

Increasing Coverage of Cervical Cancer



A Practical Guide to Cervical Screening in Primary Care

NHS England South (Wessex)

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Part One: Introduction and Overview of the Programme

1. Introduction

In many areas of the UK, cancer remains the single largest cause of premature death. Late stage diagnosis of cancer diagnosis results in poorer survival rates, worse patient experience and significantly increases costs. Cancer screening offers the best opportunity to diagnose more cancers earlier and to improve outcomes for patients by treating cancer sooner.

Cervical screening aims to reduce the numbers of deaths from cervical cancer by:

- ✓ finding and treating precancerous cell changes, thereby preventing cervical cancer
- ✓ identifying the very early signs of cervical cancer, leading to a greater chance of survival and less aggressive treatment.

Patients diagnosed through screening usually have early stage disease, and five year survival for these patients is 93% compared to less than 10% at stage four disease.

Overall coverage of cervical cancer screening across Wessex is higher than the national average. However, there is wide variation between, and within, CCGs. Our deprived urban communities have particularly low rates of coverage. Moreover, in common with the rest of the country, cervical screening coverage has been decreasing steadily over a number of years. Uptake amongst younger women is particularly low.

Evidence shows that simple interventions delivered through primary care have a significant impact on improving participation in screening, and can overcome some of the barriers and inequalities experienced by different groups. There is also evidence that the quality of experience is key to ensuring that women return for screening at regular intervals.

This guide is aimed at all members of the practice team involved in the cervical screening process. Drawing together practical information and tips from a range of sources, it aims to help GP practices identify actions that will result in improved screening uptake, including amongst those who often find services hard to reach.

The guide is not exhaustive, nor is it intended to replace or duplicate national guidance. It should be read in conjunction with national guidance available on

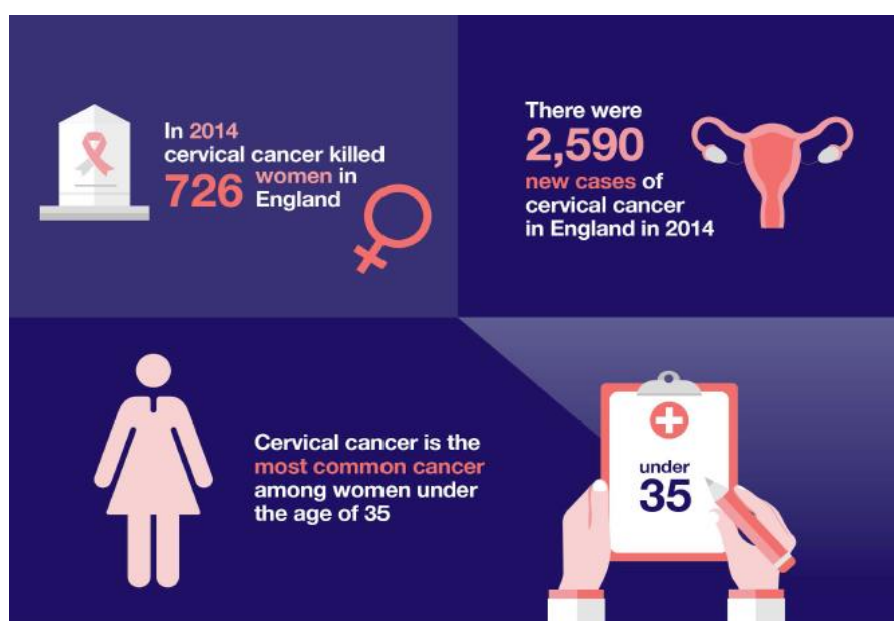
<https://www.gov.uk/topic/population-screening-programmes/cervical>

Further resources and official guidance are signposted throughout the document and summarised in Part 3 for ease of reference.

2. Cervical Cancer and the NHS Cervical Screening Programme: the Basics

Key Statistics

- ✓ Cancer of the cervix is the second most common cancer among women worldwide
- ✓ Cervical cancer is the twelfth most common cause of cancer deaths in women in the UK, accounting for about 2% of all cancers in women in the UK
- ✓ Over 3200 women were diagnosed with cervical cancer in 2013 in the UK
- ✓ Over three-quarters (78%) of cervical cancer cases were diagnosed in 25 to 64 year olds in the UK between 2010 and 2012
- ✓ Deaths from cervical cancer have fallen in England by over 70% since the early 1970s, with the lowest number (721) recorded in 2013
- ✓ 83% of women survive cervical cancer for at least one year
- ✓ 67% of women diagnosed with cervical cancer during 2010-2011 in England and Wales survived for five years
- ✓ It is estimated that cervical screening saves approximately 4500 lives per year in England
- ✓ Incidence of cervical cancer in the UK decreased by nearly half between the late 1980s, when the programme was introduced, and the early 2000s (from 16.2 to 8.7 per 100,000 female population), and mortality rates reduced by almost two-thirds (from 6.4 to 2.1 per 100,000)
- ✓ This reduction has slowed in recent years and, in the last decade; incidence has risen by 4%, mainly in younger women, coinciding with a slow decline in screening coverage. Incidence is projected to rise by 43% between 2014 and 2035



History of the Screening Programme

Mid 1960s	Cervical screening begins
1988	Establishment of the national programme with the introduction of computerised call/recall systems
2004	Introduction of Liquid-based Cytology (LBC) which significantly reduced the amount of inadequate cervical screening results
2008	England started offering HPV vaccination to all girls aged 12 to 13 to protect against cervical cancer
2012	Introduction of HPV triage and test of cure
2019	HPV as the primary test to be introduced

At its peak, the screening programme exceeded the national coverage target of 80%. However, in the last decade, cervical screening coverage has declined steadily. In March 2016, 72.7% of women were recorded as having been screened adequately in England, compared to 73.5% in March 2015 and 75.7% in March 2014. Rates in younger women are much lower than in the higher age group.



Screening in Wessex

By December 2016, cervical screening coverage in Wessex was 73.5%, with a range at CCG level of 68% to 76%. Practice level coverage (excluding practices serving specific populations) ranged from 48% to 88%.

3. Aim of the NHS Cervical Screening Programme (NHSCSP)

- ✓ The aim of the NHSCSP is to reduce the number of people who develop invasive cervical cancer and the number of people who die from it.
- ✓ It does this by offering regular screening to eligible people to identify and treat conditions which might otherwise develop into invasive cancer.

4. Eligibility and Recommended Screening Intervals

- ✓ Cervical screening is offered every three years in women aged 25-49 and every five years in women aged 50-64 as shown in the table below

Age group (years)	Frequency of screening
24.5	First invitation*
25 to 49	Three-yearly
50 to 64	Five-yearly
65+	Invitation as required for women who have had recent abnormal tests. Women who have not had an adequate screening test reported since age 50 may be screened on request.

*Note: women are invited 6 weeks before they reach 24.5 years of age but should not be screened until they are at least 24 years and 6 months

Women who are not sexually active

- ✓ If a woman has never been sexually active, research evidence shows that their chance of developing cervical cancer is very low. This is not 'no risk', only very low risk. In these circumstances, an individual might choose to decline the invitation for cervical screening.
- ✓ For women who are not currently sexually active but have had sexual partners in the past, it is recommended that they continue to attend for screening.

Lesbian and Bisexual women

- ✓ Historically lesbian women have been advised by health workers or other lesbians that they do not need screening as they do not have sex with men. Between 3% and 30% of lesbians are infected with HPV, which can lead to cervical cancer, so they are at risk.
- ✓ Regardless of sexual orientation, women should be offered screening.

Transgender

- ✓ Transgender men are eligible for, and entitled to, screening, if they still have a cervix.
- ✓ Transgender men registered as male will not receive an invitation but may arrange an appointment with their GP practice every three to five years (depending on their age).
- ✓ Transgender women registered as female will receive automatic screening invitations, until they are ceased by their GP.

Non-NHS cervical screening tests

- ✓ Tests carried out privately or abroad do not affect a woman's entitlement to NHS screening.
- ✓ The NHS has no responsibility for the quality of non-NHS tests, although the results may be recorded on an individual's NHS screening record to complete their screening history.

