

# **CONSENT TO CANCER SCREENING**

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## Consent to Cancer Screening

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## **PREFACE**

This guidance replaces *Consent to Cancer Screening* (NHS Cancer Screening Series No 4, January 2008), and incorporates revisions and additional content in line with the Mental Capacity Act 2005.

The national office of the NHS Cancer Screening Programmes is grateful to the Public Health and Medical Ethics Department and the Scientific Development and Bioethics Division at the Department of Health for help and advice in drafting this guidance.



# 1. INTRODUCTION

## 1.1 Participation in cancer screening programmes

People participating in cancer screening should do so with the knowledge of the inherent benefits and disadvantages of the process. This is to enable individuals to make an informed choice about whether or not to take up their screening invitation. It is essential that both the public and health professionals understand that any screening programme incurs both false positive and false negative results. Nevertheless, cancers and their precursor lesions may be found and treated at an earlier stage. High quality screening, suitably audited and monitored and carried out by trained staff, should ensure that any risks are minimised and the benefits are maximised.

It is essential that screening programmes have good quality educational and advisory materials available, which take an honest, accurate and informed approach. This will help to ensure that all parties, including the participants, general practitioners, service providers and service commissioners, together with the wider community, have a clear understanding of the screening programme, and will help to reduce the risk of any misunderstandings about the accuracy of the process.

## 1.2 Informed consent

A screening participant's valid consent is paramount in the provision of a successful screening service. Written consent to screening is not required. For participants to make an informed decision and therefore give valid consent, they should be provided with sufficient information and support about the screening process. Guidance on the nature of information required is available from the General Medical Council (GMC) in the document *Consent: Patients and Doctors Making Decisions Together*.<sup>1</sup> For cancer screening, this includes information about:

- the purpose of any proposed investigation or treatment and what it will involve
- the potential benefits, risks and burdens, and the likelihood of success, for each option
- the people who will be mainly responsible for and involved in participants' care.

And, as appropriate:

- the diagnosis and prognosis
- any uncertainties about the diagnosis or prognosis, including options for further investigations
- options for treating or managing the condition, including the option not to treat.

When carrying out screening, practitioners should be aware of the legal requirements regarding consent. Detailed guidance on the relevant legal issues of consent can be found in the Department of Health (DH) publication *Reference Guide to Consent for Examination or Treatment*.<sup>2</sup> This can be downloaded from the DH website at [www.dh.gov.uk/consent](http://www.dh.gov.uk/consent).

### **1.3 Information materials**

Information materials about the NHS Cancer Screening Programmes are regularly reviewed. Guidance on the content and format of written information (letters and leaflets) sent to screening participants for breast and cervical screening is available to download or to order via the NHS Cancer Screening Programmes' website at [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk).<sup>3,4</sup> A summary of the evidence base for patient information about bowel cancer screening is also available.<sup>5</sup>

## 2. CONSENT TO BREAST SCREENING

### 2.1 Information for women who are invited or who request screening

The NHS Breast Screening Programme (NHSBSP) routinely invites women between the ages of 50 and 70 to attend breast screening by mammography every three years. Women aged over 70 are not invited routinely, but are encouraged to request a screening appointment. An extension to the age range for invitations to breast screening was announced in the 2007 Cancer Reform Strategy, commencing April 2008.<sup>6</sup> By 2012, women will receive a screening invitation every three years between the ages of 47 and 73 (ie women will receive nine screening invitations) with a guarantee of the first invitation by the age of 50.

Women who are invited for breast screening or who request screening should be informed about the benefits and disadvantages of the test as explained in the NHS information leaflet *Breast Screening: The Facts*.<sup>7</sup> This leaflet must be included with all invitations to breast screening, and sent with a confirmation of appointment to all women who have requested a screening appointment. Copies of the leaflet (in 19 languages) are available to download from the NHS Cancer Screening Programmes' website at [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk), and English language leaflets can be ordered from the DH publications orderline ([dh@prolog.uk.com](mailto:dh@prolog.uk.com)).

