

# Opting-out from the Scottish Cervical Screening Programme

Guidance paper for  
healthcare professionals

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## **Opting out from the Scottish Cervical Screening Programme Guidance paper for healthcare professionals**

This document aims to

1. Clarify the criteria that must be met for opting out of the cervical screening programme
2. Provide advice on the correct use of a disclaimer form
3. Review the implications of opting out of the cervical screening programme
4. Review the potential barriers to cervical screening
5. Highlight the needs of vulnerable populations in the context of cervical screening

### **Aims of the Scottish Cervical Screening Programme**

The Scottish Cervical Screening Programme (SCSP) aims to reduce the number of people who develop invasive cancer and the number dying from the disease by testing for HPV, which is the main cause of cervical cancer. HPV is very common. Four out of 5 people in Scotland will have HPV at some point in their lives. As there are usually no symptoms, many people have it for months or years without knowing it.

During screening a sample is taken from the cervix, and tested for HPV in the first instance. If it is found to be HPV positive, or if a participant is on a non-routine pathway (for example, they have had abnormal screening results in the past), then their sample is also tested using cytology. By doing this, it is possible to identify changes in individual cells which could lead to developing invasive cancer at a later date. Prompt treatment can result in permanent removal of affected areas of the cervix and prevent the development of cancer.

Screening, however, also has the potential to cause both physical and psychological harm to invitees. A balance must be struck between maximising effectiveness and minimising harm.

In Scotland, eligible people (women, trans men and non-binary individuals with a cervix) are routinely invited every five years between the ages of 25 and 64 plus 364 days. Those on non-routine recall are called more frequently and are invited up to the age of 70, plus 364 days.

## 1. Opting-out

Opting-out refers to the intention of removing oneself from a programme and choosing not to be part of the activity. In the context of the Scottish Cervical Screening programme this means someone choosing to remove themselves from the programme so that they will no longer be invited for a test

The term opting-out should not be confused with the term exclusion. An exclusion status is an action which is carried out by a health professional or automatically by SCCRS. These exclusions are listed in **Appendix 1**.

Some people may choose not to be invited for future cervical screening tests. If this is the case, they may ask to have their name removed from the list of eligible people. Before this request can be implemented, the following conditions must be satisfied:

- The person must be offered sufficient information to enable them to make an informed decision about withdrawing from the cervical screening programme – this must be in a format which is accessible to them. It should include information on the condition being screened for, the screening process (including risks and benefits) and the consequences of attending or ceasing.
- The person must be informed that withdrawing from the programme will prevent them from receiving any future invitations or reminders about cervical screening.
- It must be made clear that they can be returned to the programme at any time at their own request.

**(Please see Appendix 2: advice to healthcare professional on appropriate use of a disclaimer form)**

### Defaulters

A defaulter is someone who does not attend for screening after an invitation and subsequent reminders.

It is important that people in the eligible age group are **not** excluded from the programme if:

- They have not attended their invitation for cervical screening and

subsequent two reminders (routine recall) or three reminders (non-routine recall)

- Their status is defaulter

### **It is unacceptable clinical practice to opt-out an individual on the basis of being a defaulter alone**

#### Defaulters: an example of good practice

An example of good practice within many GP practices for people defaulting is the use of an alert system. By placing an alert on the individual's notes, health care professionals within the Practice will be able to approach the subject of cervical screening with them when they attend the Practice for other health reasons. The use of this system was found to lead to an opportunistic uptake of screening.

## **2. Disclaimer form**

### Appropriate use

1. It is essential that a healthcare professional discusses opting-out with the individual. It is the healthcare professional's responsibility to ensure that the person has the opportunity to be fully informed of the benefits and risks of undergoing screening and the risks/benefits to them of opting out.
2. Some people may not wish to enter into a discussion and this must be respected, and can be documented in the notes.
3. If the patient wishes to opt-out it is then the responsibility of the GP practice to issue a disclaimer form for signature
4. Disclaimers should be used with **caution**. People should sign only when the GP/Practice Nurse has made efforts to ensure they are making an informed decision
5. Disclaimers should only be signed by the participant in the presence of the GP/Practice Nurse and **not posted out** to the individual
6. The disclaimer form should be kept in the patient's notes

### 3. Implications of opting- out

A signed disclaimer form (**Appendix 2**) from the individual participant means that they will be removed from Call/Recall and will therefore not receive any further screening invitations.

