Opting-out women from the Scottish Cervical Screening Programme

Guidance paper for healthcare professionals

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Opting women 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 women out of the cervical screening programme
2. Provide advice on the correct use of a disclaimer form
3. Review the implications of opting women 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 women who develop invasive cancer and the number of women who die from the disease by detecting precancerous changes. By taking a cytological sample (smear) from the cervix, followed where necessary by a diagnostic test, 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 women aged 20-60 years (25-64 years from April 2016) are invited to have a free cervical smear every three years with just over 405,000 cervical screening tests being processed in 2012-2013. Of the women eligible for screening in Scotland, over 73% have been screened in the last five years, and it is estimated that up to 250 cases of cervical cancer have been prevented annually. Since 1987, the incidence of invasive cervical cancer has fallen by 32.1% in Scotland, with a 46% reduction in deaths from the disease.
1. Opting-out women

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

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.

Opting-out

Women in the eligible age group can be opted-out of the programme only if both the following conditions are satisfied:

- The woman requests to be removed from the screening programme
- An in-depth discussion with a healthcare professional takes place (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 to note that the number of women presenting as defaulters within a practice does not affect the Practices’ performance targets as these women are not included in uptake rates and there is no financial penalty for the Practice if women do not attend their smear.

It is important that women 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), hereinafter referred to as defaulters

- If their status is as a defaulter then this must be kept as such. 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 women defaulting is the use of an alert system. By placing an alert on the individual woman’s notes, health care professionals within the Practice will be able to approach the subject of cervical screening with the woman when she attends the Practice for other health reasons. The use of this system was found to lead to an opportunistic uptake of smears.

**2. Disclaimer form**

**Appropriate use**

1. It is essential that a healthcare professional discusses opting-out with the individual woman. It is the healthcare professional’s responsibility to ensure that the woman is fully informed of the benefits of undergoing screening and the risks of opting out.

2. If after this discussion the patient still wishes to opt-out it is then the responsibility of the GP practice to issue a disclaimer form for signature.

3. Disclaimers should be used with **caution**. Women should sign only after the aforementioned discussion with the GP/Practice Nurse has taken place to ensure she is making an informed decision.

4. Disclaimers should only be signed by the woman in the presence of the GP/Practice Nurse and **not posted out** to the women.

5. 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 woman means that she will be removed from Call/Recall and will therefore not receive any further screening invitations.

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

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

- Only once the GP/Practice Nurse has signed the disclaimer form, should the exclusion status be applied to the woman’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 woman on routine or non-routine follow up, the alert will be deleted

- If a patient contacts the Call/Recall office to advise she has received an opted out confirmation letter and disputes this, Call/Recall staff will close the status and contact the Practice

4. Opting-out reversal

If a woman’s opted out exclusion is closed down on SCCRS or if they subsequently have a smear reported on SCCRS, then they will be immediately opted back into the programme.
5. Barriers to screening

Women should be encouraged to make an informed choice. Women have the right to not attend their appointment but ultimately 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 women 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 smear testing from other women, 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 smear taker
- Ethnic differences, for example language barriers

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 a smear test

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
• Uncertainty about the test and / or the outcome of the test
• The implications of a ‘not normal’ result
• The importance of cervical screening in a woman’s life

Factors in considering attitudes and beliefs

• Appreciate that cervical screening needs to be seen in the context of a women’s general health and family priorities
• Recognise the complexity of the relationship between knowledge, attitudes, beliefs and behaviour
• Avoid inducing guilt in women who do not attend
• Discuss the limitations as well as the benefits of cervical screening
• Acknowledge that there is some controversy about cervical screening

Factors that may cause dissatisfaction with cervical screening

• Inadequate information or communication
• Unclear or ambiguous information
• Impersonal treatment by smear takers
• Unanticipated discomfort or pain caused by taking the cervical smear, particularly where this is not well managed by the smear 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 smear
6. 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. Women with learning disabilities are living longer and fuller lives and should have access to cervical screening on the same basis as other women. It is also not good practice for health professionals to assume that these women 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 women 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 ethnic minority women where there is the potential for conflicting issues of practices, expectations and beliefs. Intercultural communication will be paramount during the smear taking process due to possible language barriers which many ethnic minority women encounter. Poor methods of communication may result in women 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 women must not be opt-ed-out of cervical screening at their parent’s request, because their parents state that they have not yet been sexually active.
Appendix 1

Exclusions

Age

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

- they are on routine recall (i.e. women who are not undergoing cytological surveillance, modified cytological surveillance or follow up after abnormal or inadequate cervical cytology or treatment) and will be over 60 at the time of their next invitation (SCCRS will call a woman on routine recall until the day before her 61st birthday)
- they are on non-routine recall and will be 69 at the time of their next invitation (SCCRS will call a woman on non-routine recall until the day before her 69th birthday).
- they have no screening history and will be 60 or over at the time of their next invitation

Healthcare professionals may exclude women 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 a Manchester repair
- they have undergone radiotherapy of the pelvis
- there is a congenital absence of the cervix

Best interest

- the woman 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)
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 individual women 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 discuss information on:

- The background of cervical screening; including the age groups of individuals who are eligible for a smear and why regular smears are important. Highlighting that a cervical smear is not a test for cancer but is a method of preventing cancer by detecting and treating early abnormalities which, if left untreated, could lead to cancer in a woman's 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 a cervical smear

- That they can change their mind at anytime to have a smear 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
Disclaimer Form

For completion by the patient

<table>
<thead>
<tr>
<th>Patient’s Full Name</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth</td>
<td></td>
</tr>
<tr>
<td>CHI Number (if known)</td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td></td>
</tr>
</tbody>
</table>

I do not wish to receive any more invitations to have cervical smears. I confirm that I have understood the information that has been provided by the practice nurse/GP explaining the purpose of cervical smear tests and how having regular smears 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 every three years for a smear.

I understand that I can change my mind and have cervical smear tests in the future. All I have to do is to contact my Practice, Family Planning Clinic or Well Woman Clinic and make an appointment.

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

*Date* ........................................

__________________________________________

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.