

Supporting the uptake of cervical screening within the Somali and Turkish speaking communities 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 the [Diverse Communities Health Voice partnership](#), we work together to gather insight from the residents our organisations represent to inform service provision and commissioning, increasing equality of access. We were commissioned to gather feedback from these groups on their experiences of accessing cancer screening services and we [published our findings](#) in 2023.

North Central London Integrated Care Board asked us to build on this research. Guided by learning from a Public Health Cancer Needs analysis, and support from North Central London Cancer Alliance, the project has focused on supporting uptake of cervical screening in the Somali and Turkish Communities. Somali and Turkish women have a higher refusal rate for cervical screening (9% and 11%) than the Islington average (3%).

The ambition of the project, led jointly by Diverse Communities Health Voice (DCHV) and the Islington GP Federation, is to implement a local cancer outreach screening model. Four DCHV partners have participated: Imece, Islington Somali Community, Jannaty and Healthwatch Islington.

Participating DCHV staff and volunteers have been trained as Cancer Champions. DCHV partners hosted a series of health information workshops aimed at Somali and Turkish speaking women aged between 25 and 49. Women who attended these workshops who weren't attending cervical screening appointments were invited to participate in one-to-one conversations with the Cancer Champions to talk through their questions and concerns. The Cancer Champions also gathered structured feedback from participants to better understand the barriers to attendance.

Islington GP Federation are leading on the call and recall element of the project (this is another route by which Somali and Turkish speaking patients can access the one-to-one support conversations) and have provided devices for Cancer Champions to book appointments for participants who have changed their mind about not attending screening. These appointments are offered at the extended hours GP hubs (The Village Practice, Islington Central Medical Centre, or Ritchie Street Group Practice) or via the Nurses Hub.

What we did

A two day Cancer Champion training programme was delivered to DCHV partners on 7 and 8 November 2023. This included a session led by the Lead Nurse and Nurse Hub Manager at the Islington GP Federation from which information resources were generated.

Partners also received training in motivational interviewing techniques to support their one-to-one conversations with residents. Motivational interviewing is a communication style that uses strategies such as reflective listening and shared decision-making, with an emphasis on enabling the interviewee to fully own their decision to take positive action.

14 health information workshops were hosted by community organisations: Imece, Islington Somali Community, Jannaty, Turkish and Kurdish Childrens Group and Manor Gardens Welfare Trust. Islington Somali Community and Jannaty had one-to-one conversations with clients who weren't attending screening appointments and were willing to discuss their concerns. Imece (whose clients are primarily Turkish, Kurdish and Cypriot Turkish women) collaborated with Healthwatch to offer the same support to Turkish speaking women.

A Turkish speaking member of staff led on the project for Healthwatch Islington. Imece enabled this member of Healthwatch staff to attend their workshops and gave her access to their client database. She made 117 phone calls from IMECE to Islington-based clients who hadn't come to the health information workshops but might still be interested in a one-to-one conversation to talk through any questions and concerns they had about cervical screening.

Social media messages promoting the project were distributed in Turkish via Manor Gardens Welfare Trust (it was not appropriate to promote via social media to clients of Imece). An online workshop was offered but there was little interest in events that weren't delivered face-to-face so this didn't go ahead. During the course of the project the Turkish and Kurdish Children's Group was identified as a good organisation to include, and they hosted a workshop.

Other DCHV partners integrated project promotion into ongoing client support activity. Tools for research data collection were developed by Healthwatch and shared across the partnership.

Health workshops

Health information workshops took place in December 2023 and from January to February 2024. There were 208 participants in total. As well as providing useful information about a range of health services including, but not limited to, cervical screening, these events enabled partners to identify women within this larger cohort who weren't attending cervical screening appointments.