Women moving into England from other areas of the UK

- ✓ The age range applies to women resident in England, and differs from some of the other UK countries, which commence at age 20.
- ✓ For women under 25 who have already had a sample and move into England from the other countries with a negative history, their next test due date will be adjusted to 24.5 years.

Immunosuppressed women

- ✓ Women on immunosuppressing medication, transplant recipients and all other forms of immunosuppression should be screened and managed in line with the Colposcopy and Programme Management guidelines dependant on their condition.

HIV positive women

- ✓ All women newly diagnosed with HIV should have cervical surveillance performed by, or in conjunction with, the medical team managing the HIV infection.

Unscheduled screening tests

- ✓ If an eligible woman has had a test within the previous routine screening interval (three to five years), additional tests should not be carried out.
- ✓ Unscheduled samples will not be accepted by the laboratory.
- ✓ The sample taker should explore the reason/s for the individual requesting screening

For information/guidance on ceasing women from the programme see Appendices 3 and 4

5. Changes to the Programme: Introduction of HPV as Primary HPV Testing in Cervical Screening

- ✓ Human papillomavirus (HPV) is a common virus transmitted through sexual contact. High risk sub-types of HPV (HR-HPV) are linked to the development of abnormal cells and can cause cervical cancer. HPV is a necessary cause of invasive cervical cancer.
- ✓ Evidence shows HPV testing is a better way of identifying women at risk of cervical cancer than the cytology (smear) test that examines cells under a microscope.
- ✓ Last year, the UK NSC (UKNSC) recommended that the HPV test should replace cytology as the first (primary) test in cervical screening.

Benefits of primary HPV testing

- ✓ Primary HR-HPV testing has higher sensitivity than primary cytology. This means using primary HR-HPV testing to screen women will identify more women at risk of developing cervical cancer and will save more lives by determining a woman's risk earlier.
- ✓ HR-HPV testing also has a lower false negative rate than cytology. This means women may not need to come for screening as often in the future. The UKNSC is currently considering the evidence for a possible extension of screening intervals.
- ✓ Younger women vaccinated against HPV types 16/18 are beginning to enter the screening programme. Primary HR-HPV testing is more appropriate for vaccinated women because the incidence of Cervical Intra-epithelial Neoplasia (CIN - abnormal cells found on the surface of the cervix) will be lower. Cytology will be reserved for women considered to be at higher risk who test HR-HPV positive.
- ✓ If HPV testing finds that a woman does not have high risk HPV then her chances of developing a cancer within 5 years are very small.

Implementation plan

- ✓ Primary HR-HPV testing will be fully implemented in late 2019. Six pilot sites in England are already using primary HR-HPV testing. Some of these sites are extending the amount of primary HR-HPV testing they are doing.

Implications for primary care

- ✓ Cervical screening/sample taking will continue to be carried out in primary care settings. HR-HPV testing is performed on liquid based cytology samples, so there will be no change to the way samples are taken.
- ✓ There are new protocols for the management and follow-up of women according to the test results and any subsequent cytology performed.
- ✓ Sample takers play an important role in providing information to women and will need to complete training before primary HR-HPV testing starts.
- ✓ Implementation of primary HR-HPV testing will coincide with centralisation of screening laboratory services. This means cervical screening samples may be sent to a different laboratory in future but providers of local colposcopy services will not change.

Further information and the pathway <https://phescreening.blog.gov.uk/2017/06/14/what-gps-need-to-know-about-the-introduction-of-primary-hpv-testing-in-cervical-screening/>

6. Organisation of the NHS Cervical Screening Programme

NHS screening programmes are overseen by a national structure which ensures that they operate to consistent, evidence-based standards and pathways.

This section of the guide describes how all NHS screening programmes are developed, overseen and delivered at national and local level. It then describes how the cervical screening programme is organised at local level.

National

- ✓ **The National Screening Committee (NSC)** is an independent committee which makes recommendations on all aspects of population screening programmes, using internationally recognised criteria and a rigorous evidence review process.
- ✓ **The Department of Health (DH)** has ultimate strategic oversight of policy and finance for the national screening programmes, and holds the other key delivery organisations (NHS England and Public Health England) to account.
- ✓ **Public Health England (PHE)** is an executive agency sponsored by the DH. Its national screening team provides advice to the DH, based on NSC recommendations, on screening policy, direction and implementation. It leads on the development of screening service specifications and standards, oversees the Screening Quality Assurance Service and assesses the long term impact and outcomes of screening. PHE also pilots and evaluates extensions changes to screening programmes, both existing and new.
- ✓ **NHS England.** Under section 7A of the NHS Act, the Department of Health delegates the commissioning of screening programmes (along with national immunisation programmes and Child Health Information Services) to NHS England. NHS England discharges its responsibility through its national, regional teams and 13 local office teams. Local teams are responsible for the delivery of high quality screening and immunisation programmes to local populations. Their role is to maximise uptake of the programmes and to implement agreed national changes to programmes safely, sustainably and promptly. They are held to account by, and provide assurance to, the DH via the national team.

Regional and Local

- ✓ **NHS England (South) Wessex - Public Health Commissioning Team (PHCT)**
 - serves the populations of Hampshire, Isle of Wight and Dorset. The team is an integrated team consisting of public health specialists (the **Screening and Immunisation Team**) and commissioners/contract managers. Collectively, the team is responsible for commissioning high quality cancer screening programmes for the Wessex population, securing value for money. It manages the performance of providers to ensure compliance with national specifications, consistent achievement of programme standards, and continuous improvement in quality/outcomes. It also leads the implementation of nationally agreed changes and developments at local level

- the **Screening and Immunisation Team (SIT)** is led by a Consultant in Public Health - Screening and Immunisation Lead (SIL) and provides specialist advice to NHS England as well as system leadership for the programmes. In addition to the responsibilities above, the SIT leads on:
 - ensuring the integrity of screening pathways
 - taking concerted action, with partners, to improve coverage levels and address inequalities
 - provision of advice and guidance to primary care and other partners about the programmes
 - oversight and management of screening and immunisation serious incidents

- ✓ **PHE Screening Quality Assurance Service (SQAS)** advises the NHS England Screening and Immunisation Team on quality issues affecting its programmes and keeps both commissioners and providers up to date on programme developments. It monitors quality standards through routine data sources and by undertaking peer review visits. It also supports the SIT and providers in the management of screening safety and serious incidents, ensuring learning is widely shared. It assesses the performance of the screening test through established QA procedures.

- ✓ **CCGs** have a general duty of quality improvement, which extends to primary medical care services delivered by GP practices, including screening and immunisations. As commissioners of treatment services that receive screen positive patients, CCGs have a role in commissioning pathways of care that effectively interface with screening services, have capacity to treat screen positive patients and meet quality standards.

- ✓ **Acute and community NHS Trusts / providers** of screening programmes are responsible for ensuring delivery of the programmes in accordance with national standards, working across organisational boundaries to ensure the integrity of pathways.

- ✓ **GP practices.** The registered list is the basis for the call and recall for most screening programmes. As well as delivering cervical screening under their contract, interventions delivered through primary care can improve participation in all screening programmes, overcoming some of the barriers experienced by different groups.

- ✓ **Strategic Clinical Network (SCNs) and Cancer Alliance (Wessex)** focus on improving health outcomes in priority service areas, including cancer. They bring together professional groups and organisations to co-ordinate improvement action across complex pathways. Cancer Alliances are working groups of all those who need to be involved to take action to improve cancer outcomes. Improving coverage of cancer screening is one of the priorities of the SCN and the two cancer alliances in Dorset and HIOW

- ✓ **Other local partners** The Screening and Immunisation Team works closely with other local and national partners such as local authority public health leads; Wessex Voices; voluntary sector, cancer charities, with a view to increasing coverage of the cancer screening programmes.

Local Organisation of the Cervical Screening Programme

This section outlines some of the core activities and responsibilities within the cervical screening programme at local level.

