





Increasing Cervical Cancer Screening Coverage:
Information for Healthcare Practitioners
Standard Operation Procedure



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## Part One: Introduction and Overview of the Programme

#### 1. Introduction

## Cervical Cancer and the NHS Cervical Screening Programme (NHSCSP)

Two women die every day from cervical cancer, yet it is one of the most preventable cancers. Around 2,700 women in England are diagnosed with cervical cancer each year and it is the second most common cancer amongst women under 35<sup>1</sup>.

Cervical screening is not a test for cancer. Cervical Screening helps prevent cervical cancer by:

- Checking for high-risk human papillomavirus (HPV) which causes nearly all cervical cancers
- This is the best way to find out who is at higher risk of developing the cervical cell changes that over time could potentially lead to cervical cancer.
- Treating precancerous cell changes, thereby preventing cervical cancer

It has been estimated that in England cervical screening prevents 70% of cervical cancer deaths and that if everyone attended screening regularly, 83% of cervical cancer deaths could be prevented.<sup>2</sup>

## Cervical Screening Coverage

The expected national standard for cervical screening coverage is 80% for eligible individuals. At March 2021 no local authority within the Bedford region met this threshold. The overall cervical cancer screening coverage across the Bedford rose in 2019 (74.5%) and 2020 (74.9%) but fell again to 73.3% at 31<sup>st</sup> March 2021, probably due to the impact on screening of the COVID-19 lockdown<sup>3</sup>. Nationally the number of people with a cervix taking up their offer of cervical screening is declining. Lower attendance is particularly evident in the youngest age groups and in underrepresented groups such as those from lower socioeconomic, ethnic minority and LGBTQ+ communities.

This guide is aimed at all members of the Primary Care team. Drawing together practical information and tips to help GP practices identify actions that will result in improved screening coverage, particularly amongst those in underserved communities. This guide is not exhaustive and should be read in conjunction with <u>national guidance</u>. Further resources are signposted throughout the document and summarised in Part 3 for ease of reference.

## 2. Primary high-risk human papillomavirus (HR HPV) testing in Cervical Screening

HPV is a common infection transmitted through sexual contact. Most sexually active people encounter HPV during their lifetime. However, for most, the virus causes no harm and the

<sup>&</sup>lt;sup>1</sup> Office for Health Improvement & Disparities (OHID) (2022) Cervical Screening Awareness Campaign. OHID Depart of Health & Social Care.

<sup>&</sup>lt;sup>2</sup> Landy, R., Pesola F., et al., Impact of cervical screening on cervical cancer mortality: estimation using stage-specific results from a nested case—control study. British Journal of Cancer volume115, pages1140–1146 (25 October 2016). Available from: https://www.nature.com/articles/bjc2016290?foxtrotcallback=true

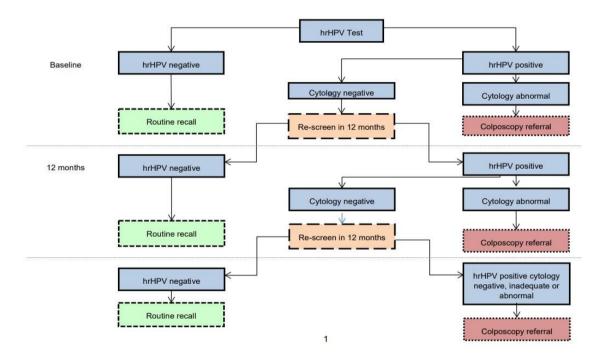
<sup>&</sup>lt;sup>3</sup> NHS Digital (2021) Cervical Screening Official Statistics 2020-21 published by NHS Digital <u>Cervical Screening Programme, England - 2020-</u>21 [NS] - NHS Digital



infection clears on its own. However, some high-risk sub-types of HPV (HR-HPV) are linked to the development of abnormal cells that can progress into cervical cancer.

In 2013, English pilots of primary HR-HPV screening began, and in 2015 the first report confirmed the feasibility of use and improved performance of primary HPV screening within the NHSCSP. Following an evidence review and public consultation the UK National Screening Committee (UK NSC) recommended the implementation of primary HRHPV testing. HR-HPV testing has higher sensitivity than primary cytology. This means using primary HR-HPV testing to screen people will identify more patients at risk of developing cervical cancer and will save more lives by determining an individual's risk earlier. HR-HPV testing also has a lower false negative rate than cytology. This means patients may not need to come for screening as often in the future. The UK National Screening Committee (NSC) is currently considering the evidence for a possible extension of screening intervals.

## Cervical screening: colposcopy and programme management Cervical screening protocol



#### Source:

 $\frac{https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/856972/Screening\_and\_colposcopy\_pathways.pdf$ 

#### **HPV Vaccine**

Studies have shown that the HPV vaccine dramatically reduced cervical cancer rates by almost 90% in 20-year-olds who were offered the vaccine at 12-13 years old<sup>4</sup>. <u>Cancer Research UK</u> states this study also shows the potential for the combination of HPV Vaccination and Cervical Screening to reduce cervical cancer to the point where

<sup>&</sup>lt;sup>4</sup> https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)02178-4/fulltext



almost no one develops it<sup>5</sup>. Primary HR-HPV testing is more appropriate for vaccinated individuals 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 those considered to be at higher risk who test HR-HPV positive.

