Promoting access to cancer screenings for people with a learning disability

A guidance and resource pack for care providers of learning disability services
Aims and purpose of guidance pack 3
Ages of invite 4
Barriers to accessing screening 5
Mental Capacity Act guidance 6-7
Best interests decision making 8-9

Resources Section

Breast Screening 10–13
• Top tips to promote access to screening
• Reasonable adjustments checklist and action plan
• Signs and symptoms

Cervical Screening 14-17
• Top tips to promote access to screening
• Reasonable adjustments checklist and action plan
• Signs and symptoms

Bowel Screening Home Test (FIT) Kit 18-21
• Top tips to promote access to screening
• Reasonable adjustments checklist and action plan
• Signs and symptoms

Bowel Scope Screening 22-23
• Top tips to promote access to screening
• Reasonable adjustments checklist and action plan

References and further guidance 24
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 programmes

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 age 70
• Trial in some areas currently invite women age 47—50 and 70—73.
• Can opt into the programme 70+ every 3 years.

Bowel scope screening
• One off invite age 55 (Flexible Sigmoidoscopy)
• Can opt into programme up to age 60
• This programme is currently being rolled out nationally and is not available in all areas.

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.
Accessing capacity for cancer screening

Assessing the capacity of a person with a learning disability to consent to Cancer Screenings.
(Breast, cervical, bowel scope and bowel home test kit.)

Does the person have capacity to consent to the cancer screening?
NB. The presence of a learning disability does not automatically mean that the person lacks capacity.

To assess capacity the following questions apply:
• Can the person understand the information?
• Can the person retain the information?
• Can the person weigh up the information?
• Can the person communicate their decision?

You must ensure that all reasonable support has been provided to enhance the person's capacity to understand the cancer screening process.
Please provide easy read information, accessible videos and you may need to repeat the information over several weeks before capacity can be assessed.
(If the answer to any one of the above questions is no, the person lacks capacity.)

This person LACKS capacity to consent to screening. Will person regain capacity in the future to make an informed decision?

This person HAS capacity to consent to screening. The person has the right to decline the screening. Does person wish to attend screening?

A BEST INTEREST’S DECISION IS REQUIRED
Involve the person where possible as well as GP/practice nurse/screening practitioner/family carers/paid carers/care coordinator/learning disability team.
Refer to guidance on making best interests decision.

Contact learning disability team for support to implement reasonable adjustments such as longer appointment slots, first or last appointment and accessible information. Arrange screening attempt.

Document best interests decision rationale/or persons decision not to attend for screening on GP records and in cancer screening section of health action plan. Ensure that the person (where possible) and carers know how to monitor for any signs or symptoms of cancer and report these to GP.

https://www.cqc.org.uk/sites/default/files/documents/rp_poc1b2b_100563_20111223_v4_00_guidance_for_providers_mca_for_external_publication.pdf
Mental Capacity Act 2005

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 persons 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.

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
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 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 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 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
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.

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 70 every 3 years.

Accessible Information and Resources

Accessible videos:
https://www.youtube.com/watch?v=HphkoUbfNQQ
(By Leicestershire Partnership NHS Trust)

Easy read guide:
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:

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<thead>
<tr>
<th>Question</th>
<th>Yes/No</th>
<th>Outcome</th>
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| Does the person have the capacity to consent to breast screening? GP and breast screening practitioner can support assessment of capacity. |        | **Yes/No**  
| • Lacks capacity: Best interests discussion required.  
| • Has capacity: Support person to make informed decision.                  |
| Does the person have a basic understanding of: What the breast screening is for? What is involved? Risk of not attending? (possible undetected cancer) |        | **Yes/No**  
| Was the person’s care coordinator or community learning disability team contacted for support? |        | **Yes/No**  
| Were all reasonable steps taken to enable the person to understand the screening? (E.g. videos, easy read resources.) |        | **Yes/No**  
| 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. |        | **Yes/No**  
| Has a best interest’s discussion taken place? (This should be with GP, family, carers, relevant professionals involved and can be via telephone conversations). |        | **Yes/No**  
| What was the outcome of the best interests meeting? |        | **Outcome and rationale:**  
| 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. |        | **Yes/No**  
| If decided NOT to attempt screening in best interests. Would breast screening be possible in the future with further support? |        | **Yes/No  Review date:**  
| Has person been offered a breast check examination at annual health check by practice nurse? |        | **Yes/No  Comments:**  
| Do family/carers/support staff know how to monitor for signs and symptoms of breast cancer? |        | **Yes/No  Comments:**  

**Completed by:**  

**Date:**  

12
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
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 mediation 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.

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.

Accessible Information and Resources

Accessible videos:

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 50 then every 5 years up to age 64.

