



Improving access to screening programmes for adults who have a Learning Disability



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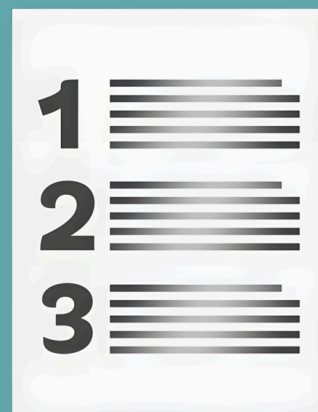


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AIMS AND OBJECTIVES FOR RESOURCE PACK

This resource pack has been created to support collaborative working, bringing together carers, professionals, and services to help break down the barriers that can stop people with a learning disability and/or autism from accessing screening.

Our aim is to give you useful information about how adult screening programmes work, and to share practical ways you can support the people you care for to take part in these important health checks.

It's not just about getting more people into appointments—it's also about making sure the experience is positive, accessible, and that the quality of the screening is as good as it can be for everyone.

If we work together, we can make a real difference; helping to improve health outcomes and reduce some of the avoidable reasons why adults with a learning disability die younger than those without.

People with a learning disability and/or autism can sometimes find it harder to get the healthcare they need.

This can lead to poorer health and, sadly, shorter lives—on average, people with a learning disability die around 20 years younger than people without a learning disability.

One reason for this is that fewer people with a learning disability take part in adult screening programmes (like checks for cancer or heart health). This might be because reasonable adjustments—like longer appointment times, easy-read information, or support to get to the appointment—aren't always offered, even though they are a legal right under the Equality Act 2010.

Sometimes, health professionals or carers might wrongly assume that someone doesn't need screening. This can be due to something called diagnostic overshadowing—when signs of illness are put down to a person's learning disability, rather than looking at what else might be going on.

Everyone has the right to good healthcare. Carers can play a key role in making sure people get the checks and support they need.

NHS NATIONAL SCREENING PROGRAMME OVERVIEW

Diabetic Eye Screening

- Offered to diabetic patients aged 12 or over
- Invited every one to two years



Cervical Cancer Screening

- First invite aged 25
- Further invites every 3 years until the age of 49
- Then every 5 years until the age of 64



Breast Screening

- First invite between age 50-53
- Further invites every 3 years up until 71st birthday
- Can choose to opt into the programme every 3 years from 70+

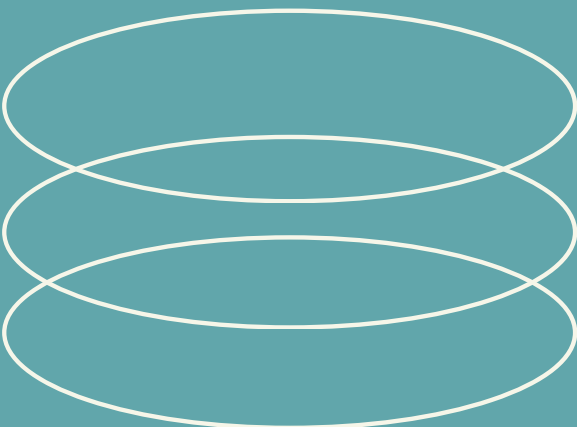
Bowel Cancer Screening

- First invite age 50 from 2025
- Further invites every 2 years up until age 74
- After the age of 75 people can self refer into the screening programme



Abdominal Aortic Aneurysm Screening (AAA)

- One off invite at the age of 65



ASSESSING MENTAL CAPACITY TO ENGAGE IN SCREENING PROGRAMMES



You must always assess the capacity of a person with a learning disability or autism to consent to any form of screening (bowel, breast, cervical, AAA or diabetic eye screening)



When supporting someone with a learning disability or autism, don't assume they can't make their own decision about a health screening. Everyone has the right to make decisions. The right support can make all the difference.

Under the Mental Capacity Act (2005), we must check a person's capacity for each specific decision. To do this, ask can the person:

- Understand what the screening is for?
- Remember the information long enough to decide?
- Think about the pros and cons?
- Tell you their decision (in any way that works for them)?

Give the Right Support First

Before saying someone "lacks capacity," you must offer support to help them understand. This might include:

- Easy Read leaflets
- Accessible videos explaining the screening
- Talking at their best time of day
- Using quiet spaces or extra time if they need it
- Having someone familiar with them to help.

Sometimes, the assessment might need to happen more than once, especially if the person is tired or anxious. If they still can't do one or more of the steps after support is given, they may lack capacity for that decision at that time. But remember capacity can change, so it's worth trying again later if needed.



Person lacks capacity to consent. Will they regain capacity in the future to make an informed decision?



Best Interest Decision is required. You must involve the person where possible as well as appropriate members of the person's wider care team (GP/ Practice Nurse/ Screening Professional/ LD Nurse)



Ensure robust documentation of best interest process and decision made in GP Records and in Health Action Plan. Alert carers/ person to possible signs and symptoms and how these can be reported.