## 3. Eligibility and Recommended Screening Intervals

Cervical screening is available to anyone with a cervix aged 24.5–64 years in the UK<sup>6</sup> as shown in the table below:

Age group	Eligible?	Frequency of screening
Under 24.5	No	Cervical screening is not recommended for anyone under the age of 24.5 as cervical cancer is very rare in under 25-year-olds (less than 1% with an average of 0 deaths).  Research suggests that the risks of offering cervical screening to those under 25 outweighs the benefits as this can lead to patients receiving unnecessary treatment.
		Please click these links for further information and advice for <u>patients</u> and <u>healthcare staff</u> on this subject
24.5	Yes	Eligible for screening, and first invitation issued (to ensure screening test can be completed by their 25th birthday).
25 to 49	Yes	Three-yearly
50 to 64	Yes	Five-yearly
65+		Those aged 65 or older will not be invited for cervical screening if their last test was normal. This is because the likelihood of developing cervical cancer is low. If they are aged 65 or over and have never had cervical screening, they are entitled to a test and should speak with their GP surgery about booking an appointment. If they are 65 or older and have had abnormal results, they will be invited for cervical screening.

#### Eligible Populations for the Cervical Screening Programme

## People with a cervix who are not sexually active

People who have never been sexually active (which includes any skin to skin contact in the genital region) have a very low risk of HPV infection. This is not 'no risk', only very low risk. In these circumstances, an individual might choose to decline the invitation for cervical screening.

For people who are not currently sexually active but have had sexual partners in the past, it is recommended that they continue to attend for screening.

#### LGBTQ+

All people with a cervix between age 25 and 64 are eligible for regular cervical screening, no matter their sexual orientation or gender identity.

Most cervical cell changes and cervical cancers are caused by persistent infection with HPV. As HPV can be passed on through any skin-to-skin contact in the genital area, people having any kind of sex are at risk of transmission.

<sup>&</sup>lt;sup>5</sup> https://news.cancerresearchuk.org/2021/11/03/the-power-of-science-hpv-vaccine-proven-to-dramaticallyreduce-cervical-cancer/

<sup>&</sup>lt;sup>6</sup> https://www.gov.uk/guidance/cervical-screening-programme-overview#:~:text=Cervical%20screening%20is%20available%20to,receive%20an%20invitation%20by%20mail



Current national IT systems do not have the facility to include individuals registered with the NHS as 'male', and current registration systems are unable to record the gender category of 'non-binary'. For eligible people not registered under the categories 'female' or 'indeterminate', screening should be offered by the person's GP practice or, where appropriate, a gender clinic healthcare team.

- 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. (See Appendix 1 for ceasing details)

## Immunosuppressed people with a cervix

People on immunosuppressant medication, transplant recipients and all other forms of immunosuppression should be screened and managed in line with the <u>Colposcopy and Programme Management guidelines</u> depending on their condition.

### HIV positive people with a cervix

All newly diagnosed people with HIV should have cervical surveillance performed by, or in conjunction with, the medical team managing the HIV infection. Annual screening should be performed.

People with a cervix moving into England from other areas of the UK

The age range applies to people resident in England. For people under 25 who

The age range applies to people resident in England. For people under 25 who have already had a sample taken and move into England from another country with a negative history, their next test due date will be adjusted to 24.5 years.

#### Self-referral into the programme

Individuals not registered with an NHS GP practice (for example, people experiencing homelessness) do not receive an invitation for cervical screening automatically. They can choose to self-refer for screening at the routine intervals if they satisfy the age and are eligible for NHS treatment, and this should be encouraged. Self-referrals can be undertaken in a GP surgery as a temporary resident or other settings (such as community and sexual health (CaSH) clinics). When this happens the sample taker must make sure they:

- confirm the individual's eligibility for screening in line with <u>national sample</u> acceptance guidance
- record accurate information about the individual's identity
- record accurate contact information (for provision of results)
- This will ensure that the individual can be followed up if necessary.

Individuals screened through this route must be informed by the sample taker that their contact details, including registered address, will be kept on record by the call and recall services and used to contact them for future screening invitations as well as to provide test results. The programme does not support anonymous screening.

#### Unscheduled screening tests

If an eligible person has had a test within the previous routine screening interval (three to five years), additional tests should not be carried out as part of the NHS cervical screening



programme. Unscheduled samples will not be accepted by the laboratory. The sample taker should explore the reason(s) for the individual requesting screening.

## Non-NHS cervical screening tests

Tests carried out privately or abroad do not affect a person's entitlement to NHS screening. The NHS has no responsibility for the quality of non-NHS tests. The results of a non-NHS screening test must not be recorded in an individual's NHS screening record but can be recorded on their patient records. Historic non-NHS test results may appear in a screening record if they were provided to the call and recall service and recorded prior to 2020.

#### Symptomatic Patients

Opportunistic screening is not appropriate for individuals who present with symptoms. Cervical screening is not a diagnostic test therefore for symptomatic individuals, appropriate gynaecological referral pathways should be followed.

