

Engaging primary care in cervical screening good practice guide

UK wide version

Together we will beat cancer



Contents

Contents	1
Statement of intent	2
Background.....	3
Introduction of primary HPV testing in cervical screening.....	4
Understanding barriers to participation.....	4
The role of the GP practice in supporting informed participation and reducing barriers to participation.....	5
Practical tips.....	6
Training	6
Access to screening	6
Information	7
Use of practice data	7
Call and recall systems	7
Eligibility	8
Templates.....	10
Safety Netting.....	12

Statement of intent

Cancer Research UK is committed to informed choice with respect to screening participation. Screening has both benefits and harms, and these must be communicated appropriately.

Cancer Research UK aims to share examples of good practice in this guide. It is up to each individual practice to explore what methods they wish to facilitate and to take responsibility to compliance with data protection processes as appropriate.

Background

This resource has been developed to help share good practice with GPs and other primary care practice staff. The guide will provide information on some of the barriers to participation in the cervical screening programme and the details of tried and tested interventions that could be used in practice, to encourage participation (through informed choice).

National Cervical Screening Programme (NCSP)

Cervical screening saves at least 2,000 lives each year in the UK ([Landy et al](#)). The screening test helps to prevent cervical cancer by picking up on changes in the cervix which could increase the risk of cervical cancer and offering further tests to those who need them. It is during this time of further tests that any changes in cells, which could develop into cancer if left untreated, can be removed.

Cervical screening coverage* has not reached its 80% target since 2005 (Department of Health and Public Health England, Public Health Wales). Lower attendance is particularly evident in the youngest as well as the oldest age groups, as well as inequalities by socioeconomic, ethnic and deprivation group.

To view the latest statistics, see: <https://bit.ly/2XofxfS>

The NCSP websites contain resources & guidance for good practice in cervical screening:

England: <https://bit.ly/2NsbNFK>

Wales: <https://bit.ly/2RvzZYG>

Scotland: <https://bit.ly/2lyHRZx>

Northern Ireland: <https://bit.ly/2H0mKgs>

* Screening coverage & uptake

Coverage - how many people who are eligible (25-64 years) for the programme have been screened adequately in last 30 months.

Uptake - how many people who have recently been invited to the programme responded to that screening round.



Eligible population:

- ✓ Cervical screening is available to anyone with a cervix aged 25-64 in England, Scotland, Northern Ireland and Wales.
- ✓ The NCSP call-recall system invites anyone registered as a woman on their GP records aged 25-49 every 3 years and 50-64 every 5 years.
- ✓ Anyone with a cervix registered as male with their GP in these age groups are eligible for screening but will not be sent invitation letters automatically. They will need to request a screening appointment through their GP.

Introduction of primary HPV testing in cervical screening

Human papilloma virus (HPV) is a common infection. Most sexually active people come into contact with HPV during their lifetime. But for most, the virus causes no harm and the infection clears on its own. However, in some cases, HPV infection can lead to cell changes that can progress into cervical cancer.

HPV primary screening is being introduced into the cervical screening programme. This means that instead of taking a sample of cells and sending them to a lab for testing, samples will be tested for HPV first. Only those that are HPV positive will be examined for signs that the cervical cells are not normal.

The change to HPV primary testing has happened in

Wales (September 2018) and will be taking place across England and Scotland in 2019/20. Northern Ireland is to be confirmed. **It currently does not affect the way or how often that people are invited or the way the cell sampling takes place.**

Testing for HPV first is a better way to screen for cervical cancer because 99.8% of all cervical cancer cases in the UK are linked to the HPV infection ([Brown et al 2018](#)).

It has been estimated that HPV primary testing in England could reduce the number of cervical cancers in women aged 25-64 by 23.9%, saving even more lives than the current test and helping to avoid unnecessary procedures for women ([Castanon et al, 2017](#)).

Note: Information on HPV vaccination can be found under [eligibility](#).

Understanding the barriers to participation

There are several barriers that may prevent those eligible from engaging with the cervical screening programme. Understanding who is not attending screening and the barriers preventing them from participating is important when looking at ways to support engagement with the programme. The reasons for non-attendance may be complex and several factors may be at play.

