



Bowel
Screening
Wales



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Bowel Screening Wales

Information booklet for care homes and associated health professionals



Available in other formats on request

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Who are Bowel Screening Wales?

We are managed by Screening Division which is part of Public Health Wales, NHS Trust. Our bowel-screening programme was launched in October 2008 and is the first national screening programme to invite men and women.

Bowel cancer is the third most common cancer in Wales. Screening detects bowel cancer at an early stage – often when there are no signs or symptoms.

What is the aim of the programme?

The aim of bowel screening is to reduce the number of people dying from bowel cancer in Wales by 15% by 2020.

Who is invited?

Bowel screening is currently offered to men and women who are aged between 60 and 74 and live in Wales. People who have had a previous bowel condition or who are being monitored are advised to contact our Freephone helpline on 0800 294 3370.

How are people invited for screening?

We get address information directly from GPs. It is important that the person's correct home address is registered with the GP. We do not hold any medical information.

A bowel-screening test kit and information pack will be sent through the post. People will be able to carry out the test in the privacy of their own home.

If the test kit result is positive, the person will need further medical investigations to find out the reason for this.

How often are people invited for screening?

People will be invited to take part in the bowel-screening programme every two years.

Family history

Some bowel cancers can run in families. If you or the person you care for is concerned about family history, please speak to a GP.

What is screening?

As defined by the National Screening Committee (2011), screening is:

'A process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition.'

The National Screening Committee (NSC) is the organisation responsible for advising ministers and the NHS in the four UK countries about all aspects of screening. It also supports putting national screening programmes in place.

Benefits and risks of screening

There are both benefits and risks to taking part in any screening programme. It is essential that the people you support understand what these are so that **they** can make an informed choice about whether to take part or not.

Benefits of screening

- If bowel cancer is found early enough there is a 90% chance of treating the disease successfully.
- Bowel screening may find polyps, which are non-cancerous but may develop into cancer if left untreated.
- People found to have polyps will be monitored.
- It has been shown that a bowel-screening programme can reduce deaths from bowel cancer by between 15% and 18%.

Risks of screening

- Like any test, screening is not 100% accurate.
- Screening can reduce the risk of developing a condition or suffering from its complications. It does not guarantee protection from the condition.
- As with all screening programmes, there may be false positive results (wrongly reported as having the condition) and false negative results (wrongly reported as not having the condition).
- Cancer may develop between screening invitations.

Promoting informed choice

Informed decision making

'An informed decision is one where a reasoned choice is made by a reasonable individual using relevant information about the advantages and disadvantages of all possible courses of action, in accord with individual beliefs.' (Becker et al. 1999)

Screening is different from clinical practice in that screening programmes invite people who are apparently 'well' to take part. If people accept an invitation for screening, it is important that they have a realistic view of what a screening test can and cannot do for them.

As a healthcare worker or healthcare provider, it is important that you support service users and clients to make an informed decision about whether to take part in screening.

To do this, people must have all the facts, good and bad, so that they can make a truly informed decision.

Informed choice and informed consent

Informed consent

'Informed consent is an ongoing agreement by a person to receive treatment, undergo procedures or participate in research, after risks, benefits and alternatives have been adequately explained.' (RCN, 2004)

To make an informed choice, a person must have:

- access to clear, concise and accurate information, in an appropriate format;
- further support, if necessary, to help them understand screening information; and
- time to consider and take in the information.

At this stage the person should be able to make an informed decision and can confirm their decision by giving informed consent (permission) to take part or not to take part in screening.

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Making decisions

As a healthcare support worker or a healthcare provider you may think that taking part in screening is straightforward. For some people, this is the case. However, for others, taking part in screening can be a complicated process with many factors to consider.

As someone who supports service users or clients, you may not always agree with an individual's decision. In fact, you may think they have made an unwise decision. On a professional or personal level, this can prove to be very challenging.

It is important to remember that your role is to provide the person with the correct information (in an appropriate format) so that they can make an informed decision to take part in screening or not. It is essential to remember that if they are able to make a decision, **their** decision **must be** accepted as being **final**.

Mental capacity

The Mental Capacity Act 2005 provides a framework for assessing whether a person has capacity (the ability) to make decisions, and defines how others can make decisions on behalf of someone who is unable to.

You may have to support service users who have varying levels of capacity (or none at all). It is very important that you know what you can and cannot do in relation to the Mental Capacity Act. The act's code of practice will also provide guidance in how to follow the act.

Any care home that has residents with dementia or learning disabilities will be directly affected by the act. Care homes will be expected to provide evidence of assessing people's capacity and any decisions they have made in a person's 'best interests' under the act.

Definition of capacity

The act defines a lack of capacity as follows.

'A person lacks capacity in relation to matter if at the **material time** he is unable to make a decision for himself in **relation to the matter** because of **impairment of or a disturbance** in the functioning of the mind or brain.'

Underlying principles of the Mental Capacity Act

The Mental Capacity Act has **five main principles**.

When assessing capacity

1. You **must** assume a person has the capacity to make a decision unless it is proved otherwise.
2. Until you have taken **all practical** steps to help someone make a decision, but without success, you cannot treat the person as lacking capacity.
3. An **unwise decision does not** in itself show the person lacks capacity.

When acting or making decisions on behalf of someone lacking capacity

4. Anything you do or any decision you make must be in the person's **best interests**.
5. Any act or decision must be the least restrictive option to the person in terms of their rights and freedom of action.

Later in this booklet you will find a number of case studies which relate specifically to bowel screening. You can also find information about care pathways on our website. You may find these helpful when supporting your service users or clients.

Before doing the test

If you are a healthcare support worker or a healthcare provider and have been asked to help someone do the test, you may find this section useful as it tells you how to use the bowel test kit.

Things to remember before doing the test

If the person you are helping has capacity to make their own decisions, please make sure that you have their consent from the outset.

If the person lacks capacity you must make sure that the appropriate power of attorney is in place or that a decision in the person's best interests has been reached and recorded.

If you are supporting a person with a learning disability you can download a pack free from our website: www.bowelscreening.wales.nhs.uk.

This pack is called 'Having a bowel test'. Information in the pack is broken down into simple, bite-size sections. You may want to work through the pack with the person you are helping before doing the test.

If you want further information about this pack you can contact us on our Freephone helpline, 0800 294 3370.

About the bowel test kit

Before doing the test, please read through the leaflet that came with the pack. This tells you what is involved and how to do the test and may make it easier when explaining the test to your family member, service user or client.

You may need to discuss how you will help the person. Jointly, you may want to decide the following.

- When is the best time to do the test
- What their bowel habits are like
- Who will fill in the details on the kit
- Who will catch the stool (poo) sample

If you want advice on carrying out the test, or would like another kit, phone our helpline (0800 294 3370) to speak to a trained advisor.

Some important things to remember

- ✓ The test should be done three times over a 10-day period.
- ✓ The stool sample must not touch the water in the toilet.
- ✓ If the stool sample has come into contact with urine it will affect the result.
- ✓ You must record the information on the test kit accurately each time the test is done.
- ✓ Wash your hands before and after doing the test.
- ✓ If necessary, wear gloves.
- ✓ Have a pen ready to fill in the person's details and write the date on the bowel test kit.
- ✓ There are three flaps on the kit for three separate bowel movements (over three separate days).
- ✓ Only open one flap at a time (on each separate visit to the toilet).
- ✓ Do not open the side of the kit marked 'DO NOT OPEN'. This must be left sealed.
- ✓ If you make a mistake, we can send out another test kit in the post.

Signs and symptoms

Bowel cancer can develop between screening tests so it is important for people to be aware of any changes in their bowels.

Your client should see their doctor if they have any of the following symptoms.

- Bleeding from the back passage or tiny traces of blood in their bowel movements.
- A change in their bowel habits (such as constipation or diarrhoea) for six weeks or more.
- Severe stomach pains, especially after eating.
- Unexplained weight loss.
- Unexplained anaemia (due to lack of iron in the blood). Symptoms of anaemia are extreme tiredness, headaches, breathlessness and pale skin.

These symptoms may be caused by a range of conditions and should be discussed with a doctor without delay.

