The NHS Bowel Cancer Screening Programme in Cheshire and Merseyside: Reaching people with a sensory impairment

Stage 2 report

Executive Summary

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October 2011
Introduction

Bowel cancer is the third most common cancer in the United Kingdom and the second leading cause of cancer deaths. Regular bowel cancer screening has been shown to reduce the risk of dying from the disease, and in 2006 the NHS National Bowel Cancer Screening Programme for England was introduced. As part of its strategy for addressing inequalities in health the NHS Bowel Cancer Screening Programme identified a need to address the accessibility of the Programme for people with a sensory impairment (a visual impairment, a hearing impairment or a dual impairment), who are likely to be a sizeable minority of the target population (people aged 60-75 years). In 2007 the NHS Bowel Cancer Screening Programme commissioned research to explore the accessibility of the first stage of the screening process, from the invitation to participate to completion of a faecal occult blood (FOB) test, for people with a sensory impairment. The research resulted in a number of recommendations to improve participation among this group in the first stage of the screening process.

A second study was commissioned that was designed to build on the earlier stage one research project. The overall aims of this study were to develop evidence-based communication guidelines for local bowel cancer screening teams for effectively engaging sensory impaired people during the entire bowel cancer screening pathway. In addition, practical advice for those with sensory impairments who had been invited to take part in the Programme was developed. Finally, the study aimed to re-examine the practicalities of completing the FOB test kit and to ascertain its user-friendliness for sensory impaired people, following the findings from the stage one project.

Study design and methodology

A participatory, user-focused approach was employed in order to try to ensure that the products of the research could empower sensory impaired people. A qualitative research strategy was adopted to explore the experiences, understandings and perceptions of the entire bowel cancer screening pathway amongst sensory impaired people, some of whom had had direct experience of participation. Focus groups and individual interviews were the data collection methods used. These were audio recorded (with consent), transcribed verbatim, and a qualitative thematic analysis of the data was carried out. Guidelines were then developed based on these findings. Additionally, the perceptions of local NHS Bowel Cancer Screening Programme staff of the guidelines were also sought.
Findings
Many of the themes that emerged from the stage one project regarding the difficulties that some people with a sensory impairment could face when negotiating the first stage of the bowel cancer screening process, that of completing the FOB test kit, were evident in the current study and were highlighted again. Indeed, some visually impaired participants in this study, who had participated in the earlier research, expressed their disappointment that, as far as they were concerned, nothing had changed. In addition some deafblind potential participants declined to take part in the study for the same reason.

Awareness of bowel cancer and bowel cancer screening was more evident among participants than in the first stage project. Practical difficulties in completing the FOB test kit were highlighted, particularly by visually impaired people. Both visually and hearing impaired participants reported difficulties with written communication, including invitation letters, information leaflets and information about test results. For visually impaired people these were focussed on issues such as font size and density, the length of documents, and distinguishing material from ‘junk mail’. For those with a hearing impairment, using less complicated vocabulary and having visual information with clear pictures was deemed important. The importance of having material available in alternative formats (for example, braille, audio, video with British Sign Language interpreter) was highlighted, as was the need to advertise the availability of such material clearly. In addition, participants thought that a record of their impairment should be made at the initial stages of their engagement with the screening programme in order that all subsequent information could be supplied to them in an appropriate format.

In terms of attending for appointments, such as for a colonoscopy, issues around transport, difficulties when initially arriving at an unfamiliar healthcare setting, the level of healthcare staff awareness of sensory impairment, the length of appointments, and the need for British Sign Language interpreters were raised. Finally, some potential improvements to the screening process in terms of changes and alternatives to written materials, changes and alternatives to the test kit, and general changes to the screening process, were suggested.

Conclusions
Based on the findings of this study, guidelines and a checklist to support the effective communication and engagement of NHS Bowel Cancer Screening Programme staff with visually and/or hearing impaired people were produced. In addition, practical advice for visually and/or hearing impaired people to enable them to successfully engage with the bowel cancer screening process were developed.
Communication guidelines to support the effective communication and engagement of bowel cancer screening staff with visually and/or hearing impaired people

Don’t be afraid to ask
- Don’t make assumptions. A lot of impairments are hidden. If you think someone may have sight or hearing problems, ask them if there is anything you can do to support them. This will vary between individuals and will depend on the setting and circumstances. Sensory impaired people usually develop strategies to achieve effective communication, so wherever possible take the lead from them, and ask if you are not sure. Be aware that many sensory impaired people use more than one communication strategy at a time.