### 2.2 Consent to breast screening

When a woman attends for breast screening, the mammography practitioner is responsible for ensuring that she is informed about the process of mammography, including the possibility of being called back for further investigations. The practitioner must be able to accurately and honestly answer any queries the woman may have. The mammography practitioner must give a full explanation of the mammography procedure including the reasons for the breast being compressed, which is uncomfortable for some women and painful for a few.<sup>8</sup> The woman should be informed and understand that she is entitled to stop the procedure at any point. The mammography practitioner must recognise if the woman withdraws her consent at any time before or during the procedure and respect this decision.

### 2.3 Suitability for mammography

All mammography practitioners working in the NHSBSP are expected to follow the Society of Radiographers' *Statements for Professional Conduct*.<sup>9</sup> This means that practitioners must not take a mammogram if, in their professional judgement, a woman is physically unsuitable for the procedure, or if she withdraws consent during the procedure. In addition, practitioners must follow relevant legislation relating to medical exposure to ionising radiation (*Ionising Radiation (Medical Exposure) Regulations (IRMER)*).<sup>10,11</sup> This means that an exposure should not be made unless it will be of benefit to the woman.

A woman who is physically unsuitable for screening should remain on the screening list so that she can consider whether her circumstances have changed at the time of each new screening invitation. Alternatively, if the woman decides after discussion with the mammography practitioner or her GP or specialist that she is unlikely ever to be suitable for screening, she may make her own informed decision that she no longer wishes to be invited for breast screening (see section 2.5).

### 2.4 Withdrawal of consent

A woman who has attended for screening may withdraw her consent before the successful completion of mammography. If she wishes, she can arrange another appointment for screening at a later date up to the time of the next screening round (at which point another invitation to screening will be issued). All women who have had incomplete mammography should be made aware of the limitations of the examination, encouraged to remain breast aware and be reminded that they will be invited for screening again in three years' time (if still within the age range for invitation). A refusal to undertake or complete a breast screening mammogram does not indicate that a woman should be ceased from the breast screening programme. The only circumstances in which a woman may be ceased are given in section 2.6.

### 2.5 Informed dissent

Some women may choose not to be invited for future screening examinations. If this is the case, the woman may ask to have her name removed from the list of eligible women. Before this request can be implemented, the following conditions must be satisfied:

- The woman must be provided with sufficient information to enable her to make an informed decision about withdrawing from the breast screening programme; this must be in a format which is accessible to her. It should include information on the condition being screened for, the screening process (including risks and benefits), and the consequences of attending or ceasing.
- The woman must be informed that withdrawing from the programme will prevent her from receiving any future invitations or reminders about breast screening.
- It must be made clear to the woman that she can be returned to the programme at any time at her own request.

The woman should put her request to withdraw from the programme in writing to confirm that she has made an informed decision. The template letters in the Appendix (form A – breast screening) have appropriate wording for this purpose. If a woman is unable to sign a standard form, for example because of a severe physical disability, then alternative methods of communication are acceptable according to individual circumstances.

A copy of the confirmation letter stating that the woman has been withdrawn (ceased) from the screening programme should be sent to her GP.

### **2.6 Ceasing from breast screening call and recall**

The only circumstances under which a woman should be ceased from breast screening call and recall are:

- if the woman has had a bilateral mastectomy
- if the woman has made her own informed decision that she no longer wishes to be invited for breast screening (see section 2.5)
- if the woman lacks the mental capacity to consent to screening and a decision has been made appropriately that it is in her best interests to remove her from the screening list (see Chapter 5).

In all other circumstances, the woman should be kept in the recall programme and sent another invitation for screening (assuming she is still eligible) so that she has the opportunity to make an informed decision about whether to accept on each and every occasion when screening is offered.

Revised guidelines for ceasing women from the NHSBSP are in preparation.<sup>12</sup>

### **2.7 Women who are terminally ill**

Women who are seriously ill, including those undergoing treatment for breast cancer, should be invited for breast screening for as long as they remain eligible. If a woman is too ill to respond to an invitation, her carer may notify the screening unit so that no reminder letters are sent. The woman should not be ceased from the programme unless any of the conditions in section 2.6 apply.