If you are caring for someone and you notice bowel changes, you should discuss their symptoms with them. If they do not have the ability to understand, you should talk to their relatives or a responsible health professional and suggest they make an appointment with their GP. If the person you care for is in a residential care home, it is advised that you discuss your concerns with the home manager and visiting GP.

Scenarios

The next section provides you with a number of situations which may help you when you are considering issues to do with consent and capacity. These scenarios are based on real-life situations. You may want to look at the mental capacity and care pathways section on our website which may help you during the course of your work.

Scenario 1

Geoff is 72 and suffers from dementia. He has recently been admitted to an Elderly Mentally Ill (EMI) care home. He has had a recent mental-capacity assessment in relation to his finances, which showed that he did not have the capacity to make financial decisions. Geoff has a family history of bowel cancer – two of his brothers died from bowel cancer at a relatively young age. Geoff also has a number of health issues which are affecting his overall quality of life. We have sent Geoff a routine bowel-screening invitation pack and bowel test kit. What happens next?

Points to consider

Just because Geoff lacks the capacity to make financial decisions, we cannot assume that he has no capacity to make other decisions. Principles 1 and 2 of the Mental Capacity Act should be carefully considered.

Geoff's scenario may have a number of possible outcomes.

Outcome 1 - After discussing the bowel-screening test with Geoff, staff are assured that he is able to retain and recall information and make an informed decision to go ahead and complete the test. Geoff can now complete the test.

Outcome 2 - After discussing all the options with Geoff, he fully understands the risks and decides he does not want to go ahead with screening. Principle 3 of the Mental Capacity Act says that an eccentric or unwise decision does not mean that the person has no capacity. So, in situations like this, the outcome of any discussions must be recorded in the appropriate care plan. Geoff should be given advice and guidance about opting out of the bowel-screening programme permanently.

Outcome 3 - If there is a reasonable belief that Geoff lacks capacity, a further mental-capacity assessment should be done in relation to bowel screening.

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Please note: If a further mental-capacity assessment is done, the person who fills in the appropriate mental-capacity decision form will be legally responsible for the assessment.

The mental-capacity assessment involves a relevant person (see below) carefully following the five main principles of the Mental Capacity Act and the code of practice to decide whether the person who may lack capacity can make decisions for themselves.

Although carers and family members can (and do) carry out informal assessments on a day-to-day basis, health or social-service professionals or solicitors must carry out formal assessments.

If after a further mental-capacity assessment it is considered that Geoff lacks capacity, a 'best interest' assessment **must** also be considered.

Scenario 2

Malcolm is a 62-year-old with mild learning difficulties. He lives in a supported-living environment and is supported closely by his healthcare support worker. Malcolm and his support worker have been reading the information we sent them about bowel screening. They have also been working through the 'Having a bowel test' learning disability pack, which explains what will happen in more detail. After discussing the test with his support worker, Malcolm feels that he is now ready to do the test. A member of his family thinks that Malcolm has enough health problems and tells Malcolm that he should not bother completing the kit. What happens?

Points to consider

No one should be stopped from making a decision just because others may think this unwise. As Malcolm has the capacity to make his own decision, it is entirely his decision whether to take part in screening or not.

Scenario 3

Josie is a 68-year-old who has had mental-health problems and has recently come to live in a residential home. Josie has capacity to make her own decisions. We have sent her a bowel test kit. She has strong views that she doesn't want to take part in bowel screening and feels that she would know if something was wrong with her. Josie has not opted out of the bowel-screening programme and has recently received her routine screening test kit. She has told staff in the home that she does not want to take part in the programme and her family are supporting her in her decision.

A healthcare assistant, who helps Josie, has a family history of bowel cancer and feels Josie's decision is unwise. Without Josie's permission she completes the test kit and returns it to us for testing.

When Josie receives her results she cannot understand how this has happened. Her results show that she needs to repeat the test. Josie speaks to a different health professional and is angry that her wishes have not been kept to. Josie becomes withdrawn.

Points to consider

As Josie has capacity to make her own decision and has clearly said she does not want to take part in the bowel-screening programme, it would appear that the healthcare assistant has broken her organisation's policies and procedures and, if it applies, their professional code of conduct.

As Josie was absolutely clear that she did not want to take part in the bowel test and did not give her consent, it could be argued that this goes against her human rights, and the healthcare assistant could face a disciplinary procedure.

As the home now knows that Josie needs to do a repeat test, they have a 'duty of care' to discuss with Josie the possible options, while respecting her decision whether or not to go ahead with the repeat test. All discussions about this matter should be recorded in Josie's care plan.

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Scenario 4

Wilf, aged 71, is recovering from a stroke and lives in a residential care home. Staff at the home are aware that, due to Wilf's condition, his capacity to make decisions comes and goes. We recently sent through a routine bowel test kit for Wilf. At the time Wilf received the test kit he had capacity and completed the test. The results showed that Wilf needed to do a further bowel test kit as the results were unclear.

Staff in the home explained to Wilf that the test needed to be repeated. However, during discussions Wilf appeared to be vacant and lacking insight. The staff contacted the most appropriate person (GP), who agreed to carry out a mental-capacity assessment. After completing this, it was considered that Wilf lacked capacity and a 'best interest' meeting was arranged. Was this course of action correct?

Points to consider

The home has correctly recognised that Wilf's capacity has changed and has passed this on to the appropriate agency for a 'best interest' meeting. At this meeting a decision will be made in Wilf's best interests.

Scenario 5

Elizabeth is a 73-year old lady who lives in a residential care home. She has recently received her routine bowel screening test kit from us. Elizabeth has capacity to make decisions for herself.

She has consistently refused to take part in bowel screening. Staff in the home have discussed at length with Elizabeth whether she wants to complete the bowel test kit but she decides that she does not want to take part.

The healthcare support worker who helps Elizabeth with her personal care has noticed that Elizabeth has blood in her stools. What should she do?

Points to consider

Our national screening programme is aimed at people who are well and does not routinely screen people with symptoms. Also, as Elizabeth is able to make her own decisions, staff at the home must respect this and not do the test on her behalf.

The healthcare support worker who helps Elizabeth should report this to the registered manager or another appropriate person. She should also make sure that she records it on Elizabeth's care plan.

An appropriate staff member should discuss with Elizabeth that her support worker has noticed blood in her stools and encourage Elizabeth to allow the home to make an appointment with her GP, or agree that the visiting GP (if this applies) can speak with her about her options.

It is important to reassure people that blood in their stools does not mean that they have bowel cancer. What it does mean is that further investigations are needed.

Frequently asked questions

1. The person that I care for is physically unable to complete their bowel-screening test kit following a stroke. Can I do the test for them?

You can do the test on their behalf as long as they have asked you to. It is very important that the person understands the information in the booklet and that completing the test may result in further tests at the hospital if blood is found in the sample.

For more advice on doing the test on behalf of someone who has a physical disability, phone our free helpline on 0800 294 3370.

2. The person that I care for has dementia. Can I do the test on their behalf?

Yes, you can do the test as long as the person has asked you to do it. It is very important that the person understands the information in the booklet and that completing the test may result in further tests at the hospital if blood is found in the sample.

If the person cannot make this decision, we recommend you discuss the situation with the person's GP and whoever has lasting power of attorney (legal authority to act) for their health and wellbeing. Following this, a 'best interest' decision will need to be made on the person's behalf. Their GP will decide if they would benefit from screening and how they would cope if they had a positive result.

For more advice, please contact your local bowel-screening regional nurse by phoning us on 0800 294 3370.

3. The person that I care for refuses to do their bowel-screening test but I have seen blood in their stools. What should I do?

Our national screening programme is aimed at people who are well and does not routinely screen people with symptoms.

You should make the person aware that you have noticed blood. If they understand your concerns you should encourage them to see their GP. If they do not understand, you should speak to their relatives and suggest they make an appointment with the person's GP, or contact the GP yourself and explain your concerns.

4. The person that I care for does not want to take part in screening but I could do the test when I help them with going to toilet. Can I do this?

No. You can only do the test on someone else's behalf if they have asked you to do so. If you do the test, you will be acting against their will.

