



Toolkit

Increasing the uptake of
Cervical Screening in people
with a learning disability



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How to put people at ease and have a conversation with patients and carers

Consider or think about:

- how the person communicates – you may need to ask carers if they will need an interpreter or signer at the screening appointment (some people with learning disabilities would also use **Makaton** rather than **British Sign Language**)
- which word the person uses for vagina so that you don't get misunderstandings
- offering a pre-visit so the person can feel safe while you explain the test
- using an alternative venue, if appropriate
- showing the speculum and sample brush to the person – let them handle it and explain how they work
- showing the person the position they will need to be in when they have the test and encouraging them to get onto the examination bed to see what this feels like
- suggesting the person practices the position at home so they feel more comfortable about it (this can be done with their clothes on in their bedroom where they feel relaxed, and carers may need to support this)
- reassuring the person that they can have a friend, relative or carer present during the test if they would like to
- offering a longer appointment and a first appointment if needed
- ways to help the person feel relaxed, such as music

Remember, the person needs to understand what will happen at the test.

They must be able to:

- remember this information for as long as it takes to do the test
- understand that by having the test it will help them to stay healthy
- give consent, by any communication means, to try to have the test done
- have an understanding of the signs and symptoms of cervical cancer (see **an easy guide to cervical screening**)

What to do if you are not sure if the person with learning disabilities consents to the screening

1. **Does the person understand the information given?**
2. **Are they able to retain the information long enough to make a decision?**
3. **Are they able to make a free choice?**

The requirements of the Mental Capacity Act must be met.

Consider whether previous assessments of capacity have been undertaken for the person for other interventions, and whether these can be used to help inform understanding of the person's general current level of capacity. This information, if available, could provide a good starting point for an assessment of capacity relating specifically to the cervical screen.

If the person has not understood enough to make their own decision on cervical screening you need to make a best interest decision for them.

To make a best interest decision, you need to have a discussion with people who know them well. These would usually be family and carers. Include the person in your discussion as much as possible. Discussions do not have to be face to face. Opinions on what is in their best interest can be collected through telephone calls.

A best interest decision is based on your reasonable belief at that time.

Also consider:

- obtaining the opinion of an independent advocate if professionals, families, and carers cannot or do not agree on what is in the person's best interest
- reviewing the person's past screening history
- their beliefs and wishes, which could influence a best interest decision for them

If the person has previously attended screening, this implies they once felt it was important. This knowledge could influence you and others when making a best interest decision for them.

When a person cannot manage to have cervical screening, you must consider other ways of keeping them safe from cervical cancer. This can include educating the person, their family and carers about the signs and symptoms of cervical cancer.

Every time a best interest decision is made that cervical screening is not appropriate, education should be given. This ensures all family and carers have up to date information.

Ceasing verses deferring people with learning disabilities

National guidance is for the preference of deferring rather than ceasing people with learning disabilities from the cervical screening programme. People with learning disabilities can often understand and consent to screening with adequate support and preparation. Learning disability alone is not a valid reason for ceasing. If the person isn't ready for a screen at a point in time, then deferring enables the situation to be revisited and with support may be able to have their cervical screen.

People with learning disabilities can be ceased from the cervical screening programme for having no cervix, having certain types of radiotherapy or under the Mental Capacity Act 2005. If a ceasing decision has to be made on behalf of a person who lacks capacity, the person who makes the decision is known as the decision-maker. This will usually be a healthcare professional such as the person's GP, or other responsible clinician if there is no GP. The decision-maker may only act if the person cannot make their own decision even with support and assistance. The decision-maker is legally accountable for any decision made which affects the person now or in the future. More information can be found at: **Ceasing and deferring women from the NHS Cervical Screening Programme** (www.gov.uk)