Participants who have been opted-out of the programme will:

- **Not be invited for further screening**
- Be contacted immediately confirming their status and thereafter will be contacted every **5 years** from SCCRS, in the form of a letter to remind them of their opted-out status.

#### **4. Alterations to SCCRS record**

- Only once the GP/Practice Nurse has signed the disclaimer form, should the exclusion status be applied to the person's SCCRS status
- When the opt out alert appears on Call/Recall, the patient's history will be checked by a Call/Recall officer
- If the Practice advises that the opt-out status has been in error the Practice should close down the exclusion, make a note of the error in the patient's medical notes and contact Call/Recall staff to ask them to apply a journal entry
- If the opt-out alert is generated for a person on routine or non-routine follow up, the alert will be deleted
- If a patient contacts the Call/Recall office to advise that they have received an opted out confirmation letter and disputes this, Call/Recall staff will close the status and contact the Practice

## **5. Opting-out reversal**

If a person's opted out exclusion is closed down on SCCRS or if they subsequently have a screening test reported on SCCRS, then they will be immediately opted back into the programme.



## **6. Barriers to screening**

Individuals should be encouraged to make an informed choice: they have the right to not take part in screening. The aim of the healthcare professional is to remove any other barriers to screening. These barriers may include personal reasons and practical reasons for non-attendance as well as factors that may influence attitudes and beliefs about screening. The Scottish Cervical Screening Programme aims to identify and tackle these barriers and ensure that participants are knowledgeable about the process, feel confident in their decisions and if they are able to do so, conveniently attend their appointments.

### Personal reasons for non-attendance

- Embarrassment
- Fear of the screening test
- Fear of what might be found
- Adverse comments about having a cervical screening sample taken (a 'smear') from health professionals, other peoples, the media or other sources
- Lack of understanding of the purpose of screening and / or the operation of the National Screening programme
- Dislike of doctors / medical service
- Previous bad experience within the health service
- Concerns about having a male sample taker
- Ethnic and cultural differences, for example language barriers, cultural beliefs
- Female genital mutilation
- Past sexual abuse or assault
- Domestic abuse
- Psychosexual and physical problems causing painful sex or apareunia

### Practical reasons for non-attendance

- Screening only available by appointment
- Appointments available only during working hours
- Fears about lack of confidentiality
- Expectation that there is a cost for having a sample taken

### Factors influencing attitudes and beliefs about screening

- Availability of adequate and appropriate information
- Attitudes and beliefs about:
  - Health issues in general
  - The seriousness of cervical cancer

- The individual's personal susceptibility to the disease
- The effectiveness of cervical screening
- The screening procedure
- Fear that it will trigger flashbacks to past traumatic events
- Uncertainty about the test and / or the outcome of the test
- The implications of a 'not normal' result
- The importance of cervical screening

#### Factors in considering attitudes and beliefs

- Appreciate that cervical screening needs to be seen in the context of a person's general health and family priorities
- Recognise the complexity of the relationship between knowledge, attitudes, beliefs and behaviour
- Avoid inducing guilt in people who do not attend
- Discuss the limitations as well as the benefits of cervical screening
- Acknowledge that there is some controversy about cervical screening
- Be sensitive to the possibility of past undisclosed assault, abuse or FGM

#### Factors that may cause dissatisfaction with cervical screening

- Inadequate information or communication
- Unclear or ambiguous information
- Impersonal treatment by sample takers
- Unanticipated discomfort or pain caused by taking the cervical sample, particularly where this is not well managed by the sample taker
- Perceived incompetence of providers
- Unsatisfactory physical environment
- Lack of privacy
- Any discrepancy between expectation and experience
- Uncertainty caused by long waiting times for results
- Inadequate time allotted to taking the sample

## **7. Vulnerable populations**

### Assessing the capacity of individuals to give consent to cervical screening

The issue of consent is central to any screening programme. As a general principle, individuals should understand the limitations and the consequences of being screened and from this information make an informed decision whether or not to accept the invitation to participate within the programme. The law assumes that every adult has the capacity to consent unless it can be shown that the person is unable to understand, retain or use the given information and to weigh it up as part of the decision making process. If a person is unable to consent to one form of medical treatment, inability to consent to a different treatment should not be assumed. No-one can consent to or refuse treatment on behalf of another adult who lacks the capacity to consent. This includes the patient's family or doctor.