The person has capacity to consent to screening; this means they have the right to refuse/ decline. Do they wish to attend for screening?



Contact SPLD for support to ensure reasonable adjustments are made; to include longer appointments, suitable time of day, easy read information, and initial visit to build up tolerance to environment.

MENTAL CAPACITY ACT 2005

To gain an understanding of a person's capacity to understand, there are a number of steps to consider in respect of their ability to communicate and express themselves. This section will guide you through some key steps required to understand a person's communication.

1. Gathering of relevant information to aid communication, such as who should be involved, what is the best time for them, what is the best environment for them, a case history and what is the decision to be made.
2. Determine how many 'Keywords' a person can understand. A Keyword level is the number of words the person is able to understand within an instruction.
3. Determine what visual information a person understands (symbolic understanding).
4. Considerations to be made about a person's communication.



TIMING

What time of day is best for the person?

Is the person more alert or more able to engage in the morning, afternoon or evening?

- People with dementia are sometimes prone to confusion in the evenings due to 'Sundowning'.
- Some people with a brain injury or a stroke may be fatigued by the afternoon.
- Some people may dislike being seen in the morning as it may disrupt their routine.
- Some people may have periods of increased or reduced alertness due to medication cycles.

Consider how long might the person be able to engage in the session?

Consider the appropriate period from introducing the topic (preparing for the MCA) to carrying out the MCA.

Will delaying the decision help the person make the decision independently?

ENVIRONMENT



What is the most suitable environment(s) to carry out the MCA – a familiar environment might include the person's home, day centre or work place. In addition, the person may benefit from visits to places relevant to the decision, such as the hospital or new house.

CASE HISTORY



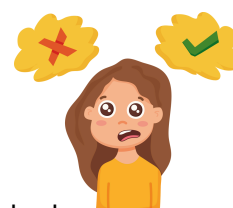
Has the person previously been seen by a speech and language therapist?
If so, what are the recommendations regarding their communication?
Ask family members/ carers about the person's communication.
Do they have any other health conditions such as vision/ sensory or sight and hearing needs?

PEOPLE TO INVOLVE



Who knows the person best?
Who best facilitates the person's communication? (These might not be the same person, for example, a person's parent may know them best, but an established carer may have better day-to-day communication with the person).
Who are the most appropriate people to involve in the MCA process e.g. other professionals?
Is an IMCA needed?

WHAT WILL THE DECISION BE?



Be clear about the decision focus of the particular **MCA**
BE SPECIFIC

This will help with deciding what kinds of communication support may be needed.

Additional considerations



Consider carrying out more than one visit to complete the assessment:

- If the person is not feeling well, consider rearranging the appointment.
- Some people may have fleeting attention, so several short sessions may be more appropriate.

Consider the person's vision:

- Do they need glasses?
- Do they have any visual difficulties such as cataracts or glaucoma?
- Remember that the person may be registered blind but this does not mean they have no vision at all. Check the extent and nature of their vision difficulties.

Consider the person's hearing:

- Do they have a hearing aid?
- Does their hearing aid work? Is it switched on? Does it have working batteries?
- Remember that a hearing aid in one ear may signify this is the ear with better hearing. The other ear may or may not have complete loss of hearing.
- Check if the person with a hearing difficulty needs an interpreter. The person may be a British Sign Language (BSL) user or may be able to lip-read.
- Referral for further help to assess with these aspects might be appropriate.

Consider sensory needs:

- People have various sensory needs. Some people may be over or under sensitive to sensory information.
- People with autism and people with dementia may be over/under sensitive to noise, smell, vision, touch, body awareness and movement.
- They may need sensory aids to be comfortable and to be able to pay attention, such as a weighted jacket, an object to fidget with, special seating, and ear protectors. Advice from Occupational Therapy (OT) can be sought.



How to test for a person's 'Keyword' Level Understanding

A **Keyword level** is the number of words the person is able to understand within an instruction.

Situational cues refer to the use of context to deduce meaning, for example 'Do you want a tea?' and pointing to the cup - this sentence requires no keyword understanding as the situational cue of pointing at the cup allows the person to infer your meaning from the accompanying gesture.

It is important to test how many keywords a person can understand, as they may mask difficulties understanding spoken language by relying on these situational and contextual cues.

Think of it as being abroad and not knowing the language. Despite not knowing the language, people's cues, facial expression, gesture and pointing can help you to understand. Context can also help your understanding

All of these aspects are important as part of the background of preparing for an MCA as part of supporting someone to engage within a screening process.

Applying the Mental Capacity Act (MCA) for screening decisions

The MCA has been in force since 2007 and applies to England and Wales. The primary purpose of the MCA is to promote and safeguard decision-making within a legal framework. It does this in two ways:



1. By empowering people to make decisions for themselves wherever possible and by protecting people who lack capacity by providing a flexible framework that places individuals at the heart of the decision-making process.
2. By allowing people to plan ahead for a time in the future when they might lack the capacity.