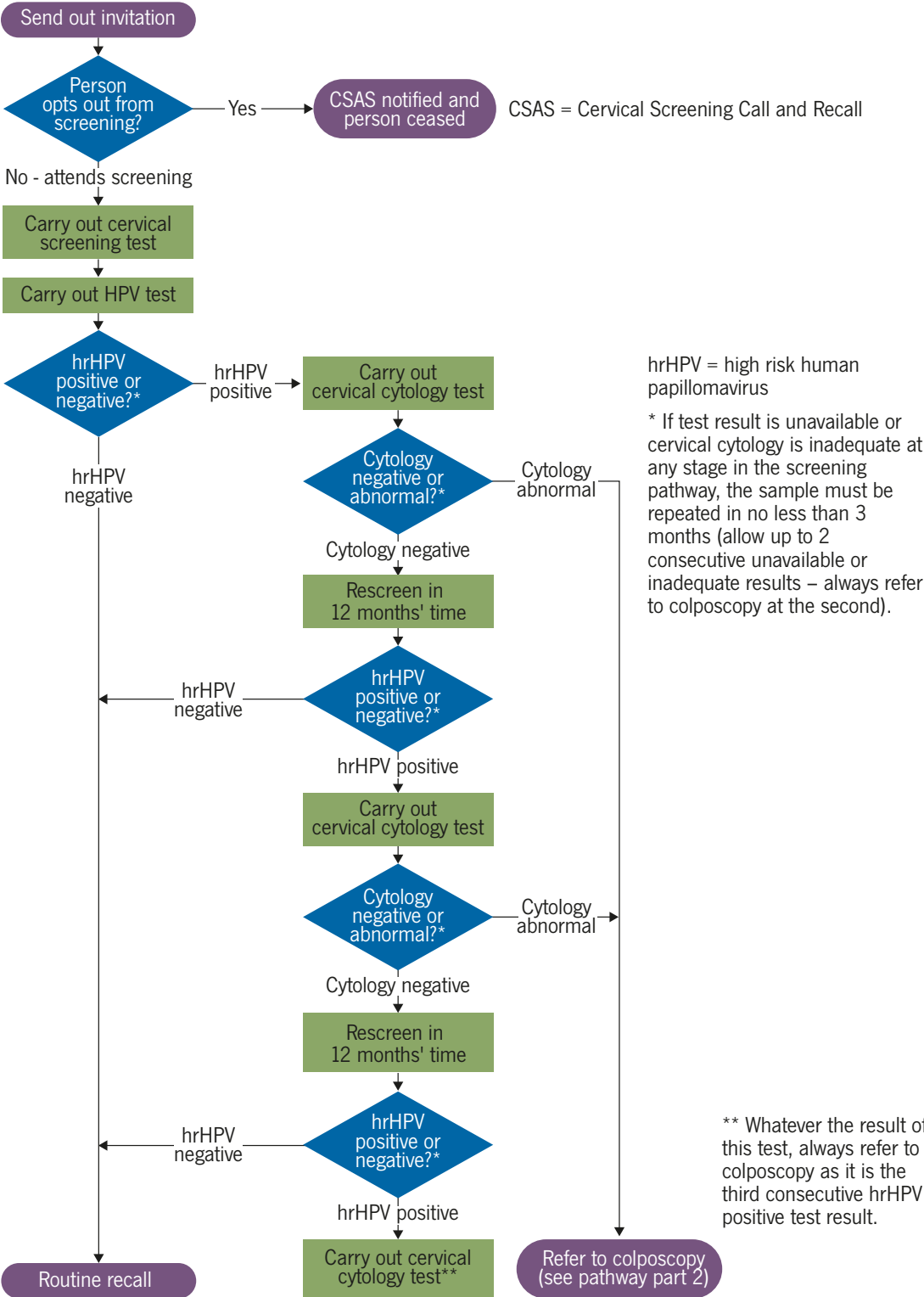
The correct deferring and ceasing forms with more details on where to submit them can be found at: **Primary Care Support CSAS**. The following link will download the **Cervical Screening Programme Deferral** online form. Here is a screenshot for reference.

The screenshot shows the 'Cervical Screening Programme Deferral' form from the NHS Cervical Screening Administration Service. The form includes fields for participant details (Full Name, NHS Number, Date of Birth, Address), deferral duration, and reasons for deferral. It also has a section for practice details (signature, name, address) and a GP National Code. A note at the bottom states: 'Please note that fields marked with an asterisk (*) are mandatory'. The document reference is PC-CS-010/001 V3.1.

