

**The
Advonet
Group**

Providing Independent Advocacy



**Leeds
Autism
AIM**

Strategies and Resources

Autistic Health Access: Cervical Cancer Screening

What are Cervical Cancer Screenings For?

Cervical Cancer Screenings are important for maintaining physical health and detecting cancer, or pre-cancerous cells early for monitoring and treatment.

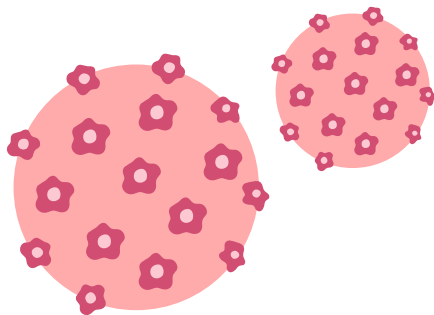
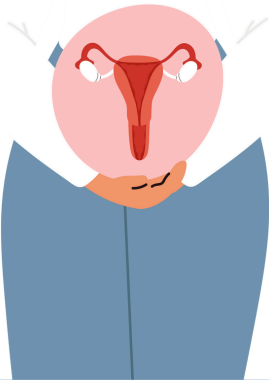
This guide will discuss autistic access to cervical cancer screening, including key information, access barriers and reasonable adjustments.

Importance of Screening:

Early detection of abnormal cells, HPV and cervical cancer help to maintain your physical health and know your own status.

Cervical cancer screening saves approximately **5,000** lives per year with early detection and treatment (UK Gov).

99.8% of cervical cancers are caused by the Human Papilloma Virus (Brown et al, 2018).



What is the Human Papilloma Virus (HPV)?

There are more than **150 different types of HPV**, many of which are asymptomatic and some which cause small white, brown, or beige warts on the skin, throat, sex organs, cervix or anus.

Up to **80%** of the sexually active population will have HPV at some point in their lives. It is spread via direct skin to skin contact and is highly contagious. It can remain dormant for years.



Prevention, Risk Reduction and HPV Vaccine

What is the HPV Vaccine? How does it help?

The HPV vaccine helps to reduce the risk of getting HPV, and this in turn helps to reduce the risks of cervical cancer, warts and cell abnormalities.

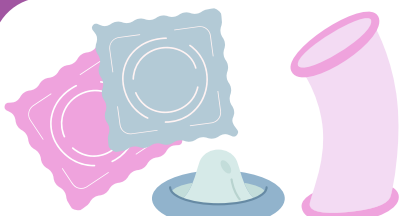
It is still extremely important to have your cervical cancer screening if you have had the HPV vaccine as it only protects against some strands of HPV, but not all of them.

Not all strands of HPV cause cancer and some are harmless, but HPV is the main cause of cervical cancer and you need to be screened regularly to improve treatment outcomes and allow for early detection.

Who should have the HPV vaccine?

The **NHS guidelines** state that following groups **should** be vaccinated for HPV:

- Everyone with a cervix and/ or uterus under 25 years old
- Everyone under 20 years old, or born in or after the year 2006
- Men aged 45 and under who have sex with men
- All women and nonbinary people under the age of 45 who feel they are at the same risk as men who have sex with men
- People with HIV and weakened immune systems



Take Precautions to Reduce Transmission Risk e.g. Dental Dams, or Condoms



Check with GP, or Sexual Health Clinic about Eligibility for Vaccine



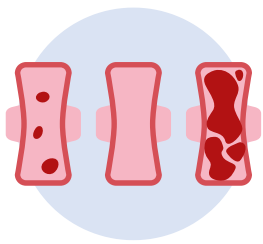
Plan and Book Vaccination Date

Symptoms of Cervical Cancer

Please visit your GP, if you have **any symptoms** of cervical cancer. Remember menstrual bleeding and vaginal discharge are not embarrassing conversations and important to your bodily health.

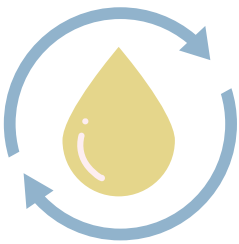
These symptoms can be common, but **please get them checked**.