Key messages:

- The Mental Capacity Act (MCA) 2005 applies to everyone involved in the care, treatment and support of people aged 16 and over living in England and Wales who are unable to make all or some decisions for themselves.
- The MCA is designed to protect and restore power to those vulnerable people who lack capacity.
- The MCA also supports those who have capacity and choose to plan for their future. This is everyone in the general population who is over the age of 16.

- All professionals have a duty to comply with the Code of Practice. It also provides support and guidance for less formal carers.
- The Act's five statutory principles are the benchmark and must underpin all acts carried out and decisions taken in relation to the Act.
- Anyone caring for or supporting a person who may lack capacity could be involved in assessing capacity. It is important to follow the two-stage test.
- The MCA is designed to empower those in health and social care to assess capacity themselves, rather than rely on expert testing. Good professional training is key
- Understanding and using the MCA supports practice; for example, application of the Deprivation of Liberty Safeguards

Your role in the MCA as a carer involved in supporting screening decisions

The MCA prohibits blanket decision-making on behalf of people with capacity issues and introduces a functional test of capacity that is **time and decision** specific.

It requires everyone who cares for or treats people with capacity issues to respect their individual rights and to act in their best interests when making decisions on their behalf.

For example, if a person has from a learning disability or early stage dementia, and needs to make a decision on whether to have breast screening, the professionals involved should make every effort to communicate the "pros and cons" of having the treatment when the patient is most alert. This is so that the patient can make a decision.

A professional becomes the decision-maker only if the patient lacks the capacity to make that decision for them and has not made a Lasting Power of Attorney (LPA) granting an attorney the power to make decisions about medical treatment.

All professionals must make the decision for the patient in their best interests and need to know when they can and cannot disclose confidential information.

Other key areas of the MCA affecting healthcare professionals are:

- Independent mental capacity advocates (IMCAs).
- The ability for adult patients to make a lasting power of attorney (LPA).
- The establishment of a new Court of Protection.
- Court-appointed deputies. GPs need to be aware of people appointed to these roles and when to involve them in decision-making about patients who lack capacity.



Appointing an Independent Mental Capacity Advocate (IMCA)

The IMCA role is relevant for a person who lacks capacity and has no family or friends whom it would be appropriate to consult, nor do they have an appointed attorney under a lasting power of attorney.

Lasting powers of attorney (LPA) (Best Practice is to see a copy of the LPA)

LPAs replaced enduring powers of attorney, which can still be used if they were made before October 2007. There are two types of LPA:

- A property and finances LPA allows an attorney to make decisions about financial matters and, unlike a personal welfare LPA, they can be used when the person still has capacity, unless otherwise specified.
- A health and welfare LPA allows an attorney to make decisions about both health and personal welfare. A health and welfare attorney, however, cannot consent to or refuse treatment when the people have capacity to make the decision themselves.

Someone making an LPA can also add restrictions or conditions on areas where they do not wish the attorney to act.

Even if an LPA includes all healthcare decisions, the attorney has no decision-making power to refuse or authorise treatment in certain situations, such as if the patient has made an advance directive to refuse treatment proposed after making the LPA.

In addition, the attorney cannot insist on treatment that a doctor does not believe is in the patient's best interest.

Court of Protection

The court has the power to make a declaration about whether an adult (or a child in some cases) has or lacks capacity, and to appoint a deputy to make a decision on behalf of a person lacking capacity. There are two kinds of deputy, one for property and financial affairs, and the other for personal welfare.

The latter can make healthcare decisions on behalf of the person if this is set out in the deputyship order, with the exception that, unlike an LPA attorney for health and welfare, a deputy can never take the decision to stop life-sustaining treatment. Disputes over a person's capacity, or what treatment is in their best interest can be referred to this court.



HOW TO IMPROVE ACCESS TO BREAST CANCER SCREENING?



The first invitation for breast screening will come between the ages of 50-53 years old
This will then be received every 3 years up until the 71st birthday.
After the age of 70, you can opt in to breast screening every 3 years.

Ways you can support access to breast cancer screening?

If someone you support is going for a breast screening, a bit of preparation and planning can make a big difference to their comfort and experience.

Here are some simple but important steps:

- Encourage women to bring along their Health Passport/My Health and Me document which details communication preferences/ likes/ dislikes and reasonable adjustments.
- Ensure that a friend/ carer supports the appointment so that the person has someone familiar with them.
- Check if the screening unit offers accessible breast screening clinics, with quieter, calmer and more spacious environments. They may also offer double length appointments and additional staff to help support.
- Contact the service and discuss any reasonable adjustments that can be implemented.
- If there is a preference in location that will enable the person to attend, it is worthwhile checking with the unit to see if this can be accommodated.
- Check if the service has a Learning Disability Champion who can support the person's visit on the day and ensure that all needs are being met.