## 4. Organisation of the NHS Cervical Screening Programme

## **National Organisations**

NHS screening programmes are overseen by a national structure which ensures that they operate to consistent, evidence-based standards and pathways.<sup>7</sup>

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.

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.

*ICBs* 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. CCGs commission colposcopy services which are part of the cervical screening pathway.

#### General practice

The General Practice (GP) registered list is the basis for the call and recall system 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 and overcome some of the barriers individuals may experience.

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

<sup>&</sup>lt;sup>7</sup> https://www.gov.uk/government/collections/cervical-screening-professional-guidance



- making adequate arrangements and reasonable adjustments to enable patients to access cervical screening
- ensuring that patients have the necessary information to make an informed choice
- operating failsafe arrangements to ensure patients have had their results and are followed up and referred appropriately for further investigation and treatment
- ensuring adequate referral processes are in place so patients who require further investigation and treatment are managed appropriately
- working to improve the coverage of the cervical screening programme
- ensuring adverse events and incidents are recorded, reported, and investigated in accordance with national guidance.

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.<sup>8</sup>

Acute and community NHS Trusts and private providers: of screening programmes are responsible for ensuring delivery of the programmes in accordance with national standards.

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

Cervical Screening Programme Leads (CSPL) 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

#### Cervical cytology training

Educational organisations that offer high quality, specialist training that is consistent with national policy recommendations and programme requirements for new cervical sample takers in the NHS Cervical Screening Programme (NHSCSP). Cervical screening: education and training - GOV.UK (www.gov.uk)

Please see Section 3 of Cervical Screening reading and further resources for local training Provider Details.

**Part Two: Maximising Screening Coverage** 

<sup>8</sup> https://www.gov.uk/government/publications/cervical-screening-good-practice-in-cervical-sample-taking



## 1. The individual's perspective: influences on coverage

There are many factors that determine whether individuals will attend for cervical screening:

- Education, knowledge and health literacy: This relates to people's perception of
  the relevance of screening, knowledge of risk and the role of screening in preventing
  cancer. Knowledge is lower in individuals who have never attended. Some people
  give low priority to their health needs and may need regular, repeated
  encouragement to attend for screening and advice.
- Accessibility: For some it is difficult to find time to attend or get an appointment at a time that is convenient. Some people may not be entitled to have time off work for appointments.
- **Fear:** People may fear the test being painful or have had a previous bad experience of screening. Some may have experienced a personal trauma such as traumatic birth, history of sexual assault, rape, or female genital mutilation (FGM).
- Embarrassment
- Pain: Those who experience pain or discomfort during the test could result in nonattendance. This is particularly important for post-menopausal people.
- Cultural beliefs and social influences: Some may perceive that screening is not relevant based on their marital status or sexual activity or they may fear the sample taker may be male or known to the patient. Friends, family and community attitudes and social pressure influence whether people will attend. Older family members may hold false beliefs about screening.

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

- From Jo's Cervical Cancer Trust:
  - Overcoming barriers to cervical screening
  - Online forum
- From GOV.UK:
  - Cervical screening: support for people who find it hard to attend -GOV.UK
  - o (www.gov.uk)

## 2. A Systematic Approach to Maximising Coverage

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 or inequalities experienced by different groups. There is also evidence that the quality of the experience is key to ensuring that individuals return for screening at regular intervals. Encouragement and endorsement by primary care practice staff, particularly GPs, is effective at providing a positive experience.

Below are some examples of interventions GP practices can implement to improve access, quality and acceptability of cervical screening.



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 inadequate sample rates are monitored, and staff supported to improve this when necessary
- each cervical sample taken has an associated result, coded properly on the clinical record and 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 coverage, for example people with learning disabilities or from ethnic minority backgrounds
- patient removals from the programme are managed in accordance with national guidance i.e., patients are invited to discuss this with an experienced nurse, nurse practitioner or GP
- screening incident management: The Cancer Screening Lead for the setting, in conjunction with Sample takers, should review any rejected samples. This should always include any sample where the laboratory has had to reject the test due to insufficient and or conflicting information, or because it was taken inappropriately.
- Sample takers should reflect on such events, make sure they are formally recorded internally, and reported as necessary according to practice or clinic clinical governance policies. For situations that fulfil the criteria of a 'screening incident', manage them in line with <u>national screening incident guidance</u>.
- recording, auditing, and reporting errors is important to identify any problems in the local sample taking process. This reduces the risk of potential incidents and gives an opportunity for learning and quality improvement.



#### 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.

Note that "Ghost" patients will negatively affect the practice's reported coverage rate.

• When carrying out a new patient check on a patient in the eligible age range, ask them when they last participated in cervical screening. Check their cervical screening status on Open Exeter (and the replacement system once available). If this is available and their screening is due or overdue, highlight this while they are with you, and offer to book an appointment for them there and then if their details are not available, advise them that they will be invited for screening when due and encourage them to attend. Add a reminder on their patient record prompting other staff to discuss screening with them.

## **Prior Notification Lists (PNLs)**

GP practices have a responsibility to provide assurance that the right individuals are being offered screening. This is managed through the prior notification list (PNL) process. The PNL is a list of individuals from the GP practice who are due to be called or recalled for screening. This provides an opportunity for practice staff to consider deferral or ceasing of individuals if appropriate.