Symptoms to Be Aware Of:



Unusual Vaginal Bleeding

This can occur between periods, after sex, or physical activity and may occur alongside other symptoms e.g. pain, or bloating.



Changes in Vaginal Discharge

This may include increased discharge, discharge that is discoloured, such as yellow, grey, brown or green and discharge with blood inside.



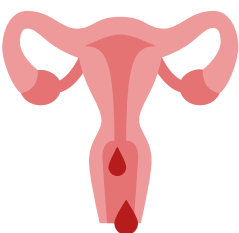
Pain During and/ or After Sex:

Feeling pain or discomfort during sex, this includes digital penetration with fingers or toys. As autistic people we can get delayed pain responses, so you may also feel pain after sex.



Lower Abdominal or Back Pain:

Persistent and regular pain in the lower abdomen and back areas can be a symptom, alongside bloating, difficulty urinating, or pain during urination and blood in the stool.



Heavier Menstrual Bleeding and/ or Cramps:

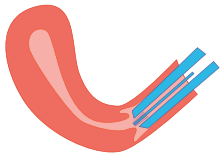
This can include more clots in the bleeding, bleeding so heavy that you need to change your menstrual products more regularly, or if you are doubling up menstrual products.

What to Prepare Before Your Screening

Planning for a cervical cancer screening, especially if it is your first time, and in most cases years have past can help improve your upcoming experience.

If you plan for your screening then you can better self-advocate for your needs and experiences, as well as implement key support options beforehand.

Below outlines some key tips on how to prepare for your appointment:



Awareness of Procedure and Follow-Up

You can educate yourself on what the cervical screening process is, and what to expect on the day. You can request a pre-appointment call or visit if you want to discuss what to expect and familiarise yourself.



Chaperone and/ Or Support Person

Check availability of support person, if you would like to be accompanied to the appointment, or request a chaperone with your GP.



Reminders and Visual Aids

Written or visual reminders can help you to plan and remember key details about your cervical cancer screening appointment e.g. when.



Knowing your Needs and Limits

Think about ways to support your needs at the appointment e.g. having autism-specific pain scales. Think about your boundaries or limitations too. Know it is okay to ask for a break, or tell them if it is painful to stop.



Request for Adjustments and/ Or Inclusive Language & Resources

Notify your GP in advance of your adjustments, or to check existing ones, if you have them flagged on your NHS patient record. Send reminder to staff to use inclusive and affirming materials, or that you may use specific words for your body parts.

Cervical Cancer Screening Process

Not everyone is invited to cervical cancer screening, but may still need one.

If you are unsure, **please check with your GP.**

Be aware that if you have a **cervix** and are between the **age of 25 to 64 years old**, then you are eligible for screening **every 3-5 years.**

Cervical Cancer Screening Steps



Book Appointment for Screening

You should be invited to book your screening, but certain groups of people will not e.g. trans men and nonbinary people, international students and refugees. Avoid booking on period.

Please use a booking system that works for you e.g. PATCHS.

Submit Adjustments or Book a Visit Beforehand

If you would like adjustments during your cervical screening, please let your GP know in advance and you can book a visit to discuss the screening beforehand.



Arrive at Appointment & Initial Checks:

You can request a quiet waiting area before the screening to reduce sensory overwhelm. Once in the room the nurse will check your name, age and sexual history, as well as allowing you time to ask questions and explain the procedure.



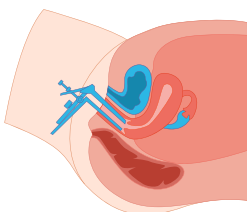
The Exam Table and Positioning:

You will remove clothes on your lower body, including underwear. You will be asked to lay down on the table with your knees bent outward and legs open. If you have mobility needs they can support this with adjustment requests.



Sampling & Cervical Cell Collection:

This test should only take 2-3 minutes, and if you need a break, or it is painful then you can let them know. The nurse will take a speculum and insert it in your vagina with lube, a small brush will be used to collect cells from your cervix.



Understanding Your Screening Results

After your sample has been collected, then it will be sent to the lab for testing.

