healthwatch Hackney

Bowel Cancer Screening

in City & Hackney

Community Voice Forum







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Introduction

Bowel cancer, the fourth most common cancer in the UK, poses a significant health challenge. Despite this, early detection through screening can significantly improve survival rates. This community Voice Public Forum, held on December 12, 2023, aimed to inform members of the public regarding prevention through screening and offer a platform for them to feed back on their experiences to the NHS Bowel Cancer Screening Service.

As of the latest UK statistics, nearly 43,000 people are diagnosed with bowel cancer annually. But as many as 54% of these cases can be prevented, with early detection. This report, stemming from the forum's discussions, aims to promote understanding of bowel cancer screening with a view to increase the uptake of the Faecal Immunochemical Test (FIT) in City and Hackney.





Executive Summary

The Community Voice Public Forum on Bowel Cancer Screening focused on raising awareness and understanding of the fourth most common cancer in the UK. Key presentations were delivered, emphasising the crucial role of early detection through screening in improving survival rates. The forum also served as a platform for public feedback, highlighting the experiences of City & Hackney residents.

Obi Onyiah, from North-East London Cancer Alliance, discussed the importance of population health screening and detailed the NHS's primary cancer screening programmes, underscoring their impact on reducing mortality and improving treatment success.

Leena Khagram, from Homerton Hospital's North-East London Bowel Cancer Screening programme, focused on the Faecal Immunochemical Test (FIT), a critical tool for early bowel cancer detection. The service has recently expanded its reach to include individuals aged 54 in England, aiming to catch the disease earlier.

Participants raised concerns about the age limitations in cancer screening programmes and the challenges faced by older individuals in accessing screenings. Feedback also highlighted the need for more accessible screening kits for people with dexterity issues and varying cultural backgrounds.

Suggestions were made for an opt-in system for regular screening reminders for the elderly and the adaptation of communication strategies to be more inclusive and flexible. The forum concluded with a commitment to address these concerns and improve the overall effectiveness of the screening programme.



Presentation by North-East London Cancer Alliance

The North-East London Cancer Alliance (NELCA) conducts campaigns to raise awareness of various cancers and focuses on early diagnosis, treatment, and personalised care, aiming to provide equal access to superior cancer services for all residents of North-East London.

Formed in April 2020, the Alliance collaborates with various stakeholders to support cancer screening and care. Obi explained population health screening, which identifies individuals at increased risk of diseases, including cancer, before symptoms appear.

He highlighted the NHS's three main cancer screening programmes (bowel, breast, and cervical) and the targeted lung health check. Emphasising the importance of early cancer detection, Obi noted that screening can lead to easier, less invasive treatments and better outcomes, providing statistics on the impact of screening in reducing mortality and improving treatment success (see slides below).

"Screening can pick up cancers early, before any symptoms appear. When diagnosed early for cancer, it's easier to treat and usually needs less invasive or toxic treatments (...) Bowel cancer screening reduces the risk of dying from bowel cancer by 25% (...) Breast screenings save 1,300 lives every year in the UK and cervical screening prevents 70% of deaths from cervical cancer."

Click here to watch recorded video presentation.





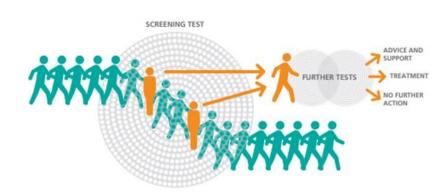
Cancer screening

Obi Onyiah– Prevention, Awareness and Screening Programme Manager NEL Cancer Alliance 5th December 2023

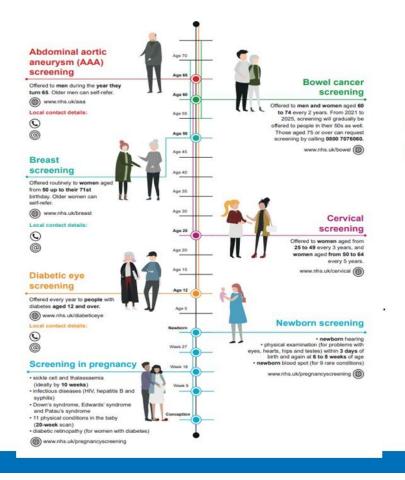
Population Health Screening



- Identifies healthy people or people who have no symptoms who may be at an increased risk of a disease or health condition.
- Most people attending screening will have a low risk of the condition they are being screened for.
- Screening picks out those with increased risk, so they can have further tests if needed and be treated sooner or given advice on how to manage their condition.