Cervical Screening Administrative Service (CSAS) must send all PNLs to GP practices 70 days prior to the individuals' next test due date (NTDDs).

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 individuals who match the exclusion criteria.<sup>9</sup>



Ceasing due to non-eligibility <sup>9</sup> (please see reference for further information)		
	Automatic ceasing at age 60 and over	
Ceasing due to age:	Ceasing at age 65 or over (for those who have had previous cervical abnormality)	
	People who do not have a cervix are not eligible for cervical screening and should be ceased from recall permanently.	
	Hysterectomy	
Ceasing due to absence of cervix:	People who have undergone a sub-total hysterectomy (where the cervix is not removed) remain eligible for recall and should continue to be offered screening.  People who have undergone a total hysterectomy (including removal of the cervix) no longer require screening and should be ceased from recall.	
	Trachelectomy People who have undergone a radical trachelectomy (removal of the uterine cervix) for cervical cancer no longer require screening and should be ceased from recall.	
Transgender (trans) people:	Anyone who has a cervix and who falls within the screening age range is eligible for screening.  A trans woman who is registered as female does not require screening and should be ceased from recall.  People registered as male (including trans men) do not receive cervical screening invitations. However, the GP practice should arrange screening for individuals (with a cervix) who would like to have it.	
Ceasing due to radiotherapy:	It is difficult to accurately report samples from people who have undergone radiotherapy for cervical, bladder, rectal and other pelvic cancers. All cases should be considered individually, and people who are unsuitable for screening should be ceased from recall.	

CSAS are required to audit annually the records of people who are ceased from recall. This is to ensure that all people who are ceased have been managed correctly. All documentation related to individual ceasing requests must therefore be retained in a secure and accessible location.

As part of the audit, GP practices are asked to verify the status of any individuals registered as a woman with the practice whose date of ceasing falls within the timeframe of the audit. This can include people who were ceased before they were registered at the current practice. Practice staff should verify the records of individual people in a timely manner to ensure that no-one is returned to recall inappropriately.<sup>10</sup>

<sup>&</sup>lt;sup>9</sup> Ceasing due to non-eligibility: <u>Ceasing and deferring women from the NHS Cervical Screening Programme - GOV.UK (www.gov.uk)</u>

<sup>&</sup>lt;sup>10</sup> Ceasing and deferring women from the NHS Cervical Screening Programme - GOV.UK (www.gov.uk)



Following screening, GPs receive copies of the result letter sent to patients – see page 17 Managing Results and Failsafe.

## **Appointments**

When setting up and offering appointments for cervical screening then in order to maximise uptake, practices should consider the following:

- Offering choice and ensure patients can book well in advance (at least 6 weeks and ideally 2 months)
- Considering whether appointment times are appropriate and sufficiently flexible.
  - Offering 'extended hours' appointments.
  - Offering early morning appointments as well as some evenings and weekends: many individuals prefer to attend early in the day for hygiene reasons
  - Offering the opportunity to book online as well as by phone or in person if possible
- Consider the needs of different patients (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 patients attending for a long-term condition or health check
- Remind patients of their appointment e.g., by text/SMS message
- Ensure practice staff are aware that an eligible individual can book at any time during their cycle for cervical screening, except when they have heavy menstrual bleeding (if a person presents with light bleeding, a sample can still be taken but there is a risk that too much blood in the sample would prevent the sample being processed). If a person is post-menopausal, they will still need to attend regular cervical screening appointments until they become 65.
- Ensure that eligible patients, particularly those from specific communities/population groups, are aware that the sample can be taken by a female doctor or nurse and that they can have a chaperone.

## Sample taker specific responsibilities

The sample taker plays a crucial role in the individual's experience: a positive experience is a key factor in an individual's decision to re-attend at the next invitation. Sample takers must:

- Keep up to date with training, changes in the programme and current best practice
- Follow all national and local guidelines for sample taking.
- Ensure they have a sample taker code on the <u>Sample Taker Register</u> (See Appendix 3 for sample taker register guide).

Sample takers should undertake continuous self-evaluation to help ensure continued competence in accordance with their professional codes of conduct. They should audit



and reflect on their own rates of inadequate tests and abnormal test results compared with the rates reported by the local laboratory.

The sample taker should:

- Ensure that people have the necessary information to make an informed choice
- Take the sample in an appropriate manner, putting the patient at ease and making adjustments for individuals as required
- Ensure the person is informed of their test result
- Ensure that the test result is followed up appropriately
- Communicate with the person if their sample is rejected and advise when another sample should be taken
- Ensure referrals take place for people who require further investigation/ treatment
- Cooperate with failsafe enquiries in a timely manner

## Test Request Forms

Sample takers are responsible for correct completion of the sample test request form. Incorrect completion of forms is the biggest reason for rejection of samples which results in anxiety and distress for patients, who must be recalled for repeat cervical screening 3 months later.

When a patient has their cervical sample test, the sample taker must complete the correct cervical sample request form.