### 3. CONSENT TO CERVICAL SCREENING

#### 3.1 Information for women who are invited or who request screening

The NHS Cervical Screening Programme (NHSCSP) routinely invites women between the ages of 25 and 64. Women aged 25–49 are invited every three years, and women aged 50–64 are invited every five years. Invitations may be issued from a primary care organisation (PCO) or from a GP practice, depending on local screening service arrangements. Women who have not had a recent screening test may be screened opportunistically.

All women who attend for cervical screening should be informed about the benefits and disadvantages of the test as explained in the NHS information leaflet *Cervical Screening: The Facts*.<sup>13</sup> This leaflet must be included with all invitations to cervical screening, or given to women to read before the screening sample is taken. Copies of the leaflet (in 19 languages) are available to download from the NHS Cancer Screening Programmes' website at [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk), and English language leaflets can be ordered from the DH publications orderline ([dh@prolog.uk.com](mailto:dh@prolog.uk.com)).

#### 3.2 Consent to cervical screening

The woman should be informed about the procedure for taking the screening sample by the sample taker. This includes the possibility of an abnormal result. The sample taker must be able to accurately and honestly answer any questions the woman may have. The woman should be informed and understand that she is able to stop the procedure at any point. The sample taker must recognise and respect if the woman withdraws her consent at any time before or during the procedure.

If the sample taker is unable to take a screening sample because a woman is physically unsuitable for cervical screening, the woman may choose to remain on the screening list so that she can consider whether her circumstances have changed at the time of each new screening invitation. Alternatively, if the woman decides after discussion with the sample taker or her GP or specialist that she is unlikely ever to be suitable for screening, she may make her own informed decision that she no longer wishes to be invited for cervical screening (see section 3.4).

#### 3.3 Withdrawal of consent

A woman who withdraws her consent during the sample taking procedure but wishes to try again at a later date is entitled to request another appointment before her next screening invitation is due (in either three or five years' time).

A refusal to undertake or complete cervical screening does not mean that a woman should be ceased from the screening programme. The only circumstances in which a woman may be ceased are given in section 3.5.

### 3.4 Informed dissent

Some women may choose not to be invited for future cervical screening tests. If this is the case, the woman may ask to have her name removed from the list of eligible women. Before this request can be implemented, the following conditions must be satisfied:

- The woman must be provided with sufficient information to enable her to make an informed decision about withdrawing from the cervical screening programme – this must be in a format which is accessible to her. It should include information on the condition being screened for, the screening process (including risks and benefits) and the consequences of attending or ceasing.
- The woman must be informed that withdrawing from the programme will prevent her from receiving any future invitations or reminders about cervical screening.
- It must be made clear to the woman that she can be returned to the programme at any time at her own request.

The woman should put her request to withdraw from the programme in writing to confirm that she has made an informed decision. The template letters in the Appendix (form B for cervical screening) have appropriate wording for this purpose. If a woman is unable to sign a standard form, for example because of a severe physical disability, then alternative methods of communication are acceptable according to individual circumstances.

A copy of the confirmation letter stating that the woman has been withdrawn (ceased) from the screening programme should be sent to her GP.

### 3.5 Ceasing from cervical screening call and recall

The only circumstances in which a woman should be ceased from cervical screening call and recall are:

- if the woman does not have a cervix (eg total hysterectomy, congenital absence of cervix)
- if the woman has made her own informed decision that she no longer wishes to be invited for cervical screening (see section 3.4)
- if the woman has undergone radiotherapy for cervical cancer
- if the woman lacks the mental capacity to consent to screening and a decision has been made appropriately that it is in her best interests to remove her from the screening list (see Chapter 5).

In all other circumstances, the woman should be kept in the recall programme and another invitation for screening issued at the appropriate interval (assuming the woman is still eligible).