Call/recall

- ✓ A fundamental principle of any screening programme is to ensure that all individuals who are eligible for screening receive appropriate invitations to participate in a timely manner.
- ✓ The call and recall system is operated by **Primary Care Support England (PCSE)** and:
 - generates Prior Notification Lists (PNLs), using the NHAIS (Open Exeter) system, of women who are due to be invited for cervical screening
 - sends invitation letters and reminder letters to women due for screening
 - records test results on a woman's screening history
 - notifies women of test results received from laboratories
- ✓ The first invitation is sent around 6 weeks before the test is due.
- ✓ Reminder letters are sent around 18 weeks after the first invitation letter and approximately 14 weeks after reminder letter, where no test has been received
- ✓ There may be a delay of several months between sending the invitation and a woman attending for her screening test. Sending invitations well before test due dates reduces possible delays

General practice

- ✓ Cervical Screening is an additional service under the GMS/PMS contract, funded as part of the global sum. GP practices and their staff are responsible for:
 - ensuring all staff are appropriately trained to carry out their responsibilities in line with national standards and guidance
 - making adequate arrangements and reasonable adjustments to enable patients to access cervical screening
 - ensuring that women have the necessary information to make an informed choice
 - operating failsafe arrangements to ensure women have had their results and are followed up and referred appropriately for further investigation and treatment
 - ensuring adequate referral processes are in place so women who require further investigation and treatment are managed appropriately
 - working to improve the uptake and coverage of the cervical screening programme
 - ensuring adverse events and incidents are recorded, reported and investigated
- ✓ Each practice or clinic where cervical samples are taken should have access to copies of screening protocols based on the national guidance for the cervical screening programme.

Sample taker specific responsibilities

- ✓ The sample taker plays a crucial role in the individual's experience: a positive experience is a key factor in a woman's decision to re-attend at the next invitation. Sample takers must:
 - follow all national and local guidelines for sample taking

- maintain competency and monitor their own practice by regular auditing of samples
- keep up-to-date with changes in the programme and current best practice
- ensure that women have the necessary information to make an informed choice
- take the sample in an appropriate manner, making adjustments for individuals as required
- ensure the woman is informed of her test result
- ensure that the test result is followed up appropriately
- communicate with the woman if her sample is rejected and advise when another sample should be taken
- ensure referrals take place for woman who require further investigation/ treatment
- cooperate with failsafe enquiries in a timely manner

Cytology laboratories

- ✓ screen cervical samples and perform HPV testing on eligible women when the samples are accompanied by an adequately completed test request form or electronic request
- ✓ notify test results and recommendations for management to the call and recall system
- ✓ inform the GP/sample taker if a woman requires urgent referral for colposcopy
- ✓ operate a laboratory failsafe system for women who require further investigation or treatment

Colposcopy clinics

- ✓ investigate and treat women with abnormal test results
- ✓ provide follow-up after treatment or discharge women back to routine recall
- ✓ cooperate with laboratory failsafe enquiries
- ✓ may take cervical samples from women referred because their cervix is difficult to visualise

Hospital-based programme co-ordinators

- ✓ may be based in a cytology or histology laboratory or in a colposcopy clinic and are responsible for:
- ✓ ensuring that systems are in place for transferring test results from the laboratory to the call and recall system
- ✓ collating histology results with cytology test results
- ✓ ensuring that laboratory failsafe measures are initiated if necessary
- ✓ taking a lead role in the audit of invasive cervical cancers

CASH/GUM Services

- ✓ From 2013, these services have been commissioned by local authority public health teams. While women are still offered the option in the invitation letter to attend their local sexual health clinic for cervical screening, many clinics no longer provide routine cervical screening and will signpost women back to their local GP. Some may offer opportunistic screening for high risk women who may not otherwise attend their GP practice. HIV positive women, who are excluded from the routine programme

For further information on the organisation of the screening programme and current guidance

<https://www.gov.uk/government/collections/cervical-screening-professional-guidance>

<https://www.gov.uk/government/publications/cervical-screening-good-practice-in-cervical-sample-taking>

Part Two: Maximising Screening Coverage

1. The individual's perspective: influences on uptake

- ✓ There are many factors that determine whether women will attend for cervical screening:
 - education, knowledge and health literacy – perception of the relevance of screening and the importance of prevention, knowledge of risk and about the role of screening in preventing cancer. Knowledge is lower in those women who have never attended. Some women give low priority to their health needs and may need regular, repeated encouragement to attend for screening and advice
 - accessibility – finding time to attend, ability to get an appointment at a time that is convenient. Some women may not be entitled to have time off for appointments
 - fear - of the test being painful, a previous bad experience of screening, a personal trauma such as traumatic birth, history of sexual assault or rape
 - embarrassment
 - pain – pain or discomfort during the test is one reason that women do not re-attend. This is particularly important for post-menopausal women
 - cultural beliefs and social influences – perceived relevance according to marital status or sexual activity, fear the sample taker may be male. Friends, family and community attitudes and social pressure influence whether women will attend, particularly in some communities. Older family members in particular may hold false beliefs about screening
- ✓ Encouragement and endorsement by primary care practice staff, particularly GPs, is effective in improving participation in cancer screening programmes
- ✓ Providing a positive experience involves:
 - offering convenient access
 - respecting the woman's privacy
 - putting her at ease
 - giving correct information and ensuring women know what to expect
 - providing a dignified and comfortable experience, tailored to meet individual needs
 - addressing cultural beliefs and barriers
 - getting the process right first time (adequate sample, properly labelled)
 - discussing abnormal results and possible treatment options knowledgeably and sensitively
 - making sure any follow up happens smoothly

Further information on People's Experiences and Barriers to Attending Screening

Jo's Cervical Cancer Trust

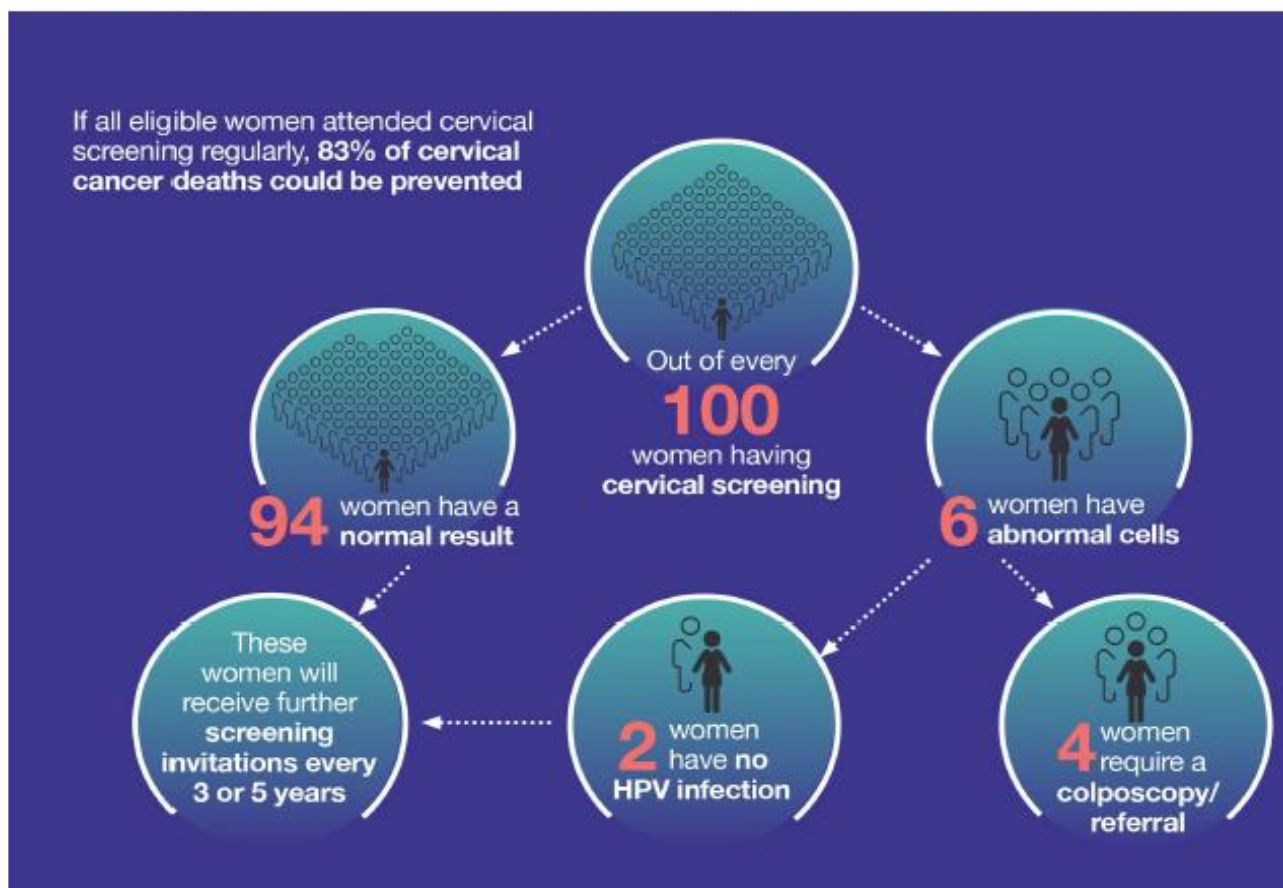
<https://www.iostrust.org.uk/information-healthcare-professionals/information-practice-nurses-and-gps/barriers-attending>

Jo's Cervical Cancer Trust online forum: <https://www.iostrust.org.uk/>

2. A Systematic Approach to Maximising Coverage

A. Role of Practice Cancer Screening Lead

- ✓ Designate a **Practice Cancer Screening Lead** to oversee and steer cervical screening and ensure that:
 - ✓ protocols and processes which follow national guidance are in place to ensure a systematic approach throughout the practice
 - ✓ all staff, including non-clinical staff
 - know the importance of cancer screening and how the programme works locally
 - can give correct information
 - are confident in opening a conversation about cervical screening
 - ✓ sample takers are properly trained and training is current
 - ✓ the quality of service is kept under review to ensure convenient access and a positive experience
 - ✓ sample taker inadequacy rates are monitored and staff supported to improve where necessary
 - ✓ each cervical sample taken has an associated result, coded properly on the clinical record. There is a robust failsafe in place
 - ✓ practice coverage and exception rates are monitored closely and action taken to improve
 - ✓ screening participation is routinely endorsed by the practice through letters, phone and face-to-face contact
 - ✓ there is proactive management of non-responders: patient notes are flagged when screening is due and when non-responders are reported
 - ✓ promotion of cancer screening takes place within the practice on an on-going basis
 - ✓ activities/materials are tailored and adaptations made to encourage people from population groups with low uptake e.g. people with learning disabilities, from ethnic minority backgrounds etc
 - ✓ patient removals from the programme are managed in accordance with national guidance i.e. women are invited to discuss this with a GP
 - ✓ incidents are reported and investigated and learning shared within the practice and with the NHS England Wessex Screening and Immunisation Team



B. Practice List Maintenance

- ✓ Ensure the practice list is accurate with correct/current address and telephone numbers by checking each time a patient attends or books an appointment
- ✓ “Ghost” patients will negatively affect the practice’s reported coverage rate
- ✓ When carrying out a new patient check on a woman in the eligible age range, ask her when she last participated in cervical screening. Check her cervical screening status on Open Exeter: if this is available and her screening is due or overdue, highlight this while she is with you, and offer to book an appointment for her there and then
- ✓ If her details are not available, advise her that she will be invited for screening when due and encourage her to attend. Add a reminder on her patient record prompting other staff to discuss screening with her

C. Prior Notification Lists (PNLs)

- ✓ This is the list of patients who are due for cervical screening sent by the Primary Care Support England (PCSE) to GP practices before women are sent their invitations
- ✓ The PNL is extracted from Open Exeter, the national patient database which ensures that the right women are invited for cervical screening at the right time

- ✓ A named lead at the GP practice receives the PNL in advance of the due date so that GPs know who is due to be screened
- ✓ The PNL extracted by the programme is only as good as information input by GP practices, including how accurate/up to date it is in terms of patient registrations, contact details, medical history, exceptions, etc.
- ✓ The Practice Cancer Screening Lead should ensure that staff check the PNL against their practice list for up-to-date patient contact details and identify any females who match the exclusion criteria.
- ✓ Following screening, GPs receive copies of the result letter sent to patients – see G. Managing Results and Failsafe.

For access to Open Exeter

<https://www.openexeter.nhs.uk/nhsia/genhelp/links.jsp>

Offer women flexible appointment times, extended hours to help increase screening uptake



D. Appointments

- ✓ When setting up and offering appointments for cervical screening:
 - offer choice and ensure women can book well in advance (at least 6 weeks and ideally 2 months)
 - consider if appointments times are appropriate and sufficiently flexible. Offer 'extended hours' appointments
 - offer early morning appointments as well as some evenings and weekends: many women prefer to attend early in the day for hygiene reasons
 - offer the opportunity to book on line as well as by phone or in person
- ✓ Take into account needs of different women (e.g. collecting children from school; working hours etc.)
- ✓ Consider whether you could offer 'two for the price of one' appointments e.g. mothers with small children attending for childhood immunisations; older women attending for a long term condition or health check
- ✓ Remind women of their appointment e.g. by text/SMS message
- ✓ Ensure practice staffs are aware that a woman can book at any time during her cycle for cervical screening, except when she has menstrual bleeding. If a woman has had her menopause, she will still need to attend regular cervical screening appointments until she becomes 65.
- ✓ Ensure that women, particularly those from specific communities/population groups, are aware that the sample may be taken by a female doctor or nurse and that they can have a chaperone - see Section I)

E. Test Request Form (HRM101)

- ✓ Sample takers are responsible for correct completion of the sample test request form. This is vital to avoid anxiety and distress for patients, who have to be recalled, and wasted NHS resources
- ✓ Incorrect completion of forms is the biggest reason for rejection of samples
- ✓ Use Open Exeter prepopulated HMR101 forms
- ✓ Do not batch print
- ✓ Print and complete the form in front of the patient along with the sample, checking the patient's identity using 3 points of identification (e.g. name, address, date of birth) to ensure that the right result goes to the right patient.
- ✓ Always include the correct sample taker code: this helps maintain the quality of the programme as it enables audit of sample taking and the identification of training needs

F. Positive Experience of the Procedure

- ✓ The quality of the sample taking experience is a key determinant in women re-attending
- ✓ Only take a sample if you have been properly trained, are up to date with your skills and knowledge and have a valid code
- ✓ Ensure that the environment is appropriate:
 - private and relaxed, screened for privacy
 - where possible, offer a room with a lockable door - this may enable women from some cultures to attend in the knowledge of complete privacy
- ✓ Provide sufficient time, normally a 20 minute appointment
- ✓ Ensure you have appropriate equipment to maximise privacy, dignity and comfort, including a range of different sized speculae, lubricant, disposable modesty sheets, tissues etc.
- ✓ Offer all women the opportunity to have a chaperone, irrespective of sample taker's gender
- ✓ Explain the purpose of screening what will happen at each step of the procedure. Women, especially those attending for the first time, may need a more detailed explanation especially of the speculum and sampling device. Give time for questions.
- ✓ Ensure that the woman has received the Cervical Screening leaflet and understood the procedure
- ✓ Obtain informed consent including discussion about HPV testing before taking the sample
- ✓ Allow women time and privacy to remove their lower clothes, get onto the couch and cover themselves before the sample is taken.
- ✓ During the procedure, explain what you are doing and what to expect.

