trust in the healthcare service and previous contact with it made them feel ignored.[1, 3]

The group sometimes has limited knowledge about health, the body and illnesses. Combined with language difficulties, this makes reaching them with information about screening and vaccines difficult. Topics related to sexuality are often strictly taboo, which makes it difficult to spread information, especially linked to screening for HPV and catch-up HPV vaccination.[1]

Home testing may also be considered strange and unpleasant.[3]

Brief facts about the target group

- Often far removed from the labour market.
- Live in socioeconomically disadvantaged areas with a high proportion of people born abroad. Have a higher risk of cancer mortality and lower uptake of cancer screening than the population as a whole.[2]
- Estimated as about 100,000 people (based on the proportion of people with a foreign background who live in disadvantaged areas and the age distribution in Sweden as a whole). [70-71]

Barriers to uptake among the target group

- Health literacy: Do not understand the importance of screening and vaccination or how it works.
- Communication from the health service does not always reach the group, partly due to the language barrier and low trust.
- Information about sexual health is taboo.

Possible contact points

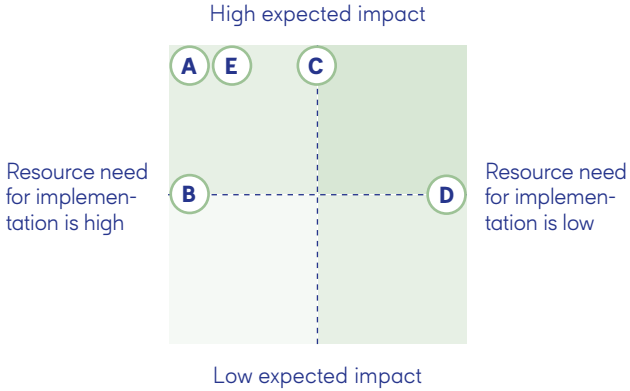
- Near the home, in laundry areas or stairwells
- Through Swedish for Immigrants courses
- Preschools
- Faith communities
- Local supermarkets
- Out in the neighbourhood[1, 3]

Relevant programmes

- ☒ Breast cancer
- ☒ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Positioning of identified tools based on estimated impact and resource need

Tools A, B, C, D and E are described on the next page.



Tools for increasing screening or vaccination programme uptake

Identified tools aimed at lowering barriers		Identified barriers	Relevant programmes	Expected impact	Resource need	Level of evidence	Source
(A) Provide information about cancer screening via civil society, ideally combined with language training*	The target group may be unused to seeking information themselves and may have limited information about their health. However, there is often an interest in practising their Swedish. Holding language training with people from the group/culture concerned who have already integrated is one way of reaching out with knowledge about screening and vaccination.	Awareness Social	All	High	High	2	1, 2, 3
(B) Communicate in places where the target group is	Because the target group is often close to the home and gains information from channels other than where healthcare is traditionally found, communication needs to take place where the target group is, such as in stairwells, laundry rooms and at Swedish for Immigrants classes.	Awareness	All	Medium	Low	3	1, 3
(C) Establish contact with key people in the neighbourhood or the cultural group	The target group sometimes has low trust in authorities and is generally sceptical about testing and vaccines. Therefore, information about screening and vaccination often gets across better if it is communicated by someone the person trusts in their own network. This might be a religious leader or a member of a women's group.	Social	All	High	Medium	1	1, 3, 6, 63
(D) Design the invitation so it is easily accessible (linguistically and visually)	Use everyday language and explain difficult terms. Make the invitation easily accessible visually, for example using fact boxes, highlighting important sentences, and using larger fonts and wider line spacing. If a language other than Swedish is used, adapt the language to the cultural context. National templates are available from the Confederation of Regional Cancer Centres in Sweden (RCC). • Invitation for breast cancer screening: cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/brostcancerscreening/kallelser--och-svarsbrev • Invitation for cervical cancer screening: cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/gynekologisk-cellprovskontroll/kallelser-och-svarsbrev • Invitation for bowel cancer screening: cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/Screening-tjock-och-andtarmscancer	Awareness	All	Medium	Low	1	1, 4, 5
(E) Work with doulas/cultural interpreters in the local community*	Having screening available in the local community and working with individuals who people in the area trust can reduce cultural barriers to uptake. A doula/cultural interpreter can be commissioned by the region and ideally will be trained in screening and vaccination.	Social	All	High	High	1	6, 63

* The tool is described in more detail on the following pages.

More detail: **Provide information about cancer screening via civil society, ideally in combination with language lessons** (A)

Description

To increase uptake among women born outside Sweden, meetings can be arranged for selected groups to discuss health-related issues. The meetings can be arranged by the region or in partnership with established civil society organisations. Group meetings are good for engaging the target group in dialogue and sharing people's concerns. The conversations tend to work best if the person organising the meeting shares the ethnic and cultural background of the participants.

There is often a desire among people born abroad to find opportunities to speak Swedish. It is therefore recommended that the meetings are combined with language training to attract more attendees. To encourage conversations in an atmosphere of trust, it can be helpful to arrange several meetings on different themes and save the more taboo subjects until once the group has got to know each other. Combining the discussions with an activity that encourages the group to relax, such as dancing lessons or a reading group, has also proved useful.

Relevant programmes

- ☒ Breast cancer
- ☒ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Relevant target groups

Women born abroad, living in socioeconomically disadvantaged areas

Examples of tried and tested experience or studies

Health/language chats over coffee in Stockholm

Peer advisors in Stockholm have tested different versions of the language training concept combined with health information. There has been good collaboration with Swedish for Immigrants, making it easier to reach out. In some cases, groups met on several occasions to build relationships. However, there have also been one-off events geared towards specific groups such as women, mothers, Arabic-speaking women and young people.

Experience shows that it is important to involve all participants so that the experience is of a discussion rather than purely being fed information. This enables peer advisors to address the concerns of participants.

It has also been important for the peer advisors to be from different ethnic and cultural backgrounds. This builds trust in the target group and means content can be tailored to the cultural context.

Courses for mothers

Mamma United is a charity that runs one course per term to empower women in socioeconomically disadvantaged areas. They work in ten municipalities and often work with property owners on funding and identifying key local people.

During the course, representatives of different functions in society come and talk about important factors in reducing the health gap. For example, these may be dieticians, midwives and police officers. Courses are for women only.[3]

What is needed for the region to introduce the tool?

Resources and organisation

- Regional peer advisors
- Coordination with other parts of the health service

Relevant external actors

- Civil society organisations
- Swedish for Immigrants
- Key local people

Important to remember

- Success depends on good support in local society and in the cultural group. It is important to be aware that there may be a lack of trust in authorities and the health service.

More detail: **Work with doulas/cultural interpreters in the local community** E

Description

People born abroad, living in socioeconomically vulnerable areas, do not always have the same trust in and understanding of the Swedish healthcare system as the population as a whole. Some also have less knowledge about the body, illnesses and how cancer risk can be reduced. Many come from cultures that look on health issues differently, which can make it difficult for healthcare staff to reach out with information within their ordinary work.

A successful strategy may therefore be to work with doulas or cultural interpreters, people who are well-integrated in the Swedish system but who have a background from another culture. They have a deeper understanding of the cultural context that leads to doubts about attending screening or being vaccinated. This means they are better equipped to answer questions and soothe fears.[63]

Relevant programmes

- ☒ Breast cancer
- ☒ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Relevant target groups

Women born abroad, living in socioeconomically disadvantaged areas

Examples of tried and tested experience or studies

"Bring a friend" in the Västra Götaland region

In 2011, the Västra Götaland region implemented the "Ta med en vän" (Bring a friend) project to increase cervical cancer screening uptake. As part of the project, about 15 local doulas were hired from different cultures, who spoke different languages. The doulas were informed about smear tests through their local community networks.