Revised guidelines for ceasing women from the NHSCSP are in preparation.<sup>14</sup>

- 3.6 Women who are terminally ill** Women who are seriously ill should be invited for cervical screening for as long as they remain eligible. If a woman is too ill to respond to an invitation, her carer may notify the woman's primary care organisation or GP practice so that no reminder letters are sent. The woman should not be ceased from the programme unless any of the conditions in section 3.5 apply.
- 3.7 Consent to colposcopy** All women offered a colposcopy examination following an abnormal cytology test result (or following persistent inadequate results) must be informed about the benefits and difficulties of the examination as explained in the NHS information leaflet *The Colposcopy Examination*.<sup>15</sup> This leaflet must be included with all colposcopy appointment letters. Copies of the leaflet (in 19 languages) are available to download from the NHS Cancer Screening Programmes' website at [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk), and English language leaflets can be ordered from the DH publications orderline ([dh@prolog.uk.com](mailto:dh@prolog.uk.com)).

### 4. CONSENT TO BOWEL CANCER SCREENING

#### 4.1 Participation in bowel cancer screening

The NHS Bowel Cancer Screening Programme (NHSBCSP) started in July 2006 and is being rolled out across England. Rollout should be completed by December 2009. The programme currently invites men and women aged between 60 and 69 to participate. People aged 70 or over can be sent a test kit on request once screening is available in their area. From 2010, the upper age limit for screening invitations will be extended to include people up to their 75th birthday. This age extension will be piloted in selected areas during 2008/09. The screening process differs from other cancer screening programmes in that the first stage is completed by participants in their own homes, without the intervention or assistance of a health professional. A faecal occult blood test (FOBT) kit is sent in the post to eligible people on the NHS list. If the recipient chooses to complete and return the test kit, valid consent to this first stage of screening is demonstrated.

#### 4.2 Information for participants

All individuals participating in the NHS Bowel Cancer Screening Programme should be informed about the benefits and difficulties of the screening process as explained in the NHS information leaflet *Bowel Cancer Screening: The Facts*.<sup>16</sup> This leaflet must be included with all invitations to bowel cancer screening, or sent with the FOBT kit to anyone eligible for screening who requests a kit. Copies of the leaflet (in 19 languages) are available to download from the NHS Cancer Screening Programmes' website at [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk), and English language leaflets can be ordered from the DH publications orderline ([dh@prolog.uk.com](mailto:dh@prolog.uk.com)).

#### 4.3 Informed dissent

Some people may choose not to receive any future invitations to participate in bowel cancer screening. If this is the case, they may ask to have their name removed from the list of eligible people. Before this request can be implemented, the following conditions must be satisfied:

- They must be provided with sufficient information to enable them to make an informed decision about withdrawing from the bowel cancer screening programme – this must be in a format which is accessible to them. It should include information on the condition being screened for, the screening process (including risks and benefits) and the consequences of attending or ceasing.
- They must be informed that withdrawing from the programme will prevent them from receiving any future invitations or reminders about bowel cancer screening.
- It must be made clear to them that they can be returned to the programme at any time at their own request.

They should put their request to withdraw from the programme in writing to confirm that they have made an informed decision. The template letters in the Appendix (form C for bowel cancer screening) have appropriate wording for this purpose. If an individual is unable to sign a standard

form, for example because of a severe physical disability, then alternative methods of communication are acceptable according to individual circumstance.

A copy of the confirmation letter stating that the participant has been withdrawn (ceased) from the screening programme should be sent to the person's GP.

Anyone who wishes to be reinstated on the list for routine screening invitations having previously withdrawn from screening is free to do so at any time (as long as they still meet the requirements for eligibility). The local screening programme hub should be contacted to arrange reinstatement.

#### 4.4 Consent to colonoscopy

If an abnormal result is obtained from the FOBt, the individual is offered further investigation – usually a colonoscopy examination. All individuals offered colonoscopy must be informed about the benefits and difficulties of the examination, as explained in the NHS information leaflet *The Colonoscopy Investigation*.<sup>17</sup> This leaflet must be included with all abnormal FOBt result letters. Copies of the leaflet (in 19 languages) are available to download from the NHS Cancer Screening Programmes' website at [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk), and English language leaflets can be ordered from the DH publications orderline ([dh@prolog.uk.com](mailto:dh@prolog.uk.com)).

If colonoscopy has been advised, an appointment is made for the individual to see a specialist screening practitioner (usually a nurse). The nurse must be able to describe the procedure, and to accurately and honestly answer any questions that the individual may have. An individual is free to choose whether or not to proceed with colonoscopy on the basis of both the written information and the information from the consultation appointment. In addition, the individual must be assessed as being medically suitable for the procedure, either by the screening practitioner or by a relevant medical specialist (should a further opinion be required).

If an individual chooses to proceed with colonoscopy, and is suitable for the procedure, then he or she will be asked to complete a standard hospital consent form according to local protocols. If the person is considered to be unsuitable for colonoscopy, an alternative imaging examination such as a barium enema or CT scan may be offered.

Everyone undergoing colonoscopy should be informed and understand that they can request that the procedure be paused or terminated. They should, however, be made fully aware prior to colonoscopy what the implications of abandoning the procedure may be. British Society of Gastroenterology (BSG) guidance states that, if an unsedated patient demands that the procedure is abandoned, then the colonoscopist must recognise and respect that consent has been withdrawn and terminate the procedure immediately.<sup>18</sup> If a sedated patient appears to withdraw consent through verbal or physical actions, the colonoscopist may pause and see if cooperation may be regained. However, if it is clear that the patient continues to withdraw consent and patient safety may be compromised, the procedure should be terminated.

### 4.5 Surveillance colonoscopies

Individuals who are found at screening colonoscopy to have high or intermediate risk polyps will be offered a surveillance colonoscopy at one or three years in accordance with BSG guidelines. Consent to colonoscopy must be obtained on each occasion in accordance with BSG guidance outlined in section 4.4.

### 4.6 Ceasing from bowel cancer screening call and recall

It is important for screening and colonoscopy staff to recognise that a refusal to undertake or complete either the FOBt kit or a further investigation does not indicate that the individual should be removed from the screening programme. The only circumstances under which an individual should be ceased from the bowel cancer screening programme are:

- if an individual has no functioning bowel
- if an individual has made his or her own informed decision that he or she no longer wishes to be invited for bowel cancer screening (see section 4.3)
- if an individual is in an alternative polyp surveillance programme more rigorous than that offered by the NHSBCSP
- if an individual lacks the mental capacity to consent to screening and a decision has been made appropriately that it is in his or her best interests to be removed from the screening list (see Chapter 5).

In all other circumstances, the individual should be kept in the recall programme and another FOBt kit issued at the appropriate time subject to the individual's continued eligibility for screening.

The reasons for ceasing from the programme must be documented on the Bowel Cancer Screening System (BCSS), and the relevant procedure in *Bowel Cancer Screening Programme Ceasing Guidelines* should be followed.<sup>19</sup> This guidance is available to download from the NHS Cancer Screening Programmes' website at [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk) or can be ordered from the DH publications orderline ([dh@prolog.uk.com](mailto:dh@prolog.uk.com)).

### 4.7 People who are terminally ill

People who are terminally ill should be invited for screening unless they have made their own informed decision to withdraw from the programme. If an individual is too ill to respond to an invitation, and his or her carer notifies the programme hub that the person will not be completing the FOB test, and that correspondence from the screening programme would cause unnecessary distress, the individual's episode should be paused to prevent reminder letters being sent. The individual should not be ceased from the programme unless any of the conditions in section 4.6 apply.

# 5. CANCER SCREENING FOR PEOPLE WHO LACK THE MENTAL CAPACITY TO CONSENT

## 5.1 Mental capacity

The decision whether or not to participate in cancer screening involves consideration of the benefits and disadvantages of the screening process. Some people who lack mental capacity may not be able to make an informed decision about this. Lack of mental capacity means the inability to make a particular decision at a particular time. This may be because of, for example, a stroke or brain injury; a mental health problem; dementia; a learning disability; or confusion, drowsiness or unconsciousness because of an illness or the treatment for it; or substance misuse. A person who cannot do one or more of the following things is deemed unable to make a decision:

- understand the information provided that is relevant to the decision
- retain that information long enough to be able to make the decision
- use or weigh up the information as part of the decision-making process.
- communicate his or her decision – this could be by talking or using sign language and includes simple muscle movements such as blinking an eye or squeezing a hand.

