

# **Cancer Screening Project in Barnet**

A report on cancer screenings for people with learning disabilities



**November 2018**

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## Introduction

### About Healthwatch Barnet

Healthwatch Barnet exists as a strong local voice for residents to contribute to the development of quality health and social care services within the borough. Healthwatch Barnet work in partnership with local charity groups who represent the variety of needs of residents and enables effective engagement with a range of user groups from all of Barnet's communities.

Healthwatch Barnet present the data gathered along with views and experiences of individuals to senior health and social care staff to raise concerns and to highlight good practice, which contributes to the improvement of services.

### About Barnet Mencap

Barnet Mencap was established in 1965 and continues to be a leading voluntary organisation within Barnet. Barnet Mencap provides a range of services for adults and children with Learning Disabilities and Autism and their Carers including supported accommodation and outreach support, advocacy and advice, volunteering, leisure activities and short breaks.

### About Expect the Best

Expect the Best is a peer-to-peer Quality Checking Service employing a team of Quality Checkers who use their own insight and experience to assess the quality of health and social care services. A key element is that Quality Checkers have a range of additional needs themselves and are instrumental in gathering meaningful feedback from people that use services. Expect the Best have worked in partnership with a number of Local Authorities, Clinical Commissioning Groups and NHS England to independently assess and report on the quality of specialist and mainstream services for people with Learning Disabilities, which in turn contributes to improvements being made.

Expect the Best were asked to carry out a research and engagement project focussed on the experiences of people with Learning Disabilities taking part in Cancer Screening in Barnet. The project initially aimed to quality check and review the Cancer screening services with a focus on Breast Cancer screening, Cervical Cancer screening and Bowel Cancer screening.

The aims and identified benefits of the project were:

- To raise awareness of Cancer Screening services for people with Learning Disabilities within Barnet.
- To improve the quality of Cancer Screening services and improve the patient experience for people with Learning Disabilities.

- To raise awareness of the barriers to accessing screening services for people with Learning Disabilities.
- To raise awareness of the communication, support needs and type of reasonable adjustments required to effectively engage patients with Learning Disabilities with screening services.
- Over time, improved Screening Services and increased awareness among people with Learning Disabilities about Cancer Screening services will lead to an increased uptake and improved health outcomes and early detection of Cancers.
- Lessons learnt, including best practice and areas for improvement, will be shared with other Barnet services who deliver Cancer Screening services, as well as wider NHS services to ensure that relevant learning is shared and improvements can be made to a wide range of services across Barnet.
- Provide Healthwatch with evidence which can be used to inform and influence at CCG and Health and Wellbeing Board meetings.

## Background

The low uptake of Cancer screening tests for patients with learning disabilities is not only a local issue in Barnet, but a national issue and health priority.

Statistics from Public Health England from 2014/15, which were the most recent available, demonstrated the contrast in uptake between local cohorts of people with and without Learning Disabilities engaging in Cancer screenings compared with the national average as follows:

Eligible women who have attended a cervical screening in the previous 5 years (women aged 25-64 years)

	No Learning Disability	Learning Disability	Difference in coverage
Barnet CCG	74%	23%	51%
England average	77%	30%	47%

The statistics for cervical screening showed that in comparison with other CCG's in London, Barnet had the joint fifth highest percentage of difference in coverage between women with and without Learning Disabilities.

Breast Cancer screening in previous 5 years (women aged 50-69 years)

	No Learning Disability	Learning Disability	Difference in coverage
Barnet CCG	54%	32%	22%
England average	68%	52%	16%

In comparison with other CCG's in London, Barnet were the fourth highest borough with a difference in coverage between women with and without Learning Disabilities.

Bowel screening in the previous 5 years (men and women aged 60-69 years)

	No Learning Disability	Learning Disability	Difference in coverage
Barnet CCG	82%	80%	2%
England average	78%	69%	9%

In comparison with other CCG's in London, for bowel screening Barnet were among the better performing boroughs with the sixth lowest percentage of difference in coverage between men and women with and without Learning Disabilities.

Key messages taken from those statistics stated that cervical Cancer screening may be lower in Learning Disability populations because of limited capacity to understand and consent to the examination.

In terms of breast screening it was identified that coverage may be lower because specialist services are required locally to anticipate and plan for the potential concerns of patients with learning disabilities, including liaison with GP surgeries to identify who may require such specialist services.