Some of these barriers may include:

- Embarrassment
- Intending to go but not getting around to it
- Finding the procedure uncomfortable or fear of pain
- Worry about what the test might find
- Previous negative screening experience
- Finding it difficult to arrange a convenient appointment time
- Perceived low risk of cancer, e.g. not currently sexually active or in a lesbian relationship
- Lack of awareness and knowledge of the purpose and benefits of the test ([Waller et al, 2009](#))

Some groups with lower participation include: ([Chorley et al, 2016](#))

- those aged 25-29 and those above 50
- those living in areas of high deprivation
- those with a learning or physical disability
- Black, Asian, Minority Ethnic (BAME) groups
- lesbian and bisexual women
- the transgender community.

The reasons for non-attendance and certain barriers may be more prominent in some of the above groups. You may be able to identify other people in your practice population who are less likely to participate in cervical screening.

The role of the GP practice in supporting informed participation and reducing barriers to participation

Studies have shown the positive impact that GP and primary care engagement can have on increasing uptake of cancer screening with eligible populations.



You can encourage informed participation in cervical screening by:

- ✓ Making sure people are aware of the programme and that it can help to prevent cervical cancer from developing
- ✓ Asking them if they have taken part, and encouraging them to participate, even if previous results have been normal
- ✓ Informing them about the benefits and the harms of screening, and encouraging them to read the information pack carefully to help them make their decision
- ✓ Ensuring that any barriers to participation are minimised

A normal result does not guarantee the patient not having or developing cervical cancer in the future. Being aware of the [symptoms](#) of cervical cancer is important too.

People may not be engaged in the programme, they might have never attended cervical screening, or they may be overdue their appointment. Some will also make an informed choice not to attend their cervical screening. It's important that all decisions are respected, and no one should feel pressured to participate.

Removing barriers to participation

Below are a range of suggested approaches that your practice could adopt to remove barriers to participation. Some are more involved than others. It is useful to find out what other practices in your area may be doing in case there is an opportunity to work together, or to share good practice.

- ✓ You could consider discussing cervical screening in conversation
 - at routine appointments
 - at health visitor appointments
 - at health checks, immunisation or phlebotomy appointments.
- ✓ Making a proactive telephone call (see [templates](#))
- ✓ Consider sending a targeted letter (see [templates](#))
 - to someone who is overdue an appointment.
 - to someone who has never attended an appointment.
- ✓ Consider sending a targeted text message (see [templates](#)).

The invitation letter templates may allow some space for additional text to be added to provide locally relevant information, such as how to book a screening appointment. Additional text must be clear, factual and of direct relevance to the screening programme.

Engagement approaches

It's vital to consider engagement approaches even after someone has booked their appointment, to ensure other barriers to participation don't come into play. While cervical screening is a familiar procedure for primary care staff, for most people it's not a routine process. Particularly if it's their first test, or first test after a period of non-attendance.

- ✓ Consider different options for reminding patients of their cervical screening appointment:
 - Telephone call
 - Text

For more details see Cancer Research UK's Evidence and Intelligence Hub:
<https://bit.ly/2T3gcov>

Practical tips

Training

- ✓ Providing training to all staff will help them understand and be able to explain the impact of cervical cancer screening, and the benefits and harms of taking part. This will mean they can help patients come to an informed choice about whether or not to take part.
- ✓ Make sure all sample takers are aware of CPD opportunities and programme updates.
 - An e-learning module on primary hrHPV (high risk HPV) testing for sample takers: <https://bit.ly/2EybExy>

Having a good experience during the cervical screening appointment can not only have an effect on general wellbeing, but also on the likelihood of someone taking part in cervical screening in the future.