Further information on taking samples

<https://www.gov.uk/government/publications/cervical-screening-good-practice-in-cervical-sample-taking>

<https://www.rcn.org.uk/professional-development/publications/pub-003105>

G. Managing Results and Failsafe

- ✓ All results should be processed within 14 days of the sample being taken. Advise women that if they have not received their results within 4 weeks, they should contact the practice ¹
- ✓ Results are sent to the practice electronically from the laboratory, which also informs PCSE
- ✓ PCSE sends the results to the woman. Women who need to attend for colposcopy will be notified by PCSE but will also be sent an appointment directly by the colposcopy department
- ✓ The practice should have a clear protocol for dealing with rejected sample and patient recall
- ✓ Each sample taker within the practice is responsible for providing a failsafe by:
 - maintaining a list of the samples they have taken
 - recording results on the list and any follow up required
 - checking the list regularly and ensuring that a result has been received from the laboratory for each sample taken: follow up missing results
 - checking that women have attended for follow up appointments as required; following up on any women who have not responded or attended follow up appointments
 - ensuring that arrangements are made for women who fall outside the call/recall system (e.g. temporary residents, those with no home address or those requesting 'no correspondence') receive their results
 - ensuring that the taking of the sample and the results are entered onto the woman's electronic record and appropriately coded
- ✓ Record the taking of the sample and the results on the woman's electronic record and code appropriately – see [Appendix 1: Read Codes](#)
- ✓ Give women test results in person when urgent referral is required
- ✓ Have a process in place to act on non-responder notifications for women who
 - have not responded to invitations for an early repeat test
 - have not attended for colposcopy
- ✓ Respond to failsafe enquiries by laboratories

¹ Note: laboratories have 10 days to process results. Sample takers should be aware that laboratories may be affected by workforce issues during the transition to HPV as the primary test, affecting their ability to meet this standard.

H. General Actions to Encourage Screening Awareness and Uptake

- ✓ Remember that some women may need regular encouragement to attend for screening and advice
- ✓ Encouragement and endorsement by primary care practice staff, particularly GPs, is effective in improving participation in cancer screening programmes
- ✓ Take a systematic approach to maximise cancer screening uptake by:
 - encouraging all staff to be opportunistic and pro-active in encouraging screening
 - sending endorsement letters to patients signed by their named GP
 - adding reminders/messages on repeat prescription slips
 - involving the practice in national screening and cancer awareness campaigns e.g. Be Clear on Cancer, Cervical Cancer Awareness Weeks
 - running targeted initiatives to prioritise new invitees who missed their appointments and the “never screened”
 - sending out text reminders to minimise DNAs
- ✓ Actively manage non-responders:
 - undertake regular searches (at least quarterly) to identify non-responders
 - add electronic alerts on patient records for DNAs/non-response, enabling ALL practice staff to encourage screening participation whenever women contact the practice
 - ensure that the issue is raised at the next appropriate visit to the practice and the woman is fully informed of the benefits of regular screening
 - send a personalised non-responder invitation signed by the woman’s named GP
 - consider sending a timed appointment with this third invitation letter, giving the woman the opportunity to rearrange if she cannot make it
- ✓ Use a different colour paper (e.g. pink) to make reminder, endorsement and non-responder letters stand out
- ✓ Bear in mind that younger women may prefer communication via text/SMS
- ✓ Ask patients for feedback on what prompts them to, or stops them from, attending to inform your action plan
- ✓ Have visible cues about cancer screening such as messages on electronic display screens, posters and leaflets in easy to read locations such as notice boards, waiting rooms, practice website etc. Use the cues to reinforce:
 - benefits of screening, early detection
 - options available to clients such as changing cervical screening appointments
 - availability of information in other languages, role of female staff etc.
- ✓ Consider a surgery campaign
 - St Mary’s Surgery, Southampton, ran “In the Pink” for a month
 - balloons, posters, defined time period. NHS England can support you with promotional materials

- weekly texts, extra on-the-day appointments
- Social media targeted at the under 35 age group. Assets are available from NHS England and from Jo's Trust who run awareness weeks in January and June each year
- Use local radio and newspapers to support. Template news releases are available from NHS England

For an Easy read poster for use in general practice. Materials can be downloaded from the NHS England website



Cervical screening saves lives.



Women 25 and over need to be checked for changes down below.



Some changes can become cancer. This cancer is called cervical cancer.



Cervical cancer can be prevented if the changes are found early enough.



Take a friend, family member or carer with you to the test for support.

Attend when invited.

I. Promoting Uptake in Key Groups

Women with Disabilities

- ✓ Disabled women have the same rights of access to screening as all other women. NEVER exclude anyone automatically from the screening programme on the grounds of physical or learning disability
- ✓ Do not make assumptions about individuals; just because someone has a disability, do not make judgments about what they can and cannot do
- ✓ Do not assume that disabled women are sexually inactive and therefore do not require screening
- ✓ Work with support workers and LD teams to promote cervical screening
- ✓ Wherever possible, provide women with disabilities with access to information to enable them to make their own decisions about whether to participate
- ✓ Make 'reasonable adjustments' to support access. Examples of practice level support for women with disabilities may include:
 - identifying patients who may have communication difficulties
 - asking people and/or their carers about their needs and preferences in advance of screening and doing the utmost to meet those needs
 - offering face-to-face communication to explain the benefits of screening
 - using pictorial guides designed to support people with learning disabilities
 - familiarising them with the cervical screening room and equipment – this could involve inviting them in for a preliminary visit
 - booking longer appointments to give them time to relax and become familiar with their surroundings and the sample taker
 - consider physical access to the practice premises, height of couch, and the need for assistance for women with physical disabilities.
 - for severely disabled or paraplegic women, consider making special arrangements, e.g. with the local colposcopy service, or at a clinic where a hoist is available
 - using braille/large print for people with visual impairments
- ✓ For women with a learning disability, the issue of consent is vital. Further information on consent and best interests decisions is available at Appendices 3 and 4
- ✓ At the appointment, check for behavioural signs of compliance with the procedure
- ✓ An 'Easy Read' leaflet is available which has been designed to be used by women with learning disabilities alongside family members or carers. The leaflet is intended to help them to make their own decisions about cervical screening, and to prepare them for the screening process. The leaflet can be accessed at:

<https://www.gov.uk/government/publications/cervical-screening-easy-read-guide>

Prioritise increasing cervical screening coverage and raise awareness of cervical screening particularly among hard to reach groups



Black and Minority Ethnic Communities

- ✓ Ensure visual cues/promotional materials in the practice promote
 - availability of information in other languages
 - availability of female staff to be involved in screening
- ✓ Use pictorial/visual invitations in letters or as a method of communication
- ✓ Ensure that the service is culturally sensitive and that a female staff member is available and trained to offer information and guidance where language barriers exist
- ✓ Be aware of cultural barriers to intimate examinations. Depending on culture, consider:
 - ensuring that women (and their menfolk) are aware that the sample may be taken by a female doctor or nurse and that they can have a chaperone
 - that their sample can be taken in a lockable room so there is no danger of anyone else entering
- ✓ Consider timing of appointments, ensuring they do not coincide with e.g. Friday prayers
- ✓ Consider how you will access interpretation services if required
- ✓ Ensure translated leaflets are available. These can be downloaded from <http://webarchive.nationalarchives.gov.uk/20150506220008/http://www.cancerscreening.nhs.uk/cervical/publications/the-facts-other-languages.html>
- ✓ Send GP endorsement letters in the patient's first language wherever possible

Lesbian/gay women

- ✓ Ensure that all staff are promoting cervical screening with lesbian women and are aware that it is necessary
- ✓ Train staff in communication and the use of non hetero-normative questioning

Transgender

- ✓ The main issue for people within the transgender group is fear of negative attitudes from staff
- ✓ Ensure that all staff have adequate training
- ✓ It is also important to make sure that staff use the right pronoun when talking to an individual. If in doubt, ask the individual how they prefer to be addressed
- ✓ Cease transgender women (male to female) from the programme so that they do not receive invitations

- ✓ Set up reminders/flags/ searches for transgender men who still have a cervix to ensure they are invited at appropriate intervals – they remain entitled to screening but will not be invited by the call/recall service
- ✓ Ensure that the laboratory is aware so that they process the sample and return the results to the practice