The statistics for bowel screening were statistically different in 6 London boroughs. However, Evidence for England suggested that death rates from colorectal Cancer in people with Learning Disabilities are significantly higher than for other populations. The lower screening coverage and higher death rates may be because screening is offered to people over the age of 60, at which stage a substantial proportion of people with Learning Disabilities will be in receipt of care and support services and screening will be dependant on whether such support is available to the individual.

Barnet Public Health coordinated two events targeted at Cancer Screening awareness and engagement across the general population.

- 1) Jo's Trust delivered a two-day awareness raising session at Brent Cross. They invited shoppers into their large trailer for a conversation on cervical cancer screening. The number of people who engaged was very low and it was reported that there was clear reluctance from the public to engage.
- 2) Barnet VCS organisations were invited to a community meeting to discuss how they can support improved early identification of Cancer symptoms and support residents living with Cancer however there was very low attendance. A handful of organisations with specific interest in health issues attended.

Public Health England considered the common barriers to accessing cervical screening for high risk groups and best practice to be shared. In terms of supporting women with Learning Disabilities, their findings were as follows:



## Barriers facing women with disabilities

The problem: **only 19%** of women with LD have recently had a smear (vs 73% in the general population)

### Barriers facing women with learning disabilities:

- Low levels of understanding about cervical cancer, the test and its relevance in women with learning disabilities
- Literacy barriers
- Practical difficulties, especially if no carer available to assist with booking an appointment/accompanying to it
- People with autism or learning disabilities feel 30% less likely to be listened to by their GP.
- GPs may wrongly assume patients are not sexually active

### Barriers facing women with physical disabilities:

- Mobility barriers for some women with physical disabilities
- Body image barriers which can affect women both with and without disabilities may be more pronounced\*



<http://www.dimensions-uk.org/wp-content/uploads/MyGPandMe-Making-primary-car-fair-Dimensions.pdf>

\* e.g. Moin, V., Duvdevany, I., & Mazor, D. (2009). Sexual identity, body image and life satisfaction among women with and without physical disability. *Sexuality and Disability*, 27(2), 83-95.



## What works for women with disabilities?

PHE and Jo's Trust have produced an EasyRead written guide and a Smear Test Film, both with close input and feedback from women with LD

### Ways to reduce distress (advice from Cancer Research UK)

Taking all of the relevant risk factors into account, if the woman or her carer and doctor decide to do a cervical screening test there are ways of reducing distress:

- the woman needs to have a good explanation of what will happen
- they need to have someone with them who they know and trust
- a series of visits to the clinic beforehand to get to know the people involved

## Methodology

### Surveys

We created an easy read survey to gather the views of local residents with Learning Disabilities about their experiences of accessing Breast, Bowel and Cervical Screening. These were distributed among the short breaks service and the outreach support service, an online version of the survey was also available although this was not in easy read, but as a tool for parents or carers to access to facilitate or provide feedback.

### Engagement Events

Expect the Best hosted two Cancer Screening Forums, one for men and another for women. The invitations were targeted towards the eligible age ranges for the screening groups and a total of 81 members were invited and encouraged to attend with a follow up phone call as a reminder of the event. Only 2 men attended the Men's Forum and 6 attended the Women's Forum.

Expect the Best utilised links within Barnet Mencap to encourage discussion by attending the Have Your Say members meeting, the over 50's Art Group and the activities facilitated by Community Opportunities Project (COP's) and the Autism Pilot Project.

A total of 14 Cervical screening, 5 breast screening and 10 bowel screening surveys were completed.

## Learning Disability Nurse Cancer Screening Project

The Community Learning Disability Nurse within the Team at Barnet Council embarked on a project focussed on Cancer Screening and Engagement. They sent out surveys to GP practices in Barnet in order to find out what service is offered to their patients with a Learning Disability, to identify barriers and areas that Practitioners would benefit from support with. 61 practices were contacted, of which 11 were returned.

Although only receiving a few responses, the Team acknowledged the demands on the time for the staff at the practices but that their input can also be seen as interfering or unnecessary, unless they have raised an issue to be supported.

The conclusions drawn from the survey were somewhat limited but reinforced general themes that are already known to the Team and are relevant for a range of health issues for people with Learning Disabilities. These include issues with communication and a lack of knowledge of Learning Disabilities.

The Team attempted to contact a local breast screening hub, however reluctance was noted to engage with the Team.