General practices should ensure that all cervical sample takers are appropriately trained to see the cervix fully when taking a sample. This is essential to ensure that the correct cells are being collected and visible abnormalities of the cervix are identified as early as possible. Should the cervix appear abnormal it might be a good idea to obtain a second opinion from an experienced colleague. Take the sample if it is due and refer immediately to gynaecology. ***Do not wait for the result of the sample prior to referring.***

The Royal College of GPs (RCGP) has published new e-learning content, to give GP and primary care colleagues practical guidance to support patients in understanding and accessing NHS screening programmes (requires registration to gain access) <https://bit.ly/2XmHJjj>

CRUK Facilitators

Contact the CRUK facilitators to see what training they can offer.

Facilitators can offer 15 minutes bite-size training and more in-depth information sessions, depending on your practices' requirements.

CRUK facilitators provide face-to-face, practical support to GP practices to improve cancer outcomes. They can work collaboratively with your practice to help implement some elements of this guide; offering advice, training and useful resources.

The CRUK facilitator programme does not operate in every locality in the UK, however, it does cover most of England and the more urban areas of Scotland, Wales and Northern Ireland. For more information, please contact facilitators@cancer.org.uk

For more information appropriate to your nation, visit:

England: <https://bit.ly/2Ey01Hb>

Wales: <https://bit.ly/2ExaRx6>

Scotland: <https://bit.ly/2Xn3Mq9>

Northern Ireland: <https://bit.ly/2T4MX4Y>

Access to screening

- ✓ Increasing accessibility, for example by arranging screening clinics at the weekend or in evenings, may address barriers to participation for some.
- ✓ Consider working with local sexual health providers to assess provision through these services.
- ✓ Offer patients the opportunity to bring someone (relative/partner) with them to their screening appointment.
- ✓ Offer timed appointments.
- ✓ Some people may prefer a female sample taker, and access to female sample takers.

Information

- ✓ Raise awareness of cervical screening within the practice (posters, opportunistic discussions, practice website).
- ✓ Ensure advice and educational material about cervical cancer and cervical screening are provided in accessible formats. See:
 - Cancer Research UK: <https://bit.ly/2GRwSZz>
 - Jo's Cervical Cancer Trust: <https://bit.ly/2TCIswf>
- ✓ Consider displaying or signposting to this useful video produced by CRUK. It addresses practical issues and potential concerns about the test. You can access the video here: <https://bit.ly/2MC5DFP>
- ✓ There are a few key questions or misunderstandings that can arise around who should take part in cervical screening and it is important that primary care team staff are equipped to provide information to patients—refer to [eligibility](#) section.

Use of practice data

- ✓ Can someone in your practice lead on the call/recall system within the practice?
- ✓ Could you look at data to see how your area is performing? ([Cancer Research UK Local Statistics](#), [Jo's Trust Statistics](#))
- ✓ Review your Prior Notification List (PNL) to ensure that those eligible are invited for screening at the appropriate time.
- ✓ Consider signing up to receive access to the lists electronically.

Note: Before any invitation is issued, GP practices are notified of individuals on their list due for cervical screening through a prior notification list (PNL). This allows the practice to manage any women who do not want or need to be screened.

- ✓ Could you review your practices' non-responders to understand the profile of those not attending their screening and then identify engagement methods to target these?

Non-Responder notifications are sent to practices if there is no record of the person attending for a test after having been sent an invitation and reminder letter.

Not all nations will receive these lists, but you could go into the call/recall system to review the lists.

- ✓ Opportunistically check details at routine appointments to be sure that women are receiving their screening invitations.
- ✓ Apply the correct clinical coding to every screening result and use a flag or alert system to identify non-responders.

Call and recall systems

Understanding the full functionality of the Cervical Call-Recall System can help practices identify where action to support cervical screening may be needed.

Functions of the system:

- ✓ Invite eligible women at appropriate intervals
- ✓ Providing Prior Notification Lists (PNLs) of patients eligible for screening to GP practices.
- ✓ Send out call and recall letters to patients eligible for cervical screening tests.
- ✓ Notifying patients of test results once received these from laboratories.
- ✓ Facilitate failsafe.

For more information on the call/recall system appropriate to your nation, visit:

England: <https://bit.ly/2tDAhCU>

Wales: <https://bit.ly/2tCGTl2>

Scotland: <https://bit.ly/2Ue5lz4>

Northern Ireland: <https://bit.ly/2Nr06z0>

Eligibility

There are a few key questions or misunderstandings that can arise around who should take part in cervical screening and it is important that primary care team staff are equipped to provide information to patients.