The provisions of the Mental Capacity Act 2005 ([www.dca.gov.uk/menincap/legis.htm](http://www.dca.gov.uk/menincap/legis.htm)) came fully into force in October 2007.<sup>20</sup> Under the provisions of the Act, people must be assumed to have capacity to make their own decisions unless it is proved otherwise. Individuals must be given all practicable help to make their own decisions before anyone treats them as not being able to do so.

People with learning difficulties may benefit from information materials in more accessible formats. The NHS Cancer Screening Programmes have produced picture leaflets entitled *An Easy Guide to Breast Screening*, *An Easy Guide to Cervical Screening*, *An Easy Guide to Bowel Cancer Screening* and *An Easy Guide to Having a Colonoscopy* which may be helpful in explaining the screening process and enabling people to make their own screening decisions.<sup>21–24</sup> The leaflets are available to download or order via the NHS Cancer Screening Programmes' website at [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk).

Some people may have a condition whereby their capacity to consent fluctuates. In such circumstances, the decision regarding screening should be delayed until the person is able to make his or her own choice.

The Mental Capacity Act also makes it clear that making a decision that might be considered unwise should not be taken to mean that the individual lacks the capacity to make that decision.

A person lacking the mental capacity to consent may have made an advance decision to refuse participation in a screening programme or associated tests or treatment at a time when he or she did have mental capacity. A valid and applicable advance decision must be followed in the same way as a contemporaneous refusal made by a person with capacity.

### **5.2 Screening under a best interests decision**

If an individual permanently lacks the mental capacity to consent to screening, a decision may be made on his or her behalf in that person's best interests. Best interests go beyond medical interests, and include factors such as previous wishes or beliefs (that is, before a loss of capacity to express these), current wishes, general well-being, and spiritual or religious welfare. There is no requirement to have more than one person make a best interests decision; however, it is expected that the person making the decision will have taken steps to ensure that it has been arrived at appropriately. In many cases, the person making a best interests decision will be a carer – either a professional carer or a family member, partner or close friend.

Making a best interests decision must involve a consideration of all relevant factors. These may include:

- the degree of risk of the condition being screened for
- the nature of the tests, and how the individual may respond to them
- the implications of an abnormal test result, including further investigations and treatment
- any previous opinions regarding screening held by the individual before capacity was lost, particularly previously expressed support for or refusal of screening
- the opinions of people that know the individual well (including family, friends, and other carers) as to what they feel the individual would want.

A best interests decision must not be based on what the person making the decision would necessarily do, and it must not be based on what is easiest for the carer or screening staff. It should be remembered that the person responsible for making the decision to proceed with (or withhold) screening in a person's best interests must be able to justify the decision. A carer who has made a best interests decision should have considered all the relevant factors, and may benefit from speaking to screening staff in order to be fully informed about the screening process and its implications for the individual concerned. Even if a carer has decided in favour of screening as a best interests decision, the screening practitioner should be able to debate that decision if he or she feels that there are valid reasons why the screening procedure may not be in the individual's best interests.

Screening practitioners should adhere to the requirements of the Mental Capacity Act 2005. Further guidance about all aspects of the Act can be found in the Code of Practice, available on the Office of the Public Guardian (OPG) website at [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm).<sup>25</sup> A copy of the OPG guidance for health care practitioners needing to make best interests decisions can also be found on the OPG website ([www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)) and at [www.cancerscreening.nhs.uk/publications/making-decisions-opg603-1207.pdf](http://www.cancerscreening.nhs.uk/publications/making-decisions-opg603-1207.pdf).<sup>26</sup>

Any best interests decision to screen or withhold screening should be clearly documented, including detailed information about who made the decision, and why the decision was considered to be in the individual's best interests.