Deciding whether a person has the capacity to consent is a matter for clinical judgement and should be made in the light of current circumstances. A clinician must determine and act in the best interests of the person in accordance with a responsible body of medical opinion. In determining the best interests of someone who cannot consent to or refuse treatment, a clinician should take into account the views and wishes expressed by the person in the past and present, as well as the views and wishes of the people who support or know the person well, concerning the likely attitude and interests of the person.

### Questions for the healthcare professional to ask in assessing capacity to consent

When a healthcare professional is assessing the ability of a person to consent, the following questions should be considered:

- Have you spent sufficient time talking with and listening to the person, determining their level of understanding, and have you involved someone who knows the person well and who may be better than you at communicating with that person?
- On what basis have you decided that the person is unable to consent, and are you sure that this is not because you disagree with the person's decisions?
- Have you fully explained, in a way that the person is most likely to understand, the proposed test, the alternatives and the risks and the benefits?
- If you decide that the person cannot consent, have you discussed this with those who support and know the person well?
- Have you recorded this discussion and any views within the patient's notes?

### Individuals with a diagnosed learning disability

Individuals with a diagnosed learning disability should not automatically be 'opted out' of the cervical screening programme. People with learning disabilities are living longer and fuller lives and should have access to cervical screening on the same basis as other people. It is also not good practice for health professionals to assume that these individuals are not sexually active based primarily on the information that they have a diagnosed learning disability and subsequently opt them out of cervical screening. Health professionals should adopt good practice to enable people who choose to attend for screening to be screened successfully through promoting access of information presented in a way which they can fully understand.

### Ethnic minority populations

It is important to be aware of the issues surrounding cervical screening of people from ethnic minorities where there is the potential for conflicting issues of practices, expectations and beliefs. Intercultural communication will be paramount during the sample taking process due to possible language barriers which many people from an ethnic minority encounter. Poor methods of communication may result in them not being able to express their thoughts and convey their experiences within the context of screening.

There may be a need for specifically targeted interventions within a small number of GP Practices. These may include the use of community health educators along with multilingual and promotional resources to address the needs of the targeted population. Young people must not be opted-out of cervical screening at their parent's request, because their parents state that they have not yet been sexually active.

### Previous sexual assault, sexual abuse and FGM

Some people may avoid cervical screening as an after effect of sexual assault or abuse, including female genital mutilation.

Examples of ways to ask about this are:

*"Has anything happened to you in the past that makes having a cervical screening test difficult for you? You don't have to give me details if you don't want to, but we can talk about things we might be able to do to help you have a sample taken"*

*"In some cultural backgrounds women are cut/circumcised when they are young girls. Women who have experienced this can find a cervical screening test more difficult. I appreciate this is a sensitive subject to talk about but is this something that has happened to you? Have you been cut/circumcised /closed when you were young?"*

In circumstances where FGM is disclosed, you should record the diagnosis and types of FGM, together with any corrective procedures, in relevant clinical records, as requested in the CMO/CNO letter CMO (2014)19 Re: female genital mutilation<sup>15</sup>. You should be aware of your local processes if FGM is identified.

Government information and guidance is on:

<https://www.gov.scot/policies/violence-against-women-and-girls/female-genital-mutilation-fgm/>

Consider this advice on intimate examination for people who have great difficulty with being examined because of previous sexual assault / abuse, including Female Genital Mutilation. With this type of vulnerability, examination should only be undertaken by experienced sample takers.

1. Take time. Book a double or triple appointment if required.
2. Ask patients if they are aware of any 'triggers', phrases or postures that are uncomfortable or may cause them distress.
3. Make it clear that patients can say 'stop' at any point, and keep checking how they are feeling throughout the visit.
4. Use a graded approach to having the complete cervical sample taken: it might take a couple of appointments to work towards having any sort of examination. The goal of the appointment might be, rather than completing the cytology, to have a visit where the patient feels in control and listened to – and will come back. The participant may want to insert the speculum themselves.
5. Frame the appointment in a way that makes patients feel as though you are working with them, rather than doing something 'to' them.
6. Use techniques such as mindfulness to encourage patients to focus on sensations in the present moment.
7. Ask the patient to describe what is happening as the examination proceeds. This active involvement of the patient helps minimise distress and encourages a sense of engagement and control.
8. Ask patients to rate their anxiety and discomfort – do not proceed if they rate it above seven or eight out of ten. Use this approach as a way of checking on the patient.
9. Encourage patients to keep their eyes open and engage with you as best they can. When keeping their eyes closed patients can dissociate or have flashbacks if triggers are present.

