



## Health Screening

Screening inequalities exist among people with a learning disability, autism or both and they are less likely to access screening.

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## Background

Screening inequalities exist among people with a learning disability, autism or both and they are less likely to access screening.

### There is evidence that:

- [people with a learning disability receive a poorer standard of care, and die earlier](#), than people without learning disabilities
- pregnant women with a learning disability struggle to understand information (which is often written) given to them during pregnancy
- [breast screening uptake is lower in women with a learning disability](#) compared to the general population
- [engagement in bowel cancer screening can be difficult for people with a learning disability](#)
- [cervical screening uptake is lower in people with a learning disability](#) compared to everyone else

## Informed choice

People with a learning disability and autistic people should be supported to make an [informed choice](#) about screening tests offered to them.

[Some screening tests in pregnancy](#) can lead to personal decisions about whether or not to continue a pregnancy. Health professionals should explain these as clearly as possible to pregnant women with a learning disability, autism or both.

It should always be an individual's personal choice whether or not to have screening.

## Signs and symptoms

It is important to help people with a learning disability, autistic people and their families or carers understand the signs and symptoms of conditions. Health professionals should explain to people that if they notice any changes in their body that are not normal, they should not wait until their next screening invitation but should see their GP straight away. Screening is for people who do not have symptoms.

Getting symptoms checked by a GP is especially important for people who decide they do not want, or cannot go ahead with, screening.

### More information on symptoms can be found at:

- [AAA \(abdominal aortic aneurysm\) symptoms](#)
- [breast cancer signs and symptoms](#)
- [signs and symptoms of bowel cancer](#)
- [cervical cancer symptoms](#)
- [diabetic retinopathy symptoms](#)

It is an individual's choice whether to have screening.

See [Opting out of screening](#) for guidance on how to opt out of each of the national NHS screening programmes.

## Barriers to screening

People with a learning disability and autistic people can find it difficult to access screening and make an informed a choice about being screened.

### This can be because of:

- practical barriers, including mobility issues and difficulty using appointment systems
- a lack of understanding of instructions, for example for bowel cancer screening kit
- a lack of family or carers to support attendance at screening and local support services
- stress and anxiety about screening often felt by people with a learning disability, autism or both
- a lack of knowledge about screening among people with a learning disability and autistic people
- communication barriers between people with a learning disability and health professionals
- a lack of knowledge among health professionals of the needs of people with a learning disability or autistic people
- a lack of awareness among screening staff about [reasonable adjustments](#), accessible information and other resources to support people with a learning disability and autistic people

## Improving access to screening

Screening providers and commissioners should be aware that it is a [legal duty to make reasonable adjustments](#) for people with a learning disability and autistic people.

All organisations that provide NHS care are legally required to follow the [Accessible Information Standard](#).

People with a learning disability and autistic people can benefit from:

- being able to access information in easy read format
- healthcare professionals taking time to ensure that they understand what is happening and the choices they can make

PHE has produced a [suite of easy guides](#) to help explain screening tests to people with a learning disability and autistic people.

In addition, local providers of bowel cancer screening, breast screening and cervical screening services can also direct people who cannot read or do not like written words to the [Beyond Words cancer screening picture stories](#). These resources, which can be downloaded and printed out from the charity's website, include suggested storylines for family members, carers or health professionals to refer to.

Providers can also use animations and other short films to help people with a learning disability understand screening. These videos can be useful for health professionals to watch with people with a learning disability and autistic people, their families or carers while talking about screening.

You can search online to find suitable video content. Do make sure to watch videos to the end to check they are accurate, appropriate and helpful to people with a learning disability, autism or both before using them.

Watch these [3 short video clips of service users with a learning disability talking about screening](#) for a powerful reminder of the importance of focusing on inequalities and reducing barriers to screening.

## Before screening appointments

The interventions suggested below will not be appropriate in all cases. You should find out how best to support each individual by talking to them and the people who support them like their families and carers. Some people might also have communication or hospital passports which will include information about how they prefer to be communicated with and other reasonable adjustments they might need.

## Information and communication

To help improve access to screening and reduce inequalities, screening providers can:

- discuss with individuals, their families, carers or others providing support such as learning disability teams or advocates, any reasonable adjustments or communication needs people may require
- consider how individuals may like information to be presented and tailor it accordingly – for example, by using easy guides, pictures, simple words, symbols, signing or a film to explain screening
- consider if an interpreter or signer will be needed at the screening appointment (some people with a learning disability will also use [Makaton](#) rather than [British Sign Language](#))
- be aware of any jargon or medical terminology health professionals may use and try to explain things in a simpler way
- find out if the individual has an up-to-date communication or [hospital passport](#) to find out how to communicate with them and make sure they understand things
- attend local advocacy groups to demonstrate screening equipment and processes
- encourage GPs to raise awareness of screening with people with a learning disability, autism or both, for example during annual health checks
- promote screening at events for people with a learning disability, autism or both
- liaise with GPs and families in cases where consent is difficult to gain
- ask GPs for [‘best interest’ decisions](#) in cases where an individual does not have the ability to consent and there is no power of attorney

## Appointment issues

Practical considerations for screening providers to take into account when organising appointments for people with a learning disability or autism can include:

- finding out if there is a learning disability liaison nurse, or other health professional involved in the person's care, who can offer support before and during the screening appointment
- thinking about the logistics for the appointment, such as checking how individuals are going to get there
- appropriately sharing information and ensuring a coordinated support package is in place so the relevant health professionals can work together – effective handovers can improve accessibility and understanding
- offering a desensitisation pre-visit to familiarise individuals with screening venues and give them the opportunity to ask questions
- showing individuals what will happen during the screening appointment and explaining what the equipment does, including any noises it makes (you can use photos if a visit is not possible)
- allowing extra time for appointments and enabling a family member, carer or chaperone to attend with the individual if needed to reduce anxiety
- offering an alternative screening venue that the individual is familiar with if appropriate
- giving individuals the chance to meet members of the healthcare team most likely to provide care
- letting individuals know they can have somebody present during appointments and help arrange this if necessary
- assessing the individual's mental capacity and any safeguarding issues that need to be considered
- checking if the appointment will take place in a quiet environment and consider a home appointment if necessary
- considering sensory issues such as lighting, heat, and smell that may trigger anxiety or sensory overload, particularly for autistic people

## During screening appointments

There are lots of specific things health professionals can do to make screening appointments better for people with a learning disability and autistic people. They should:

- use simple language, avoiding long words and long sentences
- consider ways to help the individual feel more relaxed and comfortable, for example allowing them to play music or wear ear muffs/ear defenders during the screening test
- speak slowly and clearly, and stop to check understanding at regular points
- show the individual the relevant screening easy guide, animation or other film and check understanding with them
- always talk directly to the person with a learning disability, not their carer or supporting professional
- find out what words the individual uses for parts of the body being looked at to avoid misunderstandings
- follow the individual's lead and go at their pace
- be aware that people with a learning disability are more likely to have hearing loss, so do check they can hear you

## Sharing information

Some GPs may be unsure about how much information they can share about their patients due to ethical and legal duties of confidentiality.

As screening is considered direct care, [GMC guidance on implied consent and sharing information](#) for direct care should apply. It is important to remember [Caldicott Principle 7](#) that [the duty to share information can be just as important as the duty to protect confidentiality](#).

GPs can be confident that screening providers have strict information governance arrangements in place to protect personal information, keeping it confidential on secure IT systems.



### **What to do next?**

This #QualityMatters should be discussed in team meetings, supervisions and placed in the Best Practice and Innovations File.