Strong local trust, speaking the women's mother tongue, and using arguments tailored to the target group enabled the message to be successfully communicated to the group. Over the course of the project, screening uptake increased by 42 percent.[64] The project ran for a year but lives on in an initiative known as "Cellprovsveckan" (Smear test week). The week is run every year in the regions of Västra Götaland and Halland.[66]

Doulas/cultural interpreters in Region Värmland

Between 2017 and 2022, Region Värmland ran a project jointly with the Swedish Association of Local Authorities and Regions (SALAR) involving cultural interpreters and cultural doulas in family centres, child health centres, midwife clinics and on labour wards. The cultural interpreters provided information on cultural differences and how Swedish society works, often linked to subjects such as maternal and child health, vaccinations and childhood illnesses.

The cultural doulas provided support and information to women giving birth and their partners. They had previous, non-medical, experience of births.[65]

What is needed for the region to introduce the tool?

Resources and organisation

- Some mapping of the target group needs to have been done to target support effectively. For example, relevant languages/cultures and potential doulas/cultural interpreters need to be identified.
- It is useful if such surveys can be done jointly with other parts of the healthcare system looking to reach the same groups.

Relevant external actors

- People with a large network and trust in local society.

Important to remember

- It is helpful to train doulas/cultural interpreters on questions to do with screening and vaccination.

Tools to increase uptake in cancer screening and catch-up HPV vaccination programmes

People with disabilities

See the explanation of the structure on page 16.

Whether their disability is physical or intellectual, people in the group are often dependent on others to a greater extent than the rest of the population. This may involve needing physical assistance or needing support in advocating for themselves in the healthcare system.[37] This means that healthcare units may need to adapt their approach to meet the needs of the group. This may involve physical adaptations being made to the clinic, but also adapting the approach and procedures surrounding the appointment itself to make people feel comfortable about coming back again next time.[40]

It is also common for people in this group to find it harder to remember their appointments. This means there may need to be special procedures to remind them about booked appointments, both to ensure they are screened or vaccinated and so that the clinic does not suffer from time wasted due to missed appointments.[40]

People in this group tend to be diagnosed with cancer at a late stage[37]. They also have a higher risk of cancer than the population in general. Studies of Swedish data have therefore highlighted that the group should be screened to a greater extent. One example is that women receiving support under LSS (the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments) have almost twice as high a risk of dying of breast cancer, which is thought to be due to late detection. [38, 39]

Brief facts about the target group

- Often diagnosed with cancer late.[37]
- People with intellectual disabilities run a greater risk of cancer than others.[39]
- Women receiving LSS support have almost twice as high a risk of dying of breast cancer.[38]
- This group has a lower screening uptake rate than the rest of the population.[41]
- This group is estimated to include about 50,000 people.[72]

Barriers to uptake among the target group

- Difficulty getting to appointments.
- Difficulty keeping track of appointment times and understanding the importance of screening and vaccination.
- Need someone else to help them.

Possible contact points

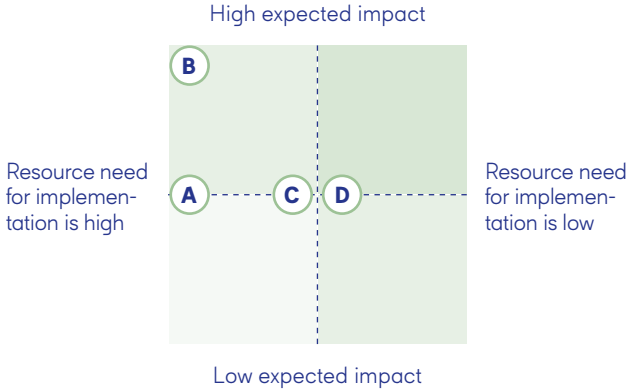
- LSS support
- Other care units

Relevant programmes

- ☒ Breast cancer
- ☒ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Positioning of identified tools based on estimated impact and resource need

Tools A, B, C and D are described on the next page.



Tools for increasing screening or vaccination programme uptake

Identified tools aimed at lowering barriers		Identified barriers	Relevant programmes	Expected impact	Resource need	Level of evidence	Source
(A) Longer smear test and vaccination appointments	A person with a physical or intellectual disability may need a longer appointment for smear tests and HPV vaccination to get the support they need. This can be especially important in creating trust for the next appointment.	Time Geography	Breast cancer Cervical cancer Catch-up HPV vaccination	Medium	High	2	8
(B) Make premises accessible and offer aids and assistance during the appointment.	Adaptations may need to be made to the clinic itself to enable the right support to be offered. This can involve help with transport and lifts. A companion may be needed to accompany people during the visit.	Geography	Breast cancer Cervical cancer Catch-up HPV vaccination	High	High	1	8, 5, 31, 32
(C) Remind people of their appointment in various ways.	People with intellectual disabilities may find it difficult to remember appointments and may therefore need reminders in several different ways. This could be by letter, postcard or phone call.	Awareness	Breast cancer Cervical cancer Catch-up HPV vaccination	Medium	Medium	2	5
(D) Home testing	One option for people who have difficulty travelling to a clinic is to be sent a test to do at home. However, they may need support at home to help them do the test.	Geography	Bowel cancer Cervical cancer	Medium	Medium	1	5, 20, 36

Tools to increase uptake in cancer screening and catch-up HPV vaccination programmes

People living in rural areas

See the explanation of the structure on page 16.

People who live in rural areas often have further to travel to screening and vaccination clinics and there may be a lack of public transport. This makes it harder to attend.[34, 36]

The distance to screening and vaccination clinics also affects the uptake rate. People with less than half an hour to travel are more likely to attend appointments.[43] This means that mobile units or home testing can be helpful to increase uptake in rural areas.[35-36]

Foreign studies have shown that a lack of awareness of the importance of screening and negative attitudes to screening are more common among those who live in rural areas, which also reduces uptake.[34]

In the US, it has also been found that there is a higher degree of stigma and fear of pain related to screening among people who live in rural areas compared with urban areas.[33]

Brief facts about the target group

- Lower uptake of cervical cancer screening compared with the population as a whole.[29]
- People with a journey of more than half an hour to a clinic are less likely to attend.[43]
- In Sweden, approximately 175,000 people live rurally.[51]

Barriers to uptake among the target group

- Distance to screening and vaccination clinics.
- Poor transport links.
- Lack of awareness and negative attitudes to screening and vaccination.

Possible contact points

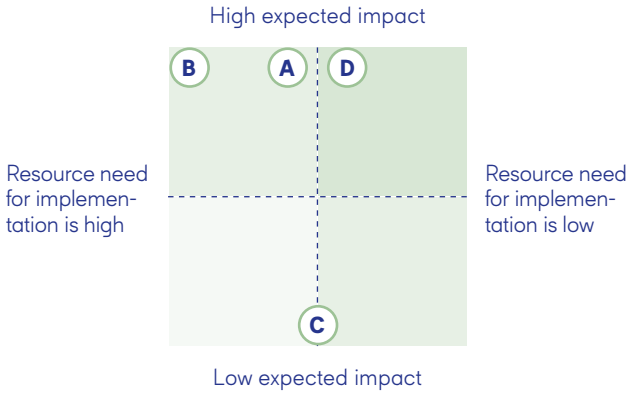
- Other healthcare units, especially district doctors.
- Local services, such as supermarkets and pharmacies.