Scott is profoundly deaf, and works as a community deaf support officer. He had participated in the NHS Bowel Cancer Screening Programme twice. Scott emphasised the importance of raising awareness of health issues within the deaf community, saying that sometimes deaf people do not insist on having things fully explained to them, or ask questions if they do not understand. He argued that healthcare professionals needed to find out the best way to communicate with individuals and thought that having interpreters at consultations was vital for many deaf people and that for others, writing things down helped. Scott considered that working with deaf community groups to highlight things like the NHS Bowel Cancer Screening Programme was a good idea and he was impressed with the BSL DVD. However, he emphasised that as many deaf people may not make their communication needs known, these alternatives needed to be offered proactively in order to reach as many people as possible.

Pat had a visual impairment and talked about how, in her experience, people with a visual impairment often varied in terms of what they could do and what they might need support with. She said that it was important for health care staff to be aware that it’s a visually impaired person they’re talking to. They also needed to appreciate differences. She gave the example of a partially sighted person, who, depending on their eye condition might be fine in bright light, but if they went into a corridor or a small room which was dark, they would suddenly be “blind as a bat to all intents and purposes”. Pat said health care staff need to ask someone how much help they need. And they must not be frightened about it.
Take your time

- Allow extra time for appointments, and consider booking a double appointment slot. Be patient and friendly. Take time to communicate and talk naturally. Make sure you are facing the person with a sensory impairment to whom you are speaking. For those who lip read make sure your mouth is visible. Speak evenly, not too fast or slow. Don’t exaggerate your mouth movements, as this will make it more difficult to lip-read.

Anoushka had a hearing impairment and she described how beneficial it would have been if she could have had more time prior to her colonoscopy appointment for someone to go through what was going to happen to her. She felt that it would have been beneficial if staff had shown more awareness towards her specific impairment and how it may impact on the procedure. Her impairment was largely hidden – she wore hearing aids and also had problems with her balance.

Talk directly to the person

- If a person with a sensory impairment has a companion, direct your conversation to the person with a sensory impairment, rather than to the person with them.

Larry, who has a visual impairment, spoke about what he saw as a difficulty in getting some healthcare workers to understand the nature of his disability: that although he may not be able to see, this did not mean he was incapable of understanding things if they were presented to him in a suitable format. He described it as a “minefield” and said that he continually has to “fight his corner”. Larry explained that he used to take his wife with him to medical appointments, but that she got so fed up with people addressing her as if he was not there that she refused to come with him anymore. Another participant in the same focus group as Larry joked that people addressed his dog rather than him, and although the group laughed, Larry thought that this was an important point. He said that he had met some very good healthcare workers, but that he perceived that others lacked any training in how to communicate with a person with a visual, or other sensory, impairment.
Ensure all information is understood and available in the appropriate format

- Make sure all information has been understood.
- All reference material should be available in a suitable format.
  - Where necessary ensure those with visual impairments have access to reference material in a format they are happy with. This could be braille, large print, audio recording or written material easily accessible via a family member. Consider audio recording appointments with visually impaired people for them to use as reference.
  - Written information might be accessible to people with a hearing impairment, but might not be as accessible to those who are deaf. Written English might be the second language of people who use British Sign Language. If necessary, write down key words, or write down the message using plain English.

Michael is a man with a visual impairment who has a good relationship with his GP. His GP has a note on his records of his communication needs, and ensures that any information that is sent to him is in a format which he can easily access. Michael could not understand why this information was not shared with the NHS Bowel Cancer Screening Programme. He had received an invitation to participate in the screening programme and a test kit in the post and had read these using his computer scanning equipment which converted the print into an audio file. However, he said that it was still difficult to understand what he was supposed to do. He contacted the screening hub and requested information in an alternative format and also sample pots rather than the card test kit, both of which he received. Michael subsequently completed the screening process. However, since then he has received a second invitation to participate in the screening programme and he expressed frustration that this was in the usual letter format with standard test kit. He could not understand why the information that he had furnished the screening hub with previously about his communication needs had not been kept on his records, so that he would receive accessible information from the start of his second invitation.
Encouraging participation in the NHS Bowel Cancer Screening Programme

- Make information easily accessible to sensory impaired people. Make use of and sign-post to the alternative format resources on the NHS Bowel Cancer Screening Programme website as these are not clearly advertised currently.
- Make visually impaired people aware of:
  - sample pots as an alternative to the FOB test kit;
  - accessing GP practice staff to talk through the process, help collect samples and feedback results of the test kit from the screening hub.
- Be aware that visually impaired people may miss symptoms due to sight problems (for example, bleeding from the back passage).

Elizabeth is a woman in her sixties with a severe visual impairment. She is an active member of her community, articulate, and interested in and knowledgeable about various health issues that affect her. She has received an invitation to participate in the NHS Bowel Cancer Screening Programme on two occasions, but both times has put the invitation straight in the bin. This, Elizabeth explains, is because there is no way that she could complete the test kit herself (or use the pots which are available on request) given her visual impairment, and she has no family or friends whom she would be comfortable to ask for help in this task. She feels frustrated that there is no alternative offered to completing the test kit herself. Elizabeth attends a well woman clinic at her doctor’s surgery and suggested that completing the test kit could be done as part of general well woman checks, stating that it would not be a problem to attend on three occasions, as would be necessary to complete the test.
Anticipating and enabling participation for those receiving abnormal results

- Check if any transport arrangements need to be made. If they do, an ambulance can be booked via the GP, at least two days in advance.
- Ask if it would be helpful for someone to meet and greet the patient. It might be useful to liaise with the reception staff in each setting. Sensory impaired people might be more prone to missing their name being called out/displayed at reception.
- Ensure interpreters are present for all appointments with deaf people who use British Sign Language. It is vital all deaf people have access to an interpreter when required. If there are no interpreters available serious consideration should be given to postponing the appointment.
- Encourage sensory impaired people to attend with a companion if they would like to. Be sensitive to the situation of sensory impaired people living on their own (for example, transport and preparing for procedures such as a colonoscopy may be more difficult).

In a focus group of people with visual impairments, a discussion about how results from the screening test could best be fed back to people took place. Having results in audio format, or given over the telephone, were both favoured options. However, Mary suggested that the **best way to feed back results would be through an individual’s GP**. She explained that **if an individual had a good relationship with their GP, and the GP understood their communication needs and preferences**, then via the GP was the best way in which results could be received. She said that by providing the results in this manner, the situation could be explained clearly and any misunderstandings hopefully cleared up.
Improving sensory impairment awareness

- Consider going on a sensory impairment awareness training course if you think it would be of benefit to you or your colleagues.
- Make a note in patient records of any sensory impairment and requirements they might have for future reference.
- Record the number of people seen with sensory impairments and make a log of requests for information in alternate formats (for future planning).

Frank is a 75 year old man with both a visual impairment (cataracts) and a problem with his hearing for which he wears a hearing aid. Potentially therefore, communicating with Frank could be difficult, and it might be expected that he would not find participating in the NHS Bowel Cancer Screening Programme very easy. However, he explained that he had enough vision to enable him to read and understand the standard information provided. He emphasised what he saw as the importance of ensuring that people with a sensory impairment had adequate and correct information about their health, and illustrates the point that assumptions should not be made about an individual’s communication needs.
Checklist for bowel cancer screening staff to support effective communication and engagement

