

Promoting access to Adult screening for people with a learning disability

A guidance and resource pack for care providers of learning disability services
Version 2 updated May 2022



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Aims and purpose of guidance pack

People with a learning disability receive a poorer standard of care, and die earlier, than people without learning disabilities.¹ People with a learning disability have a poorer uptake of the adult screening programmes compared to the general population.² This is due to a number of barriers Byrnes et al, 2019, discussions include; a lack of understanding, feelings of fear and anxiety, knowledge of paid workers and lack of education and training.³

Carers or professionals may make assumptions that a person cannot tolerate screening without completing an assessment. The Equality Act 2010 states that you must make reasonable adjustments for people with a learning disability to have equal access to health care.⁴

To support care providers of learning disability services with knowledge and understanding of the national screening programmes, the mental capacity act and best interest decisions guidance.

This pack includes practical guidance on supporting access to screenings, person centered assessment/checklists and screening action plans.

In addition this pack can provide guidance for health care professionals such as GPs, practice nurses, learning disability nurses, social workers, care coordinators and cancer screening practitioners who are supporting and promoting access to cancer screening for people with learning disabilities.



¹<https://www.england.nhs.uk/publication/leder-action-from-learning/>

²Heslop et al (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): final report. Norah Fry Research Centre

³Byrnes et al (2019) Attitudes and perceptions of people with a learning disability, family carers and paid carers towards cancer screening programmes in the United Kingdom: A qualitative systematic review and meta-aggregation.

⁴Equality Act (2010) <https://www.gov.uk/guidance/equality-act-2010-guidance>

NHS cancer screening programmes overview



Diabetic eye screening

- One off invite age 12 for those with diagnosis or diabetes
 - Invited at least once a year.
-



Cervical screening

- First invite age 25
 - Further invites every 3 years up to age 49, then every 5 years up to age 64.
-



Breast screening

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



Bowel screening home test (FIT) kit

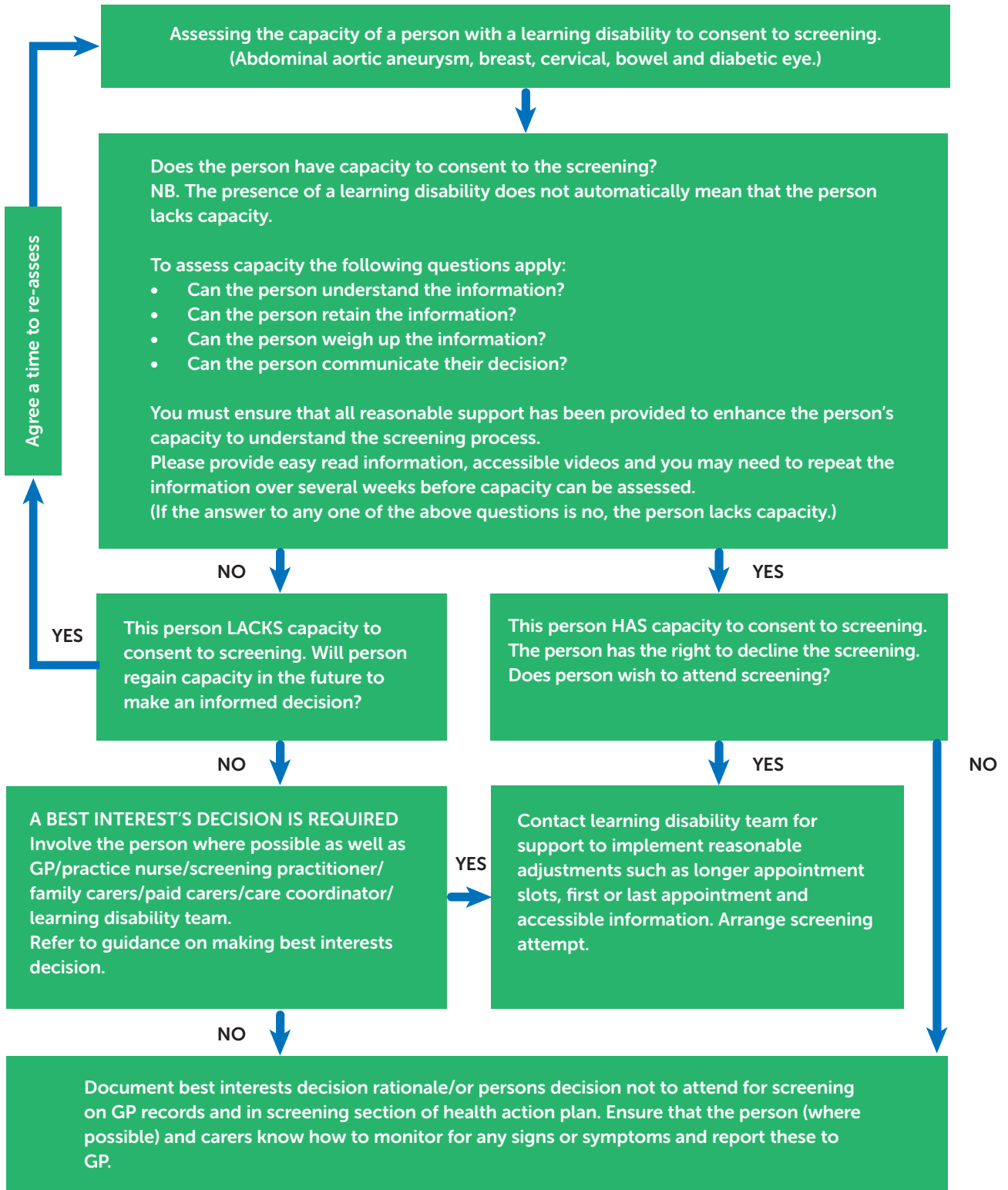
- First invite age 60
 - Further invites every 2 years up to age 74
 - Can opt into programme 74+ every 2 years.
-



