

Cancer Screening for People with Learning Disabilities in Brent



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EXECUTIVE SUMMARY

The national uptake of cancer screening for people with learning disabilities is poor. Despite efforts, both on a national and local scale, to reduce this health inequality, there are a number of barriers that prevent people with learning disabilities from attending cancer screening.

Healthwatch Brent aimed to explore the understanding of cancer screening from local residents with learning disabilities. Using focus group methods, the team spoke with 28 service users in Brent about cancer, cancer screening, the difficulties with accessing services and what would make screening easier for them.

A number of key themes emerged:

- Only 11 respondents had been screened for bowel, breast or cervical cancer
- The group had a good understanding and awareness of cancer and cancer screening
- There was less clarity about how screening and self-checks are performed, which often led to respondents choosing not to attend or self-examine
- The respondents found easy read information and related medical letters (invitations, results letters) about cancer and screening were not readily available
- It was reported that there are a lack of reasonable adjustments before and during appointments

Informed by the residents' insights, Healthwatch Brent recommends the following:

Easy read material

- Provide information about cancer and screening (and self-examinations) in easy read formats in primary care settings.
- Where possible, ensure correspondence letters are sent to people with learning disabilities in easy read.
- Promote information on cancer, other health conditions and self-care in easy read to reach all members of the community.

Reasonable adjustments

Ensure Public Health England guidance¹ on providing reasonable adjustments for cancer screening is followed by frontline staff when booking and screening patients with additional support needs.

- Ensure frontline staff receive learning disability awareness training, including avoiding the use of jargon and building rapport with patients prior to screening.
- Healthcare professionals to provide support and assistance with bowel cancer self-screening tests and self-screening procedures.
- Utilise existing models, such as the Annual Health Checks and Health Passports, to raise awareness of cancer screening.
- Where possible, offer extended appointments at locations convenient to the patient to reduce anxiety over screening.
- Consider the development of a dedicated learning disability cancer screening nurse.

Healthwatch Brent

- Produce this report in easy read.
- Continue the promotion of Public Health England easy read materials for cancer and cancer screening.
- Monitor diversity data in future reports to ensure representation from Brent's community.

ACKNOWLEDGEMENTS

Healthwatch Brent would like to thank all who contributed to this project:

The residents of Brent who took the time to share their views

The community groups who welcomed the team and provided their insights;

The Advocacy Project, Brent Mencap and Certitude

Brent CCG for their detailed and insightful feedback during the planning activity

The team of staff at Healthwatch Brent

¹ Public Health England (2015) Making reasonable adjustments to cancer screening
https://www.ndti.org.uk/uploads/files/Updated_reasonable_adjustments_in_cancer_screening_report.pdf

INTRODUCTION

Healthwatch Brent is part of a national network led by Healthwatch England, which was established through the Health and Social Care Act in 2012, to give service users of health and social care services a powerful voice both locally and nationally. We are the independent voice for people's views on Brent services, both good and bad. We listen to local people and feedback patient experience and liaise with local commissioners and decision makers, in order to improve services.

There are wide disparities in the uptake of cancer screening between people with learning disabilities and those without. General uptake of the National Cancer Screening Programme in Brent is lower compared to the national and London average². For people with learning disabilities, it is predicted that this uptake is even lower.

Healthwatch Brent aimed to identify the level of understanding and awareness Brent residents with learning disabilities had of cancer screening. The two main objectives of the project were:

- Identify the experiences and knowledge of cancer symptoms and cancer screening
- Identify how people with learning disabilities would like information about cancer symptom checking and screening presented to them

BACKGROUND

It is well evidenced that, nationally, people with learning disabilities are subject to wide health inequalities³. Public Health England is committed to reducing these inequalities including those identified in cancer screening uptake. NHS England, too, has made cancer screening for all the population a clear priority in their Long Term Plan.

