

Understanding people's experiences of Bowel Screening in Blackburn with Darwen

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healthwatch
Blackburn with Darwen

About us

Healthwatch was established under the Health and Social Care Act 2012 as an independent consumer champion to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

There are over 150 local Healthwatch across England. The role of a local Healthwatch is to:

- Listen to people, especially those who are most vulnerable, to understand their experiences and what matters most to them
- Influence those who have the power to change services so that they better meet people's needs now and into the future
- Empower and inform people to get the most from their health and social care services and encourage other organisations to do the same

Find out more at: www.healthwatchblackburnwithdarwen.co.uk

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Summary

This report provides insights from multiple focus groups conducted across different communities to identify barriers, challenges, and actionable recommendations for improving bowel screening programs. Participants highlighted a range of issues, from cultural stigmas to practical barriers, offering valuable suggestions to enhance accessibility, awareness, and participation.

Key Findings

- **Awareness:** While many participants were familiar with bowel screening due to receiving kits or recommendations from healthcare providers, gaps in knowledge about eligibility and the process were common, particularly among younger or underserved groups.
- **Participation Barriers:** Emotional factors, including fear of results and embarrassment, were significant deterrents. Practical challenges such as unclear instructions and concerns about hygienic sample collection further discouraged some individuals.
- **Cultural Sensitivity:** In some communities, cultural taboos and misconceptions about illness limited open discussions about bowel health, highlighting the need for tailored outreach.



Introduction

Bowel screening is a public health programme aimed at detecting early signs of colorectal cancer before symptoms appear.

Colorectal cancer remains one of the leading causes of cancer-related deaths worldwide, affecting both men and women. Screening is crucial because early-stage colorectal cancer often presents no symptoms, leading many cases to be diagnosed at an advanced stage, where treatment is less effective, and survival rates are lower. By promoting regular screening, health systems aim to reduce the impact of colorectal cancer.

NHS Bowel Screening Programme

An invite is sent to people aged **54 to 74** years for bowel cancer screening every 2 years. People older than this can ask for a screening kit every 2 years by calling the free helpline on **0800 707 60 60**. The programme is gradually expanding to make it available to eligible people aged **50** and over.

People eligible for bowel cancer screening get an invitation letter, along with an information leaflet explaining screening and its possible benefits and risks. About a week later, the programme sends a FIT (faecal immunochemical test) kit with instructions on how to use it at home. Results are sent out 2 weeks after the laboratory receives the completed kit.

Blackburn with Darwen's current screening data

Blackburn with Darwen's Bowel screening coverage is **63.7%** compared to national screening average of **60%**. The goal is to reach a target uptake rate of **72%** to ensure more people have access to early detection and life-saving interventions.

As Blackburn with Darwen has a low uptake this was a key driver for our research, we also wanted to make sure we spoke to underrepresented communities to understand their views and experiences of undertaking bowel screening.

*<https://fingertips.phe.org.uk/static-reports/public-health-outcomes-framework/at-a-glance/E06000008.html>

The Lancashire Bowel Cancer Screening Programme Health Promotion Team

In order to raise awareness of the importance of bowel screening, the BCSP HP Team provide information & support at low uptake GP surgeries across Lancashire and South Cumbria. They deliver BCSP training to frontline staff and members of the community, attend/deliver events and conferences, working with key partners to increase the uptake of the bowel screening kits. They also have a programme called Call For a Kit (CFAKC) which engages with the hardest-to-reach communities in Lancashire and helps save lives by early intervention and early detection of bowel cancer, it involves holding specific clinics within GP practices where individuals (non-responder patients - NRP) who have not completed the Bowel Cancer Screening Programme are invited to the GP surgery by the practice to meet members of the BCSP Health Promotion Team. They arrange a 15-minute clinic appointment where the kit is shown, multi-lingual leaflets are given, and a video is shown on how to complete the kit.

Methodology

We conducted **6** focus groups with the aim of engaging with a wide range of individuals in our community with regard to age and ethnicity. Overall, we spoke to residents from the following groups

Group	Date	Members
Men in Sheds - BRFC Community Trust (Men's group)	01/08/2024	8 - 2 South Asian and 6 White British 34-78
Talk ourselves well (Men's group)	10/10/2024	5 White British men, 1 White Other man and 1 Chinese man aged between 23-64
Kiran Women's group	01/10/2024	9 ladies all South Asian heritage background aged 60-75
Little Harwood women's group	03/10/2024	13 South Asian women aged 37 - 74
St Lukes community group	18/11/2024	4 White British women all aged 74
Ash Grove community group - Darwen	08/01/2025	7 white British women & 1 White British male aged from 27-64

We engaged with a total of **46** residents

We also carried out a survey understanding people's attitudes to Bowel Screening in BwD in conjunction with UCLan. We engaged with a further 37 residents through this survey. The results are due to be published soon by UCLan and Healthwatch Blackburn with Darwen's engagement is recognised in the report.

With Thanks

We would like to thank all the community groups for letting us attend and engage with the members for their valuable feedback.



Findings

At each focus group we asked the questions below.



Awareness

We asked the groups “How familiar are you with the bowel screening programme”

We found awareness levels varied significantly across focus groups. Some participants, particularly older White British adults, were familiar with bowel screening due to receiving kits in the post or recommended from their doctor.

In South Asian communities, we discussed that cultural norms sometimes hinder open discussions about health, contributing to low awareness. Not one member of the Little Harwood ladies group knew what age bowel screening started. They were shocked at how early screening starts.

We observed that the men’s group we attended had limited awareness of bowel screening among the participants; only two out of seven men were familiar with the programme. One participant learnt about bowel screening after a personal health scare (finding blood in his stool) and now actively promotes it among friends and family. We found speaking about bowel screening with the group really encouraged them to ask questions and find out more about screening. They suggested more public conversations to increase awareness, as people are less likely to understand the importance if it’s not widely discussed.

We found people who were under the age of screening said that they tended to blank things out because they are not relevant to them at that time. However, after discussions we had, they felt it was important to know about it to be able to talk to others and didn’t realise that the age range was being lowered to 50.

Where did you first hear about Bowel Screening?

“My doctor told me about it and sent one for me”

“I received one in the post, my carer told me how important it was to do - she helped me with instructions”

“I just received it in the post”

“My doctor mentioned I would be getting one”

“I’m not sure I think I just received it in the post?”

“I saw my dad with the envelope and asked what’s that? He explained what it was and why he was doing it”

From the feedback from this question, it was clear to observe that most of the participants had first heard about the Bowel Screening kit by receiving one in the post with a select few being informed by their doctor beforehand.

Concerns and Participation

Do you have any concerns about completing a bowel screening kit?

The majority of the feedback was positive, and people did not have any concerns about completing the kit. Most stated that they found it ok and easy to complete now it's changed to the one sample kit. It was encouraging to hear that the majority of residents we spoke to who were eligible for screening completed the kit and found it straightforward.

"It's much better now they have made it simple to complete"

"Not at all I find it very simple"

"No it's fine for me, I always make sure I do it as my sister had bowel cancer and I know it can run in the family"

"It was a bit daunting at first when I looked at the kit but once I completed it, it was fine"

"Erm, my main concern was how I was going to catch the stool without it touching the water in the toilet."



We did however find concerns for completing the kit when talking to the South Asian women's groups -

Language barriers were a significant factor in not understanding instructions and limited knowledge of what the test was for.

"I had to ask my niece how to do it, I've done it twice and had it sent back both times as incorrect. It's embarrassing having to ask someone for help"

“I didn’t do it the first time but the second time it was ok, it looked too complicated the first time”

“It’s not easy to understand the instructions when English isn’t your first language, I managed though”

“People don’t understand the instructions and think they will do it wrong so they don’t bother”

“I didn’t know how to complete - I didn’t understand the instructions”

“Just a bit nervous about doing it”



“I have completed the kit once years ago but I wasn’t sure how to do it. I did what I could but I never heard anything back, I presumed that I hadn’t completed it correctly. I really do want to complete the kit, I feel guilty that they send them to me and I don’t do them. I don’t understand how to follow the instructions, I’ve only got sons at home, I don’t feel comfortable asking them to help me. I want to complete the test as I know how important they are for staying healthy. If someone was to show me what to do that would help me.”

We passed the lady’s details on to Bowel Cancer Screening Programme Health Promotion Team, they gave her a call, talked her through the process and sent her a new kit in the post.

Are there any reasons which might discourage you from participating in Bowel Screening?

Participants expressed concerns about the outcomes of the test. The idea of receiving a cancer diagnosis was daunting, with some saying they "don't want it to be me". Several participants believed that they were not at risk, which led to avoidance. Others mentioned that "people bury their heads in the sand" instead of taking preventative measures. The term "cancer" itself was reported to deter engagement, as it is often associated with death rather than treatable outcomes and presents a barrier to people completing the test. Suggestions were made if the screening could be advertised as a "Health Check" they felt this would encourage more uptake.

Embarrassment and practicalities were factors, collecting stool samples was considered awkward and unhygienic with participants feeling embarrassed to discuss the process or ask for help.