### **5.3 Ceasing in a person's best interests**

It is important for screening staff to recognise that a person who lacks the mental capacity to consent to screening should not be permanently removed from a screening recall programme unless a best interests decision to do so has been taken on his or her behalf. In most cases, the least restrictive option is for that person to remain in call/recall and receive screening invitations at routine intervals. The invitations can be considered and accepted or declined on each occasion.

In exceptional circumstances, a care team may decide that it is in the best interests of a person who lacks mental capacity to withdraw from a cancer screening programme. Screening staff should be satisfied that the best interests decision has been reached in accordance with the Code of Practice (see section 5.2). The person making the best interests decision to cease a person from screening should be aware that the person can be reinstated onto the screening list at any time (if still within screening age) if circumstances change and screening is then considered to be in the person's best interests.

### **5.4 Lasting Power of Attorney**

The Mental Capacity Act provides for decisions about the health care (including participation in screening) of a person who lacks mental capacity to be made by a legally accountable decision maker only if he or she has been authorised to do so. This may be someone nominated under a Lasting Power of Attorney, or a deputy appointed by the Court of Protection. Decisions made by them must be accepted as if they were made by the person lacking capacity. However, those decisions must be made in accordance with the same processes of any other person acting in the individual's best interests.

### **5.5 Additional guidance: bowel cancer screening**

Some people who need help to make an informed decision about bowel cancer screening; for example, people with a learning difficulty may also need additional help to use the FOBt kit, because the test is completed by the individual at home rather than screening being carried out by a screening practitioner.

If a carer is making a best interests decision for a person who lacks the mental capacity to make his or her own decision about bowel cancer screening, the carer must have received and understood information relating to the entire screening process, including the possibility of further investigations. A best interests decision must not be based on the completion of the FOBt kit alone, but must also consider the implications and risks of colonoscopy should the screening participant receive an abnormal screening test result. If it seems likely that an individual will be unable to tolerate or comply with the colonoscopy procedure, an alternative method of investigation, such as imaging, may be offered. A carer should seek advice from the NHS Bowel Cancer Screening Programme freephone helpline (0800 707 60 60) before making a best interests decision about bowel cancer screening. A statement to this effect is included in the screening invitation letter.

A copy of the OPG guidance for carers needing to make best interests decisions can also be found on the OPG website ([www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)) and at [www.cancerscreening.nhs.uk/publications/making-decisions-opg602-1207.pdf](http://www.cancerscreening.nhs.uk/publications/making-decisions-opg602-1207.pdf).<sup>27</sup>

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**APPENDIX: TEMPLATE LETTERS FOR PEOPLE WISHING TO  
WITHDRAW FROM A SCREENING PROGRAMME**

**Form A: Breast screening**

[Name]  
[Address 1]  
[Address 2]  
[Town], [Postcode]  
[Screening number]

NHS Breast Screening Programme  
[Breast Screening Unit]  
[Address 1]  
[Address 2]  
[Town], [Postcode]

Dear

Women aged 50 to 70 are invited for breast screening every three years. The risk of dying from breast cancer can be significantly reduced by having regular screening.

I understand that you do not wish the NHS Breast Screening Programme to invite you for future screening tests. I enclose the leaflet *Breast Screening: The Facts*, which explains the benefits and disadvantages of breast screening, and the importance of screening in reducing deaths from breast cancer. If you need further information please do not hesitate to contact your General Practitioner (GP), or your local breast screening unit.

We need your written instruction to remove your name from the list of women invited for breast screening. I would be grateful, therefore, if you could **sign and return** the lower part of this letter to confirm that you do not wish to receive any future invitations to be screened for breast cancer or any further information about the NHS Breast Screening Programme.

We will send you written confirmation when your name has been removed from the screening list.

If you wish to restore your name to the screening list at any time, please contact your GP or local screening unit.

You may wish to keep the top part of this letter for future reference.

Yours sincerely,

Clinical Director  
Breast Screening Unit

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To: [Clinical Director], [Breast Screening Unit]

Please do not send me any further invitations to participate in the NHS Breast Screening Programme. I assume full responsibility for this decision and confirm that I have understood the leaflet *Breast Screening: The Facts* which explains the benefits and disadvantages of breast screening and the importance of screening in reducing deaths from breast cancer.