Abdominal aortic aneurysm screening

- One off invite in 65th year.
-

Assessing capacity for screening



Mental Capacity Act 2005

Mental capacity guidance

The Mental Capacity Act (2005) is a law that protects vulnerable people over 16 around decision making it states:

‘Every adult, whatever their disability, has the right to make their own decisions wherever possible. People should always support a person to make their own decisions if they can. This might mean giving them information in a format that they can understand (such as easy read or a video).

If a decision is too big or complicated for a person to make, even with appropriate information and support, then people supporting them must make a ‘best interests’ decision on their behalf.’

www.legislation.gov.uk/ukpga/2005/9/contents

5 principles of mental capacity

1. Must always assume capacity unless proven otherwise
2. Person must be given all practical support to make own decision about care or treatment
3. Must respect the person’s right to make an unwise decision if they have capacity
4. Anything done on behalf of the person must be in best interests
5. The decision made in best interests must always be the least restrictive option.

Assessing mental capacity

Any health care professional can assess capacity. This is usually the health care professional who will be carrying out the intervention. For screening this could be the person’s GP, or practice nurse (cervical screening) or screening practitioner (breast, bowel, abdominal aortic aneurysm, or diabetic eye screening). Assessment is done in partnership with those who know the person well such as parents, carers and the learning disability team (Mencap 2016). Many people with a learning disability have the mental capacity to make decisions about screening but need additional support to understand the relevant information.



Assessing capacity

A two stage test

Stage 1: Is there an impairment or disturbance of functioning in the adults mind or brain?

If the person has a learning disability the answer is: YES

Stage 2: Does this impairment cause the person to lack capacity regarding this specific decision.

1. Can the person understand the information?
2. Can the person retain the information?
3. Can the person weigh up the information?
4. Can the person communicate their decision?

If you have given all reasonable support to enable the person to understand (i.e easy read information over a reasonable time period) and the answer to any of these 4 questions is NO then the person lacks capacity and a best interest's decision meeting is needed.

Getting it right charter ✓

See the person, not the disability. All people with a learning disability have an equal right to healthcare.