Your results will be sent to you within **14 days**, either via letter, text, call, or via the NHS App. You may be invited to an appointment to discuss the results, and if you have not heard anything please contact your GP.

Negative Test

If you receive a negative test then this means the sample did not detect any HPV, or abnormal cells.

Your next cervical cancer screening will be in 3-5 years. Please get back in touch with your GP, if you have any concerning symptoms and you require earlier retesting.

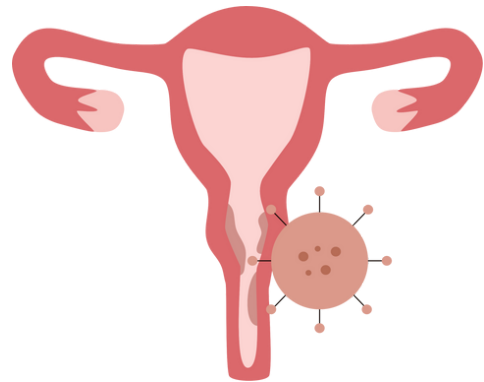


Positive Test for HPV

If you receive a positive test for HPV. Then you will be invited for screening in 1 year.

If you test positive again, you will be invited for re-testing again in 1 year.

If you still have HPV after 2 years, you'll be asked to have a colposcopy.



Positive Test for Abnormal Cells

You are likely to get an urgent referral for more tests, or to see a specialist in hospital if the test results show that you have abnormal cells. This does not definitely mean you have cancer.

You will have further testing and be referred to a specialist for a colposcopy exam to look at your cervix.



Access Barriers for Autistic Adult

What are the access barriers to cervical cancer screening for autistic adults?

Autistic adults can face multiple access barriers to health care and this includes during cancer screening processes. This can be due to lack of inaccessible information, staff training or a lack of support for adjustments, for example. **Please see barriers pictured below.**

How do we address the access barriers?

We can address the access barriers collectively and personally by implementing reasonable adjustments (**go to page 6**) and consulting with medical staff about access needs. As well as providing patient feedback, joining patient health forums, or contacting your MP.



**Unclear Invite, or
Communication**



**Lack of Travel Support,
or Travel Plan Guidance**



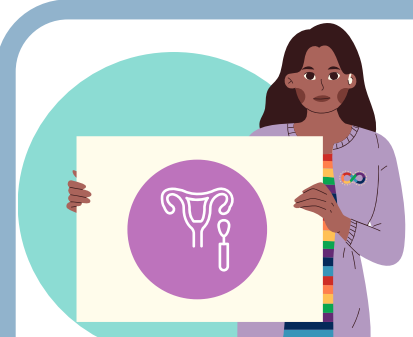
**Inaccessible
Appointment Booking**



**Sensory Overwhelm
from the Room**



**Medical Trauma from
Able/Disablism**



**Lack of Autism-
Specific Resources**

Intersectional Access Barriers

What are the intersectional access barriers to cervical cancer screening for autistic adults?

Autistic adults can face multiple access barriers to cancer screening, which can be compounded by intersectional health barriers. Intersectional health barriers are for example being autistic and a refugee, and not having access to an accessible translation service. **Please see barriers pictured below.**

How do we address the intersectional access barriers?

We can address the intersectional access barriers collectively and personally by implementing reasonable adjustments (**go to page 6**) and consulting with medical staff about access needs. As well as pushing for systemic and inclusive change to improve screening options for all.



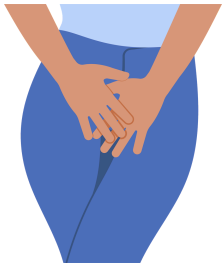
**Financial/ Time Limits
e.g. Working Two Jobs**



**Lack of Culturally
Sensitive Training & Info**



**Lack of Translation
Services e.g. British
Sign Language**



**Fear of Intimate Exams
Due to Past Trauma, or
Bodily Taboo**



**Inconsistent Screening
Invites for Trans People
and Refugees**



**Exclusionary Language
& Resources e.g.
Trans Erasure**

Reasonable Adjustment Checklist

Mobility Access e.g. adjustable exam tables, or wedges to support legs in position.