Some reasonable adjustments that can be made:

- Allowing extra time for appointments to make sure communication is as clear as it can be.
- Using simple language, avoiding long words and long sentences.
- Offer a 'pre-visit' – many units can do this, and they can be very reassuring.
- Showing women the mammography machine and explain any noise and movement it makes.
- Consider ways to help the woman feel relaxed, such as allowing her to play music during the mammogram.
- Using accessible videos or easy read information prior to the appointment.
- **Video:** [Taking the fear out of Breast Screening](#)
- **Easy Guide:** [breast-screening-information-for-women-with-learning-disabilities](#)
- <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2017/03/Easy-read-breast-cancer-leaflet.pdf>

HOW TO IMPROVE ACCESS TO BREAST CANCER SCREENING?

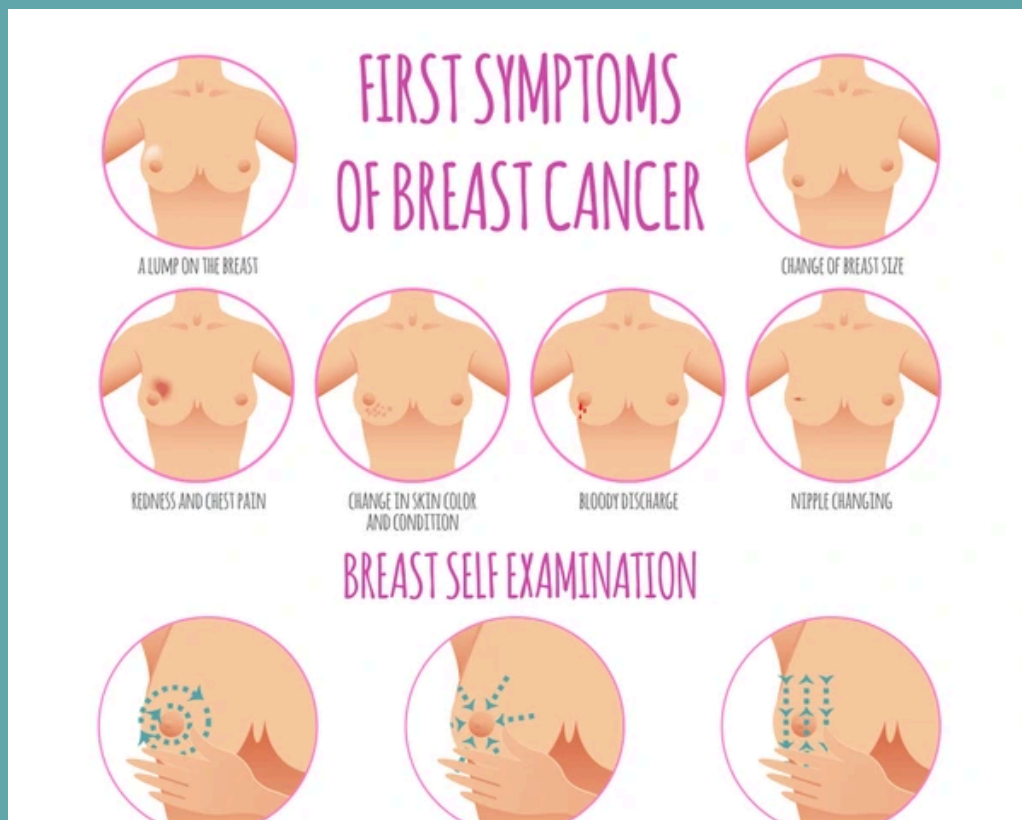


The symptoms listed here are more likely to be signs of other conditions that aren't cancer. As carers, you play an important role in helping the person you support get any unusual changes checked out, even though these symptoms are more likely to be linked to other conditions than cancer.

Look out for:

- A new lump or thickening in the breast, chest, or armpit.
- Skin changes on the breast, chest, or nipple (e.g., puckering, dimpling, redness, or a rash).
- Changes in the look or position of the nipple.
- Any change in size, shape, or feel of the breast or chest.
- Fluid leaking from the nipple (if not pregnant or breastfeeding).
- Unexplained pain in the breast, chest, or armpit.

If you notice any of these signs, it's important to help the person get checked by a healthcare professional for reassurance.