I understand that my name can be restored to the screening list at any time at my request to my GP or local screening unit.

Name:

Address:

NHS No.:

Signed:

Date of birth:

Dated:

**Form B: Cervical screening**

  
**Cancer Screening Programmes**

[Name]  
[Address 1]  
[Address 2]  
[Town], [Postcode]  
[Screening number]

NHS Cervical Screening Programme  
[Call & Recall Office]  
[Address 1]  
[Address 2]  
[Town], [Postcode]

Dear

Women aged 25 to 49 are invited for cervical screening every three years, and women aged 50 to 64 are invited every five years. The risk of developing cervical cancer can be significantly reduced by having regular screening.

I understand that you do not wish the NHS Cervical Screening programme to invite you for future screening tests. I enclose the leaflet *Cervical Screening: The Facts* which explains the benefits and disadvantages of cervical screening, and the importance of screening in reducing deaths from cervical cancer. If you need further information please do not hesitate to contact your General Practitioner (GP).

We need your written instruction to remove your name from the list of women invited for cervical screening. I would be grateful, therefore, if you could **sign and return** the lower part of this letter to confirm that you do not wish to receive any future invitations to be screened for cervical cancer or any further information about the NHS Cervical Screening Programme.

We will send you written confirmation when your name has been removed from the screening list.

If you wish to restore your name to the screening list at any time, please contact your GP.

You may wish to keep the top part of this letter for future reference.

Yours sincerely,

Screening Programme Manager  
Call & Recall Office

✂—————

To: [Screening Programme Manager], [Call & Recall Office]

Please do not send me any further invitations to participate in the NHS Cervical Screening Programme. I assume full responsibility for this decision and confirm that I have understood the leaflet *Cervical Screening: The Facts* which explains the benefits and disadvantages of cervical screening and the importance of screening in preventing cervical cancer and reducing deaths from it.

I understand that my name can be restored to the screening list at any time at my request to my GP.

Name:

Address:

NHS No.:

Signed:

Date of birth:

Dated:

**Form C: Bowel cancer screening**



**Cancer Screening Programmes**

[Name]  
[Address 1]  
[Address 2]  
[Town], [Postcode]  
[Screening number]

NHS Bowel Cancer Screening Programme  
[Regional Programme Hub]  
[Address 1]  
[Address 2]  
[Town], [Postcode]  
Freephone: 0800 707 60 60

Dear

Men and women aged 60 to 69 are invited to carry out a bowel cancer screening test every two years. The risk of dying from bowel cancer can be significantly reduced by having regular screening.

I understand that you do not wish the NHS Bowel Cancer Screening Programme to invite you for future bowel cancer screening tests. I enclose the leaflet *Bowel Cancer Screening: The Facts* which explains the benefits and disadvantages of bowel cancer screening, and the importance of screening in reducing deaths from bowel cancer. If you need further information please do not hesitate to contact your General Practitioner (GP), or the screening programme using the Freephone number above.

We need your written instruction to remove your name from the list of people invited for bowel cancer screening. I would be grateful, therefore, if you could **sign and return** the lower part of this letter to confirm that you do not wish to receive any future invitations to be screened for bowel cancer or any further information about the NHS Bowel Cancer Screening Programme.

We will send you written confirmation when your name has been removed from the screening list.

If you wish to restore your name to the screening list at any time, please contact the screening programme using the Freephone number.

You may wish to keep the top part of this letter for future reference.

Yours sincerely,  
Clinical Director

Regional Programme Hub

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To: [Clinical Director], [Regional Programme Hub]

Please do not send me any further invitations to participate in the NHS Bowel Cancer Screening Programme. I assume full responsibility for this decision and confirm that I have understood the leaflet *Bowel Cancer Screening: The Facts* which explains the benefits and disadvantages of bowel cancer screening and the importance of screening in reducing deaths from bowel cancer.

I understand that my name can be restored to the screening list at any time at my request to the screening programme.

Name:

Address:

NHS No.:

Signed:

Date of birth:

Dated: