

NHS BOWEL CANCER SCREENING PROGRAMME

Ceasing Screening Subjects from Call/Recall Clarification of guidance

1. INTRODUCTION

A screening subject who is ceased from call/recall on the bowel cancer screening system (BCSS) will, regardless of eligibility, be sent no further correspondence in any current screening episode, or relating to any future screening episode, other than a letter to confirm the ceasing.

Ceasing a person from call/recall has a significant and potentially permanent effect and should therefore be used with caution. Great care is required to ensure that ceasing is carried out correctly and appropriately. Ceasing is appropriate only if an individual will never require screening and/or intends never to participate in the screening programme.

Ceasing is not appropriate if the individual 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. A person who is currently ineligible for the NHS Bowel Cancer Screening Programme (NHS BCSP) may become eligible in the future and any decision about ceasing should take individual circumstances into account.

2. BACKGROUND

Ceasing guidance for the NHS BCSP was written drawing from experience in breast and cervical screening programmes and with advice from individuals who had been involved in the bowel screening pilot. The guidance was published as BCSP Publication No. 2 in October 2007. Over time, hubs running call/recall and NHS BCSP professional QA committees identified the need for changes in some areas and so a paper proposing a set of revised ceasing policies was discussed at the Advisory Committee meeting in May.

This document summarises the ceasing policies agreed by the Advisory Committee. **A full guidance document detailing national policies, administration, responsibilities and practical aspects of implementation is in preparation and will be published later this year.**

It should be noted that BCSS does not currently fully support the existing guidance and therefore amendments to the system and some reporting of individuals is already required. Once the new guidance document is published and the IT system amended, a national audit exercise will be undertaken.

3. REASONS FOR CEASING

3.1 No functioning large bowel

A small number of people do not have a functioning bowel and therefore screening is not possible in the current NHS BCSP.

People who contact the hub to advise that they have no functioning bowel may be ceased immediately provided that they are certain of the extent of their surgery or it can be verified by their GP or consultant. The hub should write to both the subject and the GP to confirm the ceasing.

Comments

No changes are required to existing guidance.

Some screening subjects ask the hub for advice because they are not sure of the extent of their surgery, which may have been carried out many years earlier. Hubs generally suggest that the FOBT kit be completed as a failsafe measure even though this is sometimes inappropriate. Uncertain cases may be investigated by the hub or referred to the appropriate SSP who can liaise with the subject, GP, hospital where treated, and clinical colleagues to determine what actions are required in each case. Where there is any doubt about a particular subject's suitability for screening, the failsafe position is to retain them in call/recall and offer screening by FOBT until it is proven that this is not required.

3.2 Informed dissent

People who indicate that they do not wish to be screened should be encouraged to remain in the call/recall system and decline their individual regular invitations rather than withdraw permanently from the screening programme. This will minimise the risks of error and of excluding people who might choose to accept a screening invitation at a later date. However, any subject who indicates that he or she is certain of their decision should have this decision respected without argument.

People who are certain that they do want to withdraw from the NHSBCSP are entitled to do so. The key requirements for informed dissent are:

- the person must be provided with sufficient information to enable an informed decision to be made about withdrawing from the screening programme; this must be in a format which is accessible to the individual. It should include information on the condition being screened for, the screening process (including risks and benefits), and the consequences of attending or ceasing. 'Sufficient' is defined by the individual themselves.
- the person must be informed that withdrawing from the programme will prevent them from receiving any future invitations or reminders about screening.
- it must be made clear to the person that he or she can return to the programme at any time at their own request.

Additionally, the person must be capable of making and communicating an informed decision.

Under the Mental Capacity Act 2005¹, individuals must be presumed to have capacity to make their own decisions unless it is proved otherwise. Ceasing decisions for people who lack mental capacity may be made by a legally-accountable decision-maker only where the individual cannot make his/her own decision even with support and assistance, and must always be in the individual's best interests. 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 by the decision-maker 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. The letter of confirmation of ceasing from the hub will provide part of such a record (see below). Ceasing in an individual's best interests is likely to be appropriate only where the individual would never be suitable for colonoscopy or surgery in the event of a positive screening result. In most cases the least restrictive alternative is for the individual to remain in call/recall and receive screening invitations at routine intervals.

The key requirements for ceasing under a 'best interests' decision are:

- the case must be considered individually, including a case conference with an appropriate family member or other personal representative of the subject
- an individual letter must be sent by the hub to the subject's responsible health professional and personal representative, copied to the GP (if different), to confirm the ceasing and to explain how to rejoin the programme if this is required
- the subject's representative(s) must confirm that the situation will be reconsidered if the subject's personal circumstances change.