Breast Cancer Screening Reasonable Adjustments Checklist (to be completed by most appropriate person)

<p>Does the person have the capacity to consent to breast screening? (GP and breast screening practitioner can support assessment of capacity) Does the person have a basic understanding of:</p> <ul style="list-style-type: none"> • What the breast screening is for? • What is involved? • Risk of not attending? (possible undetected cancer) 	<p>Yes/No Outcome:</p> <ul style="list-style-type: none"> • Lacks capacity: Best interests discussion required. • Has capacity: Support person to make informed decision
<p>Was the person's care coordinator or community learning disability team contacted for support?</p>	<p>Yes/No Action taken:</p>
<p>Were all reasonable steps taken to enable the person to understand the screening? (E.g., videos, easy read resources.)</p>	<p>Yes/No Action taken:</p>
<p>Does the person have any known family history of breast cancer? This can be discussed with GP who can refer to cancer family history service if needed</p>	<p>Yes/No Action taken:</p>
<p>Has a best interest's discussion taken place? (This should be with GP, family, carers, relevant professionals involved and can be via telephone conversations)</p>	<p>Yes/No Action taken:</p>
<p>What was the outcome of the best interests meeting?</p>	<p>Yes/No Action taken:</p>
<p>Were reasonable adjustments explored with the screening unit? (Pre visit to breast unit, one appointment for each breast, liaison with breast unit for support/distractions/ familiar people present)</p>	<p>Yes/No Action taken:</p>
<p>If decision is NOT to attempt screening in best interests, consider if breast screening would be possible in the future with further support?</p>	<p>Yes/No Action taken:</p>
<p>Has practice nurse offered person a breast check examination at annual health check?</p>	<p>Yes/No Action taken:</p>
<p>Do family/carers/support staff know how to monitor for signs and symptoms of breast cancer? (If screening is considered not in best interests, then provide an appropriate breast care action plan for staff to physically monitor for signs and symptoms)</p>	<p>Yes/No Action taken:</p>

HOW TO IMPROVE ACCESS TO CERVICAL CANCER SCREENING



First invite to attend will be at age 25.
Further invites will then be every 3 years up to the age of 49.
Then invited every 5 years up to the age of 64.

Ways you can support access to cervical cancer screening

Prepare and Support the Appointment:

- Talk about cervical screening during annual health checks with clinicians.
- Seek help from the Health Equalities Team for health promotion or additional support.
- Provide easy-to-read information both before the appointment and during any Mental Capacity Act (MCA) or Best Interest discussion.
- If the person lacks capacity, ensure a Best Interest meeting is completed.
- Always support with a trusted carer or family member to reassure the person during the procedure.

Make Reasonable Adjustments:

- Have a pre-visit to explain the procedure and show any equipment that will be used.
- Offer an accessible video or easy-read materials (including a social story) to review before the appointment.
- Ensure a suitable environment, such as low lighting and distraction materials, is available.
- Help the person get comfortable in the correct position before the appointment.
- Offer any prescribed medication to manage anxiety or discomfort.

Incorporate Key Information into Health Plans:

- Include information in the Health Action Plan or My Health and Me document about:
 - Signs and symptoms for carers to look for.
 - The person's communication needs (e.g., whether an interpreter or Makaton signer is needed).
- **Important Reminder:** Never assume that not being sexually active means a woman should not have cervical screening.



HOW TO IMPROVE ACCESS TO CERVICAL CANCER SCREENING

Other reasonable adjustments include:

- Ask the woman what word she uses for her vagina. Using her preferred language can help avoid misunderstandings and shows respect for her comfort and communication style.
- If appropriate, and if she's comfortable, show her the speculum and the small brush used during the screening. Let her handle them and explain what each one is for in a simple, calm way.
- Support her in understanding the position used during the test (often lying on her back with knees apart). If she's happy to, encourage her to try lying on the examination couch (fully clothed) to see what it feels like.
- You might suggest she practices the position at home, in a familiar and relaxed place like her bedroom, with her clothes on. This can help her feel more prepared.

- If it is not in the women's best interests to have cervical screening completed then this should be clearly documented on the GP Records.
- Carers should remain vigilant to the signs and symptoms that can occur to show potential abnormality. This includes:
 - vaginal bleeding that's unusual for them – including bleeding during or after sex, between periods or after the menopause, or having heavier periods than usual
 - changes to vaginal discharge
 - pain during sex
 - pain in the lower back, between their hip bones (pelvis), or in their lower tummy
- **Easy Read:** [Cervical screening: an easy guide - GOV.UK](#)
- **Video:** [Cervical Cancer Screening BLMK ICB](#) – see link to Breaking Barriers to Healthcare video
- **Picture guide:** [Beyond Words picture guide to Cervical Screening](#)

Cervical Cancer Screening Reasonable Adjustments Checklist (to be completed by most appropriate person)