5. I carried out the test on behalf of the person that I care for, but I had a letter to say the test kit was 'spoilt' and I need to repeat the test. What did I do wrong?

A small percentage of bowel-screening test kits returned are spoilt. This means that we are unable to screen the test kit in the laboratory. There may be many reasons for this - the test may not have been done correctly or some of the person's details may have been missing. When you are doing the test, it is very important you follow the step-by-step instructions in this booklet. Make sure you check the test kit before you return it in the post.

If you have any questions about doing the test on behalf of someone else, phone our helpline on 0800 294 3370.

6. The person that I care for suffers from diarrhoea or constipation. Can I do the test for them?

If the person that you care for is suffering from either diarrhoea or constipation, we would advise you to phone our helpline to discuss their symptoms. A trained advisor will discuss with you whether or not you should do the test.

If the person is experiencing persistent bowel changes, it is important that they get medical advice.

7. I take care of the hygiene needs of a disabled or infirm person who suffers from incontinence. Can I do the test for them?

You can do the test as long as they have asked you to. It is very important that they fully understand the information in the booklet and that carrying out the test may result in further tests.

For more advice on doing the test on behalf of someone who has a disability, please speak to your regional nurse by phoning our helpline on 0800 294 3370.

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8. The person I care for has recently moved into a care home. Will they still receive a bowel-screening test kit?

If they have changed address, it is very important that they or a member of their family give their GP their new contact details. We automatically get address details from GPs, so it is very important that records are updated to make sure we invite people for screening at the right time.

9. The person that I care for suffers from inflammatory bowel disease. Should they do the test?

If the person that you care for suffers from inflammatory bowel disease such as colitis or Crohn's disease it is important that you speak to your bowel-screening regional nurse for advice. The person may be being monitored as part of a surveillance programme and not need to be screened. To speak to your regional nurse, phone our helpline on 0800 294 3370.

10. A resident in our care home has recently died. Do I need to tell you to remove her from your records?

There is no need to tell us if a care-home resident dies as we automatically update our records from GP information.

You are unlikely to receive a test kit for someone who has died, but if you do, please tell us.

11. What is a polyp?

A polyp is a small growth on the lining of the bowel. Some are attached by a stalk, others are flat without a stalk. Polyps are usually removed during a colonoscopy (if they are left they could develop into cancer).

12. What does the specialist screening practitioner (SSP) do?

SSPs work for Bowel Screening Wales but are based in local hospitals. Their role is to support people who have had a positive test result and who may need further investigation.

The SSP will carry out a telephone assessment with the person who received the positive result or whoever is supporting them. This assessment will make sure that the person is suitable for a colonoscopy. This telephone call may last for up to an hour. If the person with the positive result (or whoever is supporting them) feels that a telephone assessment is not appropriate, the SSP can carry out a face-to-face assessment.

The SSP will explain everything clearly to the person and their family or carers and discuss with them any concerns or questions that they may have.

13. What happens if the person that I care for is not fit enough for a colonoscopy?

If they are not fit enough for a colonoscopy, the SSP will refer them to a screening colonoscopist for review. The colonoscopist will assess whether they could have an alternative examination, such as a CT scan.

If a scan is not suitable, we will agree an individual management plan. If our quality assurance advisors and Head of Programme agree, the person will no longer be included in the screening programme and we will tell their GP. If we consider the person is only temporarily unfit, we will set a date for a review.

Contact information

Bowel Screening Wales Free phone Helpline on:

0800 294 3370

Or visit the Bowel Screening Wales website at:

www.bowelscreening.wales.nhs.uk

Useful Links

Age Cymru

<http://www.ageuk.org.uk/cymru/>

Alzheimer's Society

<http://alzheimers.org.uk/>

Bowel Cancer UK

<http://www.bowelcanceruk.org.uk>

Carers Wales

<http://www.carersuk.org/wales>

Disability Wales

<http://www.disabilitywales.org/>

Learning Disability Wales

<http://www.learningdisabilitywales.org.uk/>

Understanding the Mental Capacity Act

http://www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/Makingdecisionsforsomeoneelse/DG_186479

Stroke Association

<http://www.stroke.org.uk/home>