Relevant programmes

- ☒ Breast cancer
- ☒ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Positioning of identified tools based on estimated impact and resource need

Tools A, B, C and D are described on the next page.



Tools for increasing screening or vaccination programme uptake

Identified tools aimed at lowering barriers		Identified barriers	Relevant programmes	Expected impact	Resource need	Level of evidence	Source
(A) Home HPV test	People living in rural areas often have further to travel to clinics, especially if they live in extremely remote locations. In this context, offering home tests for cervical cancer screening can be useful.	Geography	Cervical cancer	High	Medium	1	20, 36
(B) Mobile units*	In rural areas, clinics are often a relatively long distance away. Having mobile screening units able to travel to the people to be screened makes it easier for people to attend appointments.	Geography	Breast cancer Cervical cancer Catch-up HPV vaccination	High	High	3	35, 36
(C) Information campaigns/ education programmes	Knowledge and attitudes to screening have proved to be a barrier for some people living in rural areas. Targeted information campaigns and/or education programmes can be effective ways of changing this.	Awareness, Social	All	Low	Medium	1	33, 34
(D) Add-on screening and vaccination	Because, as a rule, people living in rural areas have further to travel to clinics, it can be useful to offer screening and HPV vaccination when they are at a medical centre or clinic for some other reason.	Geography	Cervical cancer Catch-up HPV vaccination	High	Medium	1	8, 29, 30

* The tool is described in more detail on the following page.

More detail: **Mobile units** (B)

Description

In rural areas, screening and vaccination clinics are often further apart. This means that people can need to travel relatively long distances to attend screening and vaccination appointments. This has been shown to have a major impact on whether or not people attend. People who can reach the clinic within half an hour are more likely to attend.

Mobile vaccination and screening units are one way to reduce distances. Mobile units can be, for example, vaccination and screening buses or mobile vaccination teams that visit rural areas and offer vaccination in temporary premises.

Relevant programmes

- ☒ Breast cancer
- ☐ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Relevant target groups

People living in rural areas

Examples of tried and tested experience or studies

The SRHR bus in Region Västra Götaland

In Region Västra Götaland there is a mobile unit known as the SRHR bus.

SRHR stands for sexual and reproductive health and rights and people can visit the bus to have a smear test but also for contraceptive advice, STI testing and to talk about sexual and reproductive health. The bus regularly visits different places in the region where people naturally spend time, such as upper secondary schools, universities, libraries and arts centres. The addresses and times where the bus will stop are shown on the region's website and publicised on social media.

The SRHR bus was initially run as a one-off project, but has become part of the ordinary local health service in the region. All visits to the bus are drop-ins and are free of charge.

Mammography buses in Norway

Norway has been running mammography screening buses in rural areas since 2008. There are four buses in total and between them they screen 40,000 women for breast cancer every year. Screening carried out on the buses is part of the national screening programme and is commissioned by the Cancer Registry, which is responsible for cancer screening in Norway.

Women who attend receive an invitation to screening in the bus in the same way as they would be invited to attend screening at a non-mobile clinic. The buses generally have a high coverage rate. Responsibility for coordinating the buses is national but the screening is carried out by regional radiography nurses.

What is needed for the region to introduce the tool?

Resources and organisation

- The region needs to provide the mobile units, e.g. buses.
- The mobile units need staffing.
- IT systems must be set up to meet the needs of the initiative, such as getting the right temporary address on the invitations.

Relevant external actors

- Local organisations able to offer premises or provide information about the mobile unit.

Important to remember

- Organise screening and vaccination in the mobile units as part of the same invitation system as the rest of the screening and vaccination service.

Tools to increase uptake in cancer screening and catch-up HPV vaccination programmes

People with mental health conditions

See the explanation of the structure on page 16.

The number of people diagnosed with mental illnesses in Sweden is growing. At the same time, several studies show lower screening uptake among people in this group. However, there is major variation in uptake in this group.

Women with milder mental illnesses attend cervical cancer screening to the same extent as the population as a whole, while women diagnosed in specialised psychiatric care or diagnosed with psychosis attend to a lower extent (6 percent and 19 percent lower respectively). Similar patterns have been found in Canada and Taiwan for women diagnosed with schizophrenia.[44]

Most people in this group are already in contact either with primary or specialist healthcare. At the same time, they often find it difficult to initiate new contacts and visit new places. Therefore there is great value in collaboration between healthcare units, especially as it is known that the anonymity of the screening system is a barrier for this target group.[44]

It has also been shown that this group benefits from mental health clinics encouraging screening and HPV vaccination, and from broader collaboration with cancer prevention services,[25-27] for example through outreach screening and vaccination at mental health clinics.[48]

It has also been found that people with schizophrenia benefit from continuity of care.[44]

Brief facts about the target group

- People with mental health diagnoses often have poorer health status and lower life expectancy than the general population.[44]
- This group runs a higher risk of dying from cancer.[44]
- Attend screening to a lower extent[25, 44-47], globally almost 25 percent lower than the population as a whole.[49]
- In total approximately 90,000 people in Sweden have a mental health diagnosis.[73]

Barriers to uptake among the target group

- Going to new places with unfamiliar people/contacts.
- Managing to undergo screening or vaccination.
- Absorbing information about the importance of screening and vaccination.

Possible contact points

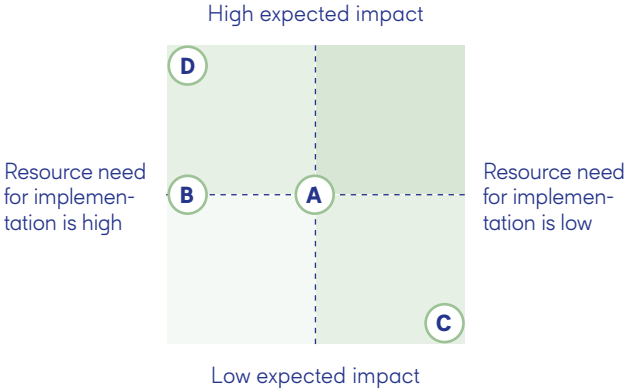
- Mental health services and other psychiatric care
- In the home
- LSS support

Relevant programmes

- ☒ Breast cancer
- ☒ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Positioning of identified tools based on estimated impact and resource need

Tools A, B, C and D are described on the next page.



Tools for increasing screening or vaccination programme uptake

Identified tools aimed at lowering barriers		Identified barriers	Relevant programmes	Expected impact	Resource need	Level of evidence	Source
(A) Collaboration between mental health and cancer/ screening/ vaccination services	The target group runs a risk of falling through the cracks, and therefore it is important that mental health and cancer/ screening/vaccination services work together to provide the care needed as seamlessly as possible. One example is taking a "person-centred, collaborative care" approach. It is also important that the person's GP encourages them to attend screening and HPV vaccination.	Time Geography Social	All	Medium	Medium	1	24, 25, 26, 27
(B) Healthcare staff with experience of working with mental health conditions carry out screening and vaccination	Healthcare staff who are used to working with people with mental health conditions find it easier to interact in a way that makes the appointment run smoothly and feel safe.	Social	Breast cancer Cervical cancer Catch-up HPV vaccination	Medium	High	1	25
(C) Information material whose message is easy to read and simplified	Make it as easy as possible for the target group to absorb information on the importance of screening and HPV vaccination by using simple language and clear messaging.	Awareness	All	Low	Low	1	25
(D) Mobile units*	The group can find going to new places challenging. It can therefore be useful to use mobile screening and vaccination units to take the service to the people concerned.	Geography	Breast cancer Cervical cancer Catch-up HPV vaccination	High	High	1	26

* The tool is described in more detail on the following page.