Cervical Screening Programme Deferral	
<small>This form should be used if a participant's next test is to be postponed. The reason for postponement and new deferral date must be specified. The participant will be invited for screening approximately 5-6 weeks before the end of the deferral period.</small>	
Participant Full Name*	Click here to enter text.
Participant NHS Number*	Click here to enter text.
Participant Date of Birth*	Click here to enter a date.
Participant Address*	Click here to enter text.
Please defer until (DD/MM/YYYY)* (See below for maximum deferral months)	Click here to enter a date.
Deferral Reason (Please select only one)*	
<input type="radio"/> Recent Test - Max 3 months	
<input type="radio"/> Pregnancy Related - Max 12 months	
<input type="radio"/> Under treatment relevant to screening - Max 12 months	
<input type="radio"/> Patient request to defer - Max 18 months	
<input type="radio"/> Under care of Colposcopy - Max 12 months	
Practice details	
Doctors/Nurse/Clinician signature*	
Full Name (Printed)*	Click here to enter text.
Date*	Click to enter a date.
Practice Name*	Click here to enter text.
GP National Code*	Click here to enter text.
Practice Address*	Click here to enter text.
<small>Next steps for Practices: Once completed and signed, please upload this form via the CSAS website. You should use the online enquiry form on the 'Contact Us' page and select the 'Deferral' option. Keep the original copy in your files.</small>	
<small>Please note that fields marked with an asterisk (*) are mandatory</small>	
<small>Document reference: PC-CS-010/001 V3.1</small>	

Map of the pathway

Flowchart part 1: sample taking and HPV testing and cytology triage



Screening Process

Eligibility

Every person who has a cervix and is within the screening age range (25-64) is eligible for NHS cervical screening regardless of their gender identity.

The patient will be invited for the first time up to 6 months before you turn 25. They will get a letter in the post inviting them to contact their GP to book an appointment.

- Patients between 25 and 49 will be invited **every 3 years**.
- Patients between 50 and 64 will be invited **every 5 years**.
- Patients aged 65 or older will only be invited if 1 of their last 3 tests gave an abnormal result.

How many invites will the patient get and who sends them?

The national screening programme invites the patient and will send out two letters.

A third reminder will come from the patient's GP surgery, this may be a letter or text message.

Who follows it up?

The patient will be informed about the result from the national programme, usually within two weeks.

What happens if it is abnormal?

The patient will be invited for further tests involving colposcopy appointment at their local hospital – see the onward pathway here **Cervical screening care pathway – GOV.UK**

Common Misconceptions

HPV can be transferred from any skin-to-skin contact of the genital area.

You do not need to have had sexual intercourse.

Sexual contact includes vaginal, oral or anal sex.

What recent changes have there been to the programme?

The screening programme is now primary HPV which means that the sample is tested for the Human Papillomavirus first and then examined for abnormal cells if HPV is found.

Is there an alternative to the GP surgery?

Your local **colposcopy unit** will take a sample for service users that find it difficult to maintain a pose or where it is difficult to see the cervix for other reasons.

Contact details:

- Princess Anne Hospital, Southampton – **023 8120 6034**
- Queen Alexandra Hospital – **023 9228 6000 ext: 4234**
- Basingstoke and North Hampshire Hospital – **01256 313353**
- Royal Hampshire County Hospital – **01962 824684**
- St Mary's Hospital, IOW – **01983 534350**
- Dorset County Hospital – **01305 255444**
- Royal Bournemouth Hospital – **01202 704740**

In Dorset, it is possible for service users to access their local sexual health service for longer appointments or for any of the reasons stated above.

Contact details:

Call **0300 303 1948**

Phoneline open 08.15-17.00 Monday - Friday (closed 12.30-13.30 for lunch)

Who should you contact if you have any problems?

The screening and immunisation teams

- Dorset: **phcontractssouthwest@nhs.net**
- Hampshire and Isle of Wight: **england.hiow-SIT@nhs.net**

Other contact details

- Hampshire and Southampton Community Learning Disability Service
 - Amy George – South East Hampshire: **023 8231 6350**
 - Becky Sparks – Southampton: **023 8231 0300**
 - Marta Coates – North and Mid Hampshire: **01962 764560**
- Portsmouth Integrated Learning Disability Service, Julie Chapman **0300 123 4019**
- IOW Learning Disability Liaison Team – Steven Reynolds
Telephone **01983 822099 ext 5478**
Liaison Mobile: **07795 121674**
Email: **iwnt.LDLiaisonTeam@nhs.net**
- Dorset: **www.dorsethealthcare.nhs.uk/learning-disabilities**

Further resources and information

- **Wessex Cancer Alliance Primary Care Toolkit**
- **Cervical screening: supporting women with learning disabilities**
- **Cervical screening: support for people who find it hard to attend**
- **Health Inequalities and Cervical Cancer – Public Health Fingertips tool**