Gypsies and Travellers

- ✓ Gypsies and Travellers may fear hostility or prejudice from healthcare staff because of lack knowledge about their beliefs and culture.
- ✓ The Travelling and Gypsy community rely heavily upon word of mouth communication. A single negative screening experience could alienate the whole local community. It is vital that staff treat the Travelling and Gypsy community with respect.
- ✓ Offer basic training for receptionists and healthcare staff in Traveller and Gypsy culture
- ✓ Levels of literacy are typically lower than average in the Travelling community. Use communication material which is largely pictorial or aimed at a reading age of around 10 years
- ✓ The Gypsy and Travelling community have set views on gender roles and may not allow women to attend for screening if they believe a male member of staff will be involved. Ensure that female staff are available to perform screening and to discuss the results. Communicate this very clearly to the community.
- ✓ Carefully select pictorial information: any pictures with any genitalia or large areas of naked flesh are potentially highly offensive.
- ✓ Send information about invitations or appointments via text message wherever possible

Further information

For information, easy read leaflet and YouTube video for women with learning disabilities

<https://www.jostrust.org.uk/about-cervical-cancer/cervical-screening-smear-test-and-abnormal-cells/women-learning-disabilities>

<https://www.gov.uk/government/publications/cervical-screening-easy-read-guide>

For tips on minority and hard to reach groups

<http://www.screening.nhs.uk/equality/tips>

<https://www.gov.uk/government/publications/nhs-population-screening-equitable-access-tips/nhs-population-screening-working-with-minority-or-hard-to-reach-groups>

For cervical screening leaflets for women considering screening in different languages:

<https://www.gov.uk/government/publications/cervical-screening-description-in-brief>

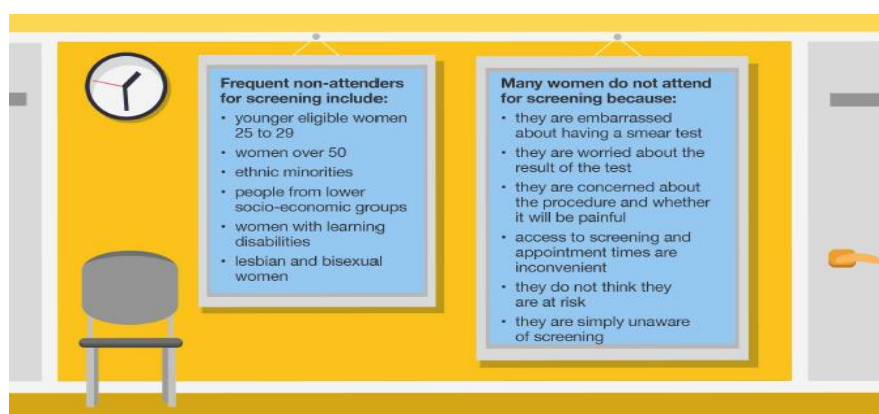
Part Three: Resources and Support

1. Knowing your Practice's Data

- ✓ Coverage measures the percentage of the total eligible population which has been screened over a defined time period. For cervical screening this is 3.5 years for the younger age range (25 to 49) and 5.5 years for the older age range (50 to 64).
- ✓ Open Exeter is the key source of data used to assess population coverage of the cervical screening programme. Latest available uptake and coverage data can be found on Open Exeter. <https://digital.nhs.uk/NHAIS/open-exeter>
- ✓ Practices often think their coverage is higher than it really is. This is because they look at their QOF data. The key differences between the two data sets are shown in the table below:

	QOF	Open Exeter
Purpose	To reward practices on a sliding scale of 45 – 80%, in accordance with QOF rules	To measure the overall population coverage of the national programme
Timescale and Age Range	% of women who have been screened in the last 5 years, irrespective of age	% of women who have been screened within 3.5 years or 5.5 years as relevant to the age of the woman
Denominator and Exceptions	Denominator excludes all those who have been excepted by the practice e.g. those who have not attended after 3 separate invitations.	Denominator includes the total eligible population with the exception only of those permanently excluded from the programme e.g. for clinical reasons such as no cervix

- ✓ NHS Digital has launched an online interactive tool which presents quarterly cervical screening coverage data obtained from the Open Exeter system. <http://www.content.digital.nhs.uk/catalogue/PUB24229>.
- ✓ PHE's fingertips tool provides profiles on cancer services at individual GP and CCG level. Data is collated by the National Cancer Registration and Analysis Services (NCRAS). As well as screening data, they include a data on two week waits, diagnostic services, emergency presentations and admissions. <https://fingertips.phe.org.uk/profile/cancerservices>
- ✓ Look at your practice-level screening coverage and uptake rates and whether you meet the targets and how your rates compare with other practices. If rates are low, discuss with your Screening and Immunisation Team (see **Contact Details**) and formulate a plan to improve.



2. Cervical Screening Resources and Further Reading

Cervical Cancer Information

- ✓ Cancer Research UK provides general information about cancer generally.
<http://www.cancerresearchuk.org/about-cancer/cervical-cancer>
- ✓ Jo's Trust is a UK charity dedicated to women affected by cervical cancer, and is a good source of data and information about cervical cancer.
<https://www.jostrust.org.uk>

NHS Cervical Screening Programme Guidance

- ✓ There is a wealth of information for professionals on the National Screening programme pages of the GOV.UK government website
<https://www.gov.uk/topic/population-screening-programmes/cervical> including:
 - Guidance for primary care professionals
<https://www.gov.uk/government/collections/cervical-screening-professional-guidance>
 - Cervical screening administration
<https://pcse.england.nhs.uk/services/cervical-screening/>
 - Sample taking training and guidance:
<https://www.gov.uk/government/publications/cervical-screening-cervical-sample-taker-training>*
<https://www.gov.uk/government/publications/cervical-screening-good-practice-in-cervical-sample-taking>*
<https://www.rcn.org.uk/professional-development/publications/pub-003105>

Information for Patients

- ✓ Information about Cervical Cancer and Cervical Screening for patients is available from NHS Choices
<http://www.nhs.uk/conditions/Cervical-screening-test/Pages/Introduction.aspx>
- ✓ Cervical Screening leaflets for women considering screening, available in a number of different languages is available on the gov.uk cancer screening pages
<https://www.gov.uk/government/publications/cervical-screening-description-in-brief>
- ✓ Jo's Trust also has a wealth of information for patients
<https://www.jostrust.org.uk/about-cervical-cancer/cervical-screening-smear-test-and-abnormal-cells/cervical-screening-in-the-uk>

Improving Uptake

- ✓ Information on barriers to attendance
<https://www.jostrust.org.uk/information-healthcare-professionals/information-practice-nurses-and-gps/barriers-attending>
- ✓ Jo's Trust award winning projects
<https://www.jostrust.org.uk/get-involved/cervical-screening-awards>

Working with Minority and Hard to Reach Groups

- ✓ For tips on minority and hard to reach groups
<https://www.gov.uk/government/publications/nhs-population-screening-equitable-access-tips/nhs-population-screening-working-with-minority-or-hard-to-reach-groups>

<https://www.gov.uk/government/publications/nhs-population-screening-equitable-access-tips/nhs-population-screening-working-with-minority-or-hard-to-reach-groups>
- ✓ For cervical screening leaflets for women considering screening in different languages:
<https://www.gov.uk/government/publications/cervical-screening-description-in-brief>
- ✓ For translated YouTube videos in Arabic, Bengali, Chinese, Hindi, Urdu, Polish and Tamil
<https://www.jostrust.org.uk/about-cervical-cancer/cervical-screening-smear-test-and-abnormal-cells/film-your-guide-cervical>

Learning Disabilities

The National Screening Programme pages, Jo's Trust and NHS England have information aimed for and at women with learning disabilities. The Office of the Public Guardian on the Gov.uk website has information about mental capacity and 'best interests' decisions.