'People with a cervix' is the most accurate and inclusive way to refer to those eligible for cervical screening, for more details on specific groups see below:

People younger than 25

We know from research that cervical cancer is very rare in those under the age of 25. Changes in the cervix are quite common in younger women, but these are unlikely to progress to cervical cancer.

Scientists have worked out that screening younger women leads to more harms than benefits, which is why it is offered from age 25 and not 20 (which was the case, most recently in Scotland). This is also the age recommended by the National Screening Committee.

People with a cervix who have never been sexually active

When we talk about being sexually active, we mean:

- having vaginal, anal or oral sex
- touching in the genital area
- sharing sex toys.

People who have never been sexually active will have a much lower risk of HPV infection, and therefore the balance of benefits and harms of cervical screening may be different. It's important to have a conversation with patients about this when discussing cervical screening.

People who have not been sexually active for a long period of time

HPV can remain dormant for many years and cell changes can also take many years to occur. This means that those who have not been sexually active for a period of time still need to go for cervical screening.

People with a cervix aged 65 or older

Those aged 65 or older will not be invited for cervical screening if:

- They have had 3 normal results in a row in England, Scotland and Northern Ireland.
- Their last test was normal in Wales

This is because the likelihood of developing cervical cancer is low.

If they are 65 or older and have had abnormal results, they will be invited for cervical screening until there is no cause for concern.

If they are aged 65 or over and have never had cervical screening, they are entitled to a test. They can speak with their GP surgery about booking an appointment.

People with a cervix who have had hysterectomies

People who have had a hysterectomy but still have their cervix may still be at risk of developing abnormal cells and should still go for regular cervical screenings.

People who have had a partial hysterectomy may still need to attend cervical screening.

The general rule is if you do not have a cervix then you do not need to go for cervical screening.

Lesbian and bisexual women, trans men and/or non-binary people

All people with a cervix between age 25 and 64 should be invited to regular cervical screening, no matter their gender identity or sexual orientation.

Male to female gender reassignment

Following gender reassignment, the individual may be recorded as female on the GP registration system and on all linked NHS national systems including cervical screening. The woman will receive automatic invitations from the call and recall system until the absence of cervix is formally notified to the programme.

Your practice should be sensitive towards trans-women, as it may be distressing for them to be told they are ineligible for the cervical screening programme.

Female to male gender reassignment

Following gender reassignment, the individual may be recorded as male on the GP registration system and will no longer receive invitations from the call and recall service. However, it is not necessarily the case that the individual will have undergone gender reassignment surgery. If the individual has not undergone a hysterectomy which included the removal of the cervix they are still eligible for screening and should be encouraged to participate.

Where the individual chooses to continue to be screened, the GP practice is responsible for managing invitations and sample taking at the appropriate intervals and for notifying results. The practice should notify the cervical screening laboratory that results should be sent back to the practice and not to the call and recall service. When gender reassignment takes place, the call and recall service must send a copy of the individual's screening history to the GP practice in a sealed envelope marked 'Strictly Private and Confidential'.

Your practice should be sensitive towards trans-men, as it may be distressing for them to continue to participate in the cervical screening programme. Sample takers are expected to provide as much support as possible to enable trans-men to be screened if they wish to do so.

HPV vaccination

All girls in their second year of secondary school are routinely invited to get the HPV vaccine between 11 and 13 years of age. The vaccine is designed to protect against two high-risk types of HPV, HPV 16 and 18. Together, these two types cause about 7 out of 10 cervical cancers.

But it doesn't protect against all types of HPV, so regular cervical screening is still important.

There is commitment to also introduce HPV Vaccine for boys in Scotland, England and Wales, which will help provide further protection for girls against the virus by reducing the ability of the virus to spread.