The Screening Timeline

 7 points where screening starts

Cancer Screening



- There are 3 cancer screening programmes in the UK:
 - Bowel
 - Breast
 - Cervical
- Targeted lung health checks are being brought in across all areas but not yet a 'screening' service.
- Cancer screening is free of charge for eligible people.
- Participation is personal choice.
- There are pros and cons which are set out in the information leaflets sent with invitation letters.
 - It's important to read these and make a choice with the right information.
- To be invited for cancer screening, you must be registered with a GP.





Why do we screen for cancer?



- Screening can pick up cancer early, before any symptoms appear.
- When diagnosed early cancer:
 - Is easier to treat.
 - Usually needs less invasive or toxic treatments.
 - Quality of life during treatment is better.
 - Has better outcomes.
- Bowel cancer screening reduces the risk of dying from bowel cancer by 25%.
- Breast screening saves 1,300 lives every year in the UK.
- Cervical screening prevents 70% of deaths from cervical cancer.

Presentation by North-East London Bowel Cancer Screening Programme

The North-East London Bowel Cancer Screening Programme aims at early detection. The service uses a home test kit called the Faecal Immunochemical Test (FIT), designed to detect tiny amounts of blood in stool samples, a potential indicator of bowel cancer. This test is crucial for identifying the disease at an early stage, significantly increasing the chances of successful treatment.

As of late 2023, the NHS has expanded this screening programme to include individuals aged 54+ in England, a move aimed at catching the disease earlier and potentially saving thousands of lives. This expansion means an additional 830,000 people in England are now eligible for the screening test.



Prior to this, the FIT kit was already available to everyone aged 56 to 74, with the option for those aged 74 and over to request a kit via a helpline.

The test is convenient and can be carried out at home. It involves collecting a small sample of stool in a tube and returning it by post for analysis. If the test detects blood, further tests like a colonoscopy may be recommended.

The service aims to diagnose bowel cancers at an earlier stage, thereby increasing the chances of successful treatment and survival. The NHS encourages everyone who is eligible and receives a kit to complete the test, as it could be life-saving.

Leena Khagram, 'Health Improvement Specialist for the NHS Bowel Cancer Screening Programme' in City & Hackney, provided an informative presentation focused on the above. She clarified that bowel cancer, also known as colon cancer, is common in the colon or rectum and often develops from polyps, which can become cancerous over time.

Emphasising the importance of early detection, she noted that bowel cancer predominantly affects people over the age of 50, though its incidence is rising among younger individuals.

Leena highlighted the key signs and symptoms of bowel cancer, such as blood in the stool, changes in bowel habits, abdominal pains, and alterations in stool consistency or appearance. She stressed the importance of visiting a GP if these symptoms persist for more than three weeks or if there is blood in the stool.

She discussed risk factors for bowel cancer, including age, gender (with higher rates in men over 40), certain health conditions (like diabetes, ulcerative colitis, or Crohn's disease), family history, obesity, and diets high in red meat. Smoking and alcohol consumption were also mentioned as risk factors.

She concluded by emphasising the life-saving potential of the screening programme and encouraged people to participate in the screening, noting the availability of resources in various languages and support provided by the NHS. The importance of regular screening as part of a healthy lifestyle, regardless of the presence of symptoms, was also highlighted.



Click <u>here</u> to watch recorded video presentation.

Bowel Cancer & Screening

Leena Khagram

Health Improvement Specialist

North-East London Bowel Cancer Screening Programme, Homerton Hospital









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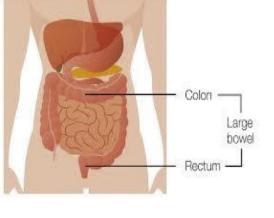
What is Bowel cancer?

- It is cancer in any part of the colon or rectum
- The lining of the bowel is formed of cells
- If cells grow too quickly, forms a clump of cells known as a polyp
 - Common as people get older
 - Not bowel cancer but can change into cancer over a number of years



- Bowel cancer is the **fourth most common** cancer in the UK.
- Almost **43,000 people** are diagnosed with bowel cancer every year in the UK.
- Around **268,000 people** living in the UK today have been diagnosed with bowel cancer.
- More than nine out of ten new cases (94%) are diagnosed in people over the age of 50.













Signs & Symptoms:

- **Blood** in the stools (faeces)
- Changes in bowel habit, such as more frequent, looser stools
- Abdominal (tummy) pain
- Change in bowel habit including diarrhoea, constipation or the feeling of incomplete emptying
- A change in the appearance or consistency of bowel movements such as thin bowel stools

Risk Factors for bowel cancer

- Age: being aged 50 and over
- Sex: Affects both men and women equally up to age 40, but after this rates are higher for men
- Health issues: Diabetes, ulcerative colitis or Crohn's disease
- **Positive family history:** immediate relative
- Obesity & high red meat diet
- Smoking and alcohol











Free NHS Bowel Screening test!

- Men and women aged between 60-74 in England are eligible
- Expanding to start from 50-59 (gradually every 4 years starting April 2021) 58, 54, 56....
- Invited every 2 years
- Must be registered with a GP practice to receive invitation
- Anyone over 74 can request a kit Freephone!

Results

- The screening hub/centre analyses the kit
- The test detects tiny amounts of blood which you cannot normally see in your stool (poo)
- Does not diagnose bowel cancer
- Results sent usually within 2 weeks

Participant Name

OFF PEEL OFF PEEL

Please make sure:

The sample bottle is in the box

You write your sample date on the bottle

You peel off the tape to seal the box Please post as soon as possible!

This is your test kit for NHS Bowel Cancer Screening. Using it takes only a few minutes. The test helps to detect bowel cancer early. The earlier bowel cancer is found, the easier it is to treat.

Instructions on using the kit are on the box (below) and on the additional information sheet enclosed. The kit has been specifically designed to be safe to send in the post.

Please make sure you have read the leaflet about bowel cancer screening that we sent to you. The leaflet tells you about screening, and its benefits and risks. The information is to help you decide whether or not you want to have bowel cancer screening. You can see a copy of the leaflet at http://www.cancerscreening.nhs.uk/bowel/publications/the-facts.html.

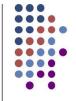
For more information about screening, or about using the test kit, call us on 0800 707 60 60. Calls are free from UK landlines. Or visit our website at http://www.cancerscreening.nhs.uk

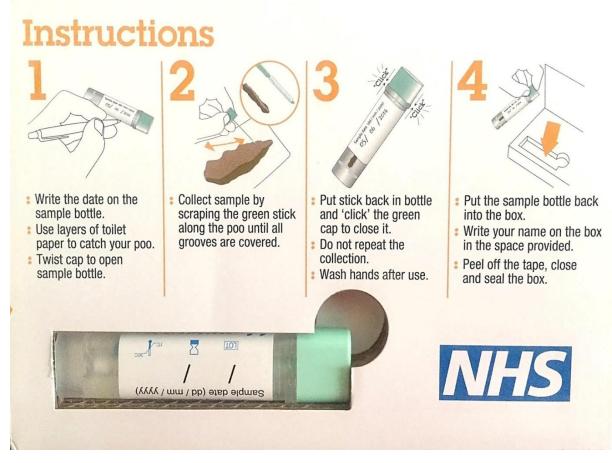












Tips for collecting your poo

Here are some ideas to make collecting your poo a bit easier. Why not practise and work out which method you find the easiest? Do not let your poo touch the water or toilet.



screening kit to take a sample and post it back as soon as possible. You may want to check your local postal collection times.

Source: Cancer Research UK

How to do the bowel screening kit in England



Get ready – collect what you need to catch your poo before you sit on the toilet.



Collect your poo - we've given you some ideas for how to do this opposite. Do not let your poo touch the water or toilet.



Put the stick back in the bottle and click the cap to close it. Do not reopen the bottle after use. Please wash your hands.



Write the date on the sample bottle in biro.



Twist the cap to open the sample bottle. Scrape the stick along the poo until all the grooves are covered. You only need a little poo to test. Please do not add extra.



Check you have written the date on your sample bottle, put the bottle in the prepaid envelope and post it back as soon as possible.



Take home messages!

Participation in screening is the biggest action you can take to diagnose bowel cancer early and prevent it:

"The test kit could save your life"

"People aged 50 or over are at greater risk even with a healthy lifestyle"

"No symptoms doesn't mean no risk"

"The test kit is free and can be completed in the privacy of your own home"

"There are bilingual members of staff who can deal with queries"

Resources

Links to Bowel cancer and screening information:

- Bowel cancer screening NHS (www.nhs.uk)
- <u>NHS London Bowel Cancer Screening Healthy London</u>
 <u>Partnership</u>

English

<u>https://www.gov.uk/government/publications/bowel-cancer-screening-easy-guide</u>

Other languages:

- <u>https://www.gov.uk/government/publications/bowel-cancer-</u> screening-benefits-and-risks
- Bowel cancer screening kit: how to use GOV.UK (www.gov.uk)

Animated visual guide in different languages:

https://vimeo.com/showcase/6663813











Participant Feedback and Q&A

Summary of points raised/responses received:

Participant:

Asked why cancer screening stops at 74, questioning the rationale given the higher cancer prevalence in older people.

Leena's Response:

Explained the history and expansion of the screening programme, initially for ages 60-69.

Mentioned logistical and research factors impacting age limits; advocated for starting screenings at 30.

Informed that older people can opt in for screenings after the cut-off age.

Participant:

Highlighted the inconsistency in breast cancer screening, which stops automatic invites at 70, requiring symptoms for further screening.¹

Leena's Response:

Disagreed with this breast screening policy (but see below footnote); explained that bowel cancer screening is available post-74 without symptom requirement.

Healthwatch Hackney Inquiry to Cancer Alliance:

Asked for assistance regarding the need for symptoms for post-70 breast cancer screening.

¹ Please note that individuals aged 71 and over are not automatically invited for breast screening. However, those who wish to continue with breast screening beyond this age have the option to do so by actively opting in. To receive breast screening every three years, eligible individuals are required to contact their local breast screening service directly and request an appointment. This policy ensures that breast screening remains accessible to all age groups, providing an opportunity for continued health monitoring and care.



Obi's response:

Lacked immediate information but promised to research and respond later.

Participant:

Inquired if those at risk can discuss screening with their GP and expect a test kit.

Leena's response:

Confirmed this, noting the GP route is available for symptomatic cases.

Participant:

Shared challenges her mother faced using the screening kit due to arthritis and a bowel condition.

Suggested improvements for the kit, considering dexterity and cultural sensitivities.

Asked about alternatives for people who always have blood in their stool.

Leena's Response:

Thanked participant for their insights and promised to use the feedback for potential improvements.

Explained the personal choice in screening for those aware of their bloodin-stool reasons.

Participant:

Discussed the anxiety caused by persistent reminders and the opt-out option.

Suggested a modified reminder system instead of complete opt-out.



Participant:

Emphasised the importance of educating young people about their bodies and menstrual cycles.

Raised issues regarding menopause and irregular bleeding.

Obi on AAA Screening:

Discussed abdominal aortic aneurysm (AAA) screening, not a national programme but available through NHS.

Noted the importance of discussing risk factors with a GP.

Participant:

Proposed an opt-in system for regular screening reminders or kits for the elderly.

Participant:

Offered ideas for kit design improvements, considering hygiene and ease of use.

Inquired about best days for posting samples to avoid delays.

Event Conclusion:

Plans to summarise and share the suggestions for service improvement.

Leena offers workshops on bowel screening in community settings.

Discussion on assistance for individuals unable to take samples independently, considering post-COVID challenges and the need for family or professional support.



