

Interventions to increase bowel screening uptake

Executive summary

Accelerate, Coordinate, Evaluate (ACE) Programme

An early diagnosis of cancer initiative supported by:

NHS England, Cancer Research UK and Macmillan Cancer Support

ACE Bowel Screening Cluster

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The ACE Programme would like to thank the following for their contributions to this report:

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About the ACE Programme

The Accelerate, Coordinate, Evaluate (ACE) Programme is an early diagnosis of cancer initiative focused on testing innovations that either identify individuals at high risk of cancer earlier or streamline diagnostic pathways. It was set-up to accelerate the pace of change in this area by adding to the knowledge base and is delivered with support from: NHS England, Cancer Research UK and Macmillan Cancer Support; with support on evaluation provided by the Department of Health's Policy Research Units (PRUs).

The first phase of the programme consisted of 60 projects split into various topic-based clusters to facilitate evidence generation and learning. The second phase (pilots live from January 2017) comprises five projects exploring Multidisciplinary Diagnostic Centre (MDC) based pathways. The learning from ACE is intended to provide ideas and evidence to those seeking to improve local cancer services. The evaluations and findings are produced independently, and are therefore, not necessarily endorsed by the three supporting organisations.

Executive Summary

The UK national cancer screening programmes are aimed at large groups of the population, most of whom have no symptoms of cancer. Essentially they are established to look for early signs that cancer is potentially developing but is as yet undiagnosed. Regular cancer screening has the potential to reduce incidence of the disease and improve outcomes for those patients whose cancers are diagnosed and can be treated.

In order to achieve the desired public health impact amongst targeted populations, cancer screening programmes require high levels of participation and it is accepted that decisions to participate in cancer screening should be free from undue pressure and coercion and be well-informed.

The NHS Bowel Cancer Screening Programme (BCSP) has been operational since 2006, with regular bowel cancer screening participation considered increasingly important in preventing and detecting cancer. It offers a significant opportunity to diagnose more cancers earlier and improve outcomes for patients by treating cancers and other conditions. Screening has been shown to reduce the risk of dying from bowel cancer by 16% in the population invited.¹

There are two aspects to the national bowel cancer screening programme:

- The original guaiac Faecal Occult Blood test (gFOBt). For men and women aged 60 to 74 in England with invitation to self-test every two years
- The more recent complementary bowel scope screening programme for all 55-year olds. A one-off flexible sigmoidoscopy test currently being rolled out.

In 2015/16, overall percentage uptake for gFOBt bowel screening (people adequately screened within 6 months of invitation) was 56.4%, with significant variation in compliance across all CCG areas. This geographical variation and the range of screening uptake achieved across different population groups presents a real opportunity to improve participation.

In January 2016, the UK National Screening Committee (NSC) recommended the use of the Faecal Immunochemical Test (FIT) as the primary test for bowel cancer screening in place of the gFOBt, which was formally announced by the government in June 2016. A national implementation group is leading the design, procurement and co-ordination of the new FIT, to be operational in England from April 2018. NHS England (NHSE) suggest almost a third of a million more people are expected to complete the FIT in 2018/19 (compared to gFOBt) and a fifth more cancers will be diagnosed earlier.²

The BCSP largely operates in parallel to primary care service provision. More should be done across the system to integrate primary care involvement with the national screening process, considering the evidence that 'more people who are sent bowel screening kits through the post, are likely to complete the test if there is endorsement from their GP on all supporting correspondence.'³

Achieving World-Class Cancer Outcomes (A Strategy for England 2015-2020)² suggests that implementation of **'feasible, acceptable and cost-effective strategies to improve screening uptake, particularly amongst non-responders, are fundamentally important for the success of the screening programmes.'**

Recent evidence published by Cancer Research UK (CRUK) and the National Cancer Registration and Analysis Service (NCRAS), suggest bowel cancer is more likely to be diagnosed at the earliest stage if it is picked up by screening; this provides a significant incentive to improve screening compliance.^{4, 5}

Purpose

The ACE Programme is organised into a series of thematic clusters; this report summarises the progress of the bowel screening cluster, incorporating local NHS projects intent on improving gFOBt screening participation, focusing in particular on effects in underserved populations. It also includes details from two projects who have been considering how reasonable adjustments to the bowel screening pathway can improve access for patients with a learning disability.

The main output for this cluster is its contribution to the evidence base of what works best in terms of **'effective intervention'** to improve bowel screening gFOBt uptake. The ACE projects have added to the growing evidence that GP endorsement and engagement in the screening process can improve uptake rates.

The ACE projects and their stakeholders are challenged by the recommendation in the Cancer Strategy for England 2015-2020² (Recommendation 10), that NHS England should incentivise GPs to take responsibility for driving increased uptake of bowel screening in the populations, with an ambition of achieving 75% uptake in all CCGs by 2020.

The evidence detailed in this report also contributes to the understanding of which interventions support the earlier diagnosis of cancer that in turn could be transformative in terms of improving survival rates, reducing mortality and improving quality of life.

The report contents will be of particular interest to commissioners of cancer services implementing Best Possible Value (BPV) pathways,⁶ designed to incentivise high quality and cost-effective care, and to public health commissioners and decision-makers modelling the effects of interventions and return on investment costs against the core value of their benefits and improved outcomes for patients.⁷

Context

A number of factors help to set the context for including **'improving bowel screening uptake'** as one of the key concepts of the ACE Programme, particularly given the significant geographical variation and range of screening uptake rates across the different population groups:

Rising incidence. Bowel cancer is the fourth most common cancer type registered in the UK, with 41,300 new cases diagnosed in the UK in 2014; that's 110 new patients diagnosed every day. Regular bowel cancer screening contributes to reducing incidence and improving outcomes for those patients who can be diagnosed and treated at an earlier stage.⁹

Mortality and late stage disease. Around 15,900 people died of bowel cancer in 2014 in the UK, that's more than 44 people every day.¹⁰ Most bowel cancers are diagnosed at a late stage of disease, with evidence indicating that patients whose cancers are diagnosed at an earlier stage almost always have improved chances of survival following successful treatment.¹¹

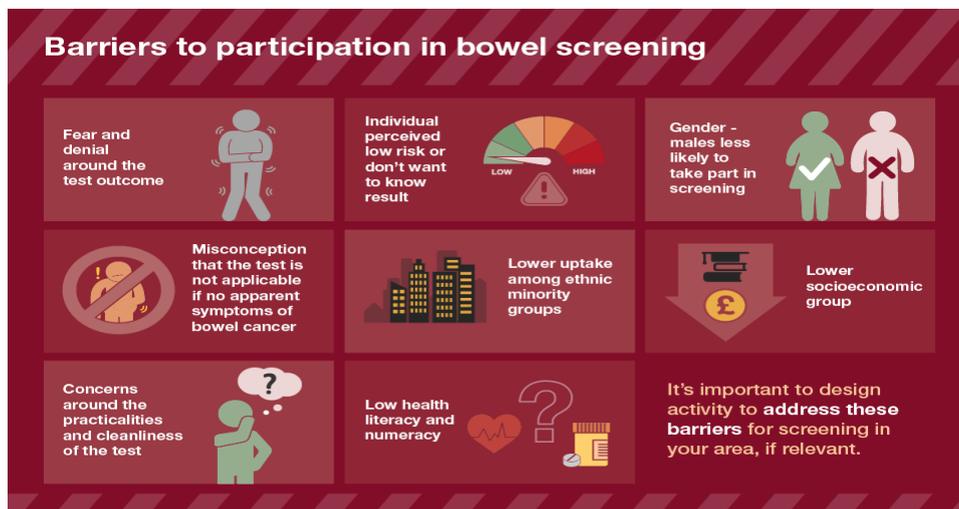
Poor survival. Improving patient survival from a diagnosed cancer is a key challenge identified in [Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020](#)² with survival estimates in the UK currently below those in many other European countries. The figures confirm the long-standing suspicion that patients diagnosed with cancer following an emergency admission to hospital are much more likely to be diagnosed at a later stage, and that bowel cancers diagnosed following screening by the national BCSP have the highest rates of survival over the time period.^{4,5}

Earlier diagnosis. An earlier cancer diagnosis makes it more likely that patients will receive treatments such as surgery and radiotherapy which contribute to the majority of cases where cancer is treated successfully. The [Routes to Diagnosis](#)⁴ intelligence suggests that of the cases picked up by [bowel screening](#) (where the stage at diagnosis was known), more than one third (37%) were caught at the earliest stage (stage one) while fewer than one in ten (8%) were advanced (stage four).

Reduce inequalities. Evidence suggests there is a strong socio-economic gradient in gFOBT uptake, with studies reporting screening rates lower in areas of deprivation and in certain ethnic groups. The feedback is that the gFOBT is impractical, unhygienic, unacceptable, and has social and cultural taboos for many population groups.¹³⁻¹⁵

Barriers to participation. Previous studies of non-responders reveal few people are really set against screening¹⁶ and following further discussion or interviews with non-responders it often results in a willingness to do the self-test.¹⁷ Those that are opposed can't face doing the gFOBT or can't face a cancer diagnosis (at least at this point in time). 'Unpleasantness,' 'disgusting test' and 'too invasive,' are some of the barriers for many considering completing the gFOBT.¹⁸

Barriers to participation in bowel screening, PHE, accessed March 2016



Interventions. There is a wide range of potential interventions to improve access and increase participation in cancer screening services. A recent review of interventions to improve uptake found those that most consistently improved screening participation were - pre-screening reminders, general practice endorsement, personalised reminders for non-participants and offering a more culturally acceptable screening test.²² CRUK has run intervention pilots in London (2014), Wales (2015) and England (2015-16),²³⁻²⁴ all aiming to explore ways of improving participation in eligible populations.

Bowel Scope. An additional bowel scope (flexible sigmoidoscopy) investigation is gradually being introduced in England as part of the national BCSP, offered to all men and women aged 55. Bowel scope screening helps to prevent cancer by finding and immediately removing adenomas and polyps, which reduces the chances of these developing into bowel cancer in the future. Recent evidence has shown people having bowel scope screening (at 55 years) have a 35% lower risk of developing bowel cancer and a 40% lower risk of dying from the disease. To put this into context that translates to approximately two fewer cases of bowel cancer and one death prevented from the disease for every 220 people screened.²⁵

Introduction of the Faecal Immunochemical Test (FIT). The introduction of the improved FIT in screening patients for bowel cancer will begin in April 2018 as the primary test of the national BCSP replacing the gFOBT in England. Positive findings from previous FIT pilots have indicated improved uptake of screening in both sexes and across all quintiles of the index of multiple deprivation, with notable improvements in the most deprived quintile.²⁶ The national FIT development team are considering the potential for risk stratification or whether positive thresholds should start high and reduce over time, based on already stretched endoscopy service provision.

Key Findings

The Programme generated informative data from twelve local projects in the bowel screening cluster. Eight of the projects were able to provide quantitative data regarding the outcome of their particular intervention, whilst the remaining projects have used aggregate-based data to illustrate progress. The following key findings and implications have been recognised by the bowel screening projects in testing their interventions:

GP endorsement & primary care engagement. For those projects using GP endorsed reminders to subjects who had not returned a completed kit within approximately three months, results varied among studies as to the strength of the effect on participation. In summary, results indicate the addition of a primary-care endorsed reminder at three months **increased participation by 3 - 5%** in absolute terms, particularly in practices with participation rates below the national average (A17, A20, A29, and A63). Estimates of the number of subjects needed to contact per additional participant ranged from 6 to 27.

The evidence gathered by the ACE projects confirms the benefits of engaging primary care in bowel screening uptake, encouraging informed choice. Most would like greater involvement and appropriate funding to sustain their interventions in the longer term.

Interventions targeted specifically at non-responders. A variety of methods were adopted, mainly by GP practices, in following up with non-responders (both first-timers and recurrent). These included: sending an additional GP endorsed reminder letter, making direct telephone contact or using pop-up prompts and alerts on GP clinical system. There is varied evidence as to whether direct telephone calls are more effective than sending letters. For some, an additional reminder letter was effective (A17, A20); others however recognise a direct conversation is required to provide a more personal touch to encourage participation (A34, A63). Emphasis is placed on consideration of the actual timing of the telephone call, the preferred use of mobile contact and the benefit of having a prepared telephone script to follow during the conversation. (A34) targeted segments of their population dominated by ethnic minority groups and provided language interpreters to overcome any translation issues; they indicate that positive conversations with patients are key to redressing the barriers and influence participation.

Varying invitation materials or strategy

Opportunistic Prompts. A number of the projects set up prompts and alerts on their GP clinical systems to endorse bowel screening opportunistically as patients contact or attend the practice. Though these prompts are difficult to evaluate, and rely on the healthcare professional to take responsibility and not overlook the reminder in favour of other competing healthcare messages, they are a visual alert to all practice staff of a patient's screening status.

Third party consent for the request of replacement kits. The approval of the third party consent protocol by the BCSP has helped to resolve the issue of the inaccessibility of kits, particularly for primary care. A number of the ACE projects have tested the protocol, establishing an e-mail facility for healthcare professionals to request replacement kits, with good results. Some of the projects (A29, A84) have also made the request proforma available on their GP clinical systems enabling all the patient's details to be automatically transferred onto the proforma for onward transmission to the screening hub. This process requires further approval by the National Screening Committee to ensure it fully conforms to the screening consent model, but demonstrates a positive integrated solution between primary care and the BCSP systems.

Reduce screening inequalities. Two of the ACE projects considered how **reasonable adjustments** to the screening pathway could help people with learning disabilities (A47, A84). Both projects have linked with dedicated local community health teams in identifying their registered client group, providing training and education sessions to health professionals and client groups, and developing practical resources to ensure participation - how to use the self-test, easy-to-read pictorial leaflets and DVD materials for patients and their carers (A47) piloted the use of an additional care note flag on the BCSP system for patients with a learning disability, populated by up to date information generated from primary care. At the start of the project 7 patients with a learning disability were known to the screening hub; at the 6-month interim reporting stage there were 209 such patients recorded. As a consequence the screening hub has tailored its screening invitation for patients with a learning disability to the community learning disability teams for additional support.

Re-engaging patients for colonoscopy testing. One of the ACE projects (A30) had a different objective in re-engaging patients with the BCSP who had previously tested positive at gFOBT screening, yet failed to attend for the required subsequent colonoscopy test at the designated screening centre in Manchester. A total of 101 letters were sent to the GPs of such non-attenders; subsequently **12 (12%) patients did re-engage and attend for colonoscopy**. Their diagnoses included high risk adenomas, lower risk polyps and other bowel pathology as well as no significant pathology. Given the high risk element of significant pathology findings, they remain a particular patient cohort that GPs should actively seek to re-engage with.

Recommendations

The ACE projects have encouraged more eligible people to come forward for bowel cancer screening, and also present feasible, acceptable, cost-effective strategies to improve uptake that should be aligned to future FIT delivery models. These key recommendations focus on making it more desirable and easier for the screening community to promote informed choice.

For policy makers & key opinion leaders:

1. The BCSP should accelerate the continuation of GP endorsed screening invitations

ACE contributes to the evidence that when a subject is made aware their GP supports bowel screening, participation is increased.

The BCSP have approved amendments to screening invitation letters, to now include positive statements of GP endorsement. ACE recommends that all GP Practices should consent to the changes (permission to include the GP Practice detail has to be renewed annually) and that implementation of these new arrangements should be accelerated by the BCSP hubs.

2. Use of e-mail to request a replacement test kit

Providing a facility for GPs and associated healthcare workers to order a replacement self-test kit on behalf of patients and using an email communication, essentially transmitted securely via an nhs.net connection to do so, can reduce some of the barriers to improving participation.

ACE recommends a standardised approach across the BCSP when replacement kits are required. Protocols have been developed by the different BCSP hubs and these examples should be considered by the BCSP for standardisation and national implementation.

ACE also recommends exploring automated request arrangements direct from GP clinical systems.

3. More timely bowel screening data & intelligence

The provision of timely bowel screening uptake and coverage data, at individual GP practice and CCG level, should be routinely available to commissioners, managers and practices. This will enable closer monitoring and evaluation of interventions and the impact of different populations groups (by age, gender and ethnicity).

For commissioners of local services:

4. Specifications should prioritise reducing inequalities in screening access

ACE recommends the BCSP should address local health inequalities with targeted segments of the population, promoting the benefits of bowel screening within the context of *informed choice*. Collaborative effort is required with local authorities, CCGs and screening partners working to identify any barriers to accessing screening in their local area and to encourage more people from hard to reach groups to participate in screening. **Tailored recruitment strategies** will be needed to address the apparent barriers to uptake in these groups, targeting those least likely to participate.

5. Different communication methods to suit the needs of different population groups should be considered

The use of evidence based interventions, such as pre-screening notification lists and more personalised reminders to non-responders are encouraged. Where appropriate, these should be adapted to suit the needs of specific population groups.

ACE recommends the CRUK developed [GP letter template](#) that can be customised by practices to send to their patients as an additional reminder, when required. Combining this with an [enhanced patient information leaflet](#) can further increase uptake. An enhanced information leaflet should include information on how to use the kit and explicitly address perceived barriers.

For GP practices:

6. The role of GP Practices in supporting screening participation should be promoted

GPs and their practice staff have a key role to play in providing details about the BCSP and, in particular, discussing the pros and cons of screening with patients so they are able to make an informed choice to participate. Having helpful healthcare messages displayed in the practice to alert people to bowel screening or discussed opportunistically during a routine visit are encouraged. These messages should highlight; the benefits of screening, that the risk of developing bowel cancer increases with age, and that if bowel cancer is diagnosed earlier, treatment can be more successful, and longer term survival improved.

The Royal College of General Practitioners has developed a [30-minute online bowel cancer screening course](#) which highlights the importance of the GP's role in the BCSP.

7. Encouraging positive dialogue and communication

ACE recommends having conversations with patients as key to resolving some of the barriers and influencing positive participation. Directly targeting segments of a practice population dominated by ethnic minority groupings and providing access to interpreters to overcome language and translation issues, are considered really important. The conversations should provide a reason to talk about screening positively.

8. Re-engaging patients for colonoscopy following positive screening test

Patients who test positive at gFOBT are normally offered a colonoscopy investigation at their local screening centre. There is variation in numbers of patients who fail to attend their colonoscopy appointment (the average rate is 20%). Recognising that for some of these patients, colonoscopy may not be the next appropriate investigation, ACE recommends, given the high risk element of significant pathology findings in this patient cohort, they are a particular group that GPs should actively seek to re-engage with.