



Promoting access to adult screening for people with a learning disability

A guidance and resource pack for healthcare professionals and care providers of learning disability services, April 2026



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Aims and purpose of guidance pack

To support care providers of learning disability services with knowledge and understanding of the national screening programmes, the Mental Capacity Act and best interests decisions guidance.

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

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

People with a learning disability receive a poorer standard of care, and shorter life expectancy, than people without learning disabilities.¹ People with a learning disability have a lower uptake of the adult screening programmes compared to the general population.² This is due to a number of barriers, including a lack of understanding, feelings of fear and anxiety, limited 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 healthcare.⁴



¹<https://www.kcl.ac.uk/ioppn/assets/pdfs/leder/2023-final-updated.pdf>

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 screening programmes overview



Diabetic eye screening

- Invite at diabetes diagnosis for those 12+
 - Every 12 months, but every 24 months if the previous two tests are normal.
-



Cervical screening

- First invite at age 25
 - Every 5 years for eligible age group 25-64 years old.
-



Breast screening

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



Lung cancer screening

- Invite at age 55-74
 - For current or previous smokers
 - Further invites every 2 years
-



Bowel cancer screening

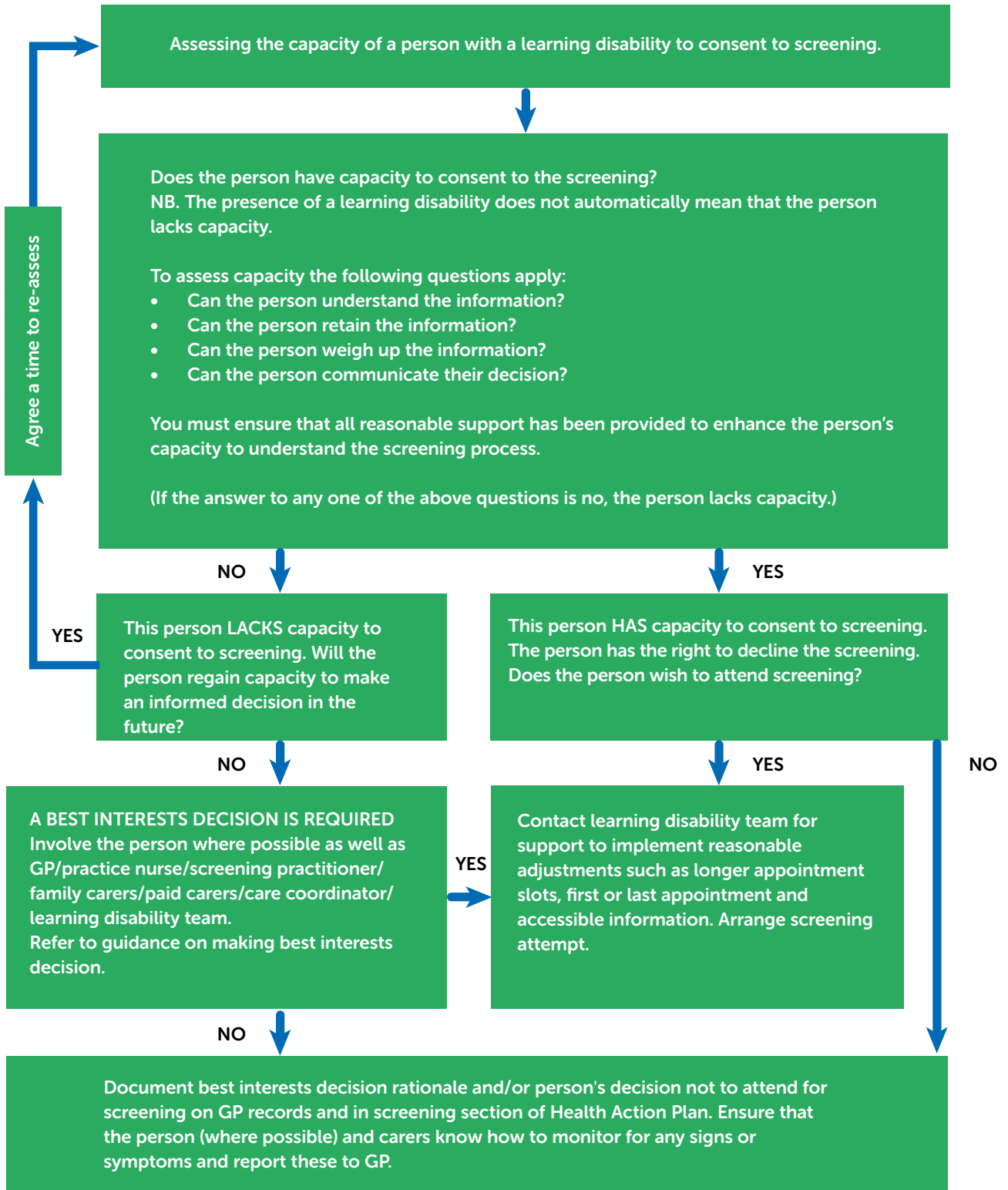
- First invite at age 50
 - Further invites every 2 years up to age 74
 - People aged 74+ can opt into programme every 2 years.
-