Please see Appendix 2 Open Exeter guide on the correct use of the HMR101 form (ensuring you follow guidance related to the correct laboratory your samples are sent to).

- For East London Foundation Trust (NBT) lab, an editable A4 HMR101 prepopulated form is used
- For Bedfordshire Pathology Services (BSPS) lab, the sample request should be placed on ICE and the ICE form printed off and sent with the sample. The service is not yet paperless and so BSPS always need to the request form to accompany the vial. The HMR101 form should not be sent with the ICE form as, when the sample arrives in the laboratory, BSPS will cross reference on Open Exeter for the history if needed.

If ICE isn't working, sample takers should revert to using HMR101 forms and submit that with the sample instead.



## Positive Experience of the Procedure

The quality of the sample taking experience is a key determinant in patients reattending. 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 help people to attend in the knowledge of complete privacy
  - Provide enough time, normally a 20-minute appointment
  - Ensure you have appropriate equipment to maximise privacy, dignity, and comfort, including a range of different sized specula, lubricant, disposable modesty blankets, tissues etc.
  - Offer all patients 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. Patients, 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 patient has received the <u>Cervical Screening leaflet</u> and understood the procedure (note this is also available in a number of alternative languages)
  - Obtain informed consent including discussion about HPV testing before taking the sample
  - Allow patients 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 can be found here

#### Visualising the Cervix and Sampling the Transformation Zone (TZ)

The laboratory has reported a worrying increase in the number of sample forms received stating cervix not visualised or women who have had a hysterectomy but where the nurse is unsure if the cervix is still in situ.

#### The whole cervix must be visualised in order to obtain a satisfactory sample.

Sample takers must visualise and assess the cervix and interpret what is seen when taking a sample and make sure the whole of the TZ has been sampled (the laboratory cannot be certain that the full circumference of the cervix has been sampled by the cellularity or cell content of the sample).



If an experienced sample taker is unable to visualise the cervix, the person should be referred to a colposcopy clinic for investigation.

- If the sample taker has any concerns about the person's health when the cervix is visualised, they should seek
  appropriate clinical advice.
- If the cervix bleeds with clinical suspicion of malignancy, and a clinician considers the cervical appearance is suspicious of malignancy, they must refer the person to a gynaecologist urgently through the cancer wait times (CWT) '2-week wait' pathway. Do not take a sample.
- Cervical screening is a screening test, not a diagnostic tool. If a person presents to their GP practice with cervical cancer symptoms, the GP should refer them to a gynaecologist.



## Managing Results and Failsafe

- Results should be processed, and people informed of their result within 14 days
  of the sample being taken. Advise patients that if they have not received their
  results within 4 weeks, they should contact the practice.
- Results are sent to the practice electronically from the laboratory, which also informs CSAS.
- CSAS sends the results to the patient. Individuals who need to attend for colposcopy will be notified by CSAS but will also be sent an appointment directly by the colposcopy department
- The practice should have a clear protocol for dealing with rejected samples and patient recall in accordance with national guidance.
- Each sample taker within the practice is professionally 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
  - following up missing results
  - checking that patients have attended for follow up appointments as required;
     following up on any patients who have not responded or attended follow up appointments
  - ensuring that arrangements are made for patients 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 patient's electronic record and appropriately coded
  - Recording the taking of the sample and the results on the patient's electronic record and code appropriately.
  - Giving patients test results in person when urgent referral is required
  - Having a process in place to act on non-responder notifications for patients who have not responded to invitations for an early repeat test have not attended for colposcopy
  - Responding to failsafe enquiries by laboratories

Please see below which emphasises the importance of sending samples to the laboratories on the same day of screening:

## Send samples to the laboratory on the day of screening

In line with the <u>cervical screening programme standard CSP-S03</u>, the majority of individuals should expect to receive their screening results in writing within 14 days from the date of the sample being taken.



To achieve this timeline, the samples should be sent to the lab **on the day** the sample is taken so they are received by the lab **within 3 days**. In some cases, laboratories are receiving a sample after 14 days of the sample taken and so it is impossible to achieve the above.

## 14-day Turn-Around Time (TAT) of cervical screening results

3 days for sample to get to the lab

7 days to process sample, including any cytology and sending results to CSAS

4 Days for the results letter to be sent out and delivered

Results letter received within 14 days of sample taken date

Please ensure that you are NOT sending samples in batches to the laboratories, but sending them on the day the sample was taken. However, if you only have one specimen collection per day and this falls at lunchtime it is acceptable to provide screening in the afternoon and send samples with the courier the next working day.

Samples must be analysed in a timely manner to identify whether an individual is HPV positive and whether they need a colposcopy referral. Furthermore, this delay in receiving screening results may lead to individuals experiencing additional anxiety. This negative screening experience could mean they are less likely to attend when they are due their next cervical screen.

General Actions to Encourage Screening Awareness and Coverage

Understanding local and patient demographic



Think about the population in your local area:

- What is the age demographic?
- Which ethnicities are represented?
- Which languages are spoken?
- Which cultures are represented?
- Are there any other demographics that you need to note (for example, working mothers)?
- Does a person from that culture traditionally go back to their country of origin to be screened? These screens do not count under the NHS Screening Programme and so additional information may need to be provided to these patients to explain why the NHS screening programme does not acknowledge these tests. See Part one section 3.1H; Non-NHS cervical screening tests)

To determine whether your current cervical screening practice is meeting the needs of your local and patient demographic, you need to understand the patients you are trying to make the test more accessible for.