The LD Nurse facilitated workshops with Service Users from Barnet Mencap and Dimensions in order to raise awareness of the types of Cancers that affect men and women, promote healthy living and how to carry out self-checks. These groups had a relatively low uptake, with a maximum of 6 participants at some of the groups and as low as 1 at another.

## Quality Checks

Expect the Best attempted contact with the Breast Screening Hub by telephone and email several times but received no response.

Expect the Best faced challenges in engaging GP practices with the Quality Checks. From the 10 practices with the lowest numbers of registered patients with a Learning Disability, one had no patients with Learning Disabilities registered, one had closed, two were merging with other practices, one did not have the resources to take part and three were non-responsive.

## Longrove Surgery

The Practice Manager Claire O'Shea and Lead Practice Nurse, Lee Pomfrett showed interest and commitment to engage with the Cancer Screening Project.

There are 80 patients registered with a Learning Disability at the surgery, it is among the top few GP practices in Barnet with the highest number of registered patients with a Learning Disability. This has increased recently due to the development of new services nearby.

The range of needs of individuals varies greatly from those who are independent and communicative, patients with Autism, Down Syndrome and those with more complex physical needs including some patients who are deaf blind and some who require around the clock care.

Lee highlighted that just a small percentage of the patients with Learning Disabilities have capacity to discuss and understand their health issues, including that of Cancer screening.

### Best Practice

Reasonable adjustments are considered to meet the needs of patients with Learning Disabilities and examples of this included a 'warm up visit' with the Practice Nurse where health issues and screening can be discussed. The Nurse had

access to a range of accessible information including the Jo's Trust booklet and online resources from Cancer Research, Macmillan and Easy Health.

The Practice had access to the newly designed Health Action Plan which included communication tools targeted at the different sexes and the Nurse spoke positively about utilising these new materials. The Annual Health Check template prompts conversations around Cancer screening and is utilised.

Support from relatives or formal support staff is welcomed and encouraged in order to effectively engage with the patient and address their health needs and extra time is also allocated for appointments when this is felt to be helpful.

### Patient Engagement

Three patients with a range of needs were invited to meet with Expect the Best during the visit, to provide feedback on their experiences with screening. On the day, one of the patients who has more complex needs and is usually supported to appointments with their parent, was unable to attend.

The feedback received contributed to the overall findings from the surveys.

### Identified Barriers

The Practice shared their experience of common barriers for patients with Learning Disabilities accessing Cancer Screening:

#### Cervical Screening:

The invitation for Cervical screening is distributed by NHS England Screening Service who do not hold data on any additional needs of the patient. Therefore, it is not in an accessible format and can easily be ignored or not understood, unless effective support is in place.

Some patients are unclear about providing information about their sexual activity but may be known to be in a relationship. Other patients are reportedly or known not to have been sexually active and therefore at a lower risk of Cervical Cancer.

The test can be very traumatic for some patients, this can be due to a variety of reasons including a low tolerance to pain, anxiety about the test, lack of concept of time and poor understanding of how to relax.

For patients with more complex needs, the patients understanding and lack of capacity to consent is the main barrier. For patients who cannot physically get into the correct position for the test, the Practice refers to Colposcopy at Barnet Hospital where a specialist chair is available to assist.

#### Breast Screening:

Fear of machinery and a very low pain tolerance, along with the lack of concept of time was felt to be a major barrier.

Some patients are physically unable to take part and use the machinery.

It was felt that the Breast Screening Hub needs to do more in terms of information, awareness raising and reasonable adjustments to ensure patients with Learning Disabilities are not excluded.

The Nurse advised that where patients have higher support needs, there are barriers to paid support carrying out physical examinations of service users' breasts. In this case, he advises on physical changes to observe and flag with the GP such as visible lumps, discolouration, discharge or any discomfort when dressing or undressing.

#### Bowel Screening:

The Nurse reported that many patients do complete this with support from Carers and being non-invasive it is easier to encourage participation.

### **Mountfield Surgery**

Mountfield Surgery is among 10 GP practices in Barnet with the lowest number of patients registered with a Learning Disability with just 3 patients registered. Expect the Best aimed to Quality Check one of the practices with low numbers to assess the quality of Cervical screening in particular and share best practice to drive improvements where needed.

Dr Robinson was encouraging of the Project but could only offer a very limited amount of time herself and of that of the Practice Nurse, so a scaled back approach was taken. On the day of the visit, Dr Robinson was unexpectedly unavailable and the Practice Nurse was able to offer us a short interview.

#### Best Practice

Reasonable adjustments are offered to meet the needