

Bowel Screening Wales

Information booklet for care homes and associated health professionals



0800 294 3370

www.phw.nhs.wales/bowel-screening

You can contact us in Welsh or English. It will take us the same amount of time to answer you, whichever language you choose.

Version 4.0 12/2024



Contents

Section	1	Page 3	Who are Bowel Screening Wales (BSW)?
Section	2	Page 4	What is screening?
Section	3	Page 5	Promoting Informed Choice
Section	4	Page 6	Mental Capacity
Section	5	Page 7	Things to remember before doing the bowel screening test kit
Section	6	Page 9	Signs and symptoms
Section	7	Page 10	Scenarios
Section	8	Page 15	Frequently asked questions (FAQ's)
Section	9	Page 18	Contact Information

Who are Bowel Screening Wales (BSW)?

We are managed by Screening Division which is part of Public Health Wales, NHS Trust. The bowel screening programme was launched in October 2008.

What is the aim of the programme?

Bowel cancer is the third most common cancer in Wales. Bowel screening aims to find cancer at an early stage when there are no signs or symptoms. Early detection is key. At least 9 out of 10 people will survive bowel cancer if it's found and treated early.

Who is invited?

Bowel screening is currently offered to people who are aged between 50 and 74 and live in Wales. Bowel screening is also available for people who are in a residential facility that are not registered with a GP, the health professional would be required to contact the Bowel Screening programme on the freephone helpline 0800 294 3370.

How are people invited for screening?

We get address information directly from GPs. It is important that the person's correct 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 place of residence.

How often are people invited for screening?

People will be automatically 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 UK National Screening Committee (2021), 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.

Benefits and risks of screening

Taking part in screening is an individual's choice. It is important that they understand the benefits and risks of screening to help decide if taking part is right for them.

Benefits of screening:

- Finding bowel cancer early gives a person the best chance of survival.
- At least 9 out of 10 people survive bowel cancer if it is found early.
- Bowel screening can help find bowel cancer early, even if a person is well and does not have any symptoms.
- People can complete the bowel test kit at their place of residence.
- The bowel screening test kit is quick and easy to do, with just one small sample of poo needed.

Risks of screening:

- Bowel screening is not 100% accurate.
- Some cancers may not be found and some cancers may not be cured.
- There may be risks with having further tests. If a person needs further tests a screening nurse or doctor will talk to them about these.

Promoting informed choice

The UK National Screening Committee (UK NSC) defines a personal informed choice as:

A decision made to accept or decline a screening test based on access to accessible, accurate, evidence-based information covering:

- the condition being screened for
- the testing process
- the risks, limitations, benefits, and uncertainties
- the potential outcomes and ensuing decisions

How can I help someone make an informed choice?

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
- Time to consider and take in the information
- The capacity to make their own decisions

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

Making decisions

As a healthcare 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 if their mind is impaired or disturbed in some way. They are unable to use and understand information to make a decision about their care and treatment and communicate any decision made' (Assessing Capacity: Consent to treatment NHS.co.uk, 2022).

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.

Things to remember before doing the bowel screening test kit

If you are a healthcare 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.

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 of health and welfare is in place or that a decision in the person's best interests has been reached and recorded.

If you are supporting a person to complete the bowel screening test, you can access additional information including easy read resources or watch the videos available on our website: www.phw.nhs.wales/bowel-screening.

Before doing the test with the person you are supporting, please read through the leaflet that came with the invitation. 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.

About the bowel test kit

The bowel screening test kit does not tell you if you have bowel cancer. The test looks for hidden blood in your poo which can be a sign of bowel cancer or other changes.

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 bowel screening test kit?
- Who will write the date on the bowel screening test kit?
- Who will collect the poo sample?

If you want advice on carrying out the test, or would like another kit, phone our freephone helpline 0800 294 3370 to speak to a member of our team.

Some important things to remember:

- √ Check the information on the test kit is correct
- √ Have a pen ready to write the date on the bowel screening test kit
- √ If necessary, wear gloves
- √ Wash hands before and after doing the test
- √ If you make a mistake, we can send out another test kit in the post

After doing the bowel screening test kit

The test kit should be posted back to the laboratory as soon as possible after completion.

Once received by the laboratory it is tested and a result letter is produced and posted within 7 days.

The test kit result will indicate one of the following:

- the kit was not suitable for testing and another kit will be issued
- further medical investigations are needed
- the person will be automatically invited to complete another FIT test in two years' time, if they are still within the eligible age range.

Signs and symptoms

Bowel cancer can develop between screening tests, so it is important for people to be aware of any changes in their bowel habits. Screening may miss some cancers, so a normal result does not mean that a person does not have, or will never develop, bowel cancer in the future.