- ✓ Cervical Screening 'easy read' leaflet for women with learning disabilities:
<https://www.gov.uk/government/publications/cervical-screening-easy-read-guide>
- ✓ For accessible information, easy read leaflet and YouTube video for women with learning disabilities
<https://www.jostrust.org.uk/about-cervical-cancer/cervical-screening-smear-test-and-abnormal-cells/women-learning-disabilities>
- ✓ Consent guidance and template letters can be found at:
<https://www.gov.uk/government/publications/cancer-screening-informed-consent>
- ✓ Mental Capacity Act Code of Practice <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

3. Contact Details

Call/Recall and Screening Administration	<p>Primary Care Support England, PO Box 350, Darlington, DL1 9QN Tel 0333 014 2884</p> <p>pcse.england.nhs.uk/ PCSE.screening-leeds@nhs.net</p>
Laboratories	<p>North and Mid Hants Programme Royal Hampshire County Hospital Winchester Cytology.Administration@hhft.nhs.uk</p> <p>Ashford & St Peters Hospital (Surrey Pathology Services) asphscreening.department@nhs.net</p> <p>Portsmouth, South East Hants and IOW Programme Queen Alexander Hospital, Cosham portsmouth.cytology@porthosp.nhs.uk</p> <p>East Dorset Programme Poole Hospital Cytology.Diary@poole.nhs.uk</p> <p>West Dorset Programme Taunton and Somerset NHS Foundation Trust, Musgrove Park CytologyFailsafe@tst.nhs.uk</p> <p>North East Hampshire Cytology, St Peter's Hospital, Guildford Road, Chertsey, Surrey, KT16 0PZ Tel 01932 723542 asphscreening.department@nhs.net</p>
Preferred Training Providers	<p>Mary White PDI Director PDI Services Tel: 01392 824894 Mob: 07714 757 706</p> <p>Wendy Lee CTL Managing Director Mobile: 07958 079 877</p>
Screening and Immunisation Team	<p>Office line: 01138249803 Email: england.wessexph@nhs.net</p>

4. Guidance and Tools Content List

The documents below can be found in the folders accompanying this guide. The items marked with * are also referenced with a hyperlink to the original website elsewhere in this document.

Folder	Sub-folder	Document
Cervical General		<ol style="list-style-type: none"> 1. Cervical Read Codes 2. Consent Guidance* 3. Sample taker good practice guidance* 4. Sample taker training guidance*
Improving Uptake	Guidance Summary A4 'Poster'	
	Uptake Guidance	1. Jo's Trust Awards*
	Uptake Tools	<ol style="list-style-type: none"> 1. GP endorsement letter for rising 25s 2. GP endorsement letter for DNAs/non-attenders 3. Jo's Trust Survey Summary 4. Patient Surveys – two examples 5. Phone script to support conversations with patients who do not attend 6. Text Message for Rising 5s and DNAs/non attenders
Learning Disability (LD)	Guidance	1. Cumbria LD Network Capacity Guidance
	Tools	<ol style="list-style-type: none"> 1. Best Interest Withdrawal Form* 2. Easy Read Cervical Screening Guide* 3. Easy Read Invitation letter 4. Easy Read information booklet* 5. Southern Health carers guide to screening
Screening Factsheets		<ol style="list-style-type: none"> 1. What is Screening 2. Criteria for Screening

Appendices

Appendix 1: Cancer Screening Read Codes

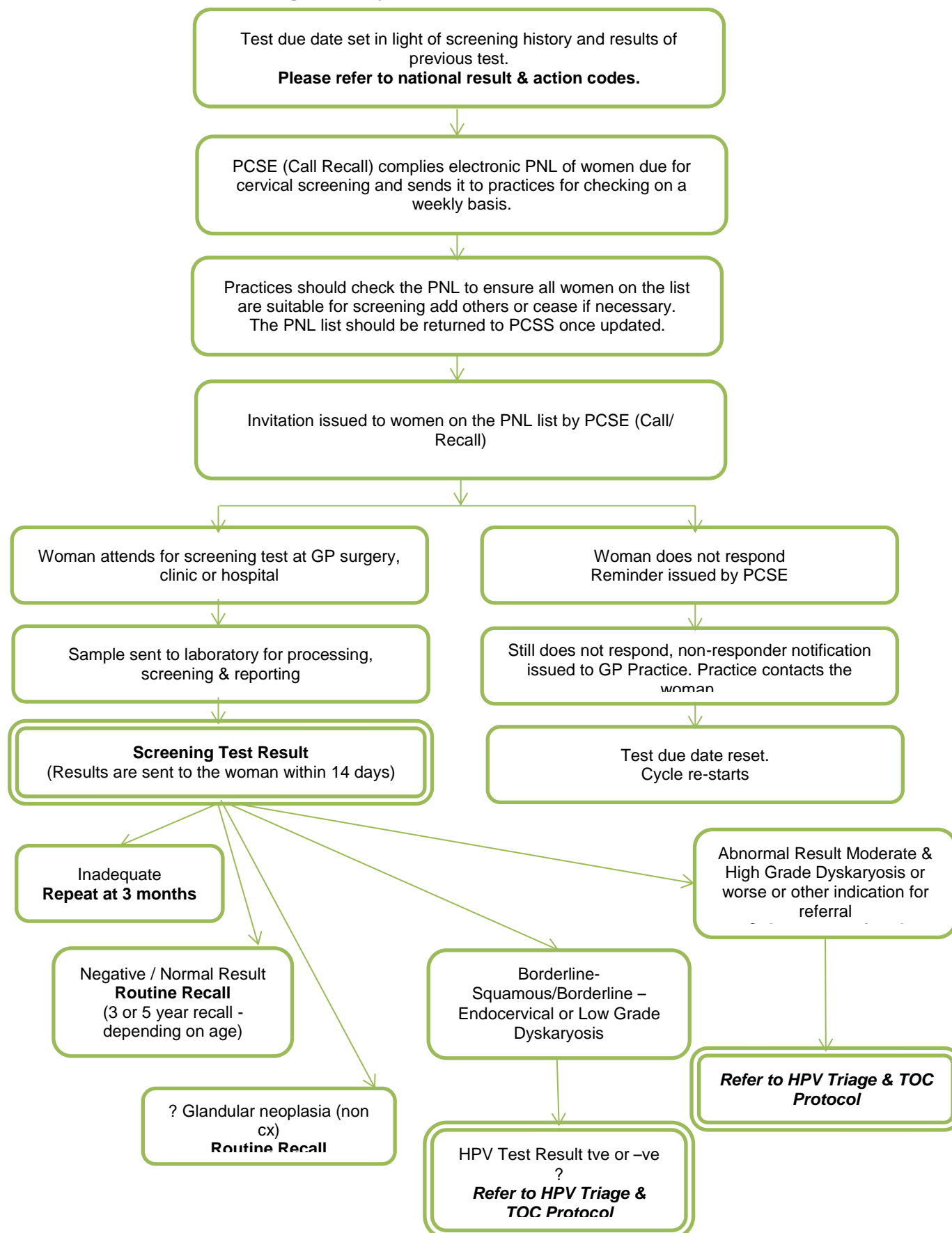
Use the read codes to identify whether patients are partaking in screening. A more detailed version of the read codes is included in the 'guidance and tools' folders accompanying this guide.