Obtaining evidence of the informed nature of a person's decision, including procedures for people with communication difficulties, is part of the ceasing administrative process. Wherever possible a standard withdrawal form or specifically-written instruction should be signed by the subject or his/her representative to confirm their informed dissent from call/recall. Alternative procedures may be appropriate for individuals who are unable or unwilling to provide signed confirmation. For example, a verbal instruction should be witnessed and documented by at least two members of staff, one at a senior level.

Each programme hub must have fully defined and documented protocols for ceasing, and these must be available to all staff who deal with queries from screening subjects and the general public.

The Data Protection Act 1998² requires that individuals who have confirmed their wish to be removed from the screening programme receive no further correspondence relating to any current, recent or future screening episode. However, unless the person has specifically requested otherwise, the hub must write to them at their registered address to confirm that recall has ceased and to give instructions on how to rejoin the programme if this is required. This is to ensure that the person understands his/her position clearly and to reduce the risk of error.

Comments

No changes are required to existing guidance.

It is recommended that 'best interests' ceasing is carried out only as a last resort and is subject to confirmation that the decision-maker has authority to make decisions on behalf of the subject. For example, an officially recognised attorney will be registered with the Office of the Public Guardian. A spouse might be asked to confirm in writing their relationship with the subject and that the decision has been made in the subject's best interests.

3.3 Automatic ceasing

Individuals who are deducted from the NHAIS population database for a permanent reason (e.g. death) are automatically ceased from call/recall on BCSS.

Comment

Where the deduction was made in error and later corrected, there is currently no system to automatically un-cessate the person on BCSS. A change request is pending for BCSS to deal with these cases so that no-one is excluded from the screening programme inappropriately.

4. SPECIAL CASES

4.1 Alternative surveillance programme

An individual who has already experienced bowel disease or who is at very high risk of bowel cancer can be the subject of a surveillance programme more rigorous than the testing offered by the NHS BCSP. However, alternative surveillance programmes cannot be assumed to obviate screening as:

- they may not monitor the entire bowel on each occasion
- they may not be a permanent arrangement or arrangements may change at a subsequent date
- the subject may be at risk of being lost to local follow-up, particularly if they move area.

Subjects should therefore be retained in call/recall and invited for screening at routine intervals. Invitations can be accepted or declined on each occasion. Subjects who contact the hub to advise that they are under surveillance due to Crohn's disease/ulcerative colitis/IBD should be asked to confirm that they have had colonoscopy in the past two years or that one is scheduled. The hub or the appropriate SSP may need to check the subject's medical records to ensure that the previous endoscopy was adequate.

Subjects whose endoscopy was adequate should be advised that they do not need to be screened at this time. Their episodes should be closed for reason 'alternative surveillance' and a recall date set two years hence. All other subjects should be advised to carry out the FOB test. A form of words for hub staff to use when discussing the need for screening and the possibility of a false positive result in a person with inflammation in the bowel is included at Appendix A.

It is recommended that subjects whose previous screening episode was closed for reason 'alternative surveillance' have a specially-worded invitation at their next episode to acknowledge their circumstances.

Subjects who wish to opt out of the NHS BCSP may do so but this will be considered as

informed dissent and will usually require a signed withdrawal form or other signed instruction.

Comments

This is a change to existing guidance and will require changes to BCSS to implement a new reason for episode closure and a new type of invitation letter. It may also be possible to enhance BCSS to identify separately those individuals who have withdrawn from the screening programme (via the informed dissent mechanism) primarily due to participation in an alternative surveillance programme. This will allow statistical reports to take account of individuals who will not benefit from screening and who it may therefore be appropriate to exclude from the denominator of the coverage calculations. The reliability of patient-volunteered information may be an issue.

An audit of subjects currently ceased due to 'alternative surveillance programme' will be required to ensure that no individuals are ceased from call/recall inappropriately. Hubs agreed at a workshop on 27/3/09 to conduct an audit of all ceased screening subjects, including those ceased due to alternative surveillance programmes, and to return to recall all those who could be. Hubs are not required to contact patients to verify their status in line with practice in other screening programmes. In uncertain cases, invitations should recommence.

4.2 Under treatment for or history of bowel cancer

In order to bring the NHS BCSP in line with established practice in the NHS Breast Screening Programme, individuals with a history of bowel cancer should be offered screening at routine intervals for as long as they remain eligible. This will provide a safety net for people at risk of recurrence. Those under active investigation or follow-up should be managed in the same way as individuals covered by alternative surveillance programmes (see section 4.1 above) to ensure that individuals who have not been fully tested elsewhere have the opportunity to be screened.

Subjects who wish to opt out of the NHS BCSP may do so but this will be considered as informed dissent and will usually require a signed withdrawal form or other signed instruction.

Comments

Bowel cancer patients are not specifically covered by existing ceasing guidance but hub protocols to date have allowed or even required such patients to be ceased from call/recall in the NHS BCSP.

Including current and former cancer patients in the screening programme will require changes to BCSS (to remove 'bowel cancer' as a reason for ceasing) and an audit of individuals currently ceased for that reason.

4.3 Patients at end of life

People who are seriously or terminally ill should be invited for bowel cancer screening for as long as they remain eligible. Every person who retains the capacity to do so is entitled to decide their own participation in the NHS BCSP, either by considering each routine invitation or by making an informed decision to withdraw from the screening programme.

If a person is too ill to respond to an invitation, his/her spouse or carer may notify the hub and request that no further correspondence be sent. In such cases the person's screening episode should be closed and his/her test-due date should be re-set with regard to his/her screening history so that he/she will be invited again at an appropriate time if he/she remains registered on the population database and eligible for screening invitations. The subject's GP should be notified of the reason for the episode closure.

For audit purposes, a brief note of the reason for episode closure should also be added to the person's screening record on BCSS.

Comment

No changes are required to existing guidance.

4.4 Physical disabilities

People with physical disabilities should be invited for bowel cancer screening for as long as they remain eligible.

A person who cannot complete the FOBT kit unaided will need support and assistance from a carer or healthcare professional. While the hub is unlikely to be able to offer assistance, it may maintain a register of local disability support groups, charities or social care organisations that can help to arrange assistance where required. SSPs in the local screening centre may also be able to assist. Medical advice from the local screening endoscopist may be required to make a decision about screening and/or endoscopy.

People who cannot participate in the screening programme due to physical disabilities should be advised which symptoms to report to their GP.

Subjects who wish to opt out of the NHS BCSP may do so but this will be considered as informed dissent and will usually require a signed withdrawal form or other signed instruction.

Comment

Existing guidance does not mention people with physical disabilities. This section clarifies that individuals (who are presumed to be mentally competent) should not be excluded from the screening programme other than at their own request.

5. SUMMARY

The proposed changes and clarifications to existing guidance are intended to improve the accessibility of bowel cancer screening to individuals with a history of, or at risk of, bowel cancer. Only individuals who cannot be screened by current methods, and those who do not wish to be invited for screening, should be excluded from the call/recall system.

Ceasing policies will need to be reviewed if there are any significant changes to screening practice, systems or technologies which would allow currently ineligible individuals to be screened. For example, a person with a redundant rectal stump remains at risk of bowel cancer but cannot be screened by FOB test, whereas he/she could be examined by flexi-sigmoidoscopy if this were to be introduced as a screening modality as a variation to the

existing screening programme.

The following actions will be required to implement new policies and procedures:

- publish revised guidance; and
- specify, develop and implement changes to BCSS to support the guidance; and
- undertake a full audit of ceased patients in line with the revised guidance; and
- educate and where necessary formally re-train hub patient-facing staff about ceasing policies and protocols, especially with regard to areas of change, to ensure that the updated protocols are implemented correctly.

REFERENCES

1. *Mental Capacity Act (2005)*. Office of Public Sector Information (OPSI), 2005.
2. *Data Protection Act (1998)*. The Stationery Office, 1998.

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Appendix A Dealing with individuals with inflammation in the bowel

Advice to subjects phoning who believe they have ulcerative colitis or Crohn's disease (also called "colitis", inflammatory bowel disease)

First ask two questions:

1. Are you currently (within the past year) attending a hospital clinic for your colitis or Crohn's?

YES / NO

2. If so have you had a colonoscopy (check they understand the term) in the past 2 years or is the consultant planning for you to have one in the next 2 years?

YES / NO

Advice

1. If answer to both questions is NO then should go ahead with screening.
2. If answer to both questions is YES then screening is unlikely to help them.
3. If in doubt (e.g. not sure if they have had a colonoscopy in past 2 years) advice is to do the tests.

Finally they should be warned

Because they have inflammation in the bowel they are more likely to have a positive test not due to cancer (in the same way that skin that is inflamed when rubbed will often bleed slightly).