

Cervical screening for people with learning disabilities: Learning resource for sample takers





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1. Why focus on people with learning disabilities

Cervical cancer is preventable. By 2040 the NHS in England is aiming for a cervical cancer incidence rate of below 4 per 100,000 women (elimination status).

To achieve this, we need to increase HPV vaccination rates and improve attendance for routine cervical screening particularly in younger people and underserved communities including patients with learning disabilities.





People with a learning disability are now living longer lives and, likely because of this, the incidence of cancer for people with a learning disability is therefore also increasing (Havas et al., 2022; Willis et al., 2018; White et al., 2023).

Many people with a learning disability have greater health needs than the general population, for example, they are more likely to experience mental ill health and chronic health problems. It has also been evidenced that the life expectancy for women and people with a cervix with a learning disability is 27 years lower than for women and people with a cervix in the general population and though improving, only 38% of people with learning disability will live beyond the age of 65, compared to 85% of the general population.

Nationally the number of women and 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 under-represented groups such as those from lower socio- economic, ethnic minorities, LGBTQ+ communities and people who have learning disabilities.

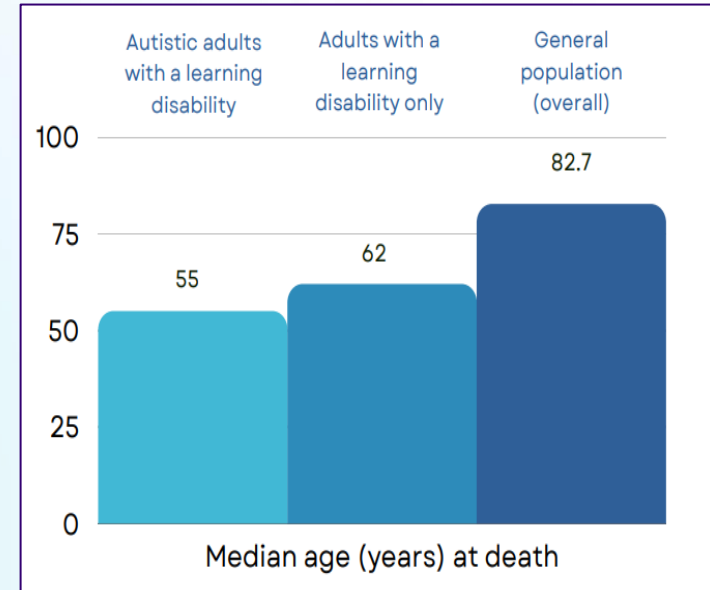
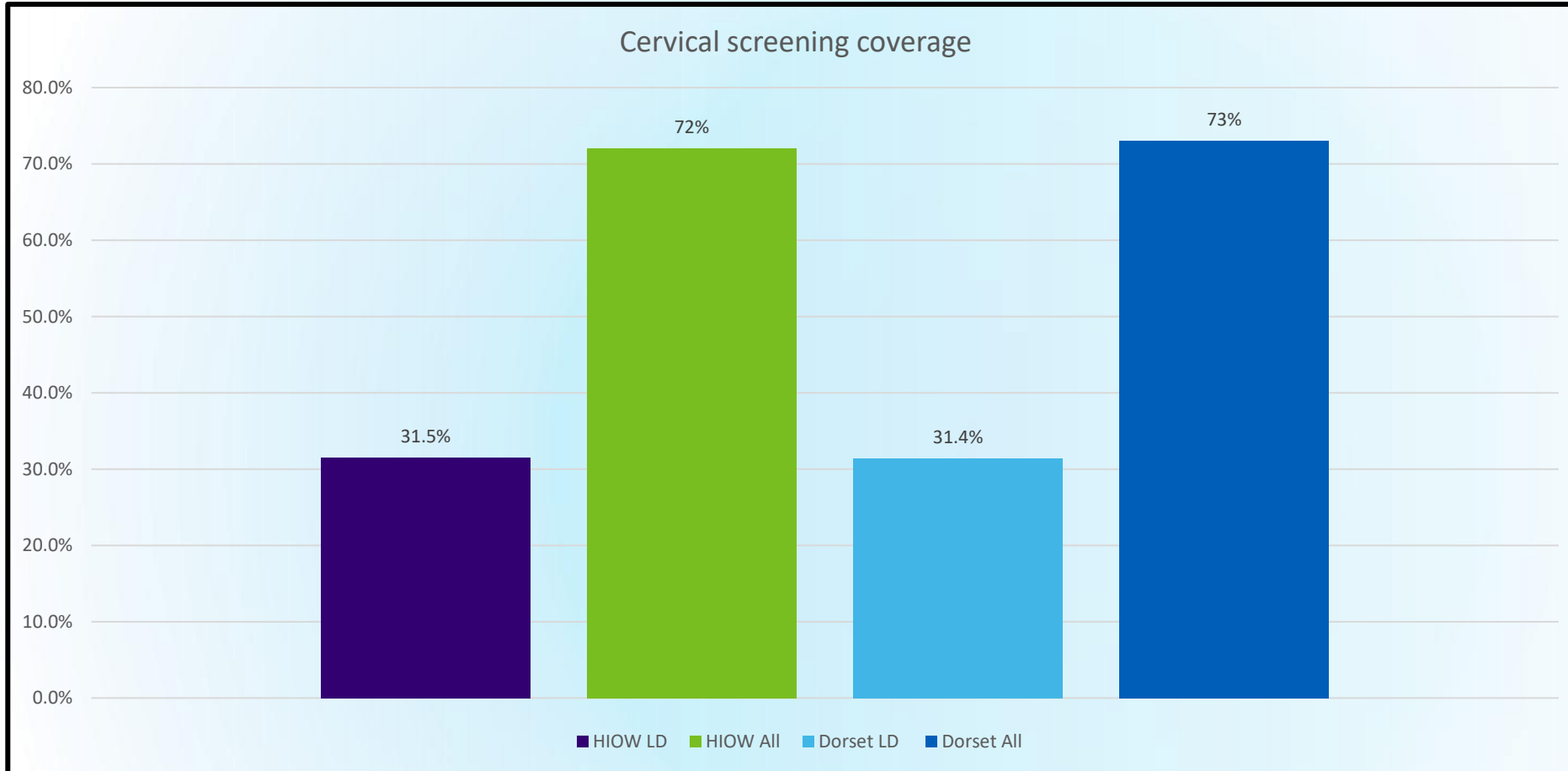


Image Source: [Master LeDeR 2023 \(2022 report\)](#)



Activity 1: Using the QI tool found [here](#) and with the support of your data lead, can you find out how many people on the learning disabilities register at your practice/PCN are or are not coming for cervical screening?

Source of data:

HIOW: March 2024 https://files.digital.nhs.uk/FC/187D35/health_care_ld_sicbl_2023-24.csv

Dorset: March 2025 DiIS

Coverage vs uptake: screening coverage measures the proportion of eligible individuals who have been adequately screened within a given timeframe, while uptake measures the proportion of invited individuals who actually attend their screening appointment





2. Misconceptions and barriers

- People with learning disabilities are not sexually active
 - *Consider their individual needs*
 - *Consider the possibility of abuse/vulnerability*
 - *Consider that they may identify as transgender, non-binary or lesbian*
- People are only at risk if they are having penetrative vaginal intercourse
 - *Cervical cancer is caused by a virus which can be transferred from any skin-to-skin contact of the genital area, not just sexual intercourse.*
 - *Sexual contact includes vaginal, oral or anal sex.*

Activity 2.1: Watch the video [Love doesn't discriminate, let's celebrate love #CelebrateTheLove](#)





Consider the following potential barriers

Invitation process:

- Letter
- NHS App
- Text
- Literacy
- Ceased in error

Psychological:

- Fear
- Trauma
- Expectations
- Previous experience
- Embarrassment
- Sensory overload

Knowledge:

- What is cancer?
- What is cervical cancer?
- What is a cervix?
- Symptoms

Carers:

- Knowledge
- Support
- Culture
- Frailty
- Social isolation

Access:

- Telephone
- E-consult
- Physical
- Transport

Communication:

- Language
- Understanding
- Appropriate resources

Environment:

- Restricted space
- Clutter
- Uninviting
- Unclear signage

Staff:

- Lack of awareness of the patient's needs
- Time
- Confidence
- Knowledge



3. Consent and best interest decisions

The patient must be able to: **Understand – Retain - Weigh up - Communicate**

Under the Mental Capacity Act (MCA) 2005, people must be presumed to have capacity to make their own decisions unless it is proved otherwise. The five key principles of the MCA are as follows:

- **Principle 1:** It should be assumed that everyone can make their own decisions unless it is proved otherwise.
- **Principle 2:** A person should have all the help and support possible to make and communicate their own decision before anyone concludes that they lack capacity to make their own decision.
- **Principle 3:** A person should not be treated as lacking capacity just because they make an unwise decision.
- **Principle 4:** Actions or decisions carried out on behalf of someone who lacks capacity must be in their best interests.
- **Principle 5:** Actions or decisions carried out on behalf of someone who lacks capacity should limit their rights and freedom of action as little as possible.

Ensuring an appropriate implementation of the Mental Capacity Act is everyone's business; this includes mental capacity assessments. If this resource highlighted any gaps or learning needs around MCA for you, please see the information on the resource pages. If you need support with a mental capacity assessment for a specific patient, please discuss this with your team leader and/or LD lead in your practice.



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 Makaton, communicative devices a person may use such as PECS (picture exchange system) or tablet apps or by simple muscle movement such as blinking or squeezing a hand.

What should you do if the person has not understood enough to make their own decision?

- You need to make a best interest decision for them.
- You need to have a discussion with people who know them well (family and carers).
- Include the person in your discussion as much as possible.
- Discussions do not have to be face to face (telephone calls acceptable).
- It all needs to be recorded in the patient's notes.

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



Unable to consent to screening

If a patient is unable to consent or declines to have screening, you must consider other ways of keeping them safe from cervical cancer. Options include:

- If the patient needs to have a general anaesthetic in a separate future procedure, for those unable to consent, it could be in their best interest to have a cervical screening test done at the same time. Ensure this is documented as a high priority medical history computer entry so the it can be reviewed should such an opportunity arise.
- Education for the patient, their family and/or carers about the signs and symptoms of cervical cancer would be considered best practice for both those who have declined screening by informed choice or who are unable to consent to cervical screening.

Every time a best interest decision is made that cervical screening is not appropriate at that time, records should be updated education should be given. This ensures that all patients and carers have up to date information. The annual learning disability health checks are an opportunity to check understanding and discuss screening.



4. Ceasing or deferring

If a best interest decision is made for an individual with learning disabilities that they cannot accept the cervical screen at the time offered or they refuse the current offer, the national guidance states a **preference of deferring** rather than ceasing from the cervical screening programme in case the offer is accepted in the future. 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 they 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, Advanced Nurse Practitioner or other responsible clinician.
- 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 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/guidance/ceasing-and-deferring-women-from-the-nhs-cervical-screening-programme)

The correct deferring and ceasing forms, with more details on where to submit them can be found at: [Cease/Defer/Reinstate/Gender Opt-In Support – NHS Cervical Screening Administration Service](https://www.nhs.uk/healthcareprofessionals/cervical-screening/cease-defer-reinstate-gender-opt-in-support)



5. Role of sample taker

A whole team approach is important to ensure women and people with a cervix can access screening. It is therefore important that all clinicians and reception staff are aware of the importance of cervical screening.

All staff should be trained in cervical screening relevant to their role:

- Sample takers are up to date with the latest training (found here: [NHS Cervical screening: cervical sample taker training - GOV.UK](#)).
- Sample takers have read and are following good practice guidance [NHS Cervical Screening Programme – Good practice guidance for sample takers - GOV.UK](#)
- Reception staff have had training on communicating about cervical screening with patients.
- Be aware of and trained in how to provide reasonable adjustments [Cancer screening: making reasonable adjustments - GOV.UK](#)
- Clinical staff to encourage and facilitate attendance at Annual Health Checks.
- Be prepared to refer to an alternative provider e.g. colposcopy, if your patient is unable to hold the position or you are unable to view the cervix.



Reasonable adjustments at your Annual Health Check



Reasonable adjustments means changing things to make it easier for you.



Asking your doctors surgery to make reasonable adjustments can help you to have a successful Health Check.



