



Public Health  
England

**NHS**

# Promoting access to cancer screenings for people with a learning disability

A guidance and resource pack for care providers of learning disability services



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# Aims and purpose of guidance pack

## Background

“People with learning disabilities have poorer health and are more likely to die at a younger age than people in the general population, in part because of poor access to health services Heslop et al 2013. People with learning disabilities have a poorer uptake of cancer screenings compared to the general population. This is due to a number of barriers such as poor prior knowledge of screening, a lack of accessible information and reasonable adjustments. 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.”

(Heslop et al 2013\*)

To support care providers of learning disability services with knowledge and understanding of the national cancer 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.

**NHS cancer screening is for people who do not have any symptoms. If you have any symptoms please contact your GP.**



# NHS cancer screening programmes

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## Cervical Screening

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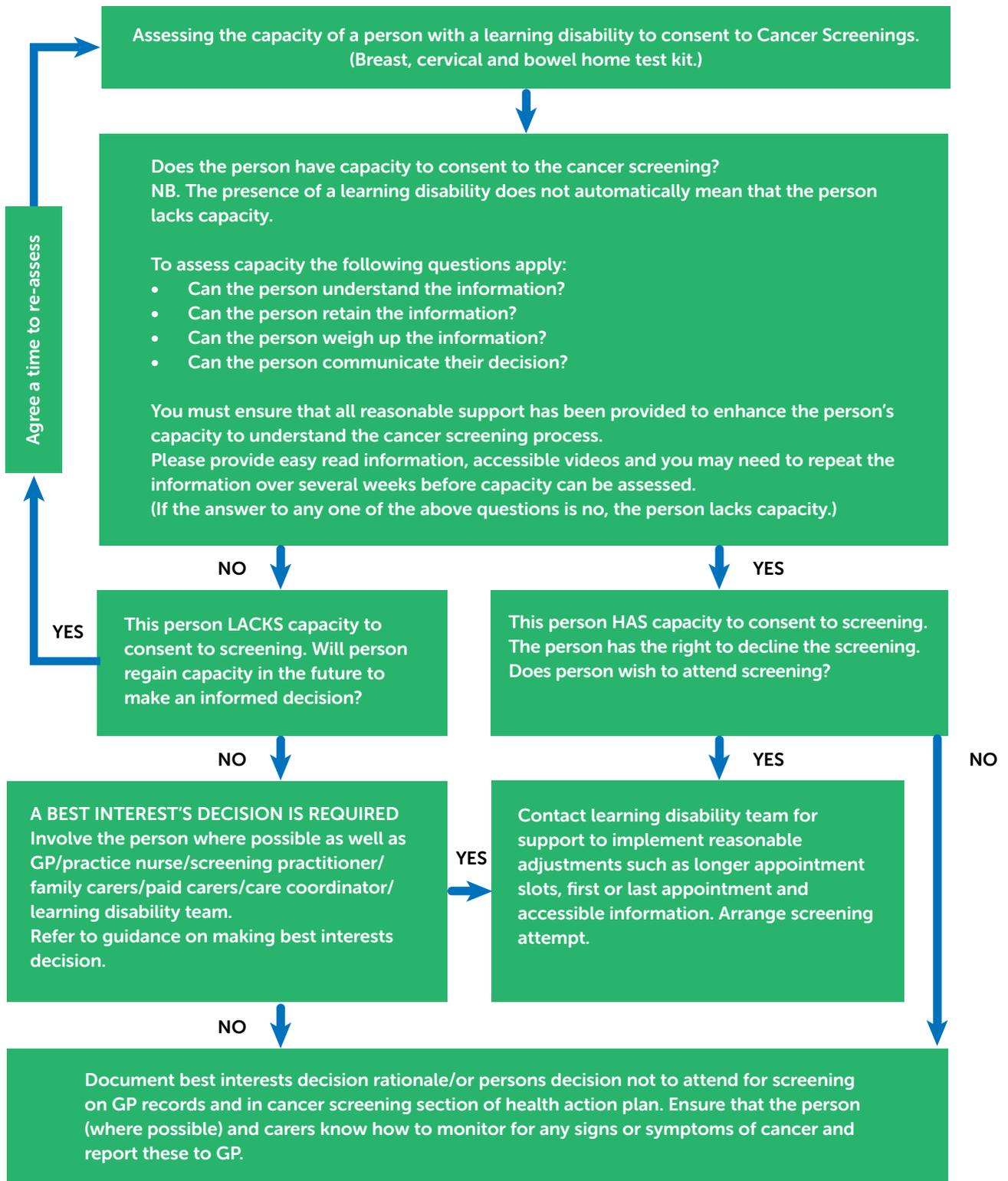


## Bowel screening home test (FIT) kit

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



# Assessing capacity for cancer 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](http://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 a cancer screening this could be the person’s GP, or practice nurse (cervical screening) or screening practitioner (breast and bowel 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

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### **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.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 cancer 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.

# 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 a cancer 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.

In some areas screening is offered from age 47 to 73.

You can opt into breast screening over age 71 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>

# 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 71st birthday.

Women can opt in over age 71.

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><b>Yes/No Outcome:</b></p> <ul style="list-style-type: none"> <li>• <b>Lacks capacity:</b> Best interests discussion required.</li> <li>• <b>Has capacity:</b> Support person to make informed decision.</li> </ul>
<p>Was the person's care coordinator or community learning disability team contacted for support?</p>	<p><b>Yes/No Action taken:</b></p>
<p>Were all reasonable steps taken to enable the person to understand the screening? (E.g. videos, easy read resources.)</p>	<p><b>Yes/No Action taken:</b></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><b>Yes/No Comments:</b></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><b>Yes/No Comments:</b></p>
<p>What was the outcome of the best interests meeting?</p>	<p><b>Outcome and rationale:</b></p>
<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><b>Yes/No Action taken:</b></p>
<p>If decided NOT to attempt screening in best interests. Would breast screening be possible in the future with further support?</p>	<p><b>Yes/No Review date:</b> <b>Comments:</b></p>
<p>Has person been offered a breast check examination at annual health check by practice nurse?</p>	<p><b>Yes/No Comments:</b></p>
<p>Do family/carers/support staff know how to monitor for signs and symptoms of breast cancer?</p>	<p><b>Yes/No Comments:</b></p>

Completed by:

Date:

# Not just a LUMP

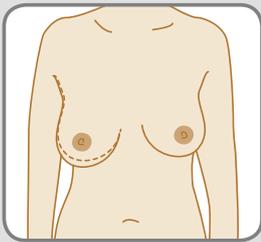
Many people think the first sign of breast cancer is a lump

Not all breast cancers show as lumps

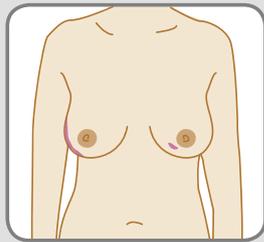
Not all lumps are breast cancer

Some benign (not cancer) conditions appear as a lump

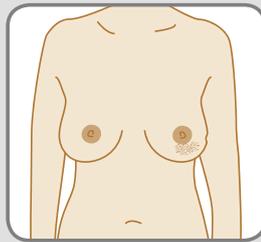
## Look out for



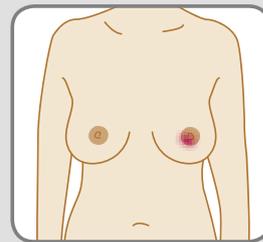
A change in size or shape



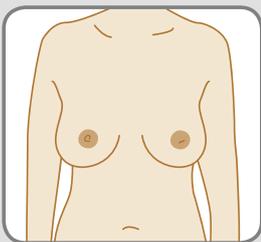
A lump or area that feels thicker than the rest of the breast



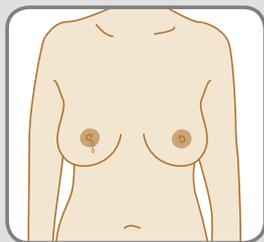
A change in skin texture such as puckering or dimpling (like the skin of an orange)



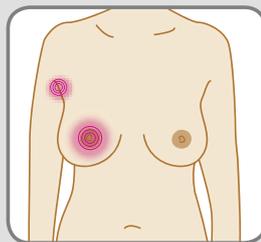
Redness or a rash on the skin and/or around the nipple



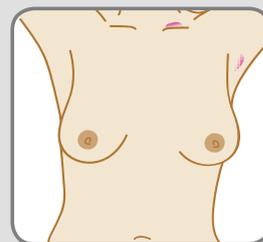
A change to the nipple, for example it has become pulled in or changed its position or shape



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](https://www.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 changes are more likely in women who have been sexually active who have been in contact with the Human Papilloma Virus (HPV). Cervical screening can detect these changes. The screening test looks for high risk HPV which could cause cell 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.
  - 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>

# Cervical cancer screening

## Reasonable adjustments checklist and action plan



First invite at age 25 and then every 3 years up to age 49 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"> <li>• What the screening is for?</li> <li>• What will happen during screening?</li> <li>• The risk of not attending screening (unidentified cell changes?)</li> </ul>	<p><b>Yes/No Outcome:</b></p> <ul style="list-style-type: none"> <li>• <b>Lacks capacity:</b> Best interests discussion required.</li> <li>• <b>Has capacity:</b> Support person to make informed decision.</li> </ul>
<p>Was the person's care coordinator, learning disability team or health facilitation team contacted for support?</p>	<p><b>Yes/No Action taken:</b></p>
<p>Were all reasonable steps taken to enable the person to understand the screening? (E.g. videos, easy read resources.)</p>	<p><b>Yes/No Action taken:</b></p>
<p>Were reasonable adjustments explored with the practice nurse such as pre visits, longer appointments, music.</p>	<p><b>Yes/No Action taken:</b></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><b>Yes/No Who attended/involved:</b></p>
<p>What was the outcome of the best interests meeting?</p>	<p><b>Outcome and rationale:</b></p>
<p>Would cervical screening be possible in the future with further support and education?</p>	<p><b>Yes/No Comments:</b></p>
<p>Does the person/family/carers support staff know how to monitor for signs and symptoms of cervical cancer?</p>	<p><b>Yes/No Review date:</b> <b>Comments:</b></p>
<p>Has cervical screening been added to health action plan?</p>	<p><b>Yes/No Any Actions:</b></p>

**Completed by:**

**Date:**

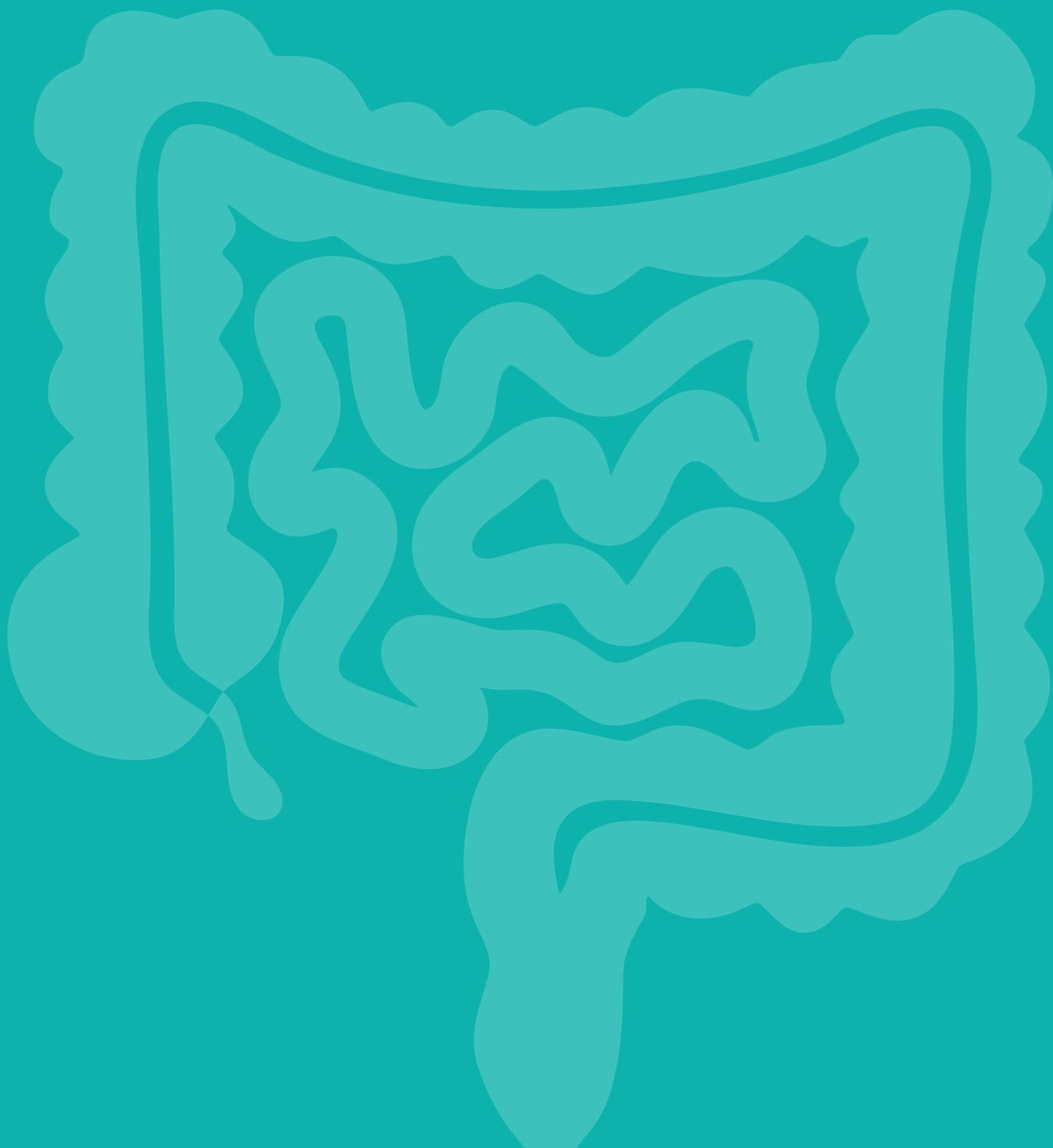
# Do you know the symptoms of cervical cancer?

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



If you have experienced any of these symptoms you should contact your GP as soon as possible.

# Bowel cancer screening





# Top tips Improving access to bowel screening

## Bowel screening FIT kit (Home Test).

First invite age 60. FIT kit delivered to home in post every two years up to age 74.

Can opt into screening after age 74.

## 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: [bowelscreening@nhs.net](mailto:bowelscreening@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](https://www.youtube.com/watch?v=m2f-wY0C_1Q)

### Easy read guide:

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

# 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"> <li>• What the screening is for?</li> <li>• What will happen during screening?</li> <li>• The risk of not completing kit? (Possible undetected cancer).</li> </ul>	<p><b>Yes/No Outcome:</b></p> <ul style="list-style-type: none"> <li>• <b>Lacks capacity:</b> Best interests discussion required.</li> <li>• <b>Has capacity:</b> Support person to make informed decision.</li> </ul>
<p>Was the person's care coordinator, learning disability team or health facilitation team contacted for support?</p>	<p><b>Yes/No Action taken:</b></p>
<p>Were all reasonable steps taken to enable the person to understand the screening? (E.g. videos, easy read resources.)</p>	<p><b>Yes/No Action taken:</b></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><b>Yes/No Action taken:</b></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><b>Yes/No Who attended/involved:</b></p>
<p>What was the outcome of the best interests meeting?</p>	<p><b>Outcome and rationale:</b></p>
<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><b>Yes/No Comments:</b></p>
<p>Does the person/family/carers support staff know how to monitor for signs and symptoms of bowel cancer?</p>	<p><b>Yes/No Comments:</b></p>
<p>Has bowel screening been added to health action plan?</p>	<p><b>Yes/No Any Actions:</b></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

# 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](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>

This resource pack was adapted from resources developed and 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, the North East and Cumbria Learning Disability Network Macmillan cancer project and Northern Cancer Alliance.

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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