Now consider the following:

What are the current numbers of patients attending cervical screening?

What is the current number of patients overdue for cervical screening?

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 coverage 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 Week, Cervical Screening Awareness Week
- 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 patients contact the practice
- Ensure that the issue is raised at the next appropriate visit to the practice and the individual is fully informed of the benefits of regular screening
- Send a personalised non-responder invitation signed by the patient's named GP
- Consider sending a timed appointment with this third invitation letter, giving the patient the opportunity to rearrange if they cannot make it



- Use a different colour paper (e.g., pink) to make reminder, endorsement and nonresponder letters stand out
- Bear in mind that younger patients 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. o weekly texts, extra on-the-day appointments
- Consider a surgery campaign, for example, some surgeries have run an "In the Pink" for a month including balloons, posters, defined time period. Social media targeted at the under 35 age group.

## Promoting Coverage in Key Groups People living with Disabilities

Women and people with a cervix who have a disability have the same rights of access to screening as all other people. NEVER exclude anyone automatically from the screening programme on the grounds of physical or learning disability. No disabled person with a cervix can be assumed to be sexually inactive. All people are entitled to information to make their decision about cervical screening and are entitled to reasonable adjustments to support them attending an appointment.

Wherever possible, provide individuals with disabilities with access to information to enable them to make their own decisions about whether to participate. An 'Easy Read' leaflet is available which has been designed to be used by individuals 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:

- Cervical screening: an easy guide GOV.UK (www.gov.uk)
- <u>Cervical Screening When You Have a Learning Disability | Jo's Cervical Cancer</u>
   Trust (jostrust.org.uk)
- What happens when I go for cervical screening (a smear test)? YouTube

Examples of practice level support for patients 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 people with physical disabilities.
- At the appointment, check for behavioural signs of compliance with the procedure
- for severely disabled or paraplegic people, 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 further information on the barriers to cervical screening experienced by people with physical disabilities and recommendations to improve access is available from a <u>report</u> conducted by Jo's Trust.

For individuals with a learning disability, the issue of consent is vital. It is important to work with individual carers, support workers and Learning Disability teams to support individuals access screening. People with learning disabilities can often understand and consent to screening with adequate support and preparation. Deferment of the current invitation is preferable to permanently ceasing from the screening programme, as the individual may be able to consent at a future time and being re-invited enables the opportunity to revisit the discussion. Further information on consent and best interests' decisions is available at:

<u>Cancer Screening: Informed Consent Mental</u>
<u>Capacity Act Code of Practice</u>

Ceasing from cervical screening recall in a person's best interests is likely to be appropriate only where the individual would never be suitable for screening or for further investigations and/or treatment in the event of a positive screening result. In most cases the least restrictive alternative is for the person to remain in recall and receive screening invitations at routine intervals.

See also Appendix 4: Making Best interest decisions and Appendix 1 Ceasing and deferring people from the NHS Cervical Screening Programme

#### **Ethnic Minorities**

- 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 patients (and their partners) 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 risk 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 translated leaflets can be downloaded here.
- Send GP endorsement letters in the patient's first language wherever possible.

#### LGBTQ+

- Ensure that all staff are promoting cervical screening with people from the LGBTQ+ population, including women who have sex with women, and are aware that it is necessary.
- Train staff in communication and the use of non-hetero-normative questioning, see further Stonewall guidance Sexual Orientation guidance for the NHS here.
- The main issue for people who identify as transgender or non-binary is the 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, please find the CSAS guidance <a href="here">here</a>.
- 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, by noting this on the relevant form, so that they process the sample and return the results to the practice.

#### Gypsy, Roma and Traveller ethnic groups

- Gypsy, Roma and Traveller ethnic groups may fear hostility or prejudice from healthcare staff because of lack knowledge about their beliefs and culture.
- The Gypsy and Traveller 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 Gypsy and Traveller community with respect.
- Offer basic training for receptionists and healthcare staff in Gypsy and Traveller and culture
- Levels of literacy are typically lower than average in the Travelling community so services can support by using communication material which is largely pictorial or aimed at a reading age of around 10 years
- The Gypsy and Traveller 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

For tips on minority and hard to reach groups and useful tips on inclusive language:

Equitable access to screening: statutory duties under Equality Act



- PHE Screening Inequalities Strategy
- Inclusive Language

## **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. 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 coverage and coverage data can be found on <a href="Open Exeter">Open Exeter</a>.

Practices often think their coverage is higher than it really is. This is because they look at their QOF data which has a different definition of who is included in the denominator. Quarterly Open Exeter coverage is widely published on GOV.UK at practice and CCG level for both the younger and older cohorts. This coverage is reviewed nationally by National Screening Committee and NHSE.

NHS Digital has launched an online interactive dashboard which presents <u>quarterly</u> <u>cervical</u> <u>screening coverage data</u> obtained from the Open Exeter system.