HPV infection

It is important to address the level of misunderstanding that exists around HPV. Eight in 10 women will have some form of HPV infection in their lifetime but only very few who have specific high-risk types of the virus will go on to develop cancer. A survey carried out [shows](#) high levels of fear or shame associated with it. With the screening programme moving to testing for HPV first, it is important to normalise the virus to ensure people fully understand what it means to have it.

Screening abroad

Local areas have reported that women originally from outside of the UK often return to their country of origin for their cervical screening. This can then impact on coverage rates in the UK and if abnormalities are detected, there may be challenges with ensuring optimal patient care if it is across different countries. It may be useful to reassure those who are eligible for cervical screening that the UK runs a high-quality programme and are introducing key technology through the move to use HPV as primary test.

Timing of screening

Avoid routine screening during pregnancy. It is not advisable to sample the cervix until 12 weeks post-natal. Mid cycle is the optimum time to get a good sample. When a woman is menstruating is not the best time to take a sample, but if this is the only opportunity then it can be taken.

Trauma and abuse

Women who have experienced sexual abuse or other sexual trauma such as rape may find it extremely difficult or distressing to participate in the programme. Sample takers are expected to provide as much support as possible to enable these women to be screened if they wish to do so. Each case must be considered individually and any decision to defer screening or be ceased from recall must be made with full informed consent.

Supporting patients to opt out should they wish to do so

It is an individual's choice whether to take part in the cervical screening programme. Should an individual wish to opt out ensure the following good practice around informed dissent is followed:

- Ensure the person has been given the relevant information about screening that explains the benefits and harms.
- Ensure the person is aware of the implications of consent or dissent.
- Ensure the person has the capacity to understand the information that has been provided. Arrange a best interest meeting if the person does not have capacity.
- Ensure the person is aware that their decision to dissent can be changed at any time, as can a decision to consent.
- Informed dissent should be clearly noted in the person's record.

It is vital that the decision to opt out comes from the patient themselves and reflects their wishes

Templates

Example letter



<Insert GP letter-head including GP practice phone number>

Dear *<insert patient name>*

We are writing to remind you that your cervical screening test (smear test) is due.

Cervical screening is a way of preventing cancer by finding and treating early changes in the neck of the womb (cervix). These changes could lead to cancer if left untreated.

Cervical screening saves 2,000 lives each year in the UK. The test takes 5 minutes and is a great way to reduce the risk of cervical cancer. For these reasons, we encourage you to consider booking an appointment to come in for the test.

Whether or not to take part in cervical screening is your choice, so you should read the information leaflet you were sent with your screening invitation to help you decide.

If you have access to the internet, further information about the test can be found here: <https://www.cancerresearchuk.org/about-cancer/cervical-cancer/getting-diagnosed/screening>

You can also contact the practice nurse who can talk to you about the test.