More detail: **Mobile units** B

Description

People with mental health conditions may be resistant to going to new places, such as vaccination and screening clinics. Because they do not encounter these providers in other contexts, they may feel anonymous and alien.

Using mobile vaccination and screening units may therefore be one solution to increase uptake. They can do outreach work in partnership with mental health services by going to places where the person is, such as a mental health clinic or the home. The person's ordinary healthcare contact encouraging screening is also highly significant. Collaboration between the screening and vaccination providers and psychiatric care improves uptake in this group.[26-27, 44, 48]

Relevant programmes

- ☒ Breast cancer
- ☐ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Relevant target groups

People with mental health conditions

Examples of tried and tested experience or studies

The SRHR bus in Region Västra Götaland

In Region Västra Götaland there is a mobile unit known as the SRHR bus.

SRHR stands for sexual and reproductive health and rights and people can visit the bus to have a smear test but also for contraceptive advice, STI testing and to talk about sexual and reproductive health.

The bus regularly visits different places in the region where people naturally spend time, such as upper secondary schools, universities, libraries and arts centres. The addresses and times where the bus will stop are shown on the region's website and publicised on social media.

The SRHR bus was initially run as a one-off project, but has become part of the ordinary local health service in the region. All visits to the bus are drop-ins and are free of charge.[67]

Mobile vaccination units at psychiatric clinics in the USA

During the COVID-19 pandemic, people with serious mental illness ran a higher risk of serious illness due to COVID-19, partly due to generally high comorbidity. People in this group were also less likely to be vaccinated than the population as a whole. Special interventions were therefore put in place to increase vaccination coverage. In Boston, Massachusetts (USA), mobile vaccination clinics were trialled in "psychiatric settings".

Initially healthcare staff from a number of psychiatric clinics were mobilised to train them in the vaccination

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programme and to understand their patients' barriers to vaccination. After that, mobile vaccination clinics (MVCs) were set up close to the psychiatric clinics. This multi-pronged approach led to a vaccination rate of 93 percent compared with 62–77 percent in Massachusetts as a whole in the same period.[74]

What is needed for the region to introduce the tool?

Resources and organisation

- It is easier to use mobile vaccination and screening units at psychiatric clinics if there is a structure for commissioning/contracts that makes it possible to bring in other providers.
- Bringing in other providers often involves training needs.

Relevant external actors

- Municipal providers which run care for the target group or provide meeting premises for homeless people.

Important to remember

- Organise screening and vaccination in the mobile units as part of the same invitation system as the rest of the screening and vaccination service.

Tools to increase uptake in cancer screening and catch-up HPV vaccination programmes

Long-term non-attendees

See the explanation of the structure on page 16.

The National Clinical Cancer Care Guidelines for Cervical Cancer Prevention define long-term non-attendees as people who have not attended screening for four years or more after being sent an invitation.[8] There is no definition for other forms of screening and catch-up HPV vaccination. Therefore, every region needs to make a decision as to how long a person must have failed to attend before tools for long-term non-attendees are activated.

Long-term non-attendees differ from other target groups in this guide because the people in this group have no other known common characteristics other than not having attended screening or not having been vaccinated.

It is likely that a large proportion of these people also belong to one of the other target groups in this guide. However, there are a number of tools that have been shown to be effective with long-term non-attendees in particular.

In a study of the effect of long-term non-attendees in cervical cancer screening in Western Sweden, midwives phoned women to book appointments. They also asked women what they needed to encourage them to attend. These needs can be grouped under different themes, where time-related and social reasons were dominant. These responses give an insight into the needs of this group but they are not necessarily applicable to the other screening programmes.[28]

Brief facts about the target group

- Two percent of people invited for cervical cancer screening do not attend at all. They then account for a high proportion of people with cancer.[36]
- Of those who do not attend for a long time and then do have a smear test, a high proportion have cell changes (which in turn can lead to cancer).[8, 50]

Barriers to uptake among the target group

- Time-related barriers, such as wishes for drop-in appointments or specific times.
- Social barriers or fear, such as a need for calm and friendly treatment or anaesthesia.
- Geographical barriers, such as having to get to a different clinic from the one that sent out the invitation.

Possible contact points

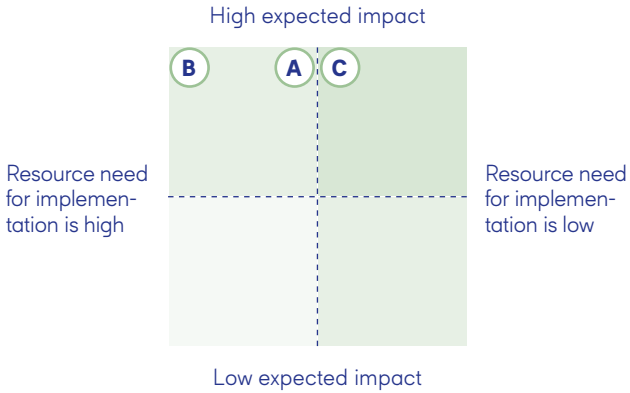
- Phone
- Other medical appointments

Relevant programmes

- ☒ Breast cancer
- ☒ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Positioning of identified tools based on estimated impact and resource need

Tools A, B and C are described on the next page.



Tools for increasing screening or vaccination programme uptake

Identified tools aimed at lowering barriers		Identified barriers	Relevant programmes	Expected impact	Resource need	Level of evidence	Source
(A) Send a home HPV test	Sending a home swab test in the post can increase uptake among long-term non-attendees. The best time to send the test out can vary, but some studies have seen good results from sending the home test with the second reminder. The National Clinical Care Guidelines for Cervical Cancer Prevention recommend sending out home tests to people who have not attended for four years or more.	Geography	Cervical cancer	High	Medium	1	8, 9, 13, 21, 52
(B) Help with booking via outreach phone calls	It can be helpful if the clinic carrying out the screening or vaccinations phones people who have a long history of non-attendance and offers to help them book an appointment. Booking centres or similar reaching out in this way has also been shown to have good results.	Time Social	All	High	High	1	8, 9, 11, 21, 28
(C) Add-on screening and vaccination	People who fail to attend may sometimes consider attending if they are offered screening or HPV vaccination while they are already at a doctor's or at a clinic for another reason.	Geography	Cervical cancer Catch-up HPV vaccination	High	Medium	1	8, 29, 30

Tools to increase uptake in cancer screening and catch-up HPV vaccination programmes

Women born in 1994–1999, catch-up HPV vaccination

See the explanation of the structure on page 16.

This target group is generally considered to have low awareness of screening for HPV and catch-up HPV vaccination. There is a risk that this leads to them not feeling that taking up their invitation is urgent.

Staff at screening and midwifery centres report that many women who come in do not understand why they have been invited to attend. The women often have not absorbed the information in the invitation. This means it is important that invitations are clear and highlight the most important points.

The target group also have some hesitancy about vaccination. Some were vaccinated with earlier versions of the HPV vaccine and may find it difficult to understand why they are now being offered a new vaccine. Some are also sceptical about vaccination in general.

Compared with other groups, this group is relatively mobile, changing job or place of study frequently and moving more often.

All in all, this means that it needs to be made very easy to attend, such as by offering a large number of appointment times to choose from and making it easy to change appointment times.