² Public Health England (2019) Public Health Profiles
<https://fingertips.phe.org.uk/search/cancer%20screening#page/0/gid/1/pat/46/par/E39000018/ati/154/are/E38000005>

³ Public Health England (2019) Supporting the health system to reduce inequalities in screening. Public Health England Screening Initiative
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/816245/PHE_Screening_inequalities_strategy_2018_1.pdf

In Brent, various local initiatives are in place to improve the uptake and experience of cancer screening for all communities. The Community Wellbeing Scrutiny Committee (February 2018) identified there is a high awareness of issues of poor uptake and need for regular health screening and promotion in Brent.

Cancer Screening

Screening identifies apparently healthy people who may be at increased risk of disease or conditions, enabling earlier treatment and better-informed decisions⁴. Screening is population-based, meaning that the test is offered to everyone in a defined population group (usually an age group and gender).

NHS England runs three National Cancer Screening Programmes:

- **Breast Screening Programme**
Offered to women aged 50-71
- **Bowel Cancer Screening Programme**
Offered to men and women aged 60-74 every 2 years
- **Cervical Screening Programme**
Women aged 25-49 receive an invitation every 3 years, women aged 50-64 every 5 years

Each year, screening programmes prevent⁵:

- 5000 deaths by cervical screening
- 2400 deaths by bowel screening
- 1300 deaths of women by screening

Barriers to screening for people with learning disabilities

The national uptake for all cancer screening programmes among people with learning disability is low. The latest figures for 2017-18 show that overall, fewer patients with learning

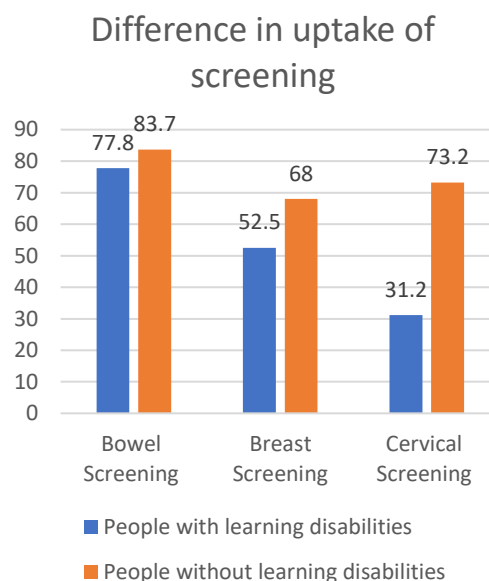
⁴ Public Health England (2019) Screening Inequalities Strategy: Supporting the health system to reduce inequalities in screening <https://www.gov.uk/government/publications/nhs-population-screening-inequalities-strategy>

⁵ Public Health England (2019) Screening Inequalities Strategy: Supporting the health system to reduce inequalities in screening.

disabilities received screening for various types of cancer than those without learning disabilities⁶:

Women with learning disabilities are least likely attend breast screening: 52.5% of patients with learning disabilities received breast cancer screening compared to 68.0% of those without learning disabilities.

While there has been an increase in people with learning disabilities receiving bowel cancer screening from 68.6% in 2014-15 to 77.8% in 2017-18, this is still lower than the 83.7% uptake of people without learning disabilities.



The differences in cervical screening is the most pronounced; 31.2% of patients with learning disabilities having cervical screening compared to 73.2% without learning disabilities.

Existing research shows that there are various practical barriers to each type of screening for people with learning disabilities. These range from legislation barriers whereby women with learning disabilities are not identified in the national cervical screening programme and are, therefore, not sent information and invitation in accessible formats⁷.

In Brent, the general uptake for the three national cancer screening programmes is lower than the national and London average⁸. With the additional barriers people with learning disabilities encounter, such as access to easy read information, fear and anxiety,

⁶ NHS Digital (2019) Health and care of people with learning disabilities, Experimental Statistics: 2017-2018 <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018>

⁷ Turner et al (2013) Improving the uptake of screening services by people with learning disabilities across the South West Peninsula- a strategy and toolkit. National Development Team for inclusion https://www.ndti.org.uk/uploads/files/Screening_Services_Strategy_Toolkit_final.pdf

⁸ Public Health England (2019) Public Health Profiles <https://fingertips.phe.org.uk/search/cancer%20screening#page/0/gid/1/pat/46/par/E39000018/ati/154/are/E38000005>

communication barriers, and reasonable adjustments not being made for their appointments⁹, it can be expected that uptake will be even lower among these groups.

