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Guidance

# Supporting people with learning disabilities to access bowel cancer screening

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Bowel cancer screening (<https://www.nhs.uk/conditions/bowel-cancer-screening/>) aims to find bowel cancer early.

Screening is carried out using the home test kit, which is offered every 2 years to people aged 60 to 74. Those older than this can ask for a screening kit every 2 years by calling the free helpline on 0800 707 60 60. The helpline offers support if people are finding it difficult or are unsure how to complete the test kit.

Studies have shown that engagement in bowel cancer screening can be 'problematic' for people with learning disabilities (<http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>).

An additional one-off test called bowel scope (<https://www.nhs.uk/conditions/bowel-cancer-screening/bowel-scope-screening/>) is being introduced by the NHS in England for people in their 56th year. People will only be invited once their GP practice is rolled out by the NHS to provide the service.

Health professionals should use this information to help people with a learning disability better understand bowel cancer screening and take part if they choose to. This advice will be particularly useful to support staff who have no first-hand knowledge of screening.

The Public Health England (PHE) screening inequalities strategy (<https://www.gov.uk/government/publications/nhs-population-screening-inequalities-strategy>) explains how PHE is working with others to remove gaps in services that prevent everyone being able to access screening.

## 1. Signs and symptoms

It is important to help people with a learning disability, their families or carers understand the signs and symptoms of bowel cancer (<https://www.nhs.uk/conditions/bowel-cancer/symptoms/>) and go to see their GP straight away if they have any concerns. They should not wait until their screening invitation. Screening is for people who do not have symptoms.

Getting symptoms checked by a GP is especially important if they decide they do not want, or cannot go ahead, with bowel cancer screening.

## 2. Benefits and risks

Bowel cancer screening can help detect bowel cancer at an early stage, when it is easier to treat. It can also be used to help check for and remove small growths in the bowel called polyps (<https://www.nhs.uk/conditions/bowel-polyps/>) which can turn into cancer over time.

The NHS website includes information about the risks of bowel cancer screening (<https://www.nhs.uk/conditions/bowel-cancer-screening/>) that people need to be aware of to help them make an informed choice.

## 3. Opting out

It is an individual's choice whether to have bowel cancer screening and they can temporarily or permanently opt out (<https://www.gov.uk/government/publications/opting-out-of-the-nhs-population-screening-programmes>).

### 3.1 Temporarily opting out

This is just for the current screening episode and the individual will continue to receive invitations in future while they remain in the eligible age range.

### 3.2 Permanently opting out

This is when the person chooses not to have any further screening invitations in the future. This is a big step and something that needs careful explanation and thought.

It is important the individual understands that opting out permanently may mean that early signs of bowel cancer could be missed in future.

You may want to discuss any questions or concerns the individual may have with someone from the local screening programme or a GP first.

## 4. Improving access to bowel cancer screening

You can help improve access and reduce inequalities by:

- helping the person to understand what bowel screening is and why it is important
- explaining what a person needs to do with the home test kit
- checking with the individual to see if they need any assistance to collect a sample, and arrange extra help if needed
- making sure they have a copy of the easy read information
- offering to help the individual to understand the easy read leaflet
- offering to support the person to get further information about screening through the freephone helpline 0800 707 60 60

## 5. Resources

Clear, concise, easy to understand information helps support communication and understanding.

Health professionals can download and print off relevant resources in colour for people who require information in an easy read format (<https://www.gov.uk/government/publications/bowel-cancer-screening-easy-guide>).

### 5.1 Easy guide to bowel cancer screening

Healthcare professionals, family and carers can use the easy guide invitation and leaflet (<https://www.gov.uk/government/publications/bowel-cancer-screening-easy-guide>) to explain bowel cancer screening to people with learning disabilities.

### 5.2 Easy read screening invitation letter

Bowel cancer screening providers can use the easy read bowel cancer screening invitation letter template (<https://www.gov.uk/government/publications/bowel-cancer-screening-easy-guide>) to send out with the easy guide leaflet.

### 5.3 Short animation

The using your bowel cancer screening kit animation (<https://vimeo.com/showcase/6663813>) explains how to use the home test kit. This short film could be used alongside the easy read guide and letter to aid understanding.