Yours sincerely,

SMS text

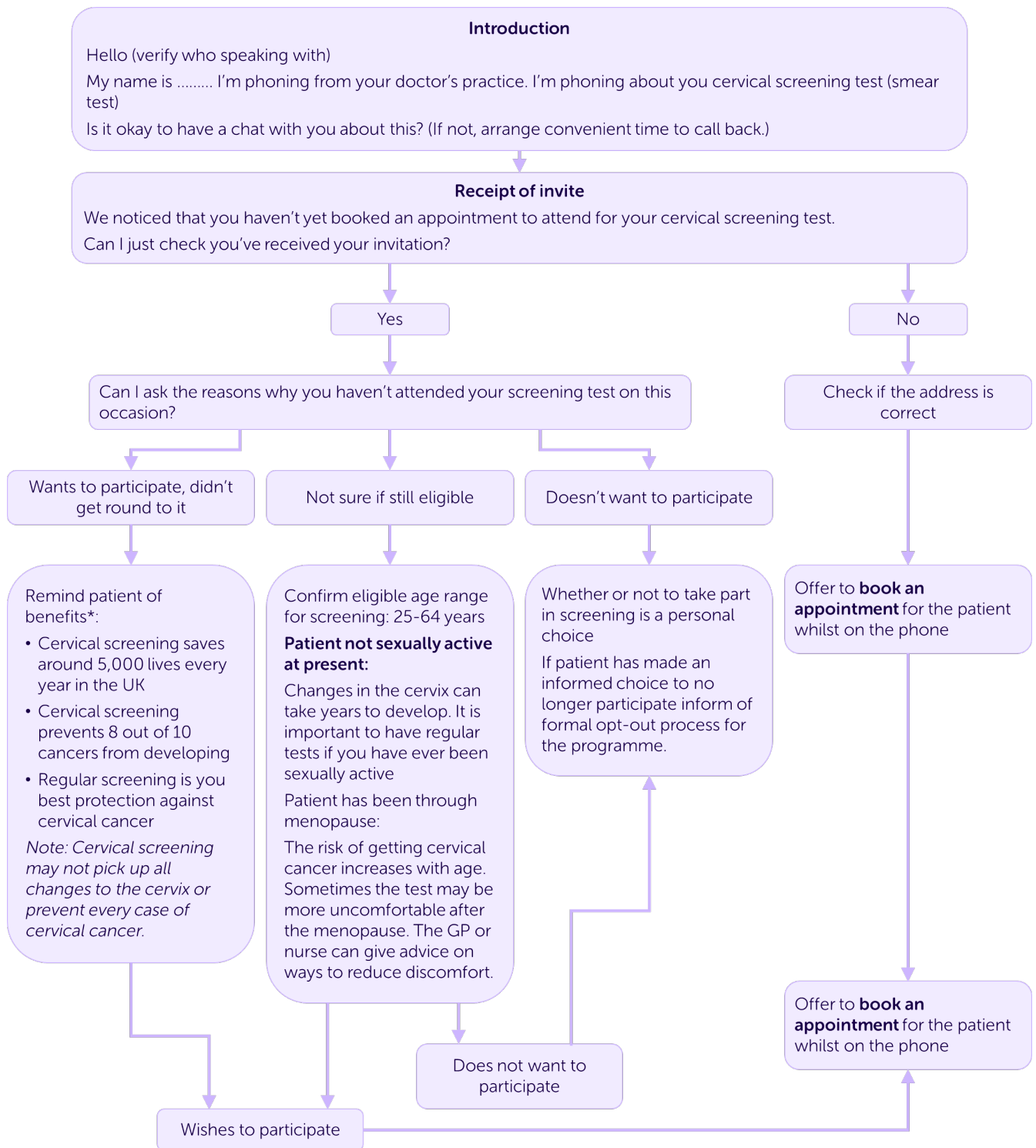
Texts can be used as an alternative to letters for patients. A few practices have used it for engaging non-responders (using it for general promotion of the programme to all eligible patients instead); therefore, it is unclear how effective this method is.



Sample text:

Dear *<Patient Name>*, we are contacting you to remind you that your cervical screening test (smear test) is overdue. Please phone the surgery if you'd like to make an appointment or to discuss any questions or concerns you have about the test.

Telephone script



*Statement of intent

Cancer Research UK is committed to informed choice with respect to screening participation. Screening has both benefits and harms, and these must be communicated appropriately.

Information on the benefits and harms of cervical screening can be found in the [PHE cervical screening leaflet](#) or on the [CRUK website](#).

Safety Netting

Safety netting relates to pro-active management of diagnostic uncertainty in primary care settings. It is a set of steps that can be taken at the consultation and at the practice level to ensure patients are monitored until their symptoms and signs are explained and results acted upon.

Patients with unreported gynaecological symptoms may make enquiries about cervical screening, in part because of a misunderstanding that screening is for patients with symptoms. This could apply to women who fall below (less than 25) or above the age range for cervical screening, as well as women of screening age. It may be useful to ask women if they are experiencing any gynae-related symptoms and advise them to book an appointment with a GP if they are. The most common symptoms of cervical cancer include unusual vaginal bleeding, pain or discomfort during sex, vaginal discharge or pain in the area between hip bones (pelvis).

Discussions with patients about opting in or out of cervical screening needs to include information around common cervical cancer symptoms and on what to do if they develop.

Patients and GPs should be aware that a previous negative cervical screening test result does not rule out cancer in patients who have gynaecological symptoms and that further investigation is needed.