Equality Monitoring (all participants were women)

Age of participants:

18-24	25-49	50-64	65-79	80+	No answer	Total
1	156	44	6	0	1	208

Ethnicity			
Black/Black British: Somali	163	Mixed Turkish/Kurdish	3
Turkish/Turkish Cypriot	26	White Other	1
Kurdish	12	No answer	3
		Total	208

Additional reach

The health information workshops delivered at Jannaty were open to women from other backgrounds (in addition to Somali and Turkish). This was seen as a more inclusive approach within Jannaty's client group. So, this project reached an additional 93 women from North African, Middle Eastern, Horn of Africa and Bangladeshi backgrounds. The women participating engaged in the discussions and contributed with questions and requests for information/advice. They also took copies of the Question & Answer document prepared for residents as part of this project.

Participant feedback on the value of the workshops

204 of the 208 workshop participants said yes, the information they were given was helpful. The remaining four found it only partially helpful. One participant who provided additional detail put this down to the size of the group.

199 of the 208 workshop participants said yes, they felt they could act on the information they had been given. The remaining 9 participants felt this only partially, and reservations about the cervical screening process were expressed where further comment was made:

'I didn't believe in this procedure in the beginning, but because it's been explained properly, I will look into it further.'

'I understand the importance of screening now, but I have to think about still. Because its invasive.'

'I'm still anxious about receiving bad news.'

(all three quotes are from Somali women aged between 25 and 49 who went on to request a one-to-one conversation to discuss their questions and concerns in more detail)

Booking cervical screening appointments as an outcome of the workshop

Five participants went on to book an appointment with a nurse to discuss their concerns, three booked the appointment themselves and the other two had the booking made on their behalf by the organisation hosting the workshop.

Five participants went on to book a smear test appointment as a result of the workshops. Three of these participants didn't book a one-to-one conversation so presumably didn't feel they needed any further support.

16 participants received signposting support for other issues not related to cervical screening.

Themes from participant feedback

We asked participants whether the information was helpful and whether they felt they could act on it (see above). We also asked participants to say a bit about why they answered these two questions in the way that they did. Analysing the comments reveals some common themes:

Participants really valued being given information in their own language. Participants were effusive about how much they had learned. Many also expressed surprise. There was a genuine and widespread lack of awareness about cervical screening. This indicates that public health messaging is not getting through to these communities by other channels. Participants described the health workshop as an 'eye-opener'.

"I found the information useful as in our culture we are not really told about these conditions and how important it is to have certain tests."

There were numerous comments from participants saying they ignored or were frustrated by the letters from their GP inviting them to screening appointments when they didn't know what the screening programme was or didn't think it was relevant to Muslim women. For these communities, the screening invitation programme does not work well in isolation. It needs to be complemented by effective information provision in community languages.

"It's not something I took notice of before and because I haven't seen anyone get cervical cancer, I ignored the doctor letters."

“The language barrier played a big role in me refusing screening. No one has explained this to me before. I've just seen letters [inviting me] for an appointment.”

It was also clear that poor information provision to these communities has had an adverse effect on the uptake of screening.

“I had a screening years ago, not fully understanding the reasons for it. So, I never went back. Now that it's been explained in Somali I understand it better. I wish this was offered back then.”

Many said that they were not aware of the role that men played as carriers of the HPV virus. However, they found it reassuring to learn that they could ask for more privacy or for a different size speculum. Many spoke about feeling empowered because of their participation.

“I walked into the session with scepticism about cervical cancer screenings, but I walked out feeling empowered and educated.”

Another common theme was participants saying that they needed time to digest the information.

One-to-one conversations

57 women were invited to participate in one-to-one conversations about cervical screening. 18 women refused. 39 women participated.

Equality Monitoring (all participants were women)

Age of participants:

18-24	25-49	50-64	65-79	80+	No answer	Total
0	37	2	0	0	0	39

Ethnicity			
Black/Black British: Somali	33	Kurdish	3
Turkish/Turkish Cypriot	3	No answer	0
		Total	39

Booking cervical screening appointments as an outcome of the conversation

Five participants asked for support to book a screening appointment as a result of their one-to-one conversation. Six asked for support to help them make their decision. Of these, four asked for support with both deciding and with booking.

Themes arising from one-to-one conversations

Eight of the 39 women said that they used to be in the habit of attending screening appointments. The reasons they gave for stopping were as follows: four had either separated from their husband or their husband had died and they felt that they no longer needed to go, one had changed GP practice and didn't receive the letter, one received the letter but 'felt lazy', one had moved cities, and one felt they had not been given enough information about screening.

Most of the cohort (31 of the 39 women) had never attended screening. The reasons they gave were varied and included: time pressures; invasive nature of the screening process; anxiety; religious reasons ('I didn't believe this type of cancer happens to Muslim women'); lack of awareness ('It never crossed my mind'); access difficulties; lack of information provision; previous bad experience (this could be a confusing experience or a painful one); no endorsement from peers ('I haven't seen anyone in my family or friends get this test done'); feeling they were too young; being unmarried.

Reasons you don't attend (Select those you agree with)

All 39 participants were invited to answer this question, selecting from a set of predefined options. Participants were invited to choose all the options they agreed with but most selected only one option (suggesting they selected the answer they identified with most strongly).

There are cultural issues that make it hard for me to attend	5
I don't understand why I personally need to go	4
I feel apprehensive about attending	4
It is difficult to get a screening appointment	3
The screening process has not been properly explained to me	3
Influence from my peers/ from other people I know	3
It is hard for me to attend the venue	2
Healthcare staff are unwelcoming	1
I have had a bad experience at a previous screening	1
I don't see the value of screening	0
Language barriers	0
Other	16

Other: Eight of the 16 women who selected Other went on to explain that they didn't attend because they were no longer with their husband or were single. Other reasons given included anxiety, lack of adequate information provision, recently having a baby, no invitation, and not being bothered.

What would make you more likely to attend?

This was a free response. These are grouped where possible, though some types of response were only given by a single participant.

If I get married	7
More sessions like these/better explanation of the reasons for screening	6
Easier access (either interpreting or appointment booking)	3
If I was sent a letter about my screening appointment	3
If I was treated with dignity/afforded privacy and comfort	2
If I could bring a friend with me	2
If it was guaranteed that the screening was pain-free	1
If GP reception staff received training	1
If weekend appointments were available	1
If the imam gave permission	1
The attitude of nursing staff is very important	1
If my GP advises me to	1
When my baby gets older	1
Nothing would make it easier	3
I now see the importance of screening	3
I now see the importance of screening and I will book an appointment	1

Feedback on previous experiences of cervical screening

12 one-to-one participants had previous experiences of cervical screening. Feedback was mixed. Seven women described the experience as good, or at least had no real complaints. The others reported negative experiences. Those who had no problems with previous screenings had stopped attending because they were no longer sexually active, didn't realise that they would still need to attend if they were only sexually active with their husbands, or only attended intermittently as they didn't feel that they were at risk.

Barriers to engagement in this research activity

At the outset of this research project our target was to engage 300 Somali and Turkish-speaking residents via health information workshops and 80 via one-to-one conversations. So far, we have reached 206 residents via workshops and 39 (though 57 participants were identified) via one-to-one conversations.

Unfortunately, it has not been possible to benefit from the call and recall element of the project as practices are yet to start /only just beginning this activity (it was anticipated that local GP practices would direct suitable Somali and Turkish speaking patients on their lists to the one-to one-support provided by the DCHV project partners). In addition, the devices that DCHV partners could use to book appointments for project participants have only reached partners after the bulk of the engagement has taken place.

