

BOWEL CANCER SCREENING PROGRAMME CEASING GUIDELINES

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I. INTRODUCTION

Men and women are entitled to bowel cancer screening beginning on or around their 60th birthday. Routine recall takes place every two years until an individual's 70th birthday. After the age of 70, people may self-refer at intervals of not less than two years.

Call and recall for the NHS Bowel Cancer Screening Programme (NHS BCSP) is managed by programme hubs using the national Bowel Cancer Screening System (BCSS). Ceasing someone from the call/recall system stops all screening programme activity for that person from the date of ceasing. Alternatives to ceasing are to close or suspend a current screening episode.

2. ELIGIBILITY FOR BOWEL CANCER SCREENING

A person is eligible for screening if he or she:

- is aged 60 or over; and
- has a functioning bowel; and
- is eligible for NHS services.

A person is ineligible for screening if he or she:

- is under age 60; or
- has no functioning bowel; or
- is not eligible for NHS services.

3. CEASING FROM CALL/RECALL

3.1 Implications of ceasing

Ceasing is a way of removing someone from call/recall in the bowel cancer screening programme. It means that the individual will be sent no future correspondence by the screening programme (other than a letter to confirm the ceasing). If the ceasing takes place while a screening episode is open, that episode will be closed immediately. If the ceasing takes place before an episode is opened, the individual will not receive a screening invitation. This applies even in the case of a first episode.

Ceasing removes someone from call/recall permanently and should therefore be used with caution. Ceasing is appropriate only if an individual will never require screening and/or never intends to participate in the programme.

Ceasing is not appropriate if someone is simply not available for screening at the time of invitation, does not want to participate now but would consider an invitation at a later date, or is temporarily ineligible for screening for any reason.

If there is any doubt about the need for ceasing or any possibility that someone may wish to be invited for screening in the future, then that individual should remain in the call/recall system.

3.2 Ceasing by the programme hub

The programme hub may use the ceasing function on BCSS for the following reasons only:

- clinical reasons
- informed dissent.

These reasons are discussed in further detail in sections 6 to 9.

3.3 Automatic ceasing

Ceasing is handled automatically by BCSS if a person is de-registered from the source population database managed by the local primary care organisation (PCO). This may be for one of the following reasons:

- the person has died
- the person has emigrated (embarkations)
- the person has moved away from his or her last known address and cannot be traced
- to correct a duplicate registration.

An informal notification of a death or change of address does not result in immediate de-registration – see section 5.

4. CLOSING A SCREENING EPISODE

If someone who has been sent a screening invitation notifies the programme hub that he or she is not able or willing to carry out the test, the programme hub should close the open episode on BCSS. The individual will then be recalled for screening two years later provided he or she remains eligible. If the individual requests screening in the intervening period, the programme hub can re-open the screening episode and a new invitation will be produced immediately. This process can also be used for individuals who complete a test kit but do not complete the screening process at any later stage.

5. SUSPENDING A SCREENING EPISODE

5.1 Temporarily unavailable

If someone (or his or her representative) informs the programme hub that he or she is temporarily unavailable for screening, it may not be appropriate to close the current episode. Instead the programme hub should suspend (pause) the episode. This prevents any further correspondence being sent to the individual for the period of suspension. The programme hub should review the episode when new information is received. An episode cannot be suspended indefinitely, and suspended episodes should be subject to close monitoring by the programme hub.

5.2 Informal notification of a death

If the programme hub is notified by a relative or carer of the recent death of someone who has been invited for screening, the programme hub should suspend (pause) any open episode relating to that individual. This prevents any further correspondence being sent to the individual for the period of suspension. This allows time for the death to be registered and formally notified to the NHS. The individual will be ceased automatically when he or she is de-registered from the population database.

5.3 Returned mail

If screening correspondence or test kits are returned undelivered, the programme hub should suspend (pause) any open episode relating to that individual. This prevents any further correspondence being sent to the individual for the period of suspension. This allows time for a change of address to be notified formally to the NHS. The programme hub should ask the local PCO to initiate the FP69 process to verify the individual's last known address. If the individual has moved away and does not formally notify a new address to the NHS, he or she will be de-registered from the population database and ceased automatically from call/recall.

6. CLINICAL REASONS FOR CEASING

6.1 No functioning bowel

A small number of people do not have a functioning bowel and therefore screening is not possible in the current NHS BCSP. The programme hub should cease such individuals from call/recall when the absence of bowel is notified. Confirmation of the person's condition may be required from his or her GP or consultant before ceasing; copies of relevant correspondence must be retained with the person's screening record. It is good practice to write to the individual to confirm that he or she has been taken out of the screening programme. The person's GP should also be notified.

An individual whose bowel is compromised temporarily, for example while anticipating restorative surgery, should not be ceased. It may be appropriate to close or suspend any current screening episode depending on the likely length of time before he or she will be able to participate – see sections 4 and 5.

6.2 Alternative surveillance programme

Someone who has already experienced bowel disease or who is at very high risk of bowel cancer can be subject to a surveillance programme more rigorous than the testing offered by the NHS BCSP. An individual in these circumstances would not benefit from additional screening. The programme hub should cease such individuals from call/recall when the alternative surveillance programme is notified. Confirmation of the person's condition may be required from his or her GP or consultant before ceasing; copies of relevant correspondence must be retained with the person's screening record. It is good practice to write to the individual to confirm that he or she has been taken out of the screening programme. The person's GP should also be notified.

An individual should be advised to remain in the screening programme if his or her alternative surveillance programme does not monitor the entire bowel, if it is not a permanent arrangement, or if there is a risk of being lost to follow up by the alternative surveillance programme because of frequent changes of address.

7. TERMINAL ILLNESS

Someone who is terminally ill should be treated as if he or she were well for as long as possible. Every individual who remains mentally competent is entitled to make his or her own decision about participating in the NHS BCSP, either by considering each routine invitation or by making an informed decision to withdraw from the screening programme – see section 8. If the individual lacks the mental capacity to make an informed decision, the decision to withdraw from the screening programme can only be made on the individual's behalf by a legally accountable decision-maker – see section 9.

In circumstances where the programme hub is informed by a spouse or carer that the individual has reached the final stages of a terminal illness and that correspondence from the screening programme would cause unnecessary distress, the programme hub should suspend any open screening episode to prevent further correspondence from being produced. The individual will be ceased automatically when the death is notified formally to the NHS.

8. INFORMED DISSENT

8.1 Establishing an informed decision

A mentally competent person who wishes to permanently withdraw from the NHS BCSP is entitled to do so. A person who lacks mental capacity may also be able to make an informed choice to withdraw – see section 8.

It is important that the person wishing to withdraw from the screening programme understands the implications of his or her decision and also understands that that he or she can be returned to call/recall at any time on request. The programme hub should make every effort to obtain written evidence of the informed nature of a person's decision. The programme hub may suspend an open episode for a short period to allow time for clarification of an informed decision and for written evidence to be obtained if possible.

If the decision is communicated by telephone and the person is unwilling or unable to confirm the decision in writing, it is advisable to ask a supervisor to witness the call so that at least two members of staff can independently confirm and document the ceasing instruction.

If a mentally competent person can neither speak nor write, the decision to withdraw may be relayed via a third party such as a spouse, carer or GP. In such cases, the programme hub should, if possible, obtain the signature or legal mark of the individual on a standard withdrawal form. If this is not possible, then the individual's representative should be asked to confirm in writing that the information given to the screening programme is a true representation of the individual's wishes. There are very few people who can neither speak nor write and so overuse of this procedure is likely to indicate abuse of the system to cease people without their informed consent.

In all cases (except where the individual has specifically stated that he or she wants no further correspondence at all) whenever someone withdraws from the screening programme by choice, **the programme hub must write to the individual at the address recorded on BCSS to confirm that recall has ceased.** This is to ensure that the individual understands his or her position clearly and to minimise the risk that someone is ceased in error.

Suggested procedures for establishing, documenting and confirming informed dissent are given in the Appendix.

8.2 Becoming ineligible

Someone who has withdrawn from the screening programme may later be found to be, or have become, ineligible for screening. It is acceptable to amend BCSS to reflect a new reason for ceasing which supersedes the original reason.

9. MENTAL CAPACITY

9.1 Lack of mental capacity

Lack of mental capacity means the inability to make a particular decision at a particular time. This may be due to a learning disability, a progressive or terminal illness or other temporary or permanent condition. The decision whether or not to participate in the NHS BCSP involves consideration of the benefits and disadvantages of the screening process. Some people may not have the mental capacity to make an informed decision about this without assistance. An individual who lacks mental capacity should therefore be supported in making an informed decision about screening using appropriate information resources and materials. Any person who can understand the issues may then choose to participate, decline an individual test or withdraw from the programme in the same way as anyone else.* An individual who remains unable to comprehend the procedures should remain in call/recall unless his or her care team† agrees that ceasing would be in the person's best interests – see section 9.3.

9.2 Mental Capacity Act 2005

On 1 October 2007, the provisions of the Mental Capacity Act 2005 come fully into force. The Act and supporting Code of Practice are available on the website of the Department for Constitutional Affairs at <http://www.dca.gov.uk/menincap/legis.htm>

The Act provides for decisions about the healthcare of an individual who lacks capacity to be made by a legally accountable decision-maker. The decision-maker may be one or more of: an attorney appointed under a Lasting Power of Attorney, a deputy appointed by the Court of Protection, an Independent Mental Capacity Advocate (IMCA) or other advocate including a responsible healthcare professional. Attorneys, deputies and advocates must only make decisions within the scope of their authority (which will be defined separately in each case) and must always act in the best interests of the person who lacks mental capacity. Decision-makers are required to make an objective decision about a person's best interests without imposing their own views. Any decision should be the least restrictive of all options and should be reviewed regularly to ensure that it remains appropriate since an individual's best interests may change over time. Decision-makers are also required to document the decision-making process and retain an auditable record of this.

Health care workers acting in a professional capacity have a legal duty to understand and work strictly to the Code of Practice. While the Act gives protection from liability to those who reasonably believe and can demonstrate that they are acting in a person's best interests, nothing in the Act excludes civil or criminal liability resulting from negligence.

*A person's withdrawal notification should be a standard form signed by the person him- or herself, but other forms of communication are acceptable – see section 8.

9.3 Ceasing in an individual's best interests

In exceptional circumstances, a care team* may decide that it is in the best interests of an individual who lacks mental capacity to withdraw from the NHS BCSP. For example, someone who would never be suitable for colonoscopy or surgery in the event of a positive test kit might be inconvenienced by screening with no benefit. Since such circumstances are expected to arise very infrequently, no suggested procedures are given for ceasing someone who lacks mental capacity other than by informed dissent. In most cases, the least restrictive alternative is for the individual to remain in call/recall and receive screening invitations at routine intervals. The invitations can be considered and accepted or declined on each occasion.

*The care team will comprise at least the professional responsible for the person's health care (usually his or her GP) and any or all formally appointed decision-makers. It may include other health care professionals in a multidisciplinary environment. The views of the person's family, friends, social worker or advocate should be taken into account, especially where such people can advise on the likely attitudes or previously held opinions of the person who lacks capacity.

10. RETURN TO RECALL ('UNCEASING')

If someone who has been ceased for any reason asks to be restored to the programme, the programme hub can 'uncease' that individual, ie return them to routine recall provided they remain eligible for screening.

If the individual has had a complete screening test in the last two years, a screening invitation will be produced at the next due date. If the previous screening episode was incomplete, then it should be re-opened and a new invitation sent immediately.

If more than two years has elapsed since the individual's last complete screening test a new episode should be opened and a invitation will be produced immediately.

11. PROGRAMME HUB PROTOCOLS

11.1 Documented protocols

Each programme hub must have fully defined and documented protocols for ceasing. These must be available to all staff in the programme hub who deal with telephone queries about the screening programme from the general public and those invited for screening.

The protocols must cover all valid reasons for ceasing, the procedures to be followed in each case and the supporting documentation required. The protocols should also cover the management of invalid requests for ceasing, the procedures for closing or suspending episodes and the requirements for the regular monitoring and review of all suspended episodes.