Cervical screening:

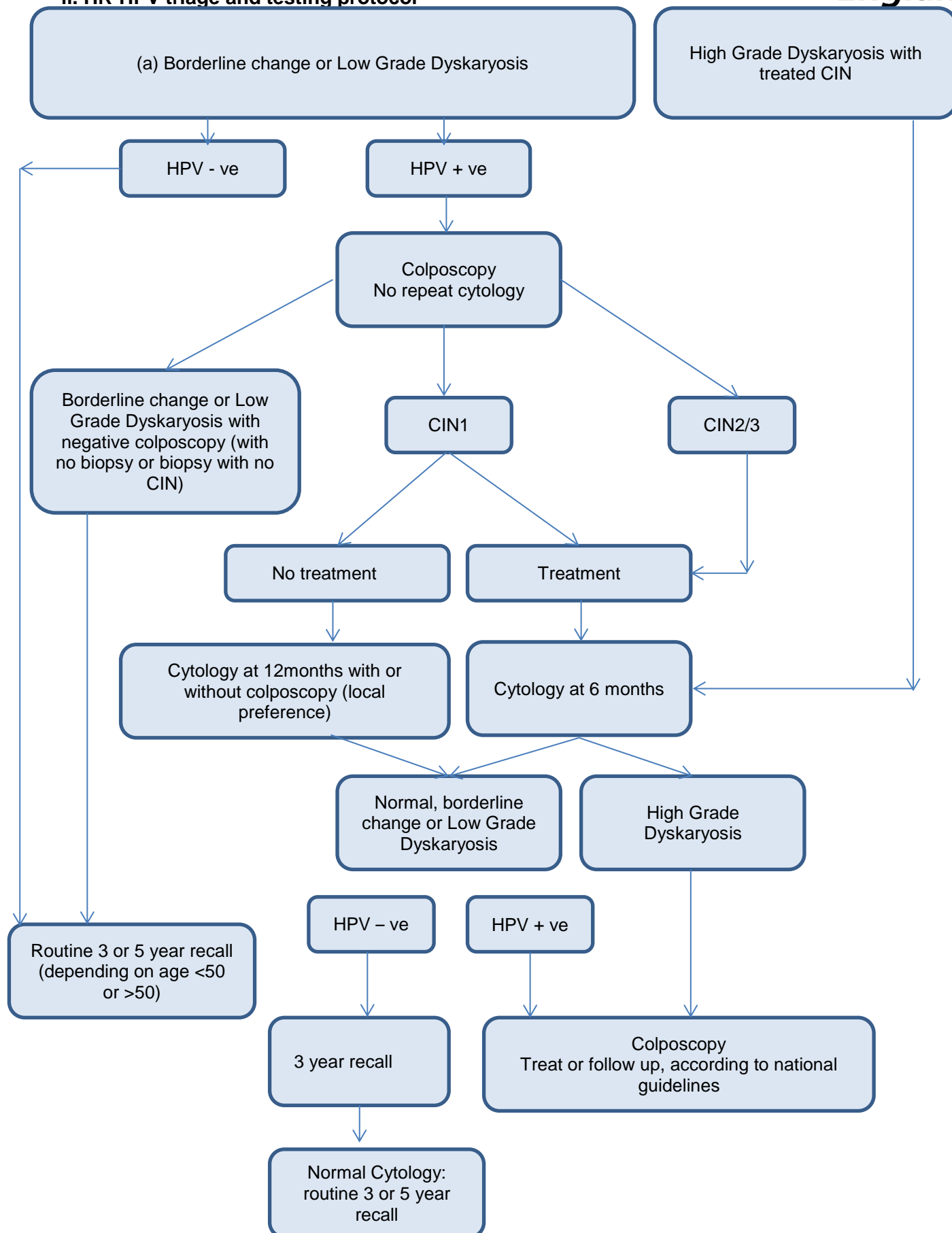
Liquid based cytology sample taken	685R
Normal 3 year (36 month recall) for women aged 25-49	4K4B
Normal 5 year (60 month recall) for women aged 50-64	4K4C
Inadequate, repeat at 3 month	4K43
Abnormal (6 month recall)	4K45
Abnormal (12 month recall)	4K47
Referred for Colposcopy	4K48
Cease recall	6855
Cervical sample refused	685L
HPV test negative	4K3E
HPV test positive	4K3D

Appendix 2: Cervical Screening Pathways

i. Screening Pathway



ii. HR-HPV triage and testing protocol



Appendix 3: Ceasing and Withdrawal from the Programme

- ✓ A woman will be automatically ceased from the screening register on the grounds of age:
 - if her next test is due after her 64th birthday and she has a suitable normal screening history
 - if she is aged 60 and has never attended for a test
- ✓ The only other circumstances for ceasing a woman from cervical screening are
 - she does not have a cervix
 - she has had radiotherapy to the pelvic area for cancer of the cervix, bladder or rectum
 - she has made an informed decision that she no longer wishes to be invited
 - she lacks the mental capacity to consent and a decision has been made appropriately that it is in her best interests to remove her from the screening list
- ✓ The following are not reasons for ceasing or withdrawing from the programme, unless the woman specifically requests to withdraw and has made an informed decision:
 - women who have never had sex with a man
 - women with a physical disability that would make taking a sample difficult
 - women who have been cut/undergone FGM
 - women with a learning disability
 - women with a terminal illness (unless judged distressing by a GP)
- ✓ When a woman asks to withdraw:
 - provide the woman with sufficient information to make an informed decision including risks, benefits and the consequences of attending or ceasing
 - inform her that withdrawal will prevent her from receiving any future invitations
 - inform her that she can be returned to the programme at any time on request
 - she must put her request in writing to confirm she has made an informed decision
 - consider offering her an appointment to discuss her decision to withdraw
 - no one else can request a woman be withdrawn except where the woman lacks mental capacity and a 'best interests' decision is made on her behalf
- ✓ Re-instatement to screening after a ceasing request
 - If a woman changes her mind about withdrawing from the programme, she can ask for a new appointment at any time and will return to routine call and recall.
 - If a woman is aged over 65 and has not been screened since the age of 50, she is entitled to a new screening appointment if she requests one.

Further information

Guidance and template letters can be found at:

<https://www.gov.uk/government/publications/cancer-screening-informed-consent>

Appendix 4: Making a 'Best Interests' Decision

The decision whether or not to participate in cancer screening involves consideration of the benefits and disadvantages of the screening process. Some people may lack mental capacity to make an informed decision. Lack of mental capacity means the inability to make a particular decision at a particular time: e.g. because of a stroke or brain injury; a mental health problem; dementia; learning disability; or substance misuse.

'Best Interests' decisions

- ✓ Under the Mental Capacity Act 2005, people must be presumed to have capacity to make their own decisions unless it is proved otherwise. Individuals must be given all practicable help to make their own decisions before anyone treats them as not being able to do so.
 - ✓ A woman has the mental capacity to consent to screening if she is able to:
 - understand the information given that is relevant to the decision
 - retain the information long enough to make a decision
 - weigh the information as part of a decision making process and understand the possible consequences
 - communicate her decision – this could be by talking, using sign language, or by simple muscle movement such as blinking or squeezing a hand
 - ✓ In some cases, and despite practical help, a woman may not have the mental capacity to consent to screening and a decision will need to be made whether it is in the woman's best interests to be screened or not. 'Best Interests' decisions go beyond medical interests, and should take account of all relevant factors. The decision must not be based on what the person making the decision would do, nor on what is easiest for the carer or screening staff. A carer making a best interests decision may benefit from speaking to screening staff in order to be fully informed about the process and its implications for the individual.
 - ✓ Any 'Best Interests' decision to screen or withhold screening (for a single occasion or permanently) should be **clearly documented**, including detailed information about **who** made the decision, and **why** the decision was considered to be in the individual's best interests. The decision maker must be able to **justify** the decision and it must be made **objectively** without the decision maker imposing their own views.
 - ✓ In most cases, and especially if capacity is intermittent, it will be in the woman's best interests to remain in call/recall and receive screening invitations at routine intervals. The invitations can be considered and accepted or declined on each occasion.
 - ✓ Only if an individual permanently lacks the mental capacity to consent can a decision be made on her behalf permanently to withdraw her from the screening programme. Screening staff should be satisfied that the 'Best Interests' decision has been reached properly. A woman ceased permanently from screening can be reinstated onto the screening list at any time.
- 'Best Interests' decisions to withdraw from the cervical screening programme**
- ✓ If a 'Best Interests' decision is made to withdraw the woman from the cervical screening programme, rather than decline each invitation, a signed consent form should be returned to Primary Care Support England (PCSE) for action. There is a sample form in the tools associated with this guide – see **Guidance and Tools Content List**

Further guidance

Consent to Cancer Screening

<https://www.gov.uk/government/publications/cancer-screening-informed-consent>

Mental Capacity Act Code of Practice

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>