Recommendations

- 1. **Implement Opt-In System:** Introduce an opt-in system for automatic reminders for elderly populations.
- 2. Alternative to Current kit for Accessibility: Offer different versions of the kit to accommodate for varying dexterity needs.
- 3. **Reminder and Communication System:** Adjust the reminder system to be more flexible, considering mental health impacts and personal preferences.
- 4. Enhance Educational Outreach: Conduct targeted educational workshops in community settings, focusing on younger people's understanding of bowel Cancer in particular.

Conclusion

This Community Voice Public Forum underscored the critical role of early detection and screening in the fight against bowel cancer, highlighting the expansion of the FIT programme to a broader age group and stressing the importance of regular screening, especially for those over 50 and/or with specific risk factors.

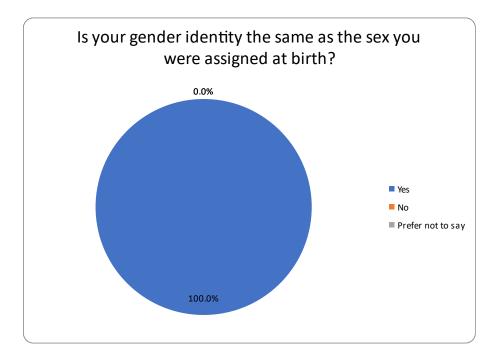
Participant feedback revealed key concerns and suggestions, ranging from age limits in screening programmes to practical challenges faced by individuals using the screening kits, particularly those with dexterity issues or cultural sensitivities.

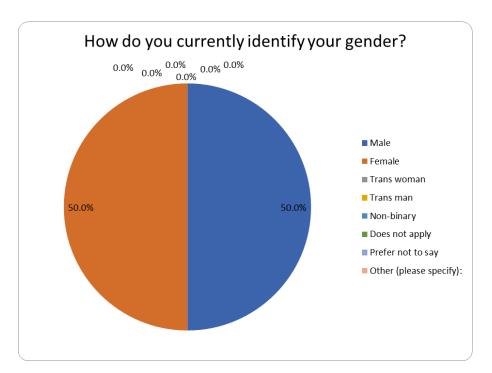
The forum concluded with a commitment to address these concerns. Our recommendations aim to enhance the effectiveness of the bowel cancer screening programme to ensure it is more inclusive and responsive to the diverse needs of City & Hackney residents.



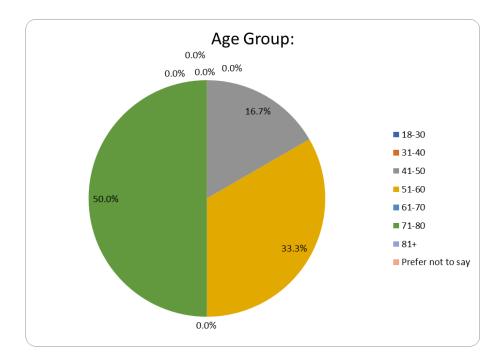
Appendix

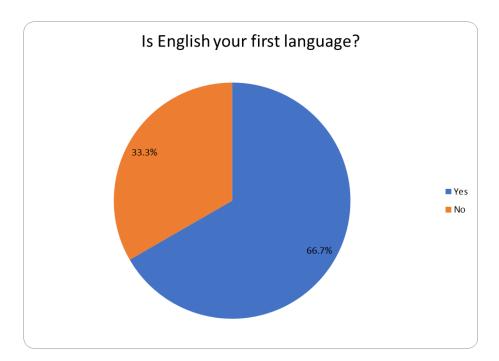
Demographics of participants



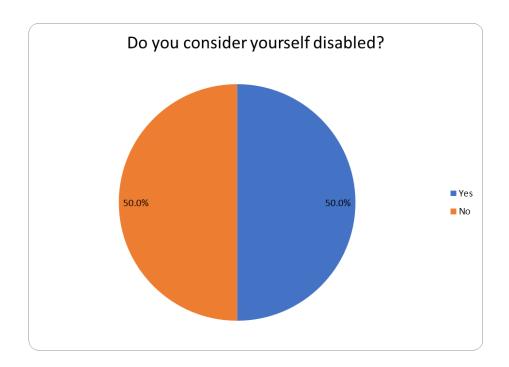


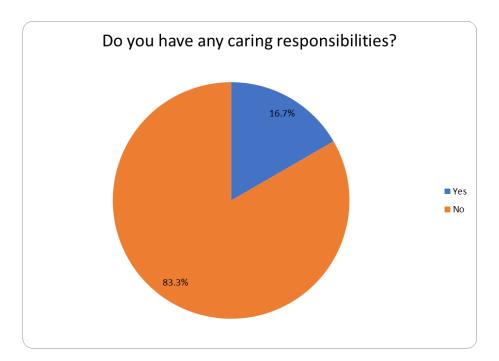








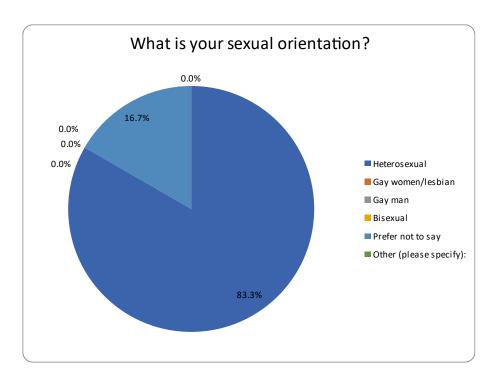


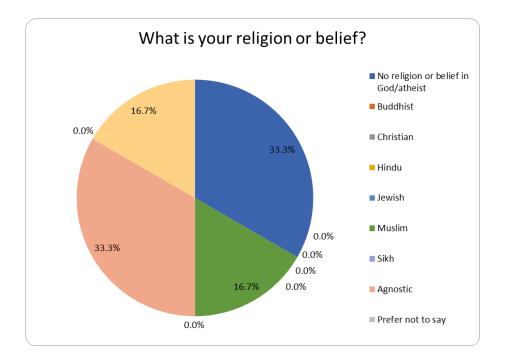




What is your Ethnicity?

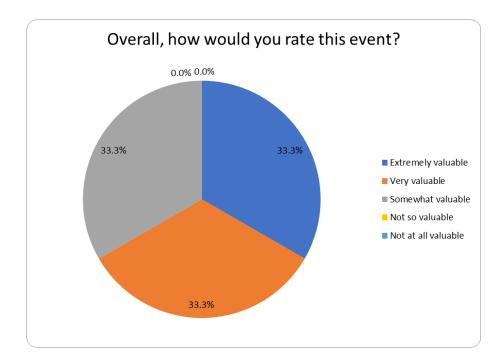
Of the six survey respondents, three said they were white, one British Bangladeshi, one Black British and one Turkish.







Forum evaluation



"I found out some valuable information about cancer screening."

"I was concerned that screening was not available after reaching 74, but I learnt that it was, if I contacted a dedicated phone number, which I did."

"It's always good to have the discussion."

"It was very valuable because people don't understand what's going to happen in that situation. It's very private, a sensitive subject and scary."

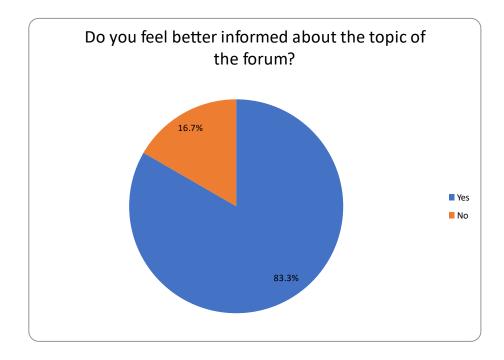
What could have been done better?

"Heard more audience members speak. And cut off those that talk too much, me included."

"It felt like providing free consultancy to those in the job roles. Simple suggestions which had not been thought of before or being told the ideas were great but they couldn't influence as it was a national programme."

"Perhaps they could look at how the device can be made to be adaptable and see if there is a national platform to discuss and invite us into those discussions?"





"I found the forum interesting and that there is an ageism issue. If you reach 70 you're only allowed screening if you have symptoms. And if you reach 74 you need to request bowel screening yourself!"

"I do think screening is an essential part of NHS for all ages, to identify early symptoms of potential problems and significantly improve the outcomes. It is (...) reassuring to know."

"I would have liked it to go into deeper depth on the subject."





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