11.2 Review of protocols

Protocols should be reviewed regularly to ensure that policies and procedures remain appropriate in the light of experience and as the screening programme evolves.

11.3 Audit of people who have been ceased

Periodic manual audit of people who have been ceased from call/recall is required in each programme hub to check that the protocols for ceasing are being followed and the documentation is complete. This is in addition to the BCSS validation and system audits.

12. SUMMARY

Ceasing a person from call/recall has a significant and potentially permanent effect. Great care is required to ensure that ceasing is carried out correctly and appropriately. Records must be maintained to demonstrate adherence to programme hub protocols and to provide evidence that all eligible individuals are given every opportunity to be screened. It is essential that adequate documentation is retained so that there is an auditable record of all ceasing. This is particularly important in cases of informed dissent where there is the possibility of future litigation if an individual ceased from the call/recall system subsequently develops bowel cancer.

The acceptable uses for ceasing are summarised in Table 1.

Table 1 Summary of acceptable reasons for ceasing

Reason for ceasing	Acceptable uses	Unacceptable uses
<i>Clinical reasons</i>		
No functioning bowel (see section 6.1)	Someone with permanent absence of entire functioning bowel	Someone with any part of a functioning bowel Someone with reversible bowel bypass
Alternative surveillance programme (see section 6.2)	Someone who will receive lifetime surveillance of entire bowel	Someone receiving monitoring of lower part of bowel only Someone receiving temporary monitoring of all or part of bowel Someone at risk of being lost to local follow up
<i>Other reasons</i>		
Informed dissent (see section 8)	Someone who makes an informed choice to withdraw from the screening programme	Decision made on behalf of someone who is seriously or terminally ill (see section 7) Decision made without legal authority on behalf of someone who lacks mental capacity (see section 9.3)

APPENDIX: SUGGESTED PROCEDURES FOR INFORMED DISSENT

RECORD KEEPING

Keep copies of all correspondence relating to the ceasing in a safe place so that there is an auditable record of the ceasing process. Letters produced using BCSS are automatically retained in the person's screening record and provide part of the auditable record of communication.

TELEPHONE INSTRUCTION FROM PERSON INVITED

If someone telephones and asks to withdraw from the screening programme

Ask the person if they would be willing to reconsider a further invitation in two years (provided that they remain eligible).

If the person is willing to reconsider a further invitation

Close the episode and do not cease the person.

If the person states that he or she definitely wants to withdraw

Close the current screening episode to prevent reminder letters being produced.

Ask the person if they would complete a standard withdrawal form which will be sent to them.

If the person is willing and able to complete a withdrawal form

Send a standard withdrawal letter and form (see sample letter A) to the person at the address recorded on BCSS. Record the date of despatch.

Enclose a copy of the leaflet *Bowel Cancer Screening: The Facts*.

When the signed form is returned, cease the person.

Write to the person at the address recorded on BCSS to confirm that they have been ceased and to explain how they can be reinstated into the programme (see sample letter B).

Send a copy to the person's GP.

If the person is unable to sign a withdrawal form

Send a standard withdrawal letter and form which allows for an alternative signatory (see sample letter C). The letter should be addressed to the person invited for screening at the address recorded on BCSS. Record the date of despatch.

Enclose a copy of the leaflet *Bowel Cancer Screening: The Facts*.

When the signed form is returned, cease the person.

Write to the person at the address recorded on BCSS to confirm that they have been ceased and to explain how they can be reinstated into the programme (see sample letter B).

Send a copy to the person's GP.

If the person is NOT willing to complete a withdrawal form

Ask for the instruction to be witnessed by a supervisor or colleague.

Make a written record of the instruction. The witness should do the same.

Tell the person that they will be sent a letter to confirm that they have been ceased and to explain how they can be reinstated into the programme (see sample letter B).

If the person specifically states that they want no further correspondence at all

Make a written record of this instruction.

Inform the person's GP that the person has been ceased.

WRITTEN INSTRUCTION FROM PERSON INVITED

If someone writes and asks to withdraw from the screening programme

Consider the letter to assess the clarity of the instruction.

If it is clear that the person wants to withdraw permanently

Cease the person.

Write to the person at the address recorded on BCSS to confirm that they have been ceased and to explain how they can be reinstated into the programme (see sample letter B).

Send a copy to the person's GP.

If it is NOT clear that the person wishes to withdraw permanently

Close the current screening episode to prevent reminder letters being produced.

Send a standard withdrawal letter and form (see sample letter A) to the person at the address recorded on BCSS. Record the date of despatch. Enclose a copy of the leaflet *Bowel Cancer Screening: The Facts*.

When the signed form is returned, cease the person.

Write to the person at the address recorded on BCSS to confirm that they have been ceased and to explain how they can be reinstated into the programme (see sample letter B).

Send a copy to the person's GP.

TELEPHONE INSTRUCTION FROM A THIRD PARTY ON BEHALF OF THE PERSON INVITED

If a third party (carer, spouse, relative or GP) telephones the programme hub to speak on behalf of a person invited for screening who wishes to withdraw from the screening programme

Ask the third party if the person invited would be willing or likely to reconsider another invitation in two years time instead (providing that person remains eligible for screening).

If the person invited would be willing or likely to consider a further invitation

Close the current episode.

If the person invited is unwilling or unable to consider a further invitation or lacks mental capacity

Explain that the person invited cannot be ceased by a third party without the person's written instruction.

If the person lacks mental capacity explain that he or she may be given assistance to make an informed decision about participating in the screening programme. Refer to care team if appropriate.

If the person invited is able to sign a withdrawal form

Suspend the current screening episode to prevent reminder letters being produced.

Send a standard withdrawal letter and form (see sample letter A) to the person at the address recorded on BCSS. Record the date of despatch.

Enclose a copy of the leaflet *Bowel Cancer Screening: The Facts*.

When the signed form is returned, cease the person.

Write to the person at the address recorded on BCSS to confirm that they have been ceased and to explain how they can be reinstated into the programme (see sample letter B). Send a copy to the person's GP.

IF A SIGNED WITHDRAWAL FORM IS NOT RETURNED, CLOSE THE CURRENT SCREENING EPISODE AND DO NOT CEASE THE PERSON.

In exceptional circumstances, a decision to cease in an individual's best interests can be made by a third party with legal authority under the provisions of the Mental Capacity Act 2005 (see section 9.3).

If the person invited is unable to sign a withdrawal form

Suspend the current screening episode to prevent reminder letters being produced.

Send a standard withdrawal letter and form which allows for an alternative signatory (see sample letter C). The letter should be addressed to the person invited for screening at the address recorded on BCSS. Record the date of despatch.

Enclose a copy of the leaflet *Bowel Cancer Screening: The Facts*.

When the signed form is returned, cease the person.

Write to the person invited at the address recorded on BCSS to confirm that they have been ceased and to explain how they can be reinstated into the programme (see sample letter B). Send a copy to the person's GP.

WRITTEN INSTRUCTIONS GIVEN BY A THIRD PARTY

If a third party (carer, spouse, relative or GP) writes to the programme hub on behalf of a person invited for screening who wishes to withdraw from the screening programme

Consider the letter to assess the clarity of the instruction.

If the letter is clear that the person invited for screening has made their own decision to withdraw permanently from screening

If the letter is not clear that the person invited for screening has made their own decision to withdraw permanently from screening

Suspend the current screening episode to prevent reminder letters being produced.

Send sample letter A and sample letter C (which allows for an authorised alternative signatory). A covering letter would be helpful to explain that the person invited for screening should complete confirmation slip A if he or she is able, or that a third party can complete confirmation slip C on his or her behalf. The letter should be addressed to the person invited for screening at the address recorded on BCSS. Record the date of despatch. Enclose a copy of the leaflet *Bowel Cancer Screening: The Facts*.

Treat the letter as a withdrawal form and cease the person.

When the signed form is returned, cease the person.

Write to the person at the address recorded on BCSS to confirm that they have been ceased and to explain how they can be reinstated into the programme (see sample letter B).

Write to the person at the address recorded on BCSS to confirm that they have been ceased and to explain how they can be reinstated into the programme (see sample letter B).

Send a copy to the person's GP.

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