“I pooped on the floor and took the sample from there, the instructions said for the sample not to touch the water so I didn’t know what else to do? I think they should provide something to poo on to take the sample from”

“People think it can’t be me who gets it so don’t bother doing the test”

“Most people don’t have the awareness of bowel cancer”

“People are in denial about it. Some are lazy and men definitely won’t ask for help if they don’t know”

“The mention of cancer makes you think you’re going to die, people don’t think you can survive it”

“The word cancer puts people off from interacting and taking interest”

“Our culture doesn’t normalise talking about it. We wait until we are really unwell before seeking help”

“Worried about what the results will be”

If you haven’t participated, what prevented you?

Members of the South Asian women’s groups felt that if you are sick then in their religion it means you are being punished, others stated in the Quran, if you are unwell you are loved and that medicine and religion can sit alongside each other.

“Too scared, don’t want it to be me”

“Men’s egos are so fragile, they don’t like knowing or doing anything like this”

“I’m not doing that! I don’t want somebody putting something up there! (Spoke to member separately to explain the process as just below screening age)

From the feedback, it was predominantly South Asian heritage residents, non-English speakers and individuals with low literacy who struggled with the instructions for the screening kit, leading to confusion or errors and not completing the kit. When speaking to the groups, they wanted more visual information with the instructions in their own language.



“I had bowel cancer when I was 35.

I had blood coming from my back passage I went to see my doctor twice and he said it was because of the spicy food I eat. I went back a couple of months later and luckily I saw a different doctor, he was concerned and sent me for tests. The test came back confirming I had bowel cancer and I needed an operation and chemotherapy. My wife dealt with a lot of it at the time and they probably didn’t explain to me how serious it was. I was lucky that my treatment was successful and the doctors were saying how lucky I was in receiving the all clear.”

When asked if he has ever received a bowel screening kit, he said yes but he didn’t know what to do with it as he can’t read English that well. He explained “If somebody explained to me what it was and how to complete I would of done it I will definitely

complete the next time I receive one”



What is the best way for healthcare providers to inform you about bowel screening programmes?

People wanted to receive information through trusted communication channels.

Text messages from their GP practice was a popular choice as it is seen as a reliable and immediate form of communication.

“I like a text message, I feel like it’s a good reminder that I’ve got an appointment or if I’ve got to make an appointment”

“I always find receiving a text helpful as it reminds me at the same time”

Phone Calls were a suggested option from the South Asian women’s groups as personalised phone calls in the individual’s first language were highlighted as an effective and trusted method, particularly in culturally diverse communities.

“Phone calls in my own language”

“A healthcare professional to ring me and give me information about it”

“Call on the phone, but from someone I trust and needs to be bilingual”

One member of a group had low levels of literacy, this was a worry for her to complete the test correctly.

“Phone call from a health professional, I can’t read so receiving letters isn’t good for me. If I spoke to someone I would be able to ask questions about the kit and how to complete it.”

{ This is the approach used by Call for a Kit Programme - Bowel Cancer Screening Programme Health Promotion Team }

Social media and **WhatsApp** were favoured for sharing short, informative videos, especially within community groups.

“WhatsApp works best, we’ve got 80 members on our group”

“Everyone is on WhatsApp, they’ve all got smartphones , so videos in different languages which could be shared would be helpful”

Using posters and advertisements. Displaying information in local shops, barbers and religious centres could reach a wider audience. TV adverts and billboards featuring simple, clear messages about the importance of bowel screening were recommended to make the programme more visible and less stigmatised.

We spoke to one member of the group who is blind and she said she would need information in Braille and someone to talk her through how to use the kit.



Improvement

Have you any ideas for improvements to the current bowel screening programme? If so, what would they be?

The focus groups suggested several key improvements to make bowel screening programmes more accessible and effective.

Simplifying the instructions for the screening kit was a top priority, with recommendations for visual aids, step-by-step illustrations, and multilingual guides to support those with literacy or language barriers.

“Pictures of the kit to promote widely so people are aware what it is and what it looks like”

“Clear instructions in my own language”

“Clear options for people with visual impairments and 1:1 guidance”

Accessibility could be enhanced by providing resources for visually impaired individuals, such as instructions in Braille or easy read. We spoke to one gentleman who could not read or write and having information in easy read is important for him.

Provision of hygienic tools like sample trays to ease the collection process was suggested by residents we spoke with. There was a lot of concern about how to obtain the sample.

Some suggestions were a box which comes with the kit which you make yourself, waxed coated cardboard or something which is made from polystyrene (which can float).