Sensory Toolkit for Sensory Regulation

Exit Plan and Word to Signify Overwhelm

Use AAC, or Visual Aids for Communication

Check for False Consent and Uncertainty

Running Consent with Clear Explanation

Show Equipment Beforehand e.g. speculum

Nonverbal Reassurance E.g. Pass Stim Tool

Sensory Inputs Reduced E.g. Lights Off

Sensory Stimulation Provided E.g. Music On

Extra Time to Better Meet Processing Needs

Visual Guides e.g. building map, or this guide

Helpful Reasonable Adjustments for Screening



**Request Chaperone, or
or Support Person**



**Written Summary &
Clear Follow-Up**



**Use of Preferred
Communication**



**A Quiet Waiting &
Recovery Space**



**Mobility Access e.g.
Adjustable Exam Table**



**Stim Toolkit for
Sensory Needs**

Trauma Informed Support at Your Screening

Autistic people are more likely to have experienced sexual trauma, than our non-autistic peers. This means that feeling safe, supported and heard in cervical cancer screenings is important for our mental wellbeing.



Inform Staff

If you feel comfortable, then you can let staff know about your history, triggers and trauma. This could be before the appointment, or during the pre-screening chat, so they can help.

Bring Support



Support could be a trusted friend, family member, support staff or a chaperone provided by the NHS. They can be at the screening appointment to reassure you and witness.



Request Running Consent

The medical staff member performing your screening can be requested to practice running consent. This is where they explain each step of the procedure as it happens, and that they check before moving on to the next step e.g. inserting speculum.

You are in Charge



Know that you are in charge and have agency over your body. You can let them know what language you prefer for your body parts at the screening. You can also request to put the speculum in yourself if this is preferable and they can guide you how to do this.



Ask for Breaks, or Grounding Time

If you feel unsure, uncomfortable or in pain. Ask them to stop, or show a flashcard that asks for a break until you are ready to continue. You can always reschedule, if you are too overwhelmed.

Plan Recovery and Transition Time



Recovering and transition time between tasks, is important to meet our sensory and emotional needs. You can request a quiet room to recover in before travelling home.

My Screening Support Plan

Use this page to add any other additional coping strategies, or adjustments that help support you before, during and after your screening.

Use any suggestions mentioned in this guide you would find helpful, as well as any additional tips, experiences and support you are aware of.

What Helps Me Before My Cervical Screening:

Example: Visit to view the screening room and equipment beforehand.

What Helps Me During My Cervical Screening:

Example: Communication flashcards e.g. 'please repeat' or 'stop'.

What Helps Me After my Cervical Screening:

Example: Sensory Support e.g. wheatie bag, comfy clothes etc.

Additional Resources

Cancer Research UK's Cervical Screening Video: https://www.youtube.com/watch?v=etyMFENlr0&embeds_referring_euri=https%3A%2F%2Fwww.bing.com%2F&embeds_referring_origin=https%3A%2F%2Fwww.bing.com&source_ve_path=MjM4NTE.

The video explains why cervical screening is so important and has animations to explain each step of the process too, and what you can expect before, during and after your appointment.

Macmillan UK Easy Read Cervical Cancer Screening Guide:

https://www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/19304-10061/MAC16302_ER_E05_CervicalScreening_20241210

NHS Scotland's British Sign Language Video for Cervical Cancer Screening:

<https://www.nhsinform.scot/translations/languages/british-sign-language-bsl/screening/cervical-screening-smear-test-bsl>

Jo's Cervical Cancer Trust Guide for Trans Men and Nonbinary People:

<https://www.jostrust.org.uk/information/cervical-screening/trans-non-binary/>. The guide explains the screening process, suitable adjustments and how testosterone can change the cervical screening exam e.g. more lubrication needed, or a smaller speculum.

Shantona - Better Together:

<https://shantona.co.uk/better-together-health-and-wellbeing-support/> - offering group and 1-1 support for diverse communities facing access barriers in healthcare.

Contact Us



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Please leave a message for the Leeds Autism AIM.



@leedsautismaim

This guide was produced by the Bradford and Craven Autism AIM Team, part of The Advonet Group. We are a free service co-led by and run for autistic adults (aged 18+) in the West Yorkshire area.