<p>Does the person have the capacity to consent to cervical screening? Does the person have a basic understanding of:</p> <ul style="list-style-type: none"> • What cervical screening is for? • What is involved? • Risk of not attending? (possible undetected cancer) 	<p>Yes/No Outcome:</p> <ul style="list-style-type: none"> • Lacks capacity: Best interests discussion required. • Has capacity: Support person to make informed decision
<p>Was the person's care coordinator or community learning disability team contacted for support?</p>	<p>Yes/No Action taken:</p>
<p>Were all reasonable steps taken to enable the person to understand the screening? (E.g., videos, easy read resources.)</p>	<p>Yes/No Action taken:</p>
<p>Does the person have any known family history of cervical cancer? This can be discussed with GP who can refer to cancer family history service if needed</p>	<p>Yes/No Action taken:</p>
<p>Has a best interest's discussion taken place? (This should be with GP, family, carers, relevant professionals involved and can be via telephone conversations)</p>	<p>Yes/No Action taken:</p>
<p>What was the outcome of the best interests meeting?</p>	<p>Yes/No Action taken:</p>
<p>Were reasonable adjustments explored with the patient? Such as pre visit, liaison with practice for support/distractions/ familiar people present)</p>	<p>Yes/No Action taken:</p>
<p>If decision is NOT to attempt screening in best interests, consider would cervical screening would be possible in the future with further support?</p>	<p>Yes/No Action taken:</p>
<p>Has practice nurse offered person cervical check examination at annual health check?</p>	<p>Yes/No Action taken:</p>
<p>Do family/carers/support staff know how to monitor for signs and symptoms of cervical cancer? Has this been included in a care plan?</p>	<p>Yes/No Action taken:</p>

WAYS TO IMPROVE ACCESS TO BOWEL CANCER SCREENING



Bowel Cancer Screening is offered to men and women aged 50 to 74 years every 2 years. The person must be registered with a GP.

What you can do to promote access to bowel cancer screening?

People with learning disabilities may need extra support to access bowel cancer screening. Here's how you can help promote engagement and ensure people receive the care they deserve. Some of the key things you can do are:

- **Mention GP Support**

- Let the person know their GP supports the screening programme. This alone can increase uptake by up to 6%.
- Use Easy Read Information
- Share an Easy Read leaflet that explains how to use the kit and answers common questions or concerns.

- **Make Reasonable Adjustments**

- Complete a reasonable adjustments checklist and action plan to help identify support needs.
- If needed, refer to the Health Facilitation Team for 1-to-1 support and health promotion work.
- Encourage clinicians to talk about screening at annual health checks.
- If the person lacks capacity, request a best interests discussion.
- Check that the person is flagged with the bowel screening hub as having a learning disability.

- **Practical Support**

- Help the person request reasonable adjustments by calling the NHS Bowel Screening Helpline: 0800 707 60 60.
- If registered for adjustments, the person will receive a FIT aid (to help complete the test).
- If they receive a non-accessible kit, they can request a more suitable one.

- **Respect Choice and Document Decisions**

- If the person has capacity and declines, or it's not in their best interests, make sure this is clearly documented along with the reason.

- **Keep Health Action Plans Updated**

- Add bowel health signs and symptoms to their Health Action Plan or 'My Health and Me' document.
- Share this information with the person and their carer.

- **Use Their Preferred Communication Style**

- Send reminder letters, texts, or calls based on how the person prefers to communicate.

- Please ensure the Bowel Screening Hub has up to date information on people who have a learning disability.
- Learning disability patients will receive easy read invites and guides.
- Local learning disability nurses can provide additional support
- **Easy Guide:** [Bowel Cancer Screening – An easy read guide](#)
- **Videos:** <https://www.guyscanceracademy.co.uk/bowelscreening>

WAYS TO IMPROVE ACCESS TO BOWEL CANCER SCREENING



One aim of the NHS Long Term Plan is that 75% of cancers will be diagnosed at an early stage. This can be achieved through targeted screening and personalised surveillance of those most at risk of developing cancer, such as those with Lynch syndrome.

Lynch syndrome is the most common form of hereditary colorectal cancer. Each year, 1,100 new cases of colorectal cancer in the UK are caused by Lynch syndrome. An estimated 175,000 people have this condition, but fewer than 5% know they have it.

What Does Lynch Syndrome Mean for Health?

- Colorectal (bowel) cancer is the primary concern for those with Lynch syndrome.
- For women, there is also an increased risk of endometrial (womb) cancer and, to a lesser extent, ovarian cancer.
- There is a small increase in the risk of other types of cancer, depending on which gene is affected and factors like age and gender.

Why is Genetic Testing Important?

- Genetic testing for Lynch syndrome involves a blood test to check for genetic changes (variants) that increase cancer risk.
- The test takes about three months to complete and helps doctors understand both the individual's and their family's future risk of developing cancer.

What Happens After a Positive Test?

- If the test is positive, individuals will undergo colonoscopy surveillance every two years to monitor for colorectal cancer.
- The results also help doctors determine the best treatments if cancer develops.

NICE Recommendations:

The National Institute for Health and Care Excellence (NICE DG27) recommends that everyone with colorectal cancer should be tested for Lynch syndrome to ensure early detection and management of associated cancer risks.

Bowel Cancer Screening Reasonable Adjustments Checklist (to be completed by most appropriate person)

<p>Does the person have the capacity to consent to bowel screening FIT Test? Does the person have a basic understanding of:</p> <ul style="list-style-type: none"> • What the bowel screening is for? • What is involved? • Risk of not attending? (possible undetected cancer) 	<p style="text-align: center;">Yes/No Outcome:</p> <ul style="list-style-type: none"> • Lacks capacity: Best interests discussion required. • Has capacity: Support person to make informed decision
<p>Was the person's care coordinator or community learning disability team contacted for support?</p>	<p>Yes/No Action taken:</p>
<p>Were all reasonable steps taken to enable the person to understand the screening? (E.g., videos, easy read resources.)</p>	<p>Yes/No Action taken:</p>
<p>Does the person have any known family history of bowel cancer? This can be discussed with GP who can refer to cancer family history service if needed</p>	<p>Yes/No Action taken:</p>
<p>Has a best interest's discussion taken place? (This should be with GP, family, carers, relevant professionals involved and can be via telephone conversations)</p>	<p>Yes/No Action taken:</p>
<p>What was the outcome of the best interests meeting?</p>	<p>Yes/No Action taken:</p>
<p>Were reasonable adjustments explored? Such as pre-test work with testing kit?</p>	<p>Yes/No Action taken:</p>
<p>If decision is NOT to attempt screening in best interests, consider if bowel screening would be possible in the future with further support?</p>	<p>Yes/No Action taken:</p>
<p>Do family/carers/support staff know how to monitor for signs and symptoms of bowel cancer?</p>	<p>Yes/No Action taken:</p>

IMPROVING ACCESS TO ABDOMINAL AORTIC ANEURYSM (AAA)



What is an abdominal aortic aneurysm (AAA)?

An abdominal aortic aneurysm (or AAA as it is commonly referred to) is a balloon-like swelling of the aorta, the main artery leading away from your heart, which passes through your abdomen. In some people, as they get older, the wall of the aorta weakens leading to swelling and bulging. It can be serious if it is not spotted early because it could get bigger and eventually burst (rupture).

AAA screening programme

AAA screening is a free NHS national screening programme that invites men aged 65 plus to attend an appointment to check if they have an abdominal aortic aneurysm. The screening is by invitation and uses an ultrasound scan. A man aged over 65, is more likely to have an abdominal aortic aneurysm than any other demographic so this is why they will be invited for screening.

Who is at risk?

Some people have a higher risk of getting an AAA including:

- Men are six times more likely to develop an aneurysm than a woman is. The chance of having an aneurysm increases with age. Two out of every three deaths from ruptured AAA in England and Wales occur in men who are over 65.
- People who smoke are 15 times more likely to get an AAA
- High blood pressure can double your risk of getting an AAA
- You are four times more likely to get an AAA if a close family member has one or has had one

What are the symptoms of having an AAA?

In most cases, an AAA has no noticeable symptoms. AAAs often grow slowly without symptoms, making them difficult to detect. However, if it becomes large, some people may develop pain or a pulsating feeling (like a heartbeat) in their tummy or persistent back pain.

If an aneurysm ruptures (bursts), it can cause:

- sudden severe pain in the tummy or lower back
- dizziness
- sweaty pale and clammy skin
- a fast heartbeat
- shortness of breath
- fainting or passing out

Men over 65 who have not previously been diagnosed with an aneurysm can request a scan by contacting their local screening service.

Reasonable adjustments

- Check and see if there are alternative appointments if the one offered is not suitable
- Asking for a reminder letter to be sent in an accessible format.
- Seeking support from the Health Facilitation Team with health promotion sessions aimed at raising awareness.
- Using easy read information to support understanding

AAA Screening Reasonable Adjustments Checklist (to be completed by most appropriate person)

<p>Does the person have the capacity to consent to AAA screening? Does the person have a basic understanding of:</p> <ul style="list-style-type: none"> • What the AAA screening is for? • What is involved? • Risk of not attending? 	<p>Yes/No Outcome:</p> <ul style="list-style-type: none"> • Lacks capacity: Best interests discussion required. • Has capacity: Support person to make informed decision
<p>Was the person's care coordinator or community learning disability team contacted for support?</p>	<p>Yes/No Action taken:</p>
<p>Were all reasonable steps taken to enable the person to understand the screening? (E.g., videos, easy read resources.)</p>	<p>Yes/No Action taken:</p>
<p>Does the person have any known family history of AAA?</p>	<p>Yes/No Action taken:</p>
<p>Has a best interest's discussion taken place? (This should be with GP, family, carers, relevant professionals involved and can be via telephone conversations)</p>	<p>Yes/No Action taken:</p>
<p>What was the outcome of the best interests meeting?</p>	<p>Yes/No Action taken:</p>
<p>Were reasonable adjustments explored?</p>	<p>Yes/No Action taken:</p>
<p>If decided NOT to attempt AAA screening in best interests, would AAA screening be possible in the future with further support?</p>	<p>Yes/No Action taken:</p>
<p>Do family/carers/support staff know how to monitor for signs and symptoms of AAA?</p>	<p>Yes/No Action taken:</p>

IMPROVING ACCESS TO DIABETIC EYE SCREENING



Diabetic eye screening is important as it helps to prevent sight loss.

It is different than a normal eye test.

People with diabetes are at risk of damage from diabetic retinopathy.

Screening can detect the condition early before someone notices any changes to their vision.

Diabetic retinopathy is a complication of diabetes where high blood sugar or sudden changes in blood sugar levels damage the retina (the back part of the eye). If left untreated, it can lead to blindness.

However, it typically takes several years for diabetic retinopathy to reach a stage where it threatens sight. Early detection and treatment are key to preventing this.

How Can Diabetes Affect the Eyes?

The retina is the light-sensitive part of the eye that converts light into signals the brain turns into images. It needs a steady blood supply, which comes through tiny blood vessels.

Over time, high blood sugar levels can damage these blood vessels, leading to three stages of retinopathy:

1. Background retinopathy: Tiny bulges form in the blood vessels, which may bleed slightly but usually don't affect vision.
2. Pre-proliferative retinopathy: Blood vessels become more severely damaged, leading to larger bleeds.
3. Proliferative retinopathy: Scar tissue and weak new blood vessels develop, causing vision loss.

How to Minimise the Risk:

- Control blood sugar levels, blood pressure, and cholesterol.
- Attend diabetic eye screening: Offered to all people with diabetes aged 12 and over to catch and treat problems early.

Why is Early Detection Important?

If a problem with the eyes is detected early during a screening, lifestyle changes and treatment can prevent it from worsening, preserving vision and eye health.

Diabetic Retinal Screening Reasonable Adjustments Checklist (to be completed by most appropriate person)

<p>Does the person have the capacity to consent to retinal screening? Does the person have a basic understanding of:</p> <ul style="list-style-type: none"> • What the screening is for? • What is involved? • Risk of not attending? 	<p>Yes/No Outcome:</p> <ul style="list-style-type: none"> • Lacks capacity: Best interests discussion required. • Has capacity: Support person to make informed decision
<p>Was the person's care coordinator or community learning disability team contacted for support?</p>	<p>Yes/No Action taken:</p>
<p>Were all reasonable steps taken to enable the person to understand the screening? (E.g., videos, easy read resources.)</p>	<p>Yes/No Action taken:</p>
<p>Does the person have any known family history of diabetic retinopathy issues?</p>	<p>Yes/No Action taken:</p>
<p>Has a best interest's discussion taken place? (This should be with GP, family, carers, relevant professionals involved and can be via telephone conversations)</p>	<p>Yes/No Action taken:</p>
<p>What was the outcome of the best interests meeting?</p>	<p>Yes/No Action taken:</p>
<p>Were reasonable adjustments explored?</p>	<p>Yes/No Action taken:</p>
<p>If decided NOT to attempt screening in best interests, would screening be possible in the future with further support?</p>	<p>Yes/No Action taken:</p>
<p>Do family/carers/support staff know how to monitor for signs and symptoms of issues?</p>	<p>Yes/No Action taken:</p>

RESOURCES

Breast Care Resources:

1. [What is Breast Screening? - Leicestershire Partnership NHS Trust](#)
2. [Breast Screening: easy read guide - GOV.UK](#)
3. [Beyond Words picture guide to Breast Screening](#)

Cervical Screening Resources:

1. [Cervical screening: an easy guide - GOV.UK](#)
2. [Cervical Cancer Screening BLMK ICB](#) – link to Breaking Barriers to Healthcare video
3. [Beyond Words picture guide to Cervical Screening](#)

Bowel Screening Resources:

1. [Bowel Cancer | Bowel Cancer UK](#)
2. [Symptoms of bowel cancer | Cancer Research UK](#)
3. [Bowel cancer - NHS](#)

AAA Screening Resources

1. [Abdominal aortic aneurysm screening: easy guide - GOV.UK](#)

Diabetic Retinopathy Screening Resources:

1. [Diabetes Eye Screening Appointment - Bedfordshire, Luton and Milton Keynes Integrated Care System](#) link to Breaking Barriers to Healthcare video for DES
2. [Home - BLMK Diabetic Eye Screening](#)
3. [Diabetic eye screening - NHS](#)
4. [Diabetic eye screening: description in brief - GOV.UK](#)
5. [Diabetic eye screening: easy read guide - GOV.UK](#)
6. [Diabetic eye screening | Retinopathy | Diabetes UK](#)

Document based on Northern Cancer Alliance Promoting Access to Cancer Screening Pack .

As part of the Breaking Barriers project, Autism Bedfordshire have filmed a number of videos aimed at supporting patients -

<https://blmkhealthandcarepartnership.org/breaking-barriers/>