Feedback from Brent carers captures their concerns around the uptake of screening highlighted in a Brent Council report¹⁰:

- Brent carers raised issues around screening for breast cancer. Due to the complexity of the health issues that people with learning disabilities face, their bodies age different; something not taken into consideration when developing screening programmes. Therefore, they often do not qualify in age for the screening where their bodies physically would do.
- People with learning disabilities may not have sufficient communication skills to inform carers when there is a problem.
- Carers often not allowed to go into the screening room, causing distress to the patient. This was raised with NHS Brent who agreed strengthened support for the role of the carers was needed.

METHODOLOGY

Data Collection

Healthwatch Brent aimed to identify people with learning disabilities' awareness and understanding of cancer screening. To do this, focus group discussions were held between July and August 2019 with service users of local community groups in Brent.

Healthwatch Brent approached 5 community groups whose main service users have learning disabilities. Three groups agreed to host focus groups between Healthwatch Brent and their service users:

- The Advocacy Project
- Certitude
- Brent Mencap

⁹ Public Health England (2015) Making reasonable adjustments to cancer screening https://www.ndti.org.uk/uploads/files/Updated_reasonable_adjustments_in_cancer_screening_report.pdf

¹⁰ Brent Council, Access to health services for people with learning disabilities <http://democracy.brent.gov.uk/documents/s3144/>

Discussions with respondents were facilitated by the Healthwatch Brent team about their knowledge, views and experience of cancer screening. In addition to the group discussion, Healthwatch Brent distributed Public Health England easy read materials on bowel, breast and cervical screening to the groups to raise awareness and gather their opinions about them.

Data Analysis

The data collected was transcribed and the three focus groups' findings were examined collectively. Thematic analysis techniques were used to analyse the data, drawing out key themes regarding the understanding and awareness of cancer screening.

FINDINGS

Healthwatch Brent engaged with 28 people with learning disabilities across three focus groups between July and August 2019.

The group discussions identified that the respondents have an understanding about cancer and cancer screening, but a less informed awareness of the procedures for screening and performing self-checking. The group suggested that more information in easy read and better communication would help alleviate some of the barriers they experience when attending cancer screening and medical appointments more generally.

The following findings offer an up-to-date snapshot of the experiences of people at the time of the focus groups and, therefore, does not aim to be representative of all Brent's residents.

Knowledge of Cancer and Screening

Participant's knowledge of cancer and cancer screening varied. All but two participants were aware of cancer, the impact their lifestyle choice has and the impact it has on people's health and lives if not treated. The group facilitator provided information using Public Health England easy read factsheets (Appendix I) about cancer for those who had a lesser understanding of it.

'I tell my sister, who smokes like a chimney, that she'll get it but she doesn't listen'

'if you don't get rid of it quickly it can kill you'

'there's different kinds of cancer, there's bowel, prostate, I recently did a bowel cancer test. I am at that age when the NHS shares information'

Much of the groups' knowledge seemed to come from other people; people they know who have cancer or who have had it in the past. The media also influenced people's understanding of cancer and screening. The group were discussing the GP examinations for prostate cancer and one participant noted that they found out about it through watching television

'I watch 'GPs Behind Closed Doors''

The media was raised again during a discussion about breast cancer screening

'I watch 'Holby City'... they check it on the big screen, an x-ray and they feel for it'

Only one person reported to be told about cancer screening and performing self-checks by a GP

'I was told in the annual check-up'

Most of the participants were aware of the self-checks they can do themselves and the national cancer screening programme. The participants were aware that they should be checking their breasts and testicles and were also aware of the prostate checks performed by their GP

'You stand in front of a camera and it takes pictures of [indicated to breast area]' this was clarified to be an x-ray

'You need your testicles tested. I was told you check them yourself or can ask a GP to do it during your annual health check'

'Need to check yourself between screenings'

However, some participants did not have a clear understanding of what they would be looking out for when checking and how the tests were performed.

'all I know is that there are tests for testicle, prostate and down below'

'I know about the testicle checks you're meant to do'

'doctors have given me a small test tube [for bowel screening] but how will it fit? I haven't done it'

Despite the groups' awareness of self-checking, not all members of the group reported to perform self-checks themselves. When discussing cancer screening and self-checks, some members of the groups appeared embarrassed to share their views and experiences

'I don't check myself'

'you go for all the funny screening'

Although not all participants reported that they check themselves or attend cancer screening appointments, they spoke about the importance of attending screening and contacting their GP with concerns

'if you find blood in the toilet, it's important to see your doctor immediately'

'I would be scared. It's not something I would want to do, but like a car needs a MOT'

'it's important that you go, can't put things off especially at our age in our 50s and 60s, we're more vulnerable. Must go even when you're scared'

Screening Attendance and Barriers

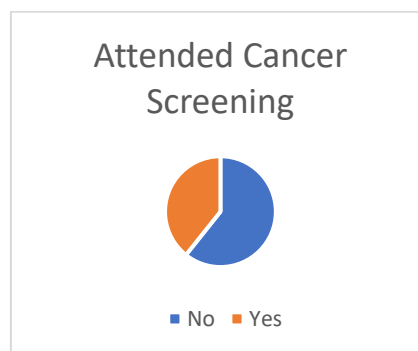


Chart 1. Number of respondents who have attended cancer screening before.

11 respondents (39%) reported that they had attended either bowel, breast or cervical cancer screening at some point in their life.

The groups demographics may have impacted the poorer attendance in the National Cancer Screening Programme. 16 respondents were male, with most under the age of 50. Therefore, they would not have been invited to complete the bowel screening test.

All 12 women engaged with were over the age of 25 and, therefore, should have been invited to attend a cervical screening test if registered with their GP.

Only 3 respondents said that they could attend screening by themselves, the remainder of the group discussed a number of barriers to attending cancer screening.

Fear

At various points of the discussion, feeling scared or embarrassed was raised as a reason why they would choose to not attend cancer screening. Those who had previously attended cancer screenings, as part of the national programme, suggested that their previous experience had deterred them from attending again

'I get letters from your GP saying you need to go for breast screening, I've been a lot, but not for down below [cervical screening]. I can't relax, there's all these noises, I was very nervous. The next time I had it, I was put to sleep to have it done. Will have it again as long as I'm put to sleep'

'It hurt like hell [cervical] my doctor made me have it but never again. I waited 20 years and kept getting letters.'

'The nurse said it doesn't hurt [cervical] but it did hurt, and I said but you're hurting me'

'I go to the breast one, I have to go more often but that hurts like hell. I don't need support, I know what to do but it squishes down and hurts like hell. I know it has to be done but wish it could be easier.'

'I went for the smear test, I wouldn't go again. It was too uncomfortable'

Another respondent suggested that they would not know how to complete the bowel cancer self-checking kit after previous experience

'I've had to do a sample for the doctors before and I found that hard'

Respondents reported that they would not only feel scared and uncomfortable whilst having the screening, but also were concerned about the results

'I don't like talking about cancer even though we have to. Too many people in my family have died but didn't tell people they had cancer, so I just don't want to know now'

'Can we just change it to a different name? it's not nice'

Understanding

This fear and anxiety respondents reported was seemingly sourced in the respondents not having enough information about the different screening processes either from not receiving information from professionals or not having discussions with family members and carers

'don't always understand, would be less fearful if I understand'

'I didn't talk about it in my family, my mom gave me a book for women's problems. It would have been easier if my mom had spoken to me about it. I don't even know if she's been for one'

Healthwatch Brent contacted numerous groups to engage with their services users. On a number of occasions, the request was not accepted; the group facilitators claimed that their service users would 'not understand the discussions' about cancer and screening or that 'they would not want to talk about that' such. While the team did not gather information about the extent of the users' disabilities, the focus groups were tailored to ensure that respondents were able to participate in discussions.