Further guidance on assessing capacity in relation to screening:

Mental capacity can be assessed by asking the person with a learning disability what they understand about the screening; if they can tell you what the screening is for, what it involves, why it is important and any risks. This does not have to be a formal meeting and is best done in a relaxed setting as part of a conversation with the individual to reduce their anxiety.

It's important that you communicate in a way the person can understand. Refer to the resource section in appendices for easy read information to help you.

Prior to assessing capacity you can ask those who care for the person to repeat this information over a number of weeks to support them to retain and understand the information so that they are given the opportunity to make an informed decision.

It is important to document this discussion and the outcome in the persons medical records and health action plan.

Mencap: Getting it right charter (2010)
<https://www.nice.org.uk/guidance/NG108?msclkid=597b5c70d04e11ec8cfaa70f532e5337>

Best interests decision making guidance

If a person lacks the capacity to consent to screening a best interest decision should be made. This should be a shared decision making process with the decision maker (usually the screening practitioner), and those who know the person well including professionals, family and carers. The learning disability team can support this process and provide guidance and support.

It is important to remember that no one can give consent on behalf of another adult. Parents cannot consent for or refuse cancer screening on the persons behalf. However their views will be considered as part of a best interests process.

Best interests checklist

When completing a best interests assessment it is important to consider the following:

- Will the person regain capacity in the future?
- Has the person been able to participate in the decision as much as possible even if they lack capacity?
- What are the persons wishes?
- Have you gathered the views of relevant people who know the person well?
- Do the benefits of screening outweigh the potential risk of distress?
- Have you considered the least restrictive option?
- Have you considered reasonable adjustments such as easy read materials/ videos, pre-visits and longer appointment slots?

In addition:

- The learning disability team can support
- An IMCA (Independent mental capacity advocate) can be contacted for support or advice if you are struggling to reach a decision.
- Consider any lasting power of attorney/ court appointed deputy that are in place

Refer to the 'Reasonable adjustments checklist and action plan' in resources section.

For more information see NICE (2018) Decision Making and Mental Capacity Guidance.

<https://www.nice.org.uk/guidance/NG108?msclkid=597b5c70d04e11ec8cfaa70f532e5337>

Best interests decision outcome?

Agreed in best interests TO attempt screening

If deemed in persons best interests to attempt screening document in the persons GP record and health action plan.

The learning disability team can support to facilitate reasonable adjustments to promote access to screenings.

A few attempts may be needed before a successful screening or it may prove too difficult in which case refer to adjacent column.

See Reasonable Adjustments Checklist and Action Plan.

Agreed in best interests NOT TO attempt screening

Based on previous attempts of medical interventions or the risk of distress (due to invasive screening) versus benefits it may be decided that screening is not in that persons best interests.

In this case it is important to:

- Document in the persons GP record and health action plan.
- An ongoing plan for symptom monitoring to be attached to persons health action plan.
- **See Reasonable Adjustments Checklist and Action Plan.**



Breast cancer screening





Top tips Improving access to breast cancer screening

First Invite age 50 - 53, then every three years up to your 71st birthday.
You can opt into breast screening over age 70 every 3 years.

What can you do as care providers to promote access to screening?

- Use the Reasonable Adjustments and best interest checklist and refer women who need additional support to the learning disability team.
- Ask practice nurses/GP to discuss screening at annual health check and if woman lacks capacity consider a best interests decision.

Ensure reasonable adjustments are offered such as:

- Accessible videos and easy read information.
- Contact screening centre and arrange longer appointment time.
- Arrange a pre visit to meet the staff and look at the equipment.
- A few attempts might be needed before a successful screening.
- Ensure breast screening is part of Health Action Plan.

If Screening is deemed not in best interests ensure breast care action plan is in place, symptom monitoring and education takes place.

Accessible Information and Resources

Accessible videos:

<https://www.youtube.com/watch?v=HphkoUbfNQQ>

(By Leicestershire Partnership NHS Trust)

Easy read guide:

<https://www.gov.uk/government/publications/breast-screening-information-for-women-with-learning-disabilities>

Books beyond words:

<https://www.booksbeyondwords.co.uk/resources-dl>

Breast cancer screening

Reasonable adjustments checklist and action plan



Support to access breast screening programme. First invite at age 50 and then every 3 years up to age 70.