<u>PHE's fingertips tool</u> provides profiles on cancer services at individual GP and CCG level. Data is collated by the National Cancer Registration and Analysis Services (NCRAS) and are an effective way to review your PCN data and identify improvements which can be made in practices of your PCN. The profiles provide reports on screening coverage and can identify health inequality populations in your area.

Please watch the navigation guide on how to use the Fingertips profiles to their full potential.

Look at your practice-level screening coverage and coverage 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 and formulate a plan to improve.

#### 2. Cervical Screening Resources and Further Reading

#### **Cervical Cancer Information**

- <u>Jo's Trust</u> is a UK charity dedicated to people affected by cervical cancer and is a good source of data and information about cervical cancer.
- <u>Cancer Research UK</u> provides general information about cancer generally.

## NHS Cervical Screening Programme Guidance

There is a wealth of information for professionals on the <u>National Screening programme pages</u> of the GOV.UK government website:

- Guidance for primary care professionals
- Cervical screening administration
- Sample taking training and guidance



#### Information for Patients

- Cervical Screening leaflets for those considering screening in multiple languages
- Jo's trust: Cervical Screening Information

## Improving Coverage

- Barriers to Cervical Screening | Jo's Cervical Cancer Trust (jostrust.org.uk)
- Cervical screening: support for people who find it hard to attend GOV.UK (www.gov.uk)

## Working with Minority and Hard to Reach Groups

- PHE Screening inequalities strategy GOV.UK (www.gov.uk)
- Equitable access to screening: statutory duties under Equality Act GOV.UK (www.gov.uk)
- Reducing cervical screening inequalities for trans people PHE Screening (blog.gov.uk)

## People living with Learning Disabilities

The National Screening Programme pages, Jo's Trust and NHS England have information aimed for and at people living 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 people with learning disabilities
- For accessible information, easy read leaflet, and YouTube video for patients with learning disabilities
  - Cervical Screening When You Have a Learning Disability | Jo's
  - Cervical Cancer Trust (jostrust.org.uk)
  - The Smear Test Film YouTube
- Consent guidance and template letters can be found at:
  - <u>Cancer Screening: Informed consent</u> o <u>Mental Capacity Act Code</u> of <u>Practice</u>
  - Ceasing and deferring women from the NHS Cervical Screening Programme

#### 3. Contact Details

Queries regarding sample transport, eligibility for screening and HPV Primary screening please contact your HPV screening laboratory for your area.

Bedford Pathology (NBT) nbn-tr.ClinicalBiochemistryNBT@nhs.net

**BLMK** (Norwich Cytology), Cervical Screening Helpdesk on 01603 286035 or email hpvrollout@nnuh.nhs.uk

#### Open Exeter



- Admin issues and questions i.e. account management and password resets, please contact PCSE by email: <a href="mailto:pcse.openexeter@nhs.net">pcse.openexeter@nhs.net</a> or by phone: 0333 014 2884
- For technical issues and questions i.e. HMR101 forms and access to screening records, please contact the Open Exeter Help Desk by email:

exeter.helpdesk@nhs.net or by phone: 0300 303 4034

Queries regarding sample taker codes/access to sample taker database please contact by phone: 0300 123 6221

Queries regarding call/recall and ceasing please contact Cervical Screening Administration Service (CSAS). Information is available on their website: https://www.csas.nhs.uk/support/

Queries regarding trainee sample takers please contact your training provider directly:

- PDI: support@pdinet.com
- Rehan Tariq at BLMK ICB rehan.tariq1@nhs.net



## **Appendices**

## Appendix 1: Ceasing and deferring people from the NHS Cervical Screening Programme

Ceasing and deferring women from the NHS Cervical Screening Programme

## **Appendix 2: Open Exeter Guide.**

Open Exeter (OE) database is used to view patients' screening record and to produce and submit cervical sample request HMR101 forms. It is run by Primary Care Support England.

Open Exeter enables a sample taker to produce pre-populated HMR101 sample request forms for the screening patient. This form is sent with the sample to the lab.

#### How to access Open Exeter

Access to Open Exeter can be found here.

Each practice should have a Primary Contact for Open Exeter. This is usually the practice manager. They are able to create user accounts for other members of staff. Every sample taker at a practice should have an account. They will be generated a User Code and password which allows the sample taker access to their account.

The User Code for Open Exeter is not the same as the Sample Taker code. Smart cards can be registered on an individual's OE account to allow them to gain quick access to their account.

#### Cervical screening patient records

Sample taker can view patient's cervical screening history including previous results and patients current recall status, and check patients screening records through Open Exeter.

OE displays the patients who are due to be invited for cervical sample from the sample taker organisation i.e., practice, hospital provider. Sample takers have the ability to.

- View recall type lists o Called o Routine o Repeat advised o Suspended o Inadequate
- Confirm if a patient should be invited
- Postpone the invitation due to recent test, pregnancy etc
- Cease an individual from recall

Sample takers can view and produce a list of patients in their organisation with no record of attending a screening test after having sent an invitation and a reminder letter. Tools within OE can generate an invitation letter to these patients.