Abdominal aortic aneurysm screening

- One-off invite in 65th year for men

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 healthcare professional can assess capacity. This is usually the healthcare professional who will be carrying out the intervention. For screening this could be the person's GP, practice nurse or screening practitioner. Assessment is done in partnership with those who know the person well such as parents, carers and the learning disability team. 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 adult's 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 interests 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.

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 person's medical records and health action plan.

Mencap: Getting it right charter (2010) <https://www.mencap.org.uk/sites/default/files/2016-07/Getting%20it%20Right%20charter.pdf>

Best interests decision making guidance

If a person lacks the capacity to consent to screening a best interests 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 screening on the person's 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 person's 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?msckid=597b5c70d04e11ec8cfaa70f532e5337>

Best interests decision outcome?

Agreed in best interests TO attempt screening

If deemed in person's best interests to attempt screening document in the person's 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 experiences of medical interventions or the risk of distress (due to invasive screening) versus benefits, it may be decided that screening is not in that person's best interests.

In this case it is important to:

- Document in the person's GP record and Health Action Plan.
- An ongoing plan for symptom monitoring to be attached to person's 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 71st birthday.
Can opt into breast screening over age 70 every 3 years.

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

- Use the Reasonable Adjustments and best interests checklist and refer women who need additional support to the learning disability team.
- Ask the GP or practice nurse to discuss screening at the annual health check and if the 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 to be in the person's best interests, ensure breast care action plan is in place, symptom monitoring and education takes place.

Accessible Information and Resources

Accessible videos:

<https://www.london-breastscreening.org.uk/>

Easy-read guide:

https://assets.publishing.service.gov.uk/media/67acc2e937726e9056af60b6/An_easy_guide_to_breast_screening_Feb25.pdf

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

Breast Screening Service:
020 3758 2025
RF-TR.LondonBreastScreeningHub@nhs.net

Breast cancer screening

Reasonable adjustments checklist and action plan



Name:

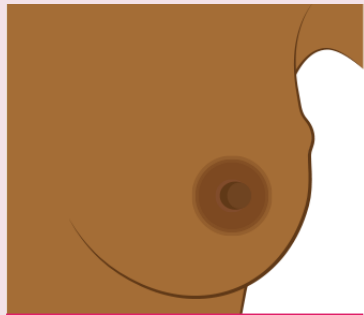
<p>Does the person have the capacity to consent to breast screening? GP and breast screening practitioner can support assessment of capacity.</p> <p>Does the person have a basic understanding of: What the breast screening is for? What is involved? Risk of not attending? (possible undetected cancer).</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 interests discussion taken place? (This should be with screening practitioner, GP, family, carers, relevant professionals involved and can be via telephone conversations).</p>	<p>Yes/No Comments:</p>
<p>Was a female nurse offered for breast checking education, and has the individual and their family/ carers been educated on how to complete monthly breast checks?</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 GP or 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?</p>	<p>Yes/No Comments:</p>