The person you care for should see their GP if they have any of the following symptoms:

Bleeding from their bottom or blood in their poo

Obvious change in bowel habits

Weight loss without trying

Extrême tiredness for no obvious reason

Lump or pain in their tummy

These symptoms may be caused by a range of conditions and should be discussed with a medical professional 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 medical professional. 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 medical professional.

Scenarios

The next section provides you with a number of examples which may help you when you are considering issues to do with consent and capacity. These scenarios are based on real-life situations.

Scenario 1

Geoff is 72 and suffers from dementia. He has recently been admitted to a residential care facility. 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.

Section 7

Please note: If a further mental capacity assessment is completed, 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 interests' assessment **must** also be considered.

Scenario 2

Malcolm is 62 years old with a mild learning disability. 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 easy read materials online, 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 screening 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 bowel 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.

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, 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 screening programme 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.

Section 7

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 fluctuates. We recently sent through a routine bowel screening 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 go for further investigations.

Staff in the home explained to Wilf that he needed to go for further investigations. However, during discussions Wilf appeared to be vacant and lacking insight. The staff contacted the most appropriate medical professional, who agreed to carry out a mental-capacity assessment. After completing this, it was considered that Wilf lacked capacity and a 'best interests' meeting was arranged.

Points to consider

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

Scenario 5

Elizabeth is a 73 year old 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 screening test kit but she decides that she does not want to take part.

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

Points to consider

Bowel Screening Wales is for people who are well and do not have symptoms. 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 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 healthcare worker has noticed blood in her stools and encourage Elizabeth to allow the home to make an appointment with her medical professional or agree that the visiting GP (if this applies) can speak with her about her health as she may require further investigations if Elizabeth consents to this.

It is important to reassure people that blood in their stools does not mean that they have cancer. It may be caused by bleeding from polyps (small growths) or other conditions such as haemorrhoids (piles).

Frequently asked questions (FAQs)

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 if 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, call our freephone helpline on 0800 294 3370.

2. The person that I care for has dementia. Can I do the test for them?

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. Providing the person understands this, you can help them complete the test kit if they have asked you to do so.

If the person cannot make this decision, we recommend you discuss the situation with the person's medical professional and whoever has lasting power of attorney (legal authority to act) for their health and welfare. Following this, a 'best interests' decision will need to be made on the person's behalf. Their medical professional will decide if they would benefit from screening and whether they are fit and well enough for further investigations to be undertaken if this was required.

For more advice, please contact the freephone helpline on 0800 294 3370.

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

The bowel 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 medical professional. If they do not understand, you should speak to their relatives and suggest they make an appointment with the person's medical professional 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 and they have fully understood the risks and benefits of completing this. If you do the test without their permission, you will be acting against their will.

5. 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 that you wait until normal bowel habits resume before doing the test.

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

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

You can do the test as long as the person has 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 at the hospital if blood is found in the sample.

You should take a sample from the middle of a formed (solid) poo. This will avoid the poo being contaminated with urine which may affect the result.

For more advice on doing the test on behalf of someone who has a disability or suffers from incontinence, please contact the freephone helpline on 0800 294 3370.

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

It is very important that they or a member of their family give their GP their new address. We automatically get address details from GPs, so it is very important that records are updated to ensure people receive their bowel screening invitation.

Section 8

8. 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.

9. Can the test kit be completed if a person is menstruating (having a period)?

No, wait until the bleeding has stopped before completing the test kit.

10. The person I care for has had a positive result, what does this mean?

When the kit was tested in our laboratory they found traces of blood in the sample. This does not always mean that the person has bowel cancer but means the person will need further medical investigations to find out the reason for the blood in the sample. The person needs to have an assessment appointment with one of our Specialist Screening Practitioners (SSP) to find out if they are suitable to have further investigations.

11. 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 investigations.

The SSP will carry out a telephone assessment with the person who received the positive result or whoever is supporting them. This assessment will ensure that the person is suitable for further investigations. 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. They will continue to support the person through the next stages.

Contact information

Call the Bowel Screening Wales Freephone Helpline (Monday-Friday 08:00-17:00, excluding bank holidays) on:

0800 294 3370

Or visit the Bowel Screening Wales website at:

www.phw.nhs.wales/bowel-screening

Or Email us on:

bowel-screening@wales.nhs.uk

Useful Links

Age Cymru

www.ageuk.org.uk/cymru/

Alzheimer's Society

www.alzheimers.org.uk/

Bowel Cancer UK

www.bowelcanceruk.org.uk

Carers Wales

www.carersuk.org/wales

Disability Wales

www.disabilitywales.org/

Learning Disability Wales

www.learningdisabilitywales.org.uk/

Understanding the Mental Capacity Act

www.gov.uk/government/publications/mental-capacity-act-code-of-practice

Stroke Association

www.stroke.org.uk/home