Women can opt in over age 70.

Name:

<p>Does the person have the capacity to consent to breast screening? GP and breast screening practitioner can support assessment of capacity.</p> <p>Does the person have a basic understanding of: What the breast screening is for? What is involved? Risk of not attending? (possible undetected cancer).</p>	<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. • Where is this documented?
<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 Comments:</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 Comments:</p>
<p>What was the outcome of the best interests meeting?</p>	<p>Outcome and rationale:</p> <ul style="list-style-type: none"> • Where is this documented?
<p>Were reasonable adjustments explored with the screening unit? Such as: pre visit to breast unit, one appointment for each breast, liaison with breast unit for mobility support and music, pictures, familiar people present.</p>	<p>Yes/No Action taken:</p>
<p>If decided NOT to attempt screening in best interests. Would breast screening be possible in the future with further support?</p>	<p>Yes/No Review date:</p> <p>Comments:</p>
<p>Has person been offered a breast check examination at annual health check by practice nurse?</p>	<p>Yes/No Comments:</p>
<p>Do family/carers/support staff know how to monitor for signs and symptoms of breast cancer? Easy read information given?</p>	<p>Yes/No Comments:</p>

Completed by:

Date:

Not just a LUMP

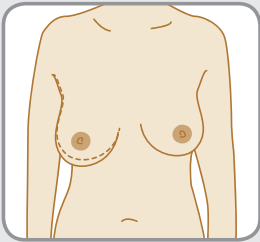
Many people think the first sign of breast cancer is a lump

Not all breast cancers show as lumps

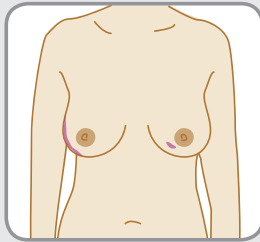
Not all lumps are breast cancer

Some benign (not cancer) conditions appear as a lump

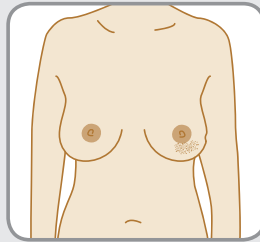
Look out for



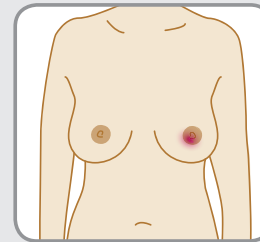
A change in size or shape



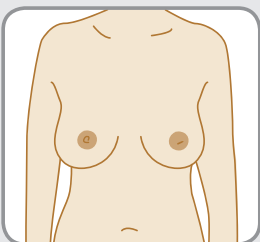
A lump or area that feels thicker than the rest of the breast



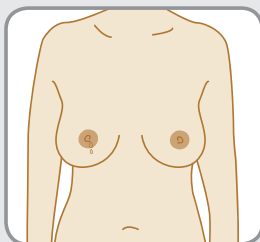
A change in skin texture such as puckering or dimpling (like the skin of an orange)



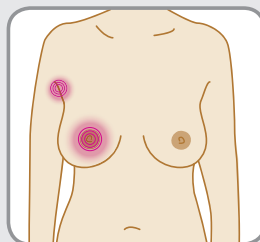
Redness or a rash on the skin and/or around the nipple



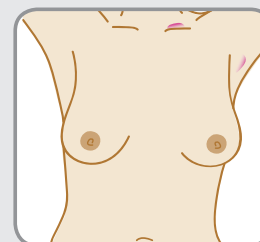
A change to the nipple, for example it has become pulled in or changed its position or shape



Liquid that comes from the nipple without squeezing



Pain in your breast or your armpit that's there all or almost all the time



A swelling in your armpit or around your collarbone

**If you notice any new change,
go to see your doctor as soon as you can.**

Breast Cancer Care is here for anyone who is worried about their breasts.
Call our free Helpline on **0808 800 6000** or visit **breastcancercare.org.uk**

Cervical cancer screening





Top tips Improving access to cervical cancer screening

First invite at age 25. Further invites every 3 years up to age 49.
Then invited every 5 years up to age 64.

What can you do as care providers to promote access to screening?

- Use the best interest and reasonable adjustments checklist and refer women who need additional support to the learning disability team.
- Ask GP or practice nurse to talk to women about screening at their annual health check. Provide easy read information and if woman lacks capacity ask for a best interests meeting with relevant people involved.
- Cervical cell changes are more likely in women who have been sexually active. Cervical screening can detect these changes. Do not assume that the woman has never been sexually active. Screening is available to all women whether they have been sexually active or not.
- Ask your GPs / practice nurse to make reasonable adjustments such as:
 - A pre-visit to talk through the procedure and explain the equipment.
 - An accessible video or easy read materials to aid understanding.
 - Making the environment comfortable with music, distractions or familiar objects.
 - Support the woman to practice lying in the right position for screening.
 - PRN anti-anxiety medication can be prescribed by GP if appropriate.
- If it is deemed not to be in the woman's best interests to have cervical screening, reason should be clearly documented on GP records and ensure the woman, parents and carers know the signs and symptoms to monitor for a cervical abnormality. Care providers to ensure this is written in persons health action plan.
- Ensure cervical screening is part of the woman's health action plan.

Accessible Information and Resources

Accessible videos:

Jo's Trust Accessible video for people with learning disabilities made by women with Learning Disabilities. <https://www.jostrust.org.uk/information/cervical-screening/cervical-screening-learning-disability>

Easy read guide:

<https://www.gov.uk/government/publications/cervical-screening-easy-read-guide>

Books beyond words:

<https://www.booksbeyondwords.co.uk/resources-dl>

Cervical cancer screening

Reasonable adjustments checklist and action plan



First invite at age 25 and then every 3 years up to age 50 then every 5 years up to age 64.

Name:

<p>Has a capacity of consent to cervical screening been completed? GP or practice nurse should support assessment of capacity.</p> <p>Is there a basic understanding of:</p> <ul style="list-style-type: none"> • What the screening is for? • What will happen during screening? • The risk of not attending screening (unidentified cell changes?) 	<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. • Where is this documented?
<p>Was the person's care coordinator, learning disability team or health facilitation 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>Were reasonable adjustments explored with the practice nurse such as pre visits, longer appointments, music.</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 Who attended/involved:</p>
<p>What was the outcome of the best interests meeting?</p>	<p>Outcome and rationale:</p> <ul style="list-style-type: none"> • Where is this documented?
<p>Would cervical screening be possible in the future with further support and education?</p>	<p>Yes/No Comments:</p>
<p>Does the person/family/carers support staff know how to monitor for signs and symptoms of cervical cancer? Easy read information given?</p>	<p>Yes/No Review date:</p> <p>Comments:</p>
<p>Has cervical screening been added to health action plan?</p>	<p>Yes/No Any Actions:</p>

Completed by:

Date:

Do you know the symptoms of cervical cancer?

There are some recognised symptoms associated with cervical cancer that you should be aware of.



Bowel cancer screening





Top tips Improving access to bowel screening

Bowel screening using FIT kit (Home Test).

Age of invite is being lowered to include people 50-74.

You receive an invite by post every 2 years.

To check age of invite in your local area call 0800 707 6060.

What can you do as care providers to promote access to bowel screening?

- Complete the reasonable adjustments checklist and action plan. Refer people who need more support to the learning disabilities team.
- Ask GP/ practice nurse to talk about screening at annual health check and if person lacks capacity request best interests discussion.
- Ask GPs / practice nurse if individual is flagged as having a learning disability with bowel screening hub, email hub details if required:
gan-tr.north-east-bowel-hub@nhs.net
- Support reasonable adjustments to be arranged such as:
 - Easy read information or video to show person how to complete kit.
 - Provide bowel cancer awareness sessions to raise awareness of the bowel screening kit (Learning Disability team can help with this).
 - Ensure bowel screening is recorded in health action plan.
- If bowel screening is not in best interests or person has capacity and declines then document rationale and ensure signs and symptoms monitoring in health action plan.

Accessible Information and Resources

Accessible videos:

https://www.youtube.com/watch?v=m2f-wY0C_1Q

Easy read guide:

<https://www.gov.uk/government/publications/bowel-cancer-screening-easy-guide>

Books beyond words:

<https://www.booksbeyondwords.co.uk/resources-dl>

Bowel cancer screening (FIT Kit)

Reasonable adjustments checklist and action plan



Bowel screening home test (FIT kit). First invite in the post at age 60 and then further invites up to age of 74. Can opt in after age 74.

Name:

<p>Does the person have the capacity to consent to bowel screening FIT kit? Does the person have a basic understanding of:</p> <ul style="list-style-type: none"> • What the screening is for? • What will happen during screening? • The risk of not completing kit? (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. • Where is this documented?
<p>Was the person's care coordinator, learning disability team or health facilitation 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 family history of bowel cancer? If so ensure this is discussed with GP who can refer to cancer family history service if needed.</p>	<p>Yes/No Action taken:</p>
<p>If person lacks capacity, 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 Who attended/involved:</p>
<p>What was the outcome of the best interests meeting?</p>	<p>Outcome and rationale:</p> <ul style="list-style-type: none"> • Where is this documented?
<p>Were reasonable adjustments explored to support the person to complete the FIT kit such as support from family members, carers, or support and education?</p>	<p>Yes/No Comments:</p>
<p>Does the person/family/carers support staff know how to monitor for signs and symptoms of bowel cancer? Easy read information given?</p>	<p>Yes/No Comments:</p>
<p>Has bowel screening been added to health action plan?</p>	<p>Yes/No Any Actions:</p>

Completed by:

Date:



Bowel Cancer UK
Beating bowel cancer together

Knowing the symptoms of bowel cancer could save your life



Bleeding from your bottom
and/or blood in your poo



A persistent and unexplained
change in bowel habit



Unexplained weight loss



Extreme tiredness for
no obvious reason



A pain or lump in your tummy

If you have any concerns or if things just
don't feel right, go and see your doctor.

[bowelcanceruk.org.uk](https://www.bowelcanceruk.org.uk)



@bowelcanceruk



/bowelcanceruk

Abdominal aortic aneurysm screening





Top tips Improving access to abdominal aortic aneurysm (AAA) screening

The aorta is the main blood vessel supplying blood to the body. It runs from the heart through the chest and abdomen. In some people, as they get older, the wall of the aorta in the abdomen can become weak. It can expand and form an abdominal aortic aneurysm.

AAA screening is offered to men in the year they turn 65, who are registered with a GP. Any men over 65 who haven't been screened can self-refer by contacting their local AAA screening service.

Screening is offered to find aneurysms early, monitor or treat them. This reduces the chances of serious problems.

What can you do as a care provider to promote access to AAA screening?

- Complete the reasonable adjustment check list and action plan.
- Ask learning disabilities team for additional support if needed.
- Ask practice nurses and GP to discuss AAA screening at annual health checks. If they lack capacity request a best interest decision with relevant people involved.
- Ensure access to easy read information and videos.
- Contact the local AAA screening service for advice or to inform them of any additional support needs. Such as:
 - Accessible videos and easy read materials
 - Longer appointment times are available
 - First or last appointment if needed
 - A pre-screening visit to meet staff and look at the equipment
 - More than one attempt to screen.

If screening is deemed not in the best interest ensure an AAA action plan is in place including education.

Accessible Information and Resources

Easy read guide:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/911844/AAA_screening_easy_guide_August_2020.pdf

A guide to abdominal aortic aneurysm (AAA) screening for people with learning disabilities.

<https://www.youtube.com/watch?v=TLE4t4jqQmw>

Abdominal aortic aneurysm (AAA)

Reasonable adjustments checklist and action plan



Support to access AAA screening.
One off invite for men aged 65.

Name:

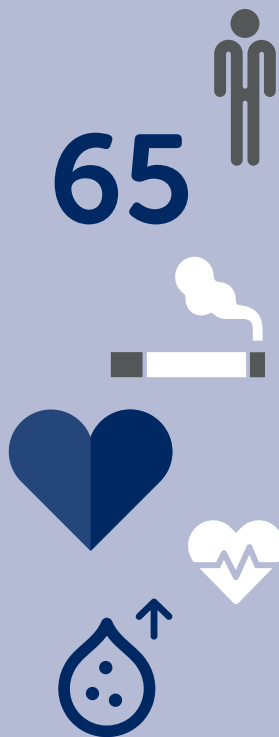
<p>Does the person have the capacity to consent to AAA screening? Does the person have a basic understanding of:</p> <ul style="list-style-type: none"> • What AAA screening is for? • What it involves • Risk of not attending. (possible undetected aneurysm). 	<p>Yes/No Outcome:</p> <ul style="list-style-type: none"> • Lacks capacity: Best interests discussion required. • Has capacity: Support person to make informed decision. • Where is this documented?
<p>Was the person's care coordinator, learning disability team or health facilitation team contacted for support?</p>	<p>Yes/No Action taken:</p>
<p>Were all reasonable steps taken to enable the person to understand screening? (e.g. video, easy read resources).</p>	<p>Yes/No Action taken:</p>
<p>Does the person have a known family history of AAA? If so discuss with GP.</p>	<p>Yes/No Comments:</p>
<p>If the person lacks capacity has a best interest discussion taken place? (This should be with GP, family, carers, relevant professionals involved and can be via telephone/video conversations).</p>	<p>Yes/No Comments:</p>
<p>What was the outcome of the best interests meeting?</p>	<p>Outcome and rationale:</p> <ul style="list-style-type: none"> • Where is this documented?
<p>Were reasonable adjustments explored with the screening team? Such as a pre visit, mobility support, music, creating a calm space, familiar people present etc.?</p>	<p>Yes/No Action taken:</p>
<p>If it was decided not to attempt screening in best interest. Would AAA screening be possible in the future with further support?</p>	<p>Yes/No Review date: Comments:</p>
<p>Do family members / carers know how to monitor for signs and symptoms of AAA? Has easy read/information been provided?</p>	<p>Yes/No Comments:</p>

Completed by:

Date:

Signs & Symptoms of abdominal aortic aneurysm (AAA)

AAAs do not usually have any obvious symptoms, it is often only picked up during screening or tests carried out for another reason.



AAA is more likely if someone is:

- a male & over 65
- has a close family history
- has been a smoker
- has high cholesterol
- has hypertension
- has atherosclerosis - fatty build up in arteries

Some people with an AAA have:

- a pulsing sensation in the tummy (like a heartbeat)
- tummy pain that does not go away
- lower back pain that does not go.

If an AAA 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.

Call 999 for an ambulance immediately if you or someone else develops symptoms of a burst AAA.

Diabetic eye screening





Top tips Improving access to diabetic eye screening

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

People with diabetes are at risk of damage from diabetic retinopathy. Screening can detect the condition early before an individual notices any changes to their vision.

Diabetic retinopathy occurs when diabetes affects small blood vessels, damaging the part of the eye called the retina. It can cause the blood vessels in the retina to leak or become blocked. This can affect sight. Untreated diabetic retinopathy is one of the most common causes of sight loss. When the condition is caught early, treatment is effective at reducing or preventing damage to sight.

Diabetic eye screening is offered to everyone with diabetes aged 12 and over once a year. Diabetic eye screening is not covered as part of your normal eye examination with an optician. Individuals should access both diabetic eye screening and normal eye examinations with an optician

What can you do as a care provider to promote access to diabetic eye screening?

- Complete the reasonable adjustments check list and action plan
- Ask learning disability team for extra support if needed
- Ask practice nurses and GP to discuss eye health and screening at annual health check. If they lack capacity request a best interest decision with relevant people involved.
- Ensure reasonable adjustments are offered such as:
 - Accessible videos and easy read materials
 - Longer appointment times are available
 - A pre-screening visit to meet staff and look at the equipment.
- Don't forget:
 - Take any glasses worn to the appointment
 - Take sunglasses to protect the eyes after eye drops have been used
 - Vision may be affected for several hours

If screening is deemed not in the best interest, ensure an action plan is in place including education.

Diabetic eye screening

Reasonable adjustments checklist and action plan



Support to access diabetic eye screening.

Invite every year from age 12 for people diagnosed with diabetes.

This check list and action plan is for adults.

Name:

<p>Does the person have the capacity to consent to Diabetic eye screening (DES). The GP and screening clinical team can support assessment of capacity.</p> <p>Does the person have a basic understanding of: What the DES is for? What is involved? Risk of not attending? (possible sight loss).</p>	<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. • Where is this documented?
<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>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 Comments:</p>
<p>What was the outcome of the best interests meeting?</p>	<p>Outcome and rationale:</p> <ul style="list-style-type: none"> • Where is this documented?
<p>Were reasonable adjustments explored with the screening unit? Such as: pre visit to screening venue, liaison with DES unit for access requirements, music, pictures, familiar people present.</p>	<p>Yes/No Action taken:</p>
<p>If decided NOT to attempt screening in best interests. Would diabetic eye 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 reduce risks of diabetic retinopathy and have action plan in place? Has easy read/information been provided?</p>	<p>Yes/No Action taken:</p>

Completed by:

Date:



Reducing your risk of diabetic retinopathy

Diabetic retinopathy is a complication of diabetes, caused by high blood sugar levels damaging the back of the eye (retina). It can cause blindness if left undiagnosed and untreated.

However, it usually takes several years for diabetic retinopathy to reach a stage where it could threaten your sight.



People can help to reduce the risk by:

- controlling blood glucose as effectively as possible
- see the doctor regularly to check blood pressure is not raised
- attend diabetic eye screening appointments
- get advice if they have a problem with their sight
- take medication as prescribed
- exercise regularly, following medical advice.

References and further guidance

Equality Act (2010) <https://www.legislation.gov.uk/ukpga/2010/15/contents>
Chapter 4

Heslop et al (2013) 'Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report'. Norah Fry Research Centre. Available: <https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

Mental Capacity Act (2005) <https://www.legislation.gov.uk/ukpga/2005/9/contents>

Mencap 2016 Mental Capacity Act Resource Pack: For family carers of people with a learning disability. https://www.mencap.org.uk/sites/default/files/2016-06/mental%20capacity%20act%20resource%20pack_1.pdf

NICE (2018) Decision Making and Mental Capacity Guidance <https://www.nice.org.uk/guidance/ng108/chapter/Recommendations>

Bowel Cancer UK (2018) Knowing the symptoms of bowel cancer could save your life Available at: <https://www.bowelcanceruk.org.uk/about-bowel-cancer/our-publications>

Jo's Cervical Cancer Trust: Do you know the symptoms of cervical cancer? <https://www.jostrust.org.uk/about-cervical-cancer/cervical-cancer/symptoms>

Breast Cancer Care How do I check my breasts? <https://www.breastcancercare.org.uk/information-support/have-i-got-breast-cancer/signs-symptoms-breast-cancer>

Credits

This resource pack was produced by County Durham Learning Disability Health Facilitation Team (TEWV), in partnership with CDDFT Learning Disability Acute Liaison Nurses, Learning Disability Community Integrated Teams, Macmillan Primary Care Nurses, and the North East and Cumbria Learning Disability Network Macmillan cancer project.

Promoting access to cancer screenings for people with a learning disability is available as a download at <https://neclldnetwork.co.uk/useful-information/>

Bowel Cancer UK, Breast Cancer Care and Jo's Trust were not involved in the making of the pack but have given permission for resources to be included in the pack

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Promoting access to Adult screening for people with a learning disability

