

Residents from communities experiencing health inequalities share feedback on cancer screening services in Islington



Healthwatch Islington

Healthwatch Islington is an independent organisation led by volunteers from the local community. It is part of a national network of Healthwatch organisations that involve people of all ages and all sections of the community.

Healthwatch Islington gathers local people's views on the health and social care services that they use. We make sure those views are taken into account when decisions are taken on how services will look in the future, and how they can be improved.

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Introduction

Healthwatch Islington champions inclusivity in health and care services. We work in partnership with a range of local, community-based organisations supporting residents experiencing health inequalities. Many of these residents face barriers that make it harder to get their voices heard. As a partnership, we work together to gather insight from the residents our organisations represent to inform service provision and commissioning, increasing equality of access.

Healthwatch Islington was commissioned to gather feedback from these groups on their experiences of accessing cancer screening services as part of our Community Research and Support Project 2022/23.

Research was conducted via one to one structured interviews and/or focus groups based on survey questions. One of the principles of our partnership is that we don't ask people to share feedback without offering them information or support in return. Information and signposting support was provided in appropriate community languages.

Participating organisations:

- ▶ Arachne Greek Cypriot Women's Group
- ▶ Choices
- ▶ Community Language Support Services
- ▶ Disability Action in Islington
- ▶ Eritrean Community in the UK
- ▶ Healthwatch Islington
- ▶ Imece Women's Centre
- ▶ Islington Bangladesh Association
- ▶ Islington Somali Community
- ▶ Jannaty
- ▶ Kurdish and Middle Eastern Women's Organisation
- ▶ Latin American Women's Rights Service

Number of residents we heard from:

- ▶ Cervical screening - 298 respondents
- ▶ Bowel cancer screening - 113 respondents
- ▶ Breast screening - 138 respondents

Additional engagement activity:

We complemented our work with communities experiencing health inequalities with some broader engagement via an online survey and conversations with residents at CallyFest and a Healthwatch stall at Chapel Market. We heard feedback on cancer screening services from an additional 74 residents via these means.

Summary of our findings

Cervical screening

- ▶ Over 85% of respondents who were invited for cervical screening attended their appointment. Of those that were eligible but did not receive an invitation (less than 5%), most said that they would attend.
- ▶ Respondents were generally positive about the idea of cervical cancer screening.
- ▶ Feedback demonstrated the importance of a warm, friendly welcome from practice staff and the provision of clear information about the screening process. This was particularly important if the patient was feeling nervous or anxious and was a significant factor in defining the patient experience.
- ▶ A small number of respondents that required adjustments to the service (FGM, rape survivor) reported experiences that did not meet their needs or preferred services that were trauma-informed.

Bowel cancer screening

- ▶ About 75% of eligible respondents had been sent a home testing kit.
- ▶ Most people who were sent a home testing kit went on to use it. Those that didn't either found the testing process distasteful, found it impractical, didn't get enough information, or did not understand what the home testing kit was.
- ▶ Experiences of using the kit were largely positive.
- ▶ Residents without recourse to language support may find the home testing kit inaccessible.

Breast screening

- ▶ 108 of the 120 respondents who were invited for breast screening attended the appointment. (16 of the 18 who didn't receive an invite also said they would attend).
- ▶ Respondents who were helped to understand what to expect from the screening process reported feeling less anxiety and having a better experience. They also valued demonstration on how to do self-checks. Lack of provision of this information could lead to a negative experience. Sometimes this was due to failure to offer interpreting.
- ▶ Feedback from other engagement Healthwatch delivered in 2022 demonstrated that some residents found the breast screening venues inaccessible.

Next steps

- ▶ We have shared this report with commissioners. We will now be working with colleagues in Public Health to carry out targeted engagement with local communities to increase understanding of the purpose and practicalities of screening services.

Cervical screening

All participating organisations gathered feedback on cervical screening services. Residents needed to be registered with an Islington GP and/or be living in Islington to participate. 298 residents gave feedback.

All women and people with a cervix between the ages of 25 and 64 are asked to go for regular cervical screening. Patients get a letter in the post inviting them to make an appointment. Patients between the ages of 25 and 49 are invited to attend a screening appointment once every 3 years. Patients aged between 50 and 64 are invited once every 5 years.

Have you been invited for a screening appointment for cervical cancer?

Yes	No	Total
284	14	298

284 respondents had been invited for a screening appointment. Of the 14 respondents who hadn't received an invitation, one wasn't registered with a GP. The remaining 13 should have expected an invitation. They were all registered at the GP with their correct address. Only one of the respondents who didn't receive an invitation said they wouldn't attend a cervical screening appointment.

If you have been invited for screening, did you attend the appointment?

Yes	No	Not answered/ Unclear	Total
242	31	11	284

If you didn't attend, what stopped you from going?

Only 31 respondents did not book a screening appointment. Reasons for not booking or attending an appointment were varied. Some simply forgot, whilst others distrusted the procedure or felt it was unnecessary. Other reasons given included pregnancy, not being sexually active, anxiety, fear of pain, prioritising other commitments, difficulties accessing the GP, and discomfort that was often linked to cultural barriers 'because of my religion', 'modesty is so much a part of my culture and I find it hard to overcome years of condition about certain things being kept for myself or for my marriage.'

Feedback on cervical screening from our online survey and face-to-face engagement at Chapel Market and the Cally Festival was broadly in line with the feedback from the partners' survey. One online respondent who was a rape survivor explained that she didn't attend her screening appointment because "the standard service is not trauma-

informed". Adjustments that would make it easier for her to use the cervical screening service in the future included "being able to choose the position and put the speculum in myself. Not having to lay on my back." She preferred to use services offered through My Body Back, a volunteer-run organisation supporting people who've experienced sexual violence.

If you didn't attend, what would you make it easier for you to attend?	
Nothing would make it easier for me to attend	6
Information to help me understand the need to go	4
Being sent a reminder	3
Home testing	3
Other suggestions	7
Don't know	6
No answer	1

Other suggestions to make it easier for respondents to attend included the provision of childcare/ creche facilities, changes in personal circumstances, and developing a less invasive screening technique.

If you attended your cervical screening appointment, when was it?

Within the last 3 years	3 to 5 years ago	More than 5 years ago	No answer
154	71	11	2

Patients aged between 50 and 64 only need to attend cervical screening every five years.

Patients between the ages of 25 and 49 should attend a screening appointment once every three years. 38 of the 147 respondents in this younger cohort who had attended their cervical screening appointment had not attended within the last three years. 33 of these had attended between three and five years ago and five had attended more than five years ago.

If you did go in the last five years: What was your experience of attending a cervical cancer screening appointment?

"It was fine. I don't really have any issues with attending these things because it's for the sake of my health so I'm pretty on top of it when I get called to go."

- Eritrean woman, 50-64

Respondents were positive about the idea of cervical cancer screening. Personal experiences of attending an appointment varied, but most respondents expressed satisfaction. It wasn't always possible to identify an overall sentiment, and some respondents who found the experience painful also appreciated that staff were kind and helpful. It was quite typical for respondents to say that they found the experience uncomfortable but could appreciate the benefits. Respondents who had been to a screening appointment before and knew what to expect tended to report less anxiety.

Quality of information provision and the customer skills of practice staff are key

Feedback demonstrated the importance of a warm, friendly welcome from practice staff and the provision of clear information about the screening process. This was particularly important if the patient was feeling nervous or anxious and was a significant factor in defining the patient experience.

"Unfortunately, I had a bad experience. The procedure was not explained to me, and I was not given enough time to settle."

- Bangladeshi woman, 25-49

Negative aspects of cervical cancer screening that were mentioned by respondents included 'having to get dressed in front of someone', a lack of information about what was involved 'many practices do not provide printed information or resources', excessive pain, and lack of interpreting. One or two respondents said they waited a long time for results, however others reported getting their results quickly.

Two respondents who had undergone FGM (female genital mutilation) described how that made cervical screening a much more painful procedure. One described an experience where adjustments were made, and one described an experience where this was not the case.

"I have a specialist who performs the smear test on me because the area is very delicate and prone to issue and as a result is very uncomfortable, but they do their best to accommodate."

- Black woman, 50-64

"Because I have cultural stitches in place it was a cause of great pain since they didn't use the device they normally use to deal with people with my kind of stitches."

- Black woman, 25-49

Bowel cancer screening

Bowel Cancer screening is currently available to everyone aged 60 to 74 years (and within the next four years to everyone aged 50 to 59 years). There is no appointment. Patients are sent a home test kit every 2 years.

It is worth noting that some research partners found it difficult to carry out conversations about bowel cancer screening with men who were eligible for the service. The researcher at Eritrean Community in the UK told us that older members of her community were embarrassed to talk to her about this subject. ECUK had a sizeable group of 15 to 20 adults that would have been great to include in this research, but who declined to participate.

There may be some learning around engaging older male researchers to have these conversations and to share information about/promote the benefits of taking up this screening. This learning should inform future engagement strategies where these groups are a demographic of interest/priority.

Have you been sent a home testing kit for bowel cancer?

Yes	No	Total
84	29	113

Of the 29 respondents who said they were not sent a home testing kit, 26 were registered with a GP practice (with their correct address), 1 was not registered, and 2 did not say. Most of these respondents (23 out of 29) said that they would use the home testing kit if they were sent one. Reasons given by those who said that they wouldn't use a kit included 'I don't like the sound of it' and 'I prefer being helped by a nurse or doctor regarding this screening'.

If you were sent a home testing kit, did you use it?

Yes	No	Total
75	9	84

75 of the 84 respondents who were sent a home testing kit went on to use it. Those that didn't either found the testing process distasteful, found it impractical, didn't get enough information, or did not understand what the home testing kit was. Three respondents said it would be easier for them to use if it came with better instructions/information, two specified that this should be in their first language (11 of the respondents who did

use the kit reported needing language support from a family member or a community support organisation to use it, so other residents without recourse to this support will find this screening inaccessible). Two respondents said that nothing would make it easier.

"I believe if something happens to me that it was God's will and that nothing can stop it from happening. The method in which I have to do it is degrading for a man to do it."

- Somali man, 50-64

If you did use a home testing kit in the last 5 years: What was your experience of this bowel cancer screening service?

69 of the respondents who had used a home testing kit said they had done so within the last 5 years. Experiences were positive. 40 people said the kit was easy to use. 11 respondents needed language support from either a community organisation or a family member, but once they had received this support, they also found the testing process straightforward.

"Many years ago, the instructions on how to carry out the test were more complicated. The new bowel screening test kit is easier and includes a small tube test to collect your poo sample, full instructions to help us complete the test and a pre-paid envelope. I managed to do the test without any difficulties."

- Greek Cypriot man 65-79

Only 6 people had anything negative to say about home testing for bowel cancer. Two people said they would rather have the test at a GP surgery or hospital and were nervous about doing it themselves. One person was already taking similar tests at hospital and felt it was strange that they were being sent home testing kits as well. One person was told they had performed the test incorrectly and was asked to redo it. One or two respondents felt that they had to wait a long time for their results. However, feedback more often suggested that follow up was efficient and results came back promptly.

Breast screening

Patients are first invited for breast screening between the ages of 50 and 53, then every 3 years until they turn 71. Trans men, trans women, or non-binary patients may be invited automatically, or may need to talk to their GP surgery or call the local breast screening service to ask for an appointment.

Have you been invited for a breast screening appointment?

Yes	No	Total
120	18	138

16 of the 18 respondents who had not been invited said yes, they would attend an appointment if they were offered one. The two who said they wouldn't said 'I can't handle the pain and it's exposing' and 'I don't want to do the breast cancer screening'. One of this cohort of 18 was not registered with a GP.

If you have been invited for screening, did you attend the appointment?

Yes	No	No answer/unclear	Total
108	9	3	120

108 of the 120 respondents who were invited for breast screening attended the appointment. Of the three cases where it was unclear, two were from respondents who were diagnosed with breast cancer so were accessing treatment elsewhere on the pathway.

The reasons given by the nine respondents who didn't attend their appointment were similar to those given for other screening services. They mentioned nerves, illness, not thinking it was important, appointments cancelled due to the pandemic, and other access difficulties 'they were always fully booked'.

"I am afraid to do it, because the x-rays could induce cancer."
- Latin American woman, 50-64

If you did go in the last five years: What was your experience of attending a breast cancer screening appointment?

98 of the 108 respondents who had attended an appointment had done so in the last five years. We asked these respondents an open question about their experience of the appointment. The topics they chose to raise helped us to understand the factors that were most important in defining the patient experience.

Themes that defined the patient experience, listed by number of respondents	
Helpfulness and professionalism of healthcare staff	38
Painful nature of the screening process	30
Quality of information provision, whether good or bad	15
Emotional impact of screening process – feelings of anxiety / feelings of relief	15
Interpreting / needing help to understand screening process in first language	8
Recognition of the preventative value of screening services	8
Issues around the accessibility of the appointment	7

36 respondents spoke about the positive impact that healthcare staff had on their experience of the screening appointment. Only two respondents had anything negative to say about the way they were treated by staff.

“The staff were caring and professional. Great customer/patient service, great and clean facilities. My doctor was kind, professional and patient. Also gave me a warm garment to wear for my test and a welcoming and large waiting room. Thank you NHS for this service.”

– Greek Cypriot woman, 50–64

30 respondents mentioned that they found the screening process painful, though some found the pain more severe than others. Where staff were supportive and kind, respondents were generally able to tolerate the pain. However, where pain was combined with staff who were felt to be uncaring, this would lead to a negative experience overall. Happily, this was rarely reported.

“I had a bad experience. The process was painful, and I had pain for a month after the screening. I asked the nurse to stop as I was in pain, but she didn't seem to care. I had a really bad and painful experience.”

– Greek Cypriot woman, 50–64

Quality of information provision

15 respondents spoke about information provision. 10 were positive about information they were given whilst five felt that better information provision would have improved their experience.

"I was happy to have a mammogram and understood why it is important to have it. I had a bit of pain during the mammogram. I was put at ease by the way the nurse treated me. In my opinion it would be helpful if we have more information about how you have a mammogram beforehand, so I knew what to expect."

- Albanian woman, 50-64

Patients who were helped to understand what to expect from the screening process reported feeling less anxiety and 'better experience during the test'. Respondents also valued the 'demonstration on how to do self-checks', 'breast changes to look out for' 'change in size or shape, new lump'.

Lack of provision of this kind of information could lead to a negative screening experience. Sometimes this was caused by a failure to offer interpreting support,

"They told me that they had to do a very thorough check which resulted in some pain and discomfort because it was a little rough. There was no interpreter who could explain this to me and it was a little hard to communicate it was rough and I also didn't understand how to do self-checks for masses."

- Eritrean woman, 50-64

Equally, some patients who did not have language support needs also felt they hadn't been told what to expect,

"It was a horrible room, it was very hurtful. They will have to change the process. I'm not going back there again - not nice, they didn't say it was going to hurt."

- White Irish woman, 50-64

Access and the location of breast screening centres

Most of the limited feedback about the accessibility of breast screening services was positive. Appointments were quick, the service was responsive.

One respondent cancelled her appointment because she "asked for a female member of staff but when I went for my appointment it was a male". She was, however, able to reschedule and was seen two weeks later.

One respondent was pleased that the location of her screening appointment ended up being nearby but, "it was not immediately obvious on the website how to change venue, quite difficult. You were just automatically allocated a location, far from the borough."

Feedback from other engagement Healthwatch delivered in 2022 demonstrated that some respondents found the breast screening venues inaccessible. None are located within the borough. Those concerns were not raised to the same extent in this research, though it should be noted that participants were not asked about this directly.

“First of all it was very stressful getting there, I had to travel from Islington to Stratford and I got totally lost trying to find the place. I was so stressed out. I arrived late due to being lost and the staff weren't very nice. The mammogram was very painful, the staff were a bit unpleasant. The whole experience was very stressful.”

- Online survey respondent, 50-64, August 2022.

“The last appointment I received by post asked me to go to the Royal Free, but the Royal Free is too far for me to attend. I don't have an easy transport route to get there from my house plus it would take a very long time and I can't leave my husband alone (I am his full-time carer). So I didn't go!”

- Asian/Asian British woman, 65-79, Chapel Market, July 2022

Advice and information

Information was shared with research participants on the three types of cancer screening, what was involved, what the benefits were, along with eligibility criteria.

343 of the 362 residents reported that, as a result of the information they had been given, they had a better understanding of the services and support available. 14 felt that this was partially true and five did not feel they had a better understanding.

348 respondents found the information helpful (a further eight found the information partially helpful) and 333 felt that they would be able to act on the information they had been given (a further 20 partially agreed). Nine respondents did not feel able to act, citing access difficulties, learning disabilities, lack of comprehension, or lack of desire.

Participants identified a further 366 people in their households or in their immediate circle who would also find the information useful who they would share it with.

Additional signposting

109 participants were given additional signposting as a result of the survey interaction.

- ▶ 8 participants were supported to book cervical screening appointments
- ▶ 14 participants were supported to request home testing kits for bowel cancer
- ▶ 4 participants were supported to book breast screening appointments.

Other additional signposting support around cancer screening included explaining the value of screenings, translating resources, and showing participants how to check their breasts for masses.

Other signposting support included (but was not limited to) the following: help to register with a GP, help to access services including food banks, dental services, digital support, mental health support, housing support, benefits, immunisations, keeping warm in winter, wellbeing activities, and pharmacy.

How was resident given advice and information?	
Conversation in community language	269
Conversation in English	35
Leaflet/written information in English	62
Translated leaflet/ written information	7

Equality Monitoring

Partners' survey participants:

Man	Woman	No answer	Total
26	334	2	362

18-24	25-49	50-64	65-79	80+	No answer	Total
1	187	102	67	3	2	362

Ethnicity	
Arab	54
Asian/Asian British Bangladeshi	31
Asian/Asian British Indian	3
Black/Black British Caribbean	4
Black/Black British Eritrean	24
Black/Black British Ethiopian	10
Black/Black British Somali	43
Black/Black British Other/unspecified	4
Greek/Greek Cypriot	63
Kurdish	13
Latin American	62
Turkish	21
White British	9
White Any Other	8
Mixed	3
Any other ethnic group	5
Unknown/No answer	4

Disability	Long term condition	Carer
102	151	74

Online survey, CallyFest, and Chapel Market participants:

Man	Woman	Non-binary	No answer	Total
2	67	1	4	74

18-24	25-49	50-64	65-79	80+	No answer	Total
0	25	35	10	1	3	74

Ethnicity	
Asian/Asian British	8
Black/Black British	10
White British	31
White Any Other	9
Mixed	2
Any other ethnic group	6
No answer	8

Disability	Long term condition	Carer
19	37	9



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