### 5.4 Colonoscopy easy read information leaflet

Colonoscopy is the first line test for further investigations. [PHE](https://www.gov.uk/government/publications/bowel-cancer-screening-colonoscopy-easy-guide) has an easy guide to having a colonoscopy (<https://www.gov.uk/government/publications/bowel-cancer-screening-colonoscopy-easy-guide>) leaflet so that people with a learning disability can understand more about any further tests they may need.

### 5.5 CTC scan easy read information leaflet

A computed tomography colonography ([CTC](#)) scan will be offered if an additional test is needed and the person is not able to have a colonoscopy for medical reasons. [PHE](#) has an easy guide to having a [CTC](#) scan (<https://www.gov.uk/government/publications/bowel-cancer-screening-an-easy-guide-to-having-a-ctc-scan>) which includes information about preparing for the appointment.

## 5.6 Easy guide to bowel scope

[PHE](#) has an easy guide to bowel scope screening (<https://www.gov.uk/government/publications/bowel-scope-screening-easy-guide>).

There are also some short films aimed at people with learning disabilities and carers (<https://www.youtube.com/playlist?list=PL6IQwMACXkj069Dsgg2o8VS67m7aTjYFO>) which health professionals can use to improve understanding of bowel scope.

Please note that bowel scope is offered as a one-off invitation to individuals in their 56th year and is currently being rolled out across England. Invitations are only sent to people registered in a GP practice that is 'live' on the bowel cancer screening system ([BCSS](#)).

## 5.7 Resources to improve access

There are resources for health professionals to help improve healthcare access (<https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability>), including guidance to assist someone with a learning disability to be screened for cancer (<https://www.gov.uk/government/publications/cancer-screening-and-people-with-learning-disabilities>).

## 5.8 Reasonable adjustments

Health services should be aware that it is a legal duty (<https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty>) to make reasonable adjustments (<https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty#what-we-mean-by-reasonable-adjustments>) for people with a learning disability.

## 6. Standards

Other useful sources of information include the Accessible Information Standard (<https://www.england.nhs.uk/ourwork/accessibleinfo/>) and the Equality Act 2010 (<https://www.gov.uk/guidance/equality-act-2010-guidance>), which legally protects people from discrimination.

## 7. Making a best interest decision

If a person lacks capacity to make choices or consent to cancer screening, a best interest decision should be made. This should be a shared decision with the decision maker and those who know the person well, including:

- professionals
- family
- carers

The screening centre should arrange the best interest meeting.

The Mental Capacity Act (<http://www.legislation.gov.uk/ukpga/2005/9/contents>) sets out the law regarding capacity and consent and the Code of Practice ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/497253/Mental-capacity-act-code-of-practice.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf)) provides guidance.

Consider:

- reviewing the individual's medical history
- the individual's beliefs and wishes, which could influence a best interest decision
- the individual's past screening history

Considering whether the person has attended bowel cancer screening regularly before can be extremely useful. It can tell us if they once felt it was important.

On some occasions, professionals, families and carers cannot, or do not, agree on what is in the individual's best interests. If this is the case, it is recommended an independent advocate (IMCA) attends the best interest meeting to ensure the individual is properly represented.

## 8. GP practices

GP practices should inform their local bowel cancer screening hub about eligible people with learning disabilities who are registered with them. This is so hubs can make reasonable adjustments, such as send out easy guides and easy invitation letters.

### 8.1 Concerns about sharing information

Some GPs may be unsure about how much information they can share about their patients due to ethical and legal duties of confidentiality.

As screening is considered direct care, [GMC](https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/using-and-disclosing-patient-information-for-direct-care#paragraph-26) guidance on implied consent and sharing information (<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/using-and-disclosing-patient-information-for-direct-care#paragraph-26>) for direct care should apply.

However, it is important to remember the Caldicott principles (<https://www.igt.hscic.gov.uk/Caldicott2Principles.aspx>) that the duty to share information can be just as important as the duty to protect confidentiality (<https://phescreening.blog.gov.uk/2018/07/30/gps-duty-to-share-information-can-be-just-as-important-as-duty-to-protect-confidentiality/>).

GPs can be confident that local screening hubs and screening centres have strict information governance arrangements in place to protect personal information, keeping it confidential on secure IT systems.

When sharing patient identifiable information by email, it should be done by NHS.net to NHS.net email accounts, or through other secure methods.

### 8.2 Health checks

The annual learning disability health check (<https://www.gov.uk/government/publications/annual-health-checks-and-people-with-learning-disabilities>) can help pick up unmet health needs and is a good opportunity for GPs to discuss bowel cancer screening. Do ask about the person's thoughts about screening and screening history.

If a person has missed their screening invitation or are not sure when they are due a screening invitation, call 0800 707 60 60.

### 8.3 Useful resources for GP surgeries

Cancer Research UK has resources for GPs to support participation in bowel cancer screening (<https://www.cancerresearchuk.org/health-professional/screening/bowel-screening-evidence-and-resources/bowel-screening-resources>).

A good practice guide (<https://www.cancerresearchuk.org/health-professional/screening/bowel-screening-evidence-and-resources/bowel-screening-resources#BowelScreeningResources0>) can be used by GPs who want to be more proactive in supporting their people in their practice to access bowel screening and there is a section on adjustments for people with learning disabilities (<https://www.cancerresearchuk.org/health-professional/screening/bowel-screening-evidence-and-resources/bowel-screening-resources#BowelScreeningResources8>).

Bowel Cancer UK provides information about bowel cancer screening to aid practice and professional development (<https://www.bowelcanceruk.org.uk/how-we-can-help/for-health-professionals/>), including links to training and how to book awareness talks.

Local screening hubs and screening centres may also be able to provide information for GP surgeries. Call the free helpline on 0800 707 60 60 to get details of your local screening centre.

Practice nurses or community learning disability nurses who work at, or support, GP practices can pass on this information to people with a learning disability.

## 8.4 Learning disabilities teams

Local learning disability teams might be able to explain bowel cancer screening and help people with their choice. They may also be able to assist someone when completing their kit or offer support if they are required to attend for further investigations.

Learning disabilities teams and screening hubs/centres should work closely together to ensure reasonable adjustments are made if required.

## 9. Support during diagnostic tests

Although the initial screening test is completed at home, bowel scope, colonoscopy and CTC scans are carried out in hospital. All members of staff should demonstrate empathy and kindness and treat each person as an individual.

There are lots of things health professionals can do to make screening appointments better for individuals with a learning disability. They can:

- offer them a pre-visit to the department before their test to look round and ask questions
- allow extra time
- make sure communication is as clear as you can by using simple language, avoiding long words and long sentences
- speak slowly and clearly, and stop to check understanding at regular points during the conversation
- find out what word the person uses for parts of the body being looked at ('stomach' or 'tummy' for example) to avoid misunderstandings
- find out if there is a learning disability liaison nurse in the hospital who can offer support
- show the person the relevant easy guide leaflet during their appointment and discuss it with them
- always talk directly to the person rather than their carer, supporting professional or family member
- follow the lead of the person with additional needs and go at their pace
- check understanding at regular intervals (people with a learning disability are more likely to have hearing loss)
- show the person what the test involves (including showing them any pictures of endoscopes or scanning machines), explain any noises and what the room might look like
- consider ways to help the person to feel more relaxed and comfortable

These are suggestions and will not be appropriate in all cases.

## 10. Further support and information

Find out what support is available in your local area. There may be a person or a local learning disability team or primary care liaison team that can help.

Your local bowel cancer screening service may have a website and many local teams have Facebook and Twitter accounts.

Promoting access to cancer screening for people with a learning disability

(<http://www.northerncanceralliance.nhs.uk/pathway/prevention-awareness-and-screening/cancer-screening/>) includes information about the mental capacity act, best interest decisions and practical tips on supporting access to screening.

PHE screening blog articles (<https://phescreening.blog.gov.uk/category/bcsp/>) provide up to date news including information about bowel cancer screening and inequalities. You can register to receive email updates (<https://phescreening.blog.gov.uk/subscribe/>). PHE also has a dedicated PHE Screening Twitter account ([https://twitter.com/PHE\\_Screening](https://twitter.com/PHE_Screening)).

Contact the PHE Screening helpdesk (<https://phescreening.blog.gov.uk/helpdesk/>) with any queries about this publication, making sure you include its full title.