The group is used to using online tools and digital channels. This makes digital communication a good accompaniment to traditional invitations by letter. This is true both of invitations and spreading information.[58]

Brief facts about the target group

- The study "Utrotningsprojektet" (the Eradication Project) offers women born in 1994–1999 both screening for HPV and vaccination.[57]
- The uptake rate varies between different regions, partly because catch-up HPV vaccination started at different times.[57]
- In total, the project covers 356,300 women in Sweden nationwide.[57]
- The coverage rate in ordinary cervical cancer screening in this group is approximately 85 percent.[56]

Barriers to uptake among the target group

- Generally low awareness of screening for HPV and HPV vaccination.
- Time-related barriers, shortage of time, such as waiting times or opening times that clash with work or study.
- A mobile group that often moves house or changes job or place of education, which risks them failing to receive invitations.

Possible contact points

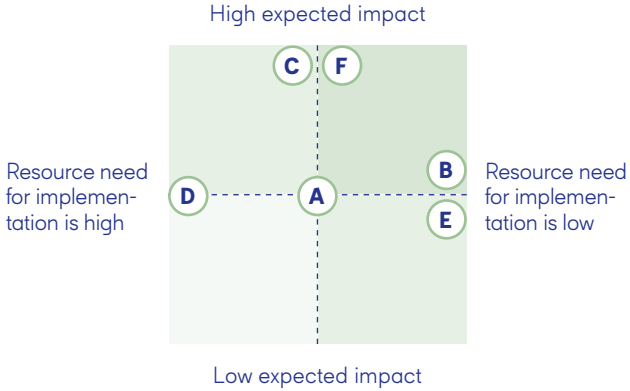
- Social media
- Online channels, the online health service 1177 and the digital postal service Kivra
- Universities
- Workplaces
- Shopping centres

Relevant programmes

- ☐ Breast cancer
- ☐ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Positioning of identified tools based on estimated impact and resource need

Tools A, B, C, D, E and F are described on the next page.



Tools for increasing screening or vaccination programme uptake

Identified tools aimed at lowering barriers		Identified barriers	Relevant programmes	Expected impact	Resource need	Level of evidence	Source
(A) Offer multiple appointment times and easy rebooking	Uptake can increase if a range of bookable appointments is offered and it is easy to cancel and rebook. One solution might be to work with the existing vaccination set-up in the region. For example, in Stockholm the COVID-19 vaccination programme used vaccination centres to increase capacity.	Time	Catch-up HPV vaccination	Medium	High	2	8, 58
(B) Awareness-raising campaign on HPV screening and vaccination*	This group has relatively low awareness of how to protect oneself from cervical cancer. Awareness-raising information campaigns about screening and catch-up HPV vaccination can be a way of increasing uptake. The target group often uses digital channels so spreading awareness on social media, for example, can work well.	Awareness	Cervical cancer Catch-up HPV vaccination	Medium	Low	2	22, 58, 62
(C) Vaccination at large workplaces and universities	Offering vaccination at universities and in workplaces is one way of getting the HPV vaccine to more people. The Västragötaland Region is one example, where COVID-19 vaccinations were offered at the Volvo factory. There are also examples of visits to universities to vaccinate students in freshers' week.	Geography	Catch-up HPV vaccination	High	Medium	3	48, 58, 62
(D) Mobile teams combined with phone contact	Mobile units can work well to increase uptake in areas where there are long distances to vaccination clinics. This has been tested in parts of northern Sweden. Women concerned were phoned and informed that the unit would be coming before it arrived.	Geography	Catch-up HPV vaccination	Medium	High	3	48, 58
(E) Educating healthcare staff	The target group can have many questions about cervical cancer screening and HPV vaccination. It is important that healthcare staff have the tools they need to answer questions and enable informed choices. Nationally produced training material is available from the Confederation of Regional Cancer Centres in Sweden: cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/gynekologisk-cellprovskontroll/presentationsmaterial	Awareness	Cervical cancer Catch-up HPV vaccination	Medium	Low	3	58, 59
(F) Offer vaccination in several locations	Offering HPV vaccination in many locations, where the target group is often found, lowers the barriers to uptake. Vaccination can be carried out at pharmacies, shopping centres, universities, workplaces and by homelessness and substance abuse charities.	Time Geography	Catch-up HPV vaccination	High	Medium	3	48

* The tool is described in more detail on the following page.

More detail: **Awareness-raising campaign on HPV screening and vaccination** B

Description

The target group generally has low awareness of how to prevent cervical cancer. Those who come to a clinic after receiving an invitation often do not understand why it is important that they attend. They also frequently have questions about vaccination. Some are sceptical about vaccines and others want to know why they need to be vaccinated again when they were vaccinated before.

Awareness-raising campaigns on screening and catch-up HPV vaccination can be helpful for this reason – ideally using digital channels such as social media, because the target group are frequent consumers of social media.[58]

Relevant programmes

- ☐ Breast cancer
- ☐ Bowel cancer
- ☒ Cervical cancer
- ☒ Catch-up HPV vaccination

Relevant target groups

Women born in 1994–1999

Examples of tried and tested experience or studies

"Sjekkdeg" in Norway

Since 2015, Norway has run an annual campaign to increase uptake of the Norwegian cervical cancer prevention programme.

The campaign runs under the hashtag #sjekkdeg (getchecked) and has a clear, simple message: Attend your smear test when you are invited to do so and reduce the risk of cervical cancer.

Working with social media influencers spreads the message to a wider audience. The material is appealing and gets the message across and is available in several languages.

Screening uptake has increased since the campaign started. The campaign includes a card which can be ticked and handed in to the screening staff. For example people can tick the box that says: "I've never done this before and am wondering what happens".[22]

"Stop HPV – bliv vaccineret" in Denmark

In May 2017, an information campaign entitled "Stop HPV – bliv vaccineret" (Stop HPV – get vaccinated) was launched in Demark to counteract the disinformation about the HPV vaccine that had gained a foothold across much of the country.

The campaign used a website and a Facebook page to communicate different types of campaign material such as personal stories, videos and factual material. Scientific material was also shared, showing the effect of vaccination.

After the campaign, higher uptake of HPV vaccination was seen, both of ordinary vaccination

continued

for the different cohorts and also catch-up vaccination. Today ordinary vaccination uptake is at almost 90 percent for both boys and girls.

One of the lessons learned is the importance of working with other organisations or people interested in spreading the same message who are highly trusted by the target group.[60–61]

What is needed for the region to introduce the tool?

Resources and organisation

- Ensure that the staff concerned have been trained and are informed about the campaign.
- Coordinate the campaign with other regional communication.

Relevant external actors

- Partnerships with external actors that the group trusts.

Important to remember

- It is important to understand how the target group operates and the reasons for their non-attendance in order to draw up a relevant campaign.