<table>
<thead>
<tr>
<th>Question</th>
<th>Tick</th>
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<tbody>
<tr>
<td>Have I asked the person for details of their sensory impairment and how this might impact on communicating throughout the appointment?</td>
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</tr>
<tr>
<td>Is transport needed?</td>
<td></td>
</tr>
<tr>
<td>Is a British Sign Language interpreter needed?</td>
<td></td>
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<tr>
<td>Is a longer (double) appointment slot necessary?</td>
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<tr>
<td>Do they need someone to meet and greet them on arrival?</td>
<td></td>
</tr>
<tr>
<td>Have I given clear explanations of treatment, assessments and diagnosis direct to the person and allowed enough time for detailed communication?</td>
<td></td>
</tr>
<tr>
<td>Has all the information been understood?</td>
<td></td>
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<tr>
<td>Do they have access to reference material in the appropriate format to refer to after the appointment?</td>
<td></td>
</tr>
<tr>
<td>Have I made a note in patient records of any sensory impairment and requirements for future appointments or communications?</td>
<td></td>
</tr>
<tr>
<td>Have I logged the number of people seen with sensory impairments and the number of requests for information in alternate formats (for future planning)?</td>
<td></td>
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<tr>
<td>Could I, or my colleagues, benefit from sensory impairment awareness training?</td>
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<tr>
<td>Generate a list of who to contact (e.g. interpreters, transport) when accessing services for those with hearing or visual impairments.</td>
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Practical advice on bowel cancer screening for visually and/or hearing impaired people

Why bowel cancer screening is important

- Bowel cancer is a treatable disease if caught early.
- Bowel cancer screening aims to detect bowel cancer at an early stage (in people with no symptoms), when treatment is more likely to be effective. It is offered every two years to all people aged 60-75 years (in Cheshire and Merseyside). Those over 75 can refer themselves for screening by asking their GP.
- The screening test is carried out in the privacy of your own home by collecting small samples of your bowel motion onto a special card (the FOB test kit) which you then send to a laboratory for testing. Results are sent back within two weeks and will tell you if you need further investigations. The test kit does not tell you if you have cancer.

Accessing information

- You can get information booklets on bowel cancer screening in large print, braille, audio, and British Sign Language from the NHS Bowel Cancer Screening Programme website – www.cancerscreening.nhs.uk/bowel – or the Department of Health publication orderline on Telephone: 0300 123 1002 or Textphone: 0300 123 1003.

Don’t be afraid to ask for support

- You can ask your GP for advice and support on bowel cancer screening.
- If you find the FOB test kit difficult to use you can ask for larger sample pots by calling the Bowel Cancer Screening helpline on 0800 707 60 60.
- If you are invited to see a nurse you can ring before the appointment to let them know if there is anything they can do to make things go more smoothly. For example you may need:
  - transport to the hospital;
  - a longer appointment, to go through all the information without rushing;
  - someone to meet and greet you;
  - a British Sign Language interpreter.
- Let bowel cancer screening staff know if you would like them to explain information in a different way. For example tell them if they should face you when talking, or if you are unable to see or hear clearly.
- Ask if there is anything you have not understood, or if you want information to take away with you.
Recommendations
Based on the findings in this report a number of recommendations are listed below, the aim of which is to help people with sensory impairments engage with the NHS Bowel Cancer Screening Programme. Although most of the recommendations from the previous report\(^1\) are still relevant, to avoid duplication only those not previously reported and those most pertinent appear below.

**Improving the recording of information about sensory impairment**
- Consider improving the recording of information about an individual’s sensory impairment and their preferred communication methods at all levels of primary and secondary care. More specifically:
  - consider including sensory impairment details with the electronic GP patient records sent to the screening hub, prior to dispensing a written invitation to the Programme;
  - consider retaining information on preferred methods of communication at the hub level so that all subsequent communications can be sent out in this format.

**Improving written information**
- The availability of alternative formats should be clearly advertised at the top of all written materials in large, clear font (as they are on the NHS Bowel Cancer Screening Programme website).
- Give consideration to making British Sign Language video versions of the leaflets available on the NHS Bowel Cancer Screening Programme website as well as on DVD (as is done for the audio versions). This should reduce costs and increase accessibility.
- Consider the feasibility of sending electronic, rather than printed, materials to those with scanning machines that convert electronic files into speech.

**Improving the accessibility of the test kit**
- That larger sample pots are available as an alternative to the FOB test kit should be clearly advertised.

• People with a sensory impairment should be involved in developing the kit, if this was an option.

**Improving access to transport**
• Advertise the availability of transport in order to facilitate people’s attendance at appointments.

**Improving sensory impairment awareness of health professionals**
• Consider sign-posting bowel cancer screening staff to sensory impairment awareness training sessions.

Copies of the full report can be obtained from the Faculty of Applied Sciences at a cost of £10.00 per report. Please email your requirements to: m.hazelton@chester.ac.uk