Beyond this, cervical screening is a sensitive issue that many women were not keen to discuss. It was particularly challenging to recruit Turkish speaking participants. As an illustration, the Turkish-speaking Healthwatch project lead phoned 117 women on Imece's client list. Of these:

- ▶ 48 women had had a smear test during the last 5 years;
- ▶ 33 didn't pick up the phone;
- ▶ 18 were wrong numbers;
- ▶ 8 women didn't want to take part in the survey

Feedback from partners

Feedback from the Cancer Champion training in November 2023

Staff and volunteers from Somali and Turkish backgrounds participating in the training shared how hard it is to speak in the communities about cancer. They don't call it cancer. They use 'C' or a different term. Families actually don't say that a loved one has passed away from cancer, because there is stigma around it. There is a belief in certain parts of the community that it may be a punishment, linked to what you may have done.

Observations from the project lead at Jannaty at the end of this phase of project

There were challenges in getting women to open up and participate. Trust and confidentiality were really important. Participants were afraid of information being shared in the community. In many of the conversations (especially in relation to 'unmarried women') from mothers about their daughters/or from the young women themselves, participants were nervous about sharing any details that could potentially identify them or their families, especially if there was a suggestion that women may have been sexually active.

In this context, access to the EMIS system to book screening appointments wasn't so useful because many women didn't want to share their contact details or any information that would make them identifiable.

Observations from Islington Somali Community at the end of this phase of project

"I think people are learning and they are changing their attitudes towards cancer. It was something like a taboo before. When they used to come before, they couldn't even say the word cancer, they used to say in Somali "the bad disease". They are now openly saying the word cancer, which is a breakthrough. They are talking about it. They are thinking about it and they are taking action - so people are understanding now the need to act and take up screening."

- Yussuf, Islington Somali Community

Case studies

Islington Somali Community

The participant, who is in her thirties, was hesitant to attend her cervical screening due to her close friend's negative experience. This hesitation was compounded by her own experience of a difficult birth, so she felt worried about attending cervical screening. The participant, who attends Islington Somali Community (ISC) regularly for support, was invited to our Cervical Screening Workshop and shared her concerns with the group. ISC's Cancer Champion was able to reassure her by describing what she could expect from her screening and what she could ask for during the appointment. The participant also benefitted from knowing ISC now had a named nurse in the GP Federation who could support her if any issues arose. She is now planning to attend.

Jannaty (case studies showing topics for future information resources to address)

The participant had not booked her smear test appointment the last time she was invited to, as she felt it may no longer be needed, as her husband had passed away. Jannaty's Cancer Champion advised her to speak to her GP as she used to go when her husband was alive.

Another participant stopped attending her smear tests when she divorced her husband. She felt there was no need to go for screening she was no longer in a relationship. As she used to go before she was divorced, Jannaty's Cancer Champion advised her that it would be for the best if she spoke to her GP about this to get their advice.

One participant asked if the HPV virus could be spread by washing the whole family's clothes together, especially when laundry is washed at different temperatures. She was worried that her daughters may be exposed to the HPV virus. They are currently not attending cervical screening as they are unmarried and are not in any relationship. Jannaty's Cancer Champion told her that they would double check and get back to her.

Turkish speaking residents

One participant didn't attend screening because she was afraid of what would happen during the appointment. She was under the impression that they would remove some tissue and that this would be painful. During the Health Information workshop, the Cancer Champion explained exactly what the procedure would involve, and the participant changed her mind and said she would contact her GP surgery to book an appointment for her smear test.

Another participant would like to attend her smear test appointments, but she is not paying attention to herself. She puts the needs of her children first. She doesn't have time for herself and isn't aware of the importance of taking up screening. This has changed after attending the health information workshops and she would like to book an appointment for her smear test.

A third participant is a Domestic Violence survivor who is getting support from Imece. She would like assistance with booking the appointment. After attending the health information workshop she reflected, "I've never thought about myself in my life. After this workshop, I started to think about myself and my body."

Recommendations

1. Some women booked screening appointments after the workshops, some after the one-to-one conversations, but many more said they needed more time, needed to reflect on what they had heard. Most participants will need to hear these messages many times. Many of the barriers are profound.
2. Many participants still felt that they no longer needed to attend screening if they were divorced or their husband had died. It would be helpful to address this specific issue more prominently in future cervical screening messaging.



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