References

Sources for the table "Cancer screening uptake in the regions and Sweden as a whole" (p. 5)

- Cancer screening uptake rate: Manual collection by RCC, 2023
- Bowel cancer screening uptake rate: Swedish quality register for colonoscopies and colorectal cancer screening (SveReKKS), 2023 (refers to uptake rates for 2022)
- Cervical cancer screening uptake rate: Swedish National Cervical Screening Registry (NKCx), 2023 (refers to uptake rates in 2022)

1	Interview with Desiree Banovici, Peer advisor coordinator, Region Stockholm	
2	Simon Efremius, Lars E Eriksson, Max Kleijberg, "Investigating Peer Advisors' Strategies to Promote Cancer Prevention and Early Detection in Swedish Communities with Challenging Socioeconomic Conditions", Health & Social Care in the Community, vol. 2023, Article ID 6692655, 13 pages, 2023.	doi.org/10.1155/2023/6692655
3	Interview with Ellen Lindahl, project manager, Mamma United	
4	Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine. 2000;25(24):3186-91.	doi.org/10.1097/00007632-200012150-00014
5	Confederation of Regional Cancer Centres in Sweden, National Clinical Cancer Care Guidelines for Colorectal Cancer Screening. 2022.	kunskapsbanken.cancercentrum.se/globalassets/kunskapsbanken/tjock--och-andtarmscancerscreening/nationellt-vardprogram-tjock-och-andtarmscancerscreening.pdf (in Swedish only)
7	Segnan N, Senore C et al, "Promoting participation in a population screening program for breast and cervical cancer: a randomized trial of different invitation strategies". Tumori. 1998 May-Jun;84(3):348-53, 2023.	doi.org/10.1177/030089169808400307
8	National Working Group on cervical cancer prevention Working Group, National Clinical Cancer Care Guidelines for Cervical Cancer Prevention 2022.	kunskapsbanken.cancercentrum.se/globalassets/vara-uppdrag/prevention-tidig-upptackt/gynekologisk-cellprovskontroll/vardprogram/nationellt-vardprogram-cervixcancerprevention.pdf (in Swedish only)
9	Camilloni L, Ferroni E, Cendales BJ, et al. Methods to increase participation in organised screening programs: a systematic review. BMC Public Health 13, 464 (2013).	doi.org/10.1186/1471-2458-13-464

10	Morrell S, Taylor R, Zeckendorf S, Niciak A, Wain G, Ross J. How much does a reminder letter increase cervical screening among under-screened women in NSW? Aust N Z J Public Health. 2005 Feb;29(1):78-84. doi: 10.1111/j.1467-842x.2005.tb00753.x. PMID: 15782877.	doi.org/10.1111/j.1467-842x.2005.tb00753.x
11	Eaker S, Adami HO, Granath F, Wilander E, Sparén P. A large population-based randomized controlled trial to increase attendance at screening for cervical cancer. Cancer Epidemiol Biomarkers Prev. 2004 Mar;13(3): 346-54. PMID: 15006907.	pubmed.ncbi.nlm.nih.gov/15006907/
12	Wang J, Elfström KM, Borgfeldt C, Dillner J. A pilot study of risk-stratified cervical cancer screening. Open Res Eur. 2022 Sep 1;1:84. doi: 10.12688/openreseurope.13398.2. PMID: 37645164; PMCID: PMC10445943.	pubmed.ncbi.nlm.nih.gov/15006907/
13	Enerly E, Bonde J, Schee K, Pedersen H, Lönnberg S, Nygård M. Self-Sampling for Human Papillomavirus Testing among Non-Attenders Increases Attendance to the Norwegian Cervical Cancer Screening Programme. PLoS One. 2016 Apr 13;11(4):e0151978. doi: 10.1371/journal.pone.0151978. PMID: 27073929; PMCID: PMC4830596.	doi.org/10.1371/journal.pone.0151978
14	Screening for squamous cervical cancer: duration of low risk after negative results of cervical cytology and its implication for screening policies. IARC Working Group on evaluation of cervical cancer screening programmes. Br Med J (Clin Res Ed). 1986 Sep 13;293(6548):659-64. doi: 10.1136/bmj.293.6548.659. PMID: 3092971; PMCID: PMC1341512.	doi.org/10.1136/bmj.293.6548.659
15	Swedish National Board of Health and Welfare. "Nationell utvärdering livmoderhalsscreening" (National evaluation of cervical cancer screening). Swedish National Board of Health and Welfare, 2020.	socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2020-6-6800.pdf (in Swedish only)
16	Swedish National Board of Health and Welfare. "Framtidens cancerscreening: Redovisning av regeringsuppdraget Framtidsinriktad omvärldsanalys om förändringar och utvecklingstendenser inom cancerscreening" (Cancer screening of the future: Report on government remit to analyse changes and development trends in cancer screening). Swedish National Board of Health and Welfare, 2019.	socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2019-4-13.pdf (in Swedish only)
17	Swedish National Board of Health and Welfare. "Screening för tjock- och ändtarmscancer: Rekommendation och bedömningsunderlag" (Screening for colorectal cancer: Recommendation and assessment grounds). Swedish National Board of Health and Welfare, 2014.	socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-screeningprogram/2014-2-31.pdf (in Swedish only)
18	RCC. "Införande av allmän tarmcancerscreening: Slutrapport och rekommendation" (Introduction of universal colorectal cancer screening: Final report and recommendations). National Working Group for the evaluation of the introduction of universal colorectal cancer screening. Confederation of Regional Cancer Centres in Sweden, 2018.	cancercentrum.se/globalassets/vara-uppdrag/prevention-tidig-upptackt/tarmcancerscreening/slutrapport_inforande_tarmcancerscreening_18-02-28.pdf (in Swedish only)
19	Public Health Agency of Sweden. "Frågor och svar om humant papillomvirus (HPV) och vaccination" (FAQ about human papillomvirus (HPV) and vaccination). Public Health Agency of Sweden, 2022.	folkhalsomyndigheten.se/smittskydd-beredskap/vaccinationer/fragor-och-svar/humant-papillomvirus/ (in Swedish only)