Communications

The groups highlighted that the form of communication, in both the inviting to screening and during the appointment, was often not appropriate to their needs. The group emphasised that it was not only with screening appointments that they experienced these challenges and often experienced barriers to attending general medical appointments

'the letter [for bowel cancer] was not in easy read. I could understand it, but I would prefer easy read'

'I usually give the letters to reception at my GP because I wouldn't understand them myself'

Other issues with the quality of letters were raised, such as the text being in small print. In addition, where the respondents had received information in easy read, they found the quality of the easy read was poor

'They sometimes just put it in any other pictures in easy read, they need to make sense'

Communication within the appointments was found, for some respondents, to act as a barrier to attending. They said that health professionals, at times, talk too fast or use jargon.

Others reported that they found the environment difficult and experienced anxiety

'I struggle with the self-check in machines and scanning the barcodes'

'Surgeries have too long waiting times and the waiting rooms are hard places'

'not easy to book an appointment'

'I was happier when the breast screening came closer, to my GP, it made it easier'

'planning the appointment and transport is hard. It's often out of the way, how to get there. Find it difficult to be rushing about, to get the ground work of the location'

Improvements

The respondents in each focus group were asked what changes would make their experience with cancer screening better. They identified improvements with communication, support during the appointment and raising awareness.

Communications

Respondents in all groups suggested that having correspondence in easy read would improve their experience. While some members of the discussion found that they were able to read letters that were not in easy read, there was a consensus that good quality easy read information about cancer, invitations for screening, referral and results letters would be beneficial to all patients with learning disabilities. Although the NHS and Public Health England currently has information about screening available in easy read, most respondents had not seen this

'I would like more information especially in easy read'

'They send all the letters in small print'

'I understand [the letters] but as I'm partially sighted, I'm scared I'll miss the appointment [details]. It needs to be bigger.'

'We don't get any letters in easy read - we don't get the reasonable adjustments'

Most respondents found that the NHS easy read guides that Healthwatch Brent distributed during the discussions were useful

'this is good because it's got the pictures'

Respondents also suggested that it would be useful for reminders about the appointment to be sent in a suitable format

'A letter to remind you about the appointment - in easy read'

Appointment support

There was a consensus across the different focus groups that more support during health-related appointments, including screening, would improve their experience. They suggested that health professionals should clearly explain the procedures, without using jargon, and ensure that the patient understands them

'medical staff using jargon. Make it clear according to our ability'

The group also suggested that it is helpful when the health professionals are aware of their learning disabilities and make reasonable adjustments. Some suggested that they would feel more comfortable talking about screening with someone of the same gender and allowing a carer, friend or relative to attend with them throughout the process.

'having someone go, having your carer go with you'

'Before appointments they should go to have a visit first to know what's happening first or have easy read descriptions of what's going to happen. It makes it less scary'

'For smear tests: people think people with learning disabilities and autism are children and are not treated like an adult'

One group suggested the possibility of recruiting for a dedicated learning disability screening nurse to support people with learning disabilities throughout the process

'Having a learning disability cancer nurse, someone to contact before and explain give screening support and hold your hand if needed'

'Macmillan put lots of money into palliative care, I'd like to see a learning disability trained cancer screening support nurse'

Raising awareness

Across the groups, there was a desire for more, accessible information about cancer, screening and self-checks. In addition, some felt that, to reduce the stigma around the topic,

it should be addressed with more positive commentary and ‘less focus on the pain and the embarrassment’. They found discussions such as the ones held in the focus groups useful and informative

‘Get people together to talk about it’

‘Stop people from being embarrassed to talk about it and things like cervixes and poo’

‘Stop people from being scared to talk about it’

CONCLUSIONS

Healthwatch Brent engaged with 28 local residents with learning disabilities to find out about their awareness and understanding of cancer screening. Using focus group methods, the team facilitated discussions with three community groups' service users. The findings show that, generally, people with learning disabilities in Brent have an understanding about cancer and screening. However, the respondents demonstrated a less clear understanding of the procedures of self-checking and screening. This was identified as one of the major barriers to attending cancer screening and performing self-checks; not having enough appropriate information available to them. Further barriers, including fear and communication before and during appointments, were identified during the group discussions.

The group highlighted a number of ways to improve their experiences with cancer screening and attending medical appointments more generally. They suggested improved communication and making reasonable adjustments before and during appointments to ensure they are comfortable and have a good understanding of the processes. In addition, the respondents want to see more positive awareness raising about cancer screening.

RECOMMENDATIONS

Healthwatch Brent recommends the following:

Easy read material

- Provide information about cancer and screening (and self-examinations) in easy read formats in primary care settings.
- Where possible, ensure correspondence letters are sent to people with learning disabilities in easy read.
- Promote information on cancer, other health conditions and self-care in easy read to reach all members of the community.

Reasonable adjustments

Ensure Public Health England guidance¹¹ on providing reasonable adjustments for

¹¹ Public Health England (2015) Making reasonable adjustments to cancer screening
https://www.ndti.org.uk/uploads/files/Updated_reasonable_adjustments_in_cancer_screening_report.pdf

cancer screening is followed by frontline staff when booking and screening patients with additional support needs.

- Ensure frontline staff receive learning disability awareness training, including avoiding the use of jargon and building rapport with patients prior to screening.
- Healthcare professionals to provide support and assistance with bowel cancer self-screening tests and self-screening procedures.
- Utilise existing models, such as the Annual Health Checks and Health Passports, to raise awareness of cancer screening.
- Where possible, offer extended appointments at locations convenient to the patient to reduce anxiety over screening.
- Consider the development of a dedicated learning disability cancer screening nurse.

Healthwatch Brent

- Produce this report in easy read.
- Continue the promotion of Public Health England easy read materials for cancer and cancer screening.
- Monitor diversity data in future reports to ensure representation from Brent's community.

RESPONSE From NHS Brent CCG

NHS Brent CCG's initial thoughts are that cancer screening is a national programme with patients being contacted directly by NHS England regarding their screening i.e. being sent bowel screening kits directly from NHSE (and not from primary care GP practices). We wondered whether Health Watch have considered their national counterparts and escalated this to be addressed at a national level due to this being such an important national concern.

We also noted, very importantly that the work focused on people with learning disabilities and less so on health professionals, social care staff, family members and carers who help and support people with learning disabilities to be screened

for cancers. As part of this work our thoughts are also that to have a comprehensive understanding of all the barriers to why take up of cancer screening is low among people with learning disabilities nationally it's important to understand the associated role and involvement of professionals, family and carer.

A further observation from the report is that it was unclear whether this work also looked at the pathways if any, used to identify and offer support to people with a learning disability prior to point of pre invite to cancer screening as well as post screening. As part of this work, we would wish for services to be able to tailor the support to people with a learning disability before, during and after the screening process if required.

We will certainly share this with the NWL Cancer Clinical Lead, the Royal Marsden Partners Cancer Alliance and the Cancer Research UK Representative for Brent who support Brent GP practices in regards to cancer care and screening and can discuss this during their visits.

NHS Brent CCG is currently participating in two projects one related to bowel screening where a company supported by Royal Marsden Partners is contacting patients on behalf of the practice to encourage bowel screening uptake. The second is the NHSE cervical screening text reminder. This will also be shared with Brent CCG primary care colleagues and Brent GP's.

Finally, we want to thank you again for this very welcome report. We have shared it with all the CCG's Clinical Directors so there may be more comments still to come.

APPENDICIES

Appendix I. Public Health England (2015) Making reasonable adjustments to cancer screening

Making reasonable adjustments to cancer screening

Easy-read summary



The NHS runs three cancer screening programmes. These are:

- breast screening
- cervical screening
- bowel screening



It can be difficult for people with learning disabilities to take part in cancer screening.



It is important to find out if people have cancer as early as possible.

This makes it easier to treat the cancer.



The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use the services. This means they need to change their services so they are easier to use.

Appendix II. Public Health easy read material used during focus groups

An easy guide to bowel cancer screening

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

An easy guide to breast screening

<https://www.gov.uk/government/publications/breast-screening-information-for-women-with-learning-disabilities>

An easy guide to cervical screening

<https://www.gov.uk/government/publications/cervical-screening-easy-read-guide>

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