There is a need to combat cultural stigma and embarrassment. Participants emphasised the need for awareness campaigns that normalise bowel health discussions in community settings, such as workshops in cafes, mosques, and schools.

“It should be talked about in a community setting like here is a good example” (South Asian women’s group). “Somebody to come and talk to us about the importance of bowel screening”

“I think they need to put some humour into it when they are advertising it. People don’t like talking about poo, when you put some humour into it people are more inclined to take part in the conversation.”

“You don’t see much about bowel cancer it should have more awareness”

Effective communication and raising awareness were spoken about frequently amongst all the groups, with preferences for trusted channels like text messages from GP practices, bilingual phone calls, and engaging video content shared via platforms like WhatsApp and TikTok.

“Simple messages to show how it can save your life, I don’t think people know how important it is!”

“Using plain language, get to the point of why the testing is done, a lot of people don’t grasp why they need to do it”

“Share information on social media platforms”

“People need to know what’s in it for me?”

“A list of consequences”

Some of the group were not clear on when their next screening date is due so they mentioned better communication about the frequency would be helpful. There was a call for clearer messaging about screening options for individuals above the age of eligibility and greater efforts to educate people about the importance of early detection. These enhancements aim to reduce barriers and encourage broader participation in bowel screening programmes.

One member of a group highlighted the results letter she received. The wording of the letter made her feel unsure about whether her result was clear. Current phrasing, such as “No abnormalities traced at this time,” can leave participants feeling uncertain about their results.



“When I received my results letter it said at this moment no abnormalities have been traced this time - It made me feel like there was still a chance I had cancer. It just didn’t make me feel reassured that I was clear and made me feel like it was a little bit pointless completing the kit. I think the response needs to be re worded to give you the confidence that you are clear.”



Recommendations

Gathering the information from multiple focus groups has identified actionable recommendations for enhancing bowel screening programmes in Blackburn with Darwen. The suggestions aim to address barriers, improve accessibility, and increase participation rates in diverse communities. The findings focus on practical, cultural, and communication-related improvements tailored to the needs of different demographic groups.

Improve Accessibility and Usability of Kits

Simplify Sample Collection

Recommendation for NHS England to simplify sample collection for bowel screening. This could be greatly improved by incorporating hygienic tools such as disposable trays, wax-coated materials, or foldable boxes into NHS England's bowel screening kits. These additions would address key concerns expressed by participants in focus groups, including confusion and discomfort about collecting samples without contamination.

Enhance Instructions

Local primary care providers can significantly improve bowel screening participation by issuing step-by-step instructions with visual aids and videos for patients whose first language is not English, have low levels of literacy or learning disabilities. This approach ensures that individuals with literacy challenges can easily understand the screening process, who would not be picked up by the centralised NHS England kit distribution system. Display posters or video loops in GP waiting rooms that explain the bowel screening process. Videos demonstrating sample collection and kit usage should be shared on accessible platforms (e.g., YouTube or the NHS app) and shared through trusted community networks.

Translate materials into multiple languages to cater for non-English speaking populations. Primary care providers should provide translated instructions in key languages relevant to their local demographics, such as Urdu, Gujarati, or Polish. Partnering with NHS England to create standardised multilingual resources would ensure consistent and high-quality communication across practices.

Address Communication Barriers

GPs to offer bilingual phone calls to allow individuals to ask questions and clarify doubts.

NHS England to lead national campaigns using platforms like Facebook, WhatsApp channels, and TikTok to share short, engaging videos explaining how to use bowel screening kits. These platforms are widely used, particularly by younger demographics and communities.



Improve Clarity of Results Letters

NHS England should standardise results letters with reassuring and clear language that emphasise positive outcomes while maintaining accuracy. The phrasing in bowel screening results letters can significantly impact how participants perceive their results. Current language, such as “no abnormalities traced at this time,” was identified in focus groups as leaving participants uncertain about their health status.

Bowel Health Discussions

Awareness Campaigns

Blackburn with Darwen Public Health can take targeted actions to reduce embarrassment and stigma around bowel health by incorporating humour and relatable storytelling by local residents into their campaigns. These initiatives can normalise discussions about bowel health and encourage participation in bowel screening programmes.

Community Engagement

Blackburn with Darwen Public Health and the VCFSE sector to hold workshops in public and community venues such as cafes, mosques, schools, and barber shops to foster open discussions and educate people before they reach screening age.

Address Fears and Misconceptions

Public Health Blackburn with Darwen and the VCFSE sector to work closely with cultural leaders to reduce stigma and encourage conversations about bowel health in communities where illness may carry social taboos. Implementing this approach would require leveraging trusted figures and venues within the community to promote bowel screening in a culturally sensitive manner.