20	Dougherty MK, Brenner AT, Crockett SD, Gupta S, Wheeler SB, Coker-Schwimmer M, Cubillos L, Malo T, Reuland DS. Evaluation of Interventions Intended to Increase Colorectal Cancer Screening Rates in the United States: A Systematic Review and Meta-analysis. JAMA Intern Med. 2018 Dec 1;178(12):1645-1658. doi: 10.1001/jamainternmed.2018.4637. PMID: 30326005; PMCID: PMC6583619.	doi.org/10.1001/jamainternmed.2018.4637
21	Albrow R, Blomberg K, Kitchener H, Brabin L, Patnick J, Tishelman C, Törnberg S, Sparén P, Widmark C. Interventions to improve cervical cancer screening uptake amongst young women: a systematic review. Acta Oncol. 2014 Apr;53(4):445-51. doi: 10.3109/0284186X.2013.869618. Epub 2014 Feb 7. PMID: 24660768.	doi.org/10.3109/0284186x.2013.869618
22	Norwegian Cancer Society. Sjekkdeg – og reduser risikoen for kreft (Get checked – and reduce the risk of cancer). 2023. [Retrieved 20.11.2023]	kreftforeningen.no/sjekkdeg/
23	Swedish Cancer Society. Arbetsgivare – var med och förändra (Employers – help to change things). 2023. [Retrieved 20.11.2023]	cancerfonden.se/om-cancer/undersokningar/screening/for-arbetsgivare
24	Thomsen MK, Jørgensen MD, Pedersen L, Erichsen R, Sørensen HT & Mikkelsen EM. Mental disorders, participation, and trajectories in the Danish colorectal cancer screening programme: a population-based cohort study. The Lancet Psychiatry. 2023. Volume 10 issue 7, P518-527. doi:	doi.org/10.1016/S2215-0366(23)00179-7
25	Murphy KA, Stone EM, Presskreischer R, McGinty EE, Daumit GL, Pollack CE. Cancer Screening Among Adults With and Without Serious Mental Illness: A Mixed Methods Study. Med Care. 2021 Apr 1;59(4):327-333. doi: 10.1097/MLR.0000000000001499. PMID: 33704103; PMCID: PMC7952680.	doi.org/10.1097%2FMLR.0000000000001499
26	Hwong AR, Irwin KE. Reducing global disparities in cancer screening for people with mental illness. Lancet Psychiatry. 2020 Jan;7(1):4-6. doi: 10.1016/S2215-0366(19)30470-5. Epub 2019 Nov 29. PMID: 31787584; PMCID: PMC7319861.	doi.org/10.1016/S2215-0366(19)30470-5
27	Irwin KE, Park ER, Fields LE, Corveleyn AE, Greer JA, Perez GK, Callaway CA, Jacobs JM, Nierenberg AA, Temel JS, Ryan DP, Pirl WF. Bridge: Person-Centered Collaborative Care for Patients with Serious Mental Illness and Cancer. Oncologist. 2019 Jul;24(7):901-910. doi: 10.1634/theoncologist.2018-0488. Epub 2019 Jan 29. PMID: 30696722; PMCID: PMC6656464.	doi.org/10.1634%2Ftheoncologist.2018-0488
28	Broberg G, Jonasson JM, Ellis J, Gyrd-Hansen D, Anjemark B, Glantz A, Söderberg L, Ryd ML, Holtenman M, Milsom I, Strander B. Increasing participation in cervical cancer screening: telephone contact with long-term non-attendees in Sweden. Results from RACOMIP, a randomized controlled trial. Int J Cancer. 2013 Jul;133(1):164-71. doi: 10.1002/ijc.27985. Epub 2013 Jan 10. PMID: 23233356.	onlinelibrary.wiley.com/doi/10.1002/ijc.27985
29	Eaker S, Adami HO, Sparén P. Reasons women do not attend screening for cervical cancer: a population-based study in Sweden. Prev Med. 2001 Jun;32(6):482-91. doi: 10.1006/pmed.2001.0844. PMID: 11394952.	doi.org/10.1006/pmed.2001.0844
30	Soneji S, Fukui N. Socioeconomic determinants of cervical cancer screening in Latin America. Rev Panam Salud Publica. 2013 Mar;33(3):174-82. doi: 10.1590/s1020-49892013000300003. PMID: 23698136; PMCID: PMC3724344.	doi.org/10.1590/s1020-49892013000300003
31	NHS England. Guidance Cervical screening: ideas for improving access and uptake. 2023.	gov.uk/guidance/cervical-screening-ideas-for-improving-access-and-uptake#additional-data-and-resources

32	Sharp L, Dodlek N, Willis D, Leppänen A, Ullgren H. Cancer Prevention Literacy among Different Population Subgroups: Challenges and Enabling Factors for Adopting and Complying with Cancer Prevention Recommendations. Int J Environ Res Public Health. 2023 May 19;20(10):5888. doi: 10.3390/ijerph20105888. PMID: 37239613; PMCID: PMC10218495.	mdpi.com/1660-4601/20/10/5888
33	Atere-Roberts J, Smith JL, Hall IJ. Interventions to increase breast and cervical cancer screening uptake among rural women: a scoping review. Cancer Causes Control. 2020 Nov;31(11):965-977. doi: 10.1007/s10552-020-01340-x. Epub 2020 Aug 25. PMID: 32840707; PMCID: PMC8657510.	doi.org/10.1007/s10552-020-01340-x
34	Wang H, Roy S, Kim J, Farazi PA, Siahpush M, Su D. Barriers of colorectal cancer screening in rural USA: a systematic review. Rural Remote Health. 2019 Aug;19(3):5181. doi: 10.22605/RRH5181. Epub 2019 Aug 9. PMID: 31394041.	doi.org/10.22605/rrh5181
35	Interview with Ole Alexander Opdahlshei, Assistant Director General, Norwegian Cancer Society	
36	Interview with Joakim Dillner, Registrar and chairman of the NKCx steering group, Professor of infectious disease epidemiology at Karolinska Institutet	
37	Tuffrey-Wijne I, Bernal J, Hubert J, Butler G, Hollins S. People with learning disabilities who have cancer: an ethnographic study. Br J Gen Pract. 2009 Jul;59(564):503-9. doi: 10.3399/bjgp09X453413. PMID: 19566998; PMCID: PMC2702015.	doi.org/10.3399/bjgp09x453413
38	Swedish National Board of Health and Welfare. Vård, insatser och stöd till personer med funktionsnedsättning (Care, interventions and support for people with disabilities). 2013.	socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/statistik/2013-2-2_vardinsatserochstodtillpersonermedfunktionsnedsattning.pdf (in Swedish only)
39	Liu Q, Adami HO, Reichenberg A, Kolevzon A, Fang F, Sandin S. Cancer risk in individuals with intellectual disability in Sweden: A population-based cohort study. PLoS Med. 2021 Oct 21;18(10):e1003840. doi: 10.1371/journal.pmed.1003840. PMID: 34673770; PMCID: PMC8568154.	doi.org/10.1371/journal.pmed.1003840
40	Edwards DJ, Sakellariou D, Anstey S. Barriers to, and facilitators of, access to cancer services and experiences of cancer care for adults with a physical disability: A mixed methods systematic review. Disabil Health J. 2020 Jan;13(1):100844. doi: 10.1016/j.dhjo.2019.100844. Epub 2019 Oct 11. PMID: 31668781.	doi.org/10.1016/j.dhjo.2019.100844
41	Shin DW, Chang D, Jung JH, Han K, Kim SY, Choi KS, Lee WC, Park JH, Park JH. Disparities in the Participation Rate of Colorectal Cancer Screening by Fecal Occult Blood Test among People with Disabilities: A National Database Study in South Korea. Cancer Res Treat. 2020 Jan;52(1):60-73. doi: 10.4143/crt.2018.660. Epub 2019 May 7. PMID: 31096735; PMCID: PMC6962481.	doi.org/10.4143/crt.2018.660
42	Henley SJ, Anderson RN, Thomas CC, Massetti GM, Peaker B, Richardson LC. Invasive Cancer Incidence, 2004-2013, and Deaths, 2006-2015, in Nonmetropolitan and Metropolitan Counties - United States. MMWR Surveill Summ. 2017 Jul 7;66(14):1-13. doi: 10.15585/mmwr.ss6614a1. PMID: 28683054; PMCID: PMC5879727.	doi.org/10.15585/mmwr.ss6614a1
43	Interview with Ulf Strömberg, Adjunct Professor at the School of Public Health and Community Medicine, University of Gothenburg	