12 **Completed by:**

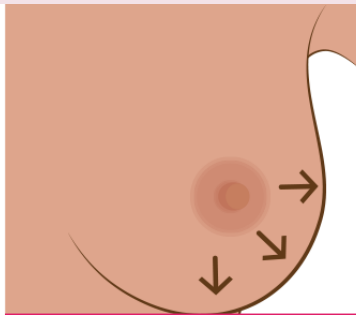
Date:

Save your life

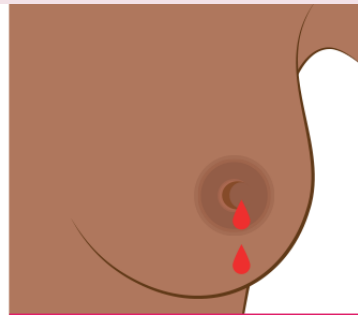
Check now for the signs of breast cancer



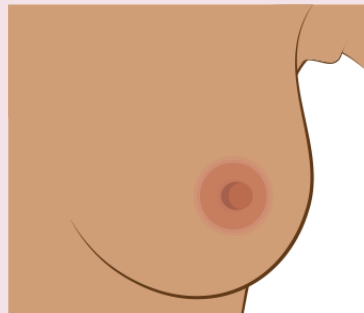
lumps



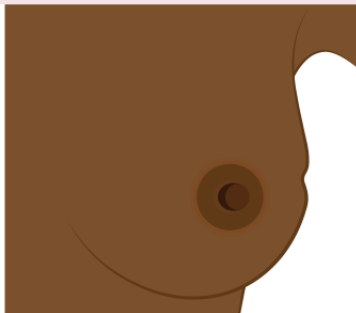
swelling



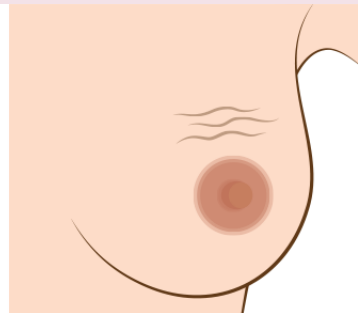
bloody leaking



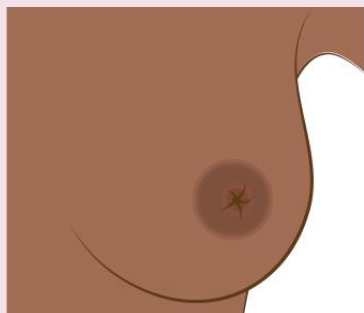
lumps in armpit



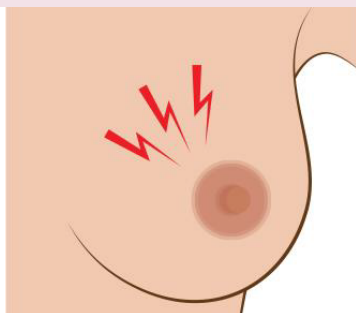
dimpling skin



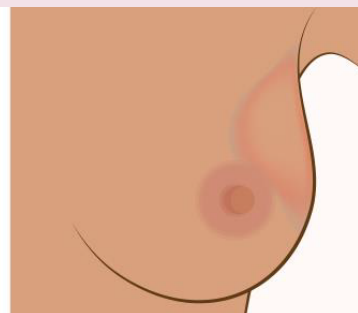
skin rash



inside out nipple



unusual pain



colour change

If you notice anything unusual see your doctor or nurse as soon as possible

With thanks to futuresdreams.org.uk

Cervical cancer screening





Top tips Improving access to cervical cancer screening

First invite at age 25 and then every 5 years up to the age of 64

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

- Use the best interests and reasonable adjustments checklist and refer women who need additional support to the learning disability team.
- Ask GP or practice nurse to talk to the woman about screening at their annual health check.
- Provide easy read information and if the 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.
- Self-sampling may be offered to some people if they are overdue their screen and are experiencing difficulties with having the routine screening.
- 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 person's Health Action Plan.
- Ensure cervical screening is part of the woman's Health Action Plan.

Accessible Information and Resources

Accessible video:

https://www.youtube.com/watch?v=ztazd__5F-l

Easy-read guide:

https://eveappeal.org.uk/wp-content/uploads/2025/10/Easy-Read-cervical-screening_updated-Oct-2025-2.pdf

Books beyond words:

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

Cervical cancer screening

Reasonable adjustments checklist and action plan



Name:

<p>Does the person have capacity to consent to cervical screening? GP or practice nurse can support assessment of capacity. 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 interests 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?</p>	<p>Yes/No Review date: Comments:</p>
<p>Has cervical screening been added to Health Action Plan?</p>	<p>Yes/No Any Actions:</p>

Completed by:

Date:

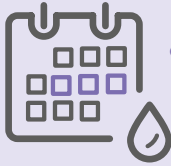


Common signs & symptoms of cervical cancer

Vaginal bleeding that is unusual for you including:



- Bleeding during or after sex



- Bleeding between your periods or after the menopause



- Heavier periods than usual



Changes to your vaginal discharge.



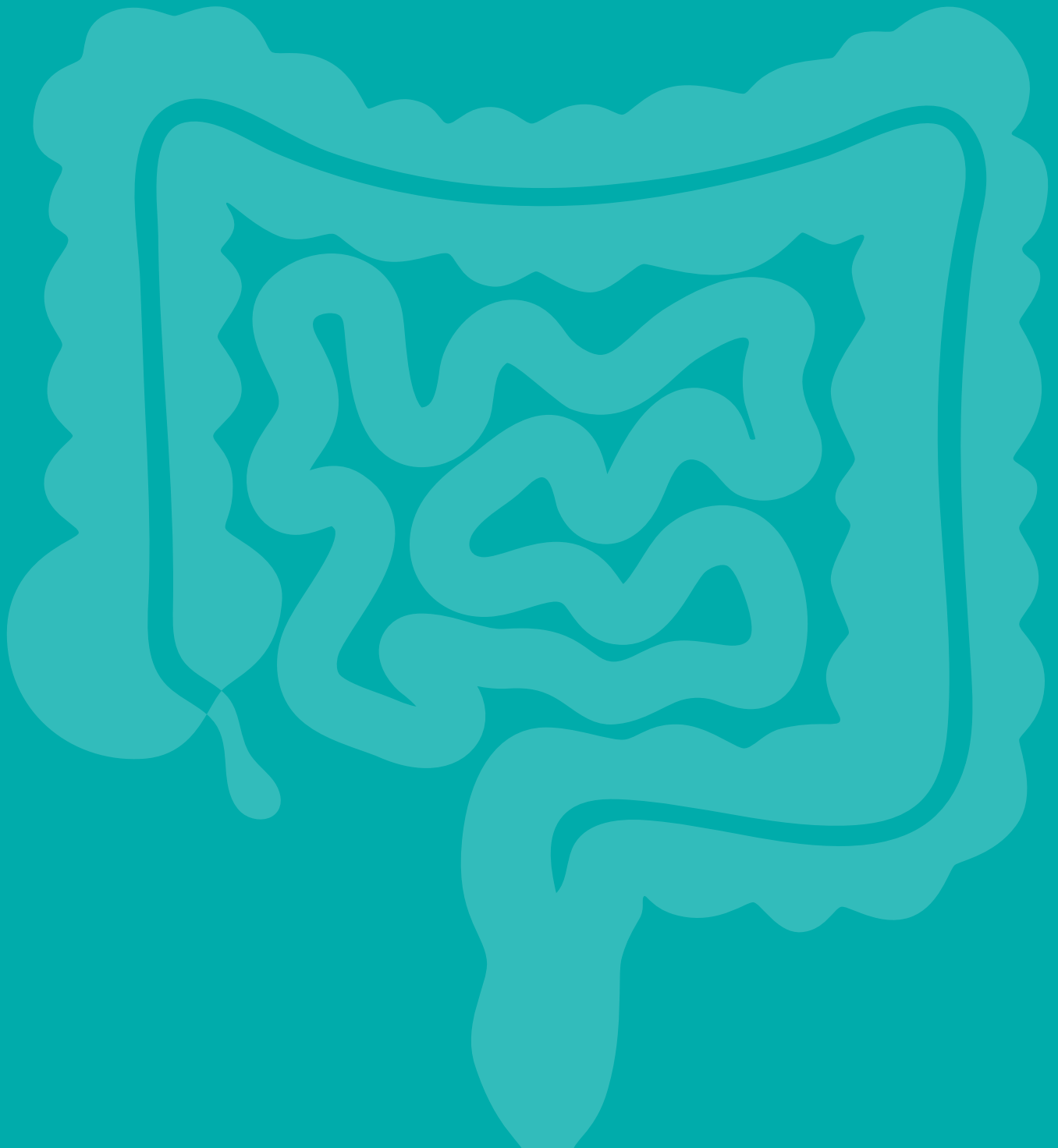
Pain in your lower back, between your hip bones (pelvis), or in your lower tummy.



Pain during sex.

These symptoms are very common and can be caused by many different conditions, but it's important to get them checked by a GP.

Bowel cancer screening





Top tips Improving access to bowel screening

Bowel cancer screening is completed using a FIT kit (Home Test).

This is for people aged between 50-74 years old.

Invitations are sent every 2 years via post.

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 disability team.
- Ask GP/ practice nurse to talk about screening at annual health check and if the 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: LNWH-tr.BCSP@nhs.net or call 0800 707 6060
- Support reasonable adjustments to be arranged such as:
 - Easy-read information or video to show person how to complete kit.
 - GP to provide bowel screening promotion and refer to the local LD team if the individual requires more specialist support.
 - 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 the rationale and ensure signs and symptoms monitoring in Health Action Plan.

Accessible Information and Resources

Accessible video:

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

Easy-read guide:

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

Books beyond words:

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

Please contact the bowel screening hub LNWH-tr.BCSP@nhs.net or call 0800 707 6060 to order a replacement bowel screening kit for the patient if it has been lost or misplaced.

Bowel cancer screening (FIT Kit)

Reasonable adjustments checklist and action plan



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 the 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 interests 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?</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

Know the symptoms of bowel cancer



Bleeding from your bottom



Blood in your poo



A change in how often you poo, or regularly having diarrhoea or constipation



Losing weight but you're not sure why



Feeling very tired all the time but you're not sure why



A pain or lump in your tummy

If you have any of these symptoms, talk to your GP and ask about an at-home test.

To find out more, visit [bowelcanceruk.org.uk/symptoms](https://www.bowelcanceruk.org.uk/symptoms)

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

Lung cancer screening





Top tips Improving access to lung cancer screening

Patients aged 55-74 who have a record of smoking in their GP notes will receive an invite to lung cancer screening.

If you would like to find out more about when the person you support could receive their invite, contact uclh.ncllunghealthcheck@nhs.net or call 0800 652 9589

Symptoms of lung cancer often do not appear until the cancer is at an advanced stage. This is why screening is so important, as it can help find lung cancer at an early stage. 3 out of 4 lung cancers picked up through screening are found at an early stage, when treatment is simpler and more successful.

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

- Ask the person you support if they have ever smoked. Even if they smoked a long time ago or only smoked occasionally, they may be eligible for screening
- Make sure any history of smoking is recorded in their GP record
- If you think the person you support should have received an invitation to lung cancer screening and hasn't, contact uclh.ncllunghealthcheck@nhs.net for advice.

When the person you support is offered lung cancer screening, ensure reasonable adjustments are offered, such as:

- Accessible videos and easy read information
- Contact their local service to ask for adjustments to the appointment, such as a longer appointment time or a face-to-face lung health check appointment
- Ask to speak to the nurse who will carry out the appointment in advance, to help them understand how best to share information needed for the assessment and how best to communicate with the person
- Ask for a pre-visit to the scanner, if the person is invited for a lung scan after their lung health check
- Practice with the person lying in the right position for their scan (flat on their back on a bed with their arms above their head), if a CT scan is needed
- Make sure that lung cancer screening is part of Health Action Plan if the person is eligible.

Accessible Information and Resources

Accessible videos:

www.lungchecklondon.org

Easy read guide:

<https://www.nclcanceralliance.nhs.uk/our-work/prevention-awareness-and-screening/healthy-lungs-healthier-you-materials/>

Lung cancer screening

Reasonable adjustments checklist and action plan



Name:

<p>Does the person have capacity to consent to lung cancer screening? As part of this, consider whether the person has a basic understanding of:</p> <ul style="list-style-type: none"> • What lung cancer screening is for (to find lung cancer early) • What will happen at the appointment (asked questions about their health and history, to work out risk of developing lung cancer) • That they may be offered a scan of their lungs if they are found to be at increased risk of lung cancer • The risk of not attending (possible undetected cancer). 	<p>Yes/No If no, please ensure a Mental Capacity Act Assessment is completed and stored in the person's file. N.B. The lung cancer screening team are responsible for completing the MCA assessment.</p> <p>Outcome:</p> <ul style="list-style-type: none"> • Has capacity - Support person to make informed decision • Lacks capacity - Best interests discussion required.
<p>Was the person's care coordinator or community learning disability team contacted for support?</p>	<p>Yes/No Action(s) taken:</p>
<p>Were all reasonable steps taken to enable the person to understand the screening (e.g. videos, easy read resources, pre-visit to scanner)?</p>	<p>Yes/No Action(s) taken:</p>
<p>Does the person have any known first degree (mother, father, brother, sister) family history of lung cancer? If yes, do they understand that this places them at greater risk of developing lung cancer?</p>	<p>Yes/No Comments:</p>
<p>Were reasonable adjustments explored with the screening provider? This could include a longer or face-to-face appointment, pre-visits to scanner, etc.</p>	<p>Yes/No Action(s) taken:</p>
<p>Has a best interests discussion taken place? This should include their family, carers, GP, and other relevant professionals involved and can take place over the phone.</p>	<p>Yes/No</p> <ul style="list-style-type: none"> • Who was involved in this discussion?
<p>What was the outcome of the best interests meeting? The best interests decision should be documented and a copy stored in the person's file.</p>	<p>Outcome:</p> <p>Rationale:</p>
<p>If the best interests decisions was not to screen the person for lung cancer, would screening be possible in the future with further support?</p>	<p>Yes/No Rationale:</p>
<p>Are family/carers/support staff aware of the signs and symptoms of lung cancer?</p>	<p>Yes/No Any Actions:</p>
<p>Has the person consented to a referral for smoking cessation? Please find the borough electronic referral forms on the Stop Smoking London website.</p>	<p>Yes/No Comments:</p>

Completed by:

Date:



Signs & symptoms of lung cancer

Symptoms include:



- Persistent or changing cough
- Coughing up blood
- Shortness of breath
- Unexplained tiredness
- Loss of appetite/weight
- Ache or pain when breathing or coughing.

It is never too late to stop smoking.



There is lots of help and support available to help people stop smoking. Please visit Stop Smoking London <https://stopsmokinglondon.com/>

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 checklist and action plan.
- Ask learning disability 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 interests 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 to be in the person's best interests, ensure an AAA action plan is in place including education.

Accessible Information and Resources

Easy read guide:

https://assets.publishing.service.gov.uk/media/68e7d734cf65bd04bad76702/AAA_screening_easy_read_guide__Oct_25.pdf

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

<https://www.youtube.com/watch?v=6yObcd9X3Uw&t=185s>

AAA North London Screening Service:

<https://www.inhealthgroup.com/aaa-screening/>

0333 009 6971

inl.London.aaa@nhs.net

Abdominal aortic aneurysm (AAA)

Reasonable adjustments checklist and action plan



Name:

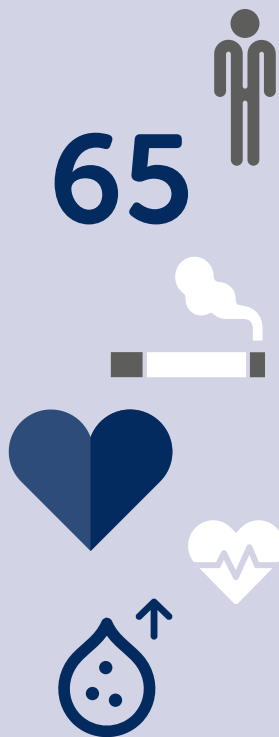
<p>Does the person have the capacity to consent to AAA screening? Does the person have a basic understanding of:</p> <ul style="list-style-type: none"> • What AAA screening is for? • What it involves • Risk of not attending. (possible undetected aneurysm). 	<p>Yes/No Outcome:</p> <ul style="list-style-type: 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 interests 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 interests. 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?</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 every 12 months, but every 24 months if the previous two tests are normal. 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 checklist 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 interests 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 after a diabetic eye screening test

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



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 and easy-read resources).</p>	<p>Yes/No Action taken:</p>
<p>Has a best interests 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.

Discussing screening during annual health checks

Everyone with a learning disability aged 14 and over is entitled to a free yearly check-up at their GP practice. This is designed to review their physical and mental health.

This helps to identify health problems early, allows for discussions about health concerns, and ensures that necessary treatments or support are put in place. These checks are part of an NHS initiative to reduce health inequalities by addressing potential unmet health needs.

Why is it important to discuss screening during annual health checks?

- People with learning disabilities are at higher risk of dying from cancer at a younger age than the general population.
- Cancer screening is vital for diagnosing cancer early, when it is easier to treat, but access can be challenging for people with learning disabilities.
- Annual health checks are a crucial opportunity to discuss cancer screening and ensure everyone has the chance to participate.

Communication strategies when discussing cancer screening

- Use simple language: Avoid jargon and long sentences.
- Speak slowly and clearly: Pause frequently to check for understanding.
- Confirm comprehension: Ask the person to explain what they have understood in their own words.
- Use visual aids: Show easy-read guides, animations, or videos to help explain the screening process.
- Talk directly to the individual: Always speak to the person with the learning disability, not their carer or a family member, unless the individual directs you to do so.
- Adapt to their communication style: Match your communication to the person's individual needs.

Make sure the patient is provided with the annual health check questionnaire before their appointment. This can help to improve the quality of the health check. The pre-check questionnaire has been embedded into EMIS. All LD AHC forms, pathways and workflows can be found on the NCL ICB General Practice website at <https://gps.northcentrallondon.icb.nhs.uk/>

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>
Cancer Screening Information and Resources: Barnet Mencap <https://www.youtube.com/watch?v=qTmFPiJKjzc>





Credits

This resource pack was produced by County Durham Learning Disability Health Facilitation Team (TEVV), 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.

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Bowel Cancer UK, Breast Cancer Care were not involved in the production 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**