These changes could be:

- Using pictures or easy read information
- A longer appointment
- Using simple language to help explain things
- Checking you understand what is being said to you
- Choosing an appointment time and day that's best for you



Contact your doctors surgery before your Health Check and let them know what reasonable adjustments you will need.



The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use the services. This means they need to change their services so they are easier to use



- As a cervical sample taker, you can:
 - Advocate for your patients to enable them to access services
 - Inform and educate patients and carers
 - Suggest quick and engaging training sessions – such as discussions on difficult scenarios or cervical screening myths and facts.
 - Take case studies to team meetings.
 - Suggest a staff newsletter with links to the latest resources or research.
- As a nursing team leader/line manager you can think about:
 - Scoping/implementing service improvement
 - Arranging educational sessions on cervical screening as part of GP Protected Learning Time (PLT)
 - Assisting with the implementation of a newsletter.
 - Promoting interdisciplinary working between staff members
 - Setting up a buddying system with other practices to share learning and tips for improving access to cervical screening



[Engaging Leadership – a better approach to leading a team? | Nursing Times](#)



6. Improvement initiatives*

Appointment familiarisation

- Use pre-exposure and desensitisation to familiarise individuals with the procedure, equipment and screening setting
- Provide social stories to explain what will happen
- Familiarise patients with the cervical screening room and equipment – this could involve inviting them in for a preliminary visit
- 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
- If not able to meet before, show a photo of screener in advance

Sensory considerations

- Booking longer appointments to give them time to relax and become familiar with their surroundings and the sample taker
- Personalise appointment times - provide dedicated time slots that are quieter, longer, in a small space etc
- Book in appointment for times when the waiting room is quiet and there is no-to very little queuing
- No sound from staff other than the screening sample taker
- No keys, or anything else that might make a noise in the room
- No perfume or aftershave to be worn by staff

Communication support

- Ensure appropriate contact made from very the start of pathway – invites with relevant information
- Use of pictorial guides designed to support people with learning disabilities
- Provide easy read resources - letters, booklets, films, audio, story boards – don't always rely on social media
- Use of braille/large print for people with visual impairments
- Use short clear instructions, using three-word sentences – 'less talk more action'
- Use Makaton symbols and signs to aid understanding

Emotional support

- Prepare people psychologically for screening to enhance understanding, increase predictability and minimise anxiety
- Provide reassurance, support and understanding to individuals and their families, carers and support workers
- At the appointment, check for behavioural signs of compliance with the procedure
- Throughout time with the patient show a positive attitude and provide emotional support

* All the above are dependent on individual needs and wants. Please take time to get to know your patient.

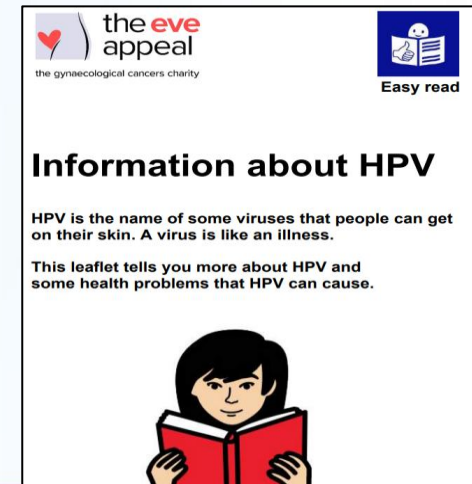


7. The annual health check

- Check HPV vaccination status and if eligible offer vaccination, provide information and support. Resources can be found [here](#) on our primary Care Toolkit 'Prevention' pages.
- Use this opportunity to familiarise patients with NHS screening programmes **before** they become eligible. For ideas see number 6.
- Use film resources, either to watch with the patient or for them to view at home.
- Ensure you have a supply of easy read materials to go through with them and their carer.
- Be ready to respond to questions and to record any adjustments needed to support the patient to attend for screening.
- Check that the patient hasn't been ceased from screening programmes in error
- Ask if the patient has access to the NHS App, provide easy read access information if required.



Activity 7: Find out who conducts annual health checks at your surgery and talk to them about how they discuss cancer screening with patients.