#### HMR101 forms for cervical screening

When an individual has their cervical sample test, the sample taker must complete a HMR101 cervical sample request form.



Open Exeter allows the sample taker to produce a pre-populated HMR101 form with the patient's demographic and clinical details and previous test results.

<u>Sample takers will need to add clinical data and their own details including their sample taker code to the form as this information is not pre-populated on the form.</u>

- 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

The form with all the relevant information will then be ready to print as a PDF and be submitted to the lab with the sample.

The type of HMR101 cervical sample request form can vary depending on the lab. The type of form can be selected in Open Exeter. For the labs in the South West.

- For NBT, an editable A4 HMR101 form is used
- For BSPS, the sample request should be placed on ICE and the ICE form printed off and sent with the sample. The service is not yet paperless and so BSPS always need to the request form to accompany the vial. The HMR101 form should not be sent with the ICE form as, when the sample arrives in the laboratory, BSPS will cross reference on Open Exeter for the history if needed.

If ICE isn't working, sample takers should revert to using HMR101 forms and submit that with the sample instead.

Results of the sample will be added to the patients' screening record on Open Exeter, once reviewed and checked by the lab.

#### Contact details

For admin issues and questions i.e., account management and password resets, please contact PCSE by email: pcse.openexeter@nhs.net or by phone: 0333 014 2884

For technical issues and questions i.e., HMR101 forms and access to screening records, please contact the Open Exeter Help Desk by email: <a href="mailto:exeter.helpdesk@nhs.net">exeter.helpdesk@nhs.net</a> or by phone: 0300 303 4034

## **Appendix 3: Sample Taker Register Guide**

In line with the national service specification for the NHS Cervical Screening programme, there is a South West Cervical Screening Sample Taker Register (STR). This is managed by the Bedford BLMK Commissioning Support Unit (CSU).

The cervical sample taker register logs all the sample takers in the South West region. It stores information on individual sample takers including their contact details, their practice/trust/sexual health setting, their training record and their sample taker code.



All health professionals that are cervical sample takers, are required to be on the register. **This includes doctors**. Their training record should be up to date and have the correct contact details.

Access to the Cervical Sample Taker Register can be found here.

#### How to add a sample taker onto the register

The most updated Sample Taker Register User Guide can be found here.

#### **GP Practice sample takers**

All practice managers were sent communications regarding how to access the sample taker register, including amending records. If you are unsure, please click on the user guide above which will direct you to the process you need to follow in order to access the register.

The practice lead for the GP practice is responsible for ensuring all new and existing sample takers working at that setting are on the STR and that their records are up to date. This includes training records for sample takers who are required to attend training and updates.

The practice lead is usually the practice manager or the lead nurse.

GPs are required to sign the 'Sample Taker Confirmation' which can be accessed once logged onto the register.

#### Hospital based/sexual health sample takers

Nurses are required to register their details and upload their training records in order to obtain a sample taker code. It is their responsibility to ensure that their records on the register are up to date.

Doctors are required to sign the 'Sample Taker Confirmation' which can be accessed once logged into the register.

A sample taker who works across settings in the Bedfordshire will only require one sample taker code BUT will need to be listed against all settings that they work from. Please contact the CSU if you require more information on how to do this.

The practice lead for the GP practice is responsible in ensuring all new and existing sample takers working at that setting are on the STR and that their records are up to date.

This includes training records for sample takers who are required to attend training and updates. The practice lead is usually the practice manager or the lead nurse.

GPs are required to sign the 'Sample Taker Confirmation' which can be accessed once logged onto the register.

#### Sample Taker Training

Appropriate sample taker training must be completed and signed off by an official sample taker training provider.



Practice leads can also access reports of sample takers who are due to complete the threeyearly update. It is the sample taker's responsibility to ensure they complete the correct training within the set timescales.

There is national guidance on the training requirements for a returning sample taker. If you require more information on this, please contact the SIT.

Training details can be found here.

## What to do if a sample taker leaves

If a sample taker decides to leave a practice, it is the responsibility of the practice lead to remove them from the sample taker register promptly.

If a sample taker moves to a new GP practice, the practice lead of their current workplace needs to remove them from their list on the register. When the sample taker starts at the new GP practice, the new practice lead will need to contact the CSU service and they will add the sample taker to their new practice. This will include moving their training records.

If a sample taker leaves a hospital or sexual health setting, it is their responsibility to contact the sample taker register to update their record.

#### **Contact Details**

Questions or Issues with the sample taker register or to access a register form, please contact SCWSU/CSU STR by email: <a href="mailto:cervicalsampletaker.scwcsu@nhs.net">cervicalsampletaker.scwcsu@nhs.net</a> or by phone: 0300 123 6221

#### Appendix 4: Making a best interest decision

The decision whether 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 person has the mental capacity to consent to screening if they are 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 their 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 patient may not have the mental capacity to consent to screening and a decision will need to be made whether it is in the patient'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 interest 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 person'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 their behalf permanently to withdraw them from the screening programme. Screening staff should be satisfied that the 'Best Interests' decision has been reached properly. An individual ceased permanently from screening can be reinstated onto the screening list at any time. For further information please see: Ceasing and deferring women from the NHS Cervical Screening Programme