10. Be aware of your own feelings and responses. If you are frustrated or pressured for time to complete the examination, then pause and take time to stand alongside the patient.

11. Patients with a history of no penetrative sex or no tampon use due to moderate to severe vaginismus might need additional support and guidance or psychosocial intervention, or a review of the need for cervical cytology.

12. Bring a sense of warmth, support and engagement to the appointment. It can be a great opportunity to provide education about genital anatomy and function.

## Appendix 1: Exclusions

### Age

Screeners should not exclude people on the basis of age. People are excluded automatically by SCCRS if:

- they are on routine recall (i.e. people who are not undergoing cytological surveillance, modified cytological surveillance or follow up after abnormal or inadequate cervical cytology or treatment) and will be over 65 at the time of their next invitation (SCCRS will call a participant on routine recall until the day before their 65<sup>th</sup> birthday)
- they are on non-routine recall and will be 71 at the time of their next invitation (SCCRS will call a participant on non-routine recall until the day before their 71<sup>st</sup> birthday).
- they have no screening history and will be 65 or over at the time of their next invitation

Healthcare professionals may exclude people from screening where anatomical considerations and protecting an individual's best interest do not allow for cervical screening to be undertaken.

### Anatomical considerations

- their cervix is 'impossible to sample'
- they have undergone a total hysterectomy
- they have undergone radiotherapy of the pelvis
- there is a congenital absence of the cervix

### Best interest

the participant will never be able to consent and it is in their best interest to cease invitation from screening (**please see further advice on vulnerable individuals**)

- the risk of physical or psychological harm is greater than the potential benefit of being screened

## **Appendix 2: Advice to healthcare professional on appropriate use of a disclaimer form**

### Disclaimer form discussion

A one-one discussion with a healthcare professional should take place with individuals who wish to opt out of cervical screening. They should be provided with information tailored directly to their needs and requirements, avoiding any unnecessary use of jargon words.

As a guide it is expected that the healthcare professional should sensitively explore any reasons why someone is not wanting to be screened, proactively asking about previous bad experiences e.g. “Some people don’t want a test because of current things, or things that happened in the past. You don’t have to give me any details if you don’t want to, but is this something that applies to you?”

Ask if they want to discuss it further and say that support is available for these sorts of problems.

Regarding opting out, discuss information on:

- The background of cervical screening; including the age groups of individuals who are eligible for screening and why regular screening is important.
- Highlight that a cervical screening test is not a test for cancer but is a way of preventing cancer by detecting and treating early abnormalities which, if left untreated, could lead to cancer in the cervix (the neck of the womb)
- Any concerns that they may have and also be prepared to discuss these barriers **(refer to above guidance on barriers to screening)** Understand and be sensitive to cultural issues in relation to screening
- What happens when they do opt out, highlight that although their name will still be included in the Scottish Cervical Call Recall System they will **not** receive any further invitations to attend for cervical screening
- That they can change their mind at any time to have screening by simply informing their healthcare provider
- That if they experience any unusual bleeding, including bleeding after sex or between periods then they should see their healthcare provider



- That they will be required to sign a disclaimer form (see below), informing them that this will be kept within their notes

Refs:

[https://www.gmc-uk.org/guidance/ethical\\_guidance/consent\\_guidance\\_part2\\_making\\_decisions\\_about\\_investigations\\_and\\_treatment.asp](https://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_part2_making_decisions_about_investigations_and_treatment.asp)

## Disclaimer Form

For completion by the patient

|                              |  |
|------------------------------|--|
| <b>Patient's Full Name</b>   |  |
| <b>Date of Birth</b>         |  |
| <b>CHI Number (if known)</b> |  |
| <b>Address</b>               |  |

I do not wish to receive any more invitations to have cervical screening. I confirm that I have understood the information that has been provided by the practice nurse/GP explaining the purpose of cervical screening tests and how having regular screening reduces the risk of developing cancer of the cervix. I also understand that I will only be contacted every five years to advise me of my 'opt-out' status and that I will not be regularly invited for screening.

I understand that I can change my mind and have cervical screening tests in the future. All I have to do is to contact my Practice and make an appointment.

**Signature of Patient**.....

**Date**.....

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**Witnessed by:**

**Signature of healthcare professional** .....

**Date**.....

**Advice for Practices**

- Please update the SCCRS application with the 'opt-out' status of the patient.
- Please keep this signed document in the patient's medical record.
- There is no requirement to send a copy of this signed disclaimer to the Screening Department.