8. Good practice examples

Three short appointments:

- **First visit:** the person met with the nurse and looked at the equipment.
- **Second visit:** the person lay on the bed fully clothed and got into the position.
- **Third visit:** They had a successful cervical screening.

Why it worked: Familiarity helped to reduce anxiety and a gentle pace helped to build trust.

Social stories:

A social story was co-created with a woman with autism and a mild learning disability to explain each step of the cervical screening process. It:

- included real photos of her GP surgery and nurse carrying out the procedure.
- used her name and preferred language.
- described the sights, sounds and feelings to expect.

Why it worked: She could rehearse the story with her support worker, reducing sensory anxiety and increasing her sense of control.



9. Case study

A Nurse completed a cervical screen for a lady with learning disabilities, having first of all provided her with information about the procedure and gaining her consent.

When the Nurse rang the lady to discuss her results the lady then said, "What screening test?"

The Nurse then had to remind the lady of the cervical screening being completed and what had happened.

The Nurse was then worried that this lady did not have the capacity to consent to the decision to have cervical screening as she had not remembered having it completed.

Learning points

Capacity is time specific. At the time of the cervical screen the patient understood the procedure, the pros and cons of not having it and had agreed to have it done.

This case study identifies the importance of good documentation within your notes of what you have done to ensure the person is providing informed consent. Just as you would "show your workings" on an exam paper, document your conversations and prior work also.



10. Reasonable adjustments aide memoir

The [Equality Act \(2010\)](#) states all organisations including health and social care, such as hospitals and **GP surgeries** must take steps to remove the barriers individuals face because of disability.

The NHS must make it as easy for people with disabilities to use health services as it is for people who do not have a disability.

Practices can have the Reasonable Adjustment Flag added to the patient's record (see resources). This is a national record that shows a person needs accommodations and may include details about their impairments and necessary adjustments.

Remember

- Reasonable adjustments are changes that can be made to support a person with a learning disability.
- Some people may not need reasonable adjustments.
- For others, these changes can help them access healthcare in a way that suits them best.

Activity 8: Print out or copy to desktop the next picture to help staff consider what they can do to support patients with learning disabilities or neuro diversity.

Communication

- Use non-technical, simple language or Makaton
- Use pictures / communication aids.
- Easy read resources
- Give clear instructions / procedures to follow
- Find out which words are used for body parts

Environment

- Pre surgery visit
- Separate entrance e.g. fire exit
- Remove unnecessary medical equipment
- No uniforms

Reasonable adjustments
(consider use of the reasonable adjustment flag).

Cervical screening specific:

- ❖ Which word does the person use for vagina?
- ❖ Show the person the speculum / sample brush
- ❖ Show the person the position they will need to be in.
- ❖ Suggest the person practices the position at home



Time

- Longer / double appointments
- Convenient times (when carer available)
- Minimise waiting times
- Specific time of the day e.g. first appointment of the day

Sensory

- No strong smells
- Reduce light/noise where possible e.g. radio
- Quiet (separate) waiting area
- Appointment at quieter time of the day
- Use of headphones



11. Resources

- [NHS App: How to get started using a computer - NHS App - How to get started using a computer - Easy Read](#)
- <https://www.makaton.org/>
- [Cancer screening: making reasonable adjustments - GOV.UK](#)
- [Relationships and Sex and Learning Disability | Mencap](#)
- [Learning disability - applying All Our Health - GOV.UK](#)
- [Reasonable Adjustment Flag - NHS England Digital](#)
- E- learning for health, Mental Capacity Act: [NHSE elfh Hub](#)
- Health professional queries / report incidents in the cervical screening programme contact:
 - HIOW england.hiow-sit@nhs.net
 - Dorset england.swvast@nhs.net



12: Drop-in sessions via teams

- Sessions are held quarterly and advertised via:
 - the WCA [Primary Care Bulletin](#) if you wish to subscribe to this bulletin, please email wessexcanceralliance@wca.uhs.nhs.uk
 - Wessex Cancer Academy [Events - Welcome to Wessex Cancer Alliance](#)
- Opportunity to share good practice, updates and discuss scenarios.
- Learning disability health facilitators will be available to support with queries.
- Sessions are open to sample takers, administrators, screening leads and cancer care coordinators.