44	Eriksson EM, Lau M, Jönsson C, et al. Participation in a Swedish cervical cancer screening program among women with psychiatric diagnoses: a population-based cohort study. BMC Public Health 19, 313 (2019).	doi.org/10.1186/s12889-019-6626-3
45	Martens PJ, Chochinov HM, Prior HJ, Fransoo R, Burland E; Need To Know Team. Are cervical cancer screening rates different for women with schizophrenia? A Manitoba population-based study. Schizophr Res. 2009 Aug;113(1):101-6. doi: 10.1016/j.schres.2009.04.015. Epub 2009 May 6. PMID: 19419843.	pubmed.ncbi.nlm.nih.gov/19419843/
46	Tilbrook D, Polsky J, Lofters A. Are women with psychosis receiving adequate cervical cancer screening? Can Fam Physician. 2010 Apr;56(4):358-63. PMID: 20393098; PMCID: PMC2860833.	pubmed.ncbi.nlm.nih.gov/20393098/
47	Hu K, Wang J, Sparén P, Herweijer E, Sjölander A, Adami HO, Valdimarsdóttir U, Sundström K, Fang F. Invasive cervical cancer, precancerous lesions, and cervical screening participation among women with mental illness in Sweden: a population-based observational study. Lancet Public Health. 2023 Apr;8(4):e266-e275. doi: 10.1016/S2468-2667(23)00026-9. PMID: 36965981.	doi.org/10.1016/s2468-2667(23)00026-9
48	SOU 2023:73. Genomförandet av vaccineringen mot sjukdomen covid-19 – en utvärdering. (Evaluation of the implementation of vaccination against COVID-19) Statens offentliga utredningar (Swedish Government Official Reports), 2023	regeringen.se/contentassets/045e47bb40f543bab98f079241b16b6d/sou-2023_73_pdf-a_webb.pdf (in Swedish with English summary)
49	Solmi M, Firth J, Miola A, Fornaro M, Frison E, Fusar-Poli P, Dragioti E, Shin JI, Carvalho AF, Stubbs B, Koyanagi A, Kisely S, Correll CU. Disparities in cancer screening in people with mental illness across the world versus the general population: prevalence and comparative meta-analysis including 4 717 839 people. Lancet Psychiatry. 2020 Jan;7(1):52-63. doi: 10.1016/S2215-0366(19)30414-6. Epub 2019 Nov 29. Erratum in: Lancet Psychiatry. 2019 Dec 4;: PMID: 31787585.	doi.org/10.1016/s2215-0366(19)30414-6
50	Interview with Björn Strander, medical advisor, gynaecologist, researcher, RCC West	
51	Growth Analysis. Befolkning, service och företagande i Sveriges gles- och landsbygder (Population, services and enterprise in Sweden's sparsely populated and rural areas). 2009.	tillvaxtanalys.se/download/18.62dd45451715a00666f1f4ad/1586366196804/Rapport_2009_10.pdf (in Swedish only)
52	Virtanen A, Nieminen P, Luostarinen T, Anttila A. Self-sample HPV tests as an intervention for nonattendees of cervical cancer screening in Finland: a randomized trial. Cancer Epidemiol Biomarkers Prev. 2011 Sep;20(9):1960-9. doi: 10.1158/1055-9965.EPI-11-0307. Epub 2011 Jul 13. PMID: 21752985.	doi.org/10.1158/1055-9965.epi-11-0307
53	Delilovic S, Bergström A, Hasson H. Strategier för att öka vaccinationstäckningen – en kunskapsöversikt. (Strategies to increase vaccination coverage – a knowledge review) Stockholm: Centre for Epidemiology and Community Medicine, Region Stockholm; 2022. Report 2022:7	folkhalsoguiden.se/49b762/globalassets/verksamheter/forskning-och-utveckling/centrum-for-epidemiologi-och-samhallsmedicin/folkhalsoguiden/rapporter-och-faktablad/rapport-2022.7-strategier-for-att-oka-vaccinationstackningen---ef.pdf (in Swedish only)
54	Mohammed H, McMillan M, Roberts CT, Marshall HS. A systematic review of interventions to improve uptake of pertussis vaccination in pregnancy. PLoS One. 2019 Mar 28;14(3):e0214538. doi: 10.1371/journal.pone.0214538. PMID: 30921421; PMCID: PMC6438510.	doi.org/10.1371/journal.pone.0214538

55	Segnan N, Patnick J, von Karsa L. European guidelines for quality assurance in colorectal cancer screening and diagnosis. European Commission, 2012	cancercentrum.se/globalassets/vara-uppdrag/prevention-tidig-upptackt/tarmcancerscreening/eu_guidelines_colorectal_cancer_screening.pdf
56	Swedish National Cervical Screening Registry. Coverage in Sweden 2014-2022 by age class. 2023.	nkcx.se/Coverage_all_e.htm
57	Confederation of Regional Cancer Centres in Sweden. Sverige på god väg att utrota livmoderhalscancer (Sweden well on the way to eradicating cervical cancer). 2023.	cancercentrum.se/utrotalivmoderhalscancer
58	Interview with Miriam Elfström, Chair of the National Working Group on Cervical Cancer Prevention (NaCx), RCC Stockholm-Gotland	
59	Confederation of Regional Cancer Centres in Sweden. Training presentation material. 2023.	cancercentrum.se/samverkan/vara-uppdrag/prevention-och-tidig-upptackt/gynekologisk-cellprovskontroll/presentationsmaterial/ (downloadable PowerPoint files, in Swedish only)
60	Hedegaard Mortensen J, Hougaard Loft L. Lessons Learned Stop HPV — get vaccinated. Danish Cancer Society, 2022.	cancer.dk/dyn/resources/File/file/5/9655/1649050131/pixi-stop-hpv-evaluering.pdf
61	Baandrup L, Valentiner-Branth P, Kjaer S. HPV vaccination crisis and recovery: the Danish case. 2023. [Retrieved 27.11.2023]	hpvworld.com/articles/hpv-vaccination-crisis-and-recovery-the-danish-case/
62	Delilovic S, Bergström A, Hasson H. Strategier för att öka vaccinationstäckningen – en kunskapsöversikt. (Strategies to increase vaccination coverage – a knowledge review) Stockholm: Centre for Epidemiology and Community Medicine, Region Stockholm; 2022. Report 2022:7	folkhalsoguiden.se/49b762/globalassets/verksamheter/forskning-och-utveckling/centrum-for-epidemiologi-och-samhallsmedicin/folkhalsoguiden/rapporter-och-faktablad/rapport-2022.7-strategier-for-att-oka-vaccinationstackningen---ef.pdf (in Swedish only)
63	Olsson E, Lau M, Lifvergren S, Chakhunashvili A. Community collaboration to increase foreign-born women's participation in a cervical cancer screening program in Sweden: a quality improvement project. Int J Equity Health. 2014 Aug 9;13:62. doi: 10.1186/s12939-014-0062-x. PMID: 25106490; PMCID: PMC4422324.	equityhealthj.biomedcentral.com/articles/10.1186/s12939-014-0062-x
64	Wiksten Å. Angereds kvinnor tog gärna med en vän (The women of Angered were keen to bring a friend). Dagens Medicin. 2012.	dagensmedicin.se/specialistomraden/kvinnohalsa/angereds-kvinnor-tog-garna-med-en-van/ (in Swedish only)
65	Region Värmland. Kulturtolkar och kulturdoulor (Cultural interpreters and cultural doulas). 2023.	regionvarmland.se/vardgivarwebben/samverkan-avtal-och-vardval/modra--och-barnhalsovard/kulturtolkar-och-kulturdoulor (in Swedish only)
66	Regional Cancer Centre West. Cellprovsveckan uppmärksammar vikten av att ta cellprov (Smear test week draws attention to the importance of having smear tests). 2023.	cancercentrum.se/vast/vara-uppdrag/prevention-och-tidig-upptackt/gynekologisk-cellprovskontroll/cellprovsveckan/ (in Swedish only)

The Swedish Cancer Society's vision is to beat cancer. We are working to ensure that fewer people get cancer and more people survive cancer by funding cutting-edge research, spreading awareness of cancer and influencing decision-makers.
The Swedish Cancer Society is an independent, non-profit, non-subsidised organisation. Our work relies entirely on bequests and donations from individuals and companies.
We are one of the largest funders of Swedish cancer research. Since 1951, we have awarded more than SEK 15 billion to the foremost research projects in Sweden. Cancer survival has more than doubled over the same period.
Thanks to the advances made by research,
today two out of three people with cancer survive.
We have come a long way but we are not there yet.

#togetheragainstcancer

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