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<th>Question</th>
<th>Yes/No</th>
<th>Outcome:</th>
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<tr>
<td>Has a capacity of consent to cervical screening been completed? GP or practice nurse should support assessment of capacity. Is there a basic understanding of: • What the screening is for? • What will happen during screening? • The risk of not attending screening (unidentified cell changes?)</td>
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<td>Was the person’s care coordinator, learning disability team or health facilitation team contacted for support?</td>
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<td>Were all reasonable steps taken to enable the person to understand the screening? (E.g. videos, easy read resources.)</td>
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<td>Were reasonable adjustments explored with the practice nurse such as pre visits, longer appointments, music.</td>
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<td>Has a best interest’s discussion taken place? (This should be with GP, family, carers, relevant professionals involved and can be via telephone conversations).</td>
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<td>Would cervical screening be possible in the future with further support and education?</td>
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<td>Does the person/family/carers support staff know how to monitor for signs and symptoms of cervical cancer?</td>
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<td>Has cervical screening been added to health action plan?</td>
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**Comments:**

**Review date:**

**Any Actions:**
Do you know the symptoms of cervical cancer?

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

- Lower back pain
- Pain during sex
- Bleeding: during or after sex, or between periods
- Post menopausal bleeding
- Unusual vaginal discharge

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

Find out more at jostrust.org.uk/symptoms
Bowel cancer screening
Top tips Improving access to bowel screening

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


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.
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

bowelcanceruk.org.uk

Registered charity number 1071038 (England & Wales) and SC040914 (Scotland).

Information correct at time of publication: August 2018. To be reviewed: August 2021.

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

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.

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<td>Does the person have the capacity to consent to bowel screening FIT kit?</td>
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<td>Lacks capacity: Best interests discussion required.</td>
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<td>Does the person have a basic understanding of:</td>
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<td>Has capacity: Support person to make informed decision.</td>
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<td>• What the screening is for?</td>
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<td>• The risk of not completing kit? (Possible undetected cancer).</td>
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<td>What was the outcome of the best interests meeting?</td>
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<td>Were reasonable adjustments explored to support the person to complete the FIT kit such as support from family members, carers, or support and education?</td>
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<td>Does the person/family/carers support staff know how to monitor for signs and symptoms of bowel cancer?</td>
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Completed by:                        Date:
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.
Top tips Improving access to bowel scope screening

One off invite at age 55 for bowel scope. People can opt into the programme up to age of 60. Bowel scope screening not only helps identify early bowel cancer it also helps to prevent bowel cancer by removing polyps that could become cancerous.

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

- Use the reasonable adjustments checklist and action plan.
- Refer people who need more support to the learning disability team.
- Ask GP/Practice nurse to discuss screening at annual health check and if person lacks capacity arrange a best interests discussion with the bowel screening practitioners.
- Ensure reasonable adjustments are offered such as:
  - Easy read information or accessible video to help person understand bowel scope screening.
  - Liaise with the bowel screening centre to arrange pre visit
  - Bowel scope screening is invasive and therefore careful person centred planning will be required to enable access.
  - Bowel preparation can be given in the screening centre instead of at home.
  - Additional sedation can be offered to help reduce anxiety.
  - Ensure bowel scope screening is in health action plan.

- If decided NOT in best interests to complete bowel scope screening document rationale in health action plan and ensure symptoms monitoring and action plan is in place.

Accessible Information and Resources

Accessible videos:
(7 parts): https://www.youtube.com/watch?v=ga5R7SXiyCY&list=PL6IqwcMACXkij069Dsg2o8Vs67m7aTjYFO

Easy read guide:
One off invite age 55 (Flexible Sigmoidoscopy) for early detection and removal of polyps that could become cancerous. Can opt into programme up to age 60.

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**Lacks capacity:** Best interests discussion required.  
**Has capacity:** Support person to make informed decision.

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<tr>
<th>Was the person’s care coordinator, learning disability team or health facilitation team contacted for support?</th>
<th>Yes/No</th>
<th>Action taken:</th>
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<tr>
<th>Were all reasonable steps taken to enable the person to understand the screening? (E.g. videos, easy read resources.)</th>
<th>Yes/No</th>
<th>Action taken:</th>
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<tr>
<th>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.</th>
<th>Yes/No</th>
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<tr>
<th>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).</th>
<th>Yes/No</th>
<th>Who attended/involved:</th>
</tr>
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</table>

| What was the outcome of the best interests meeting? | | Outcome and rationale: |
|---|---|

| Would bowel screening be possible in the future with further support and education? | Yes/No | Comments: |
|---|---|

| Does the person/family/carers support staff know how to monitor for signs and symptoms of bowel cancer? | Yes/No | Comments: |
|---|---|

| Has bowel scope screening been added to health action plan? | Yes/No | Any Actions: |
|---|---|

Completed by:              Date:
References and further guidance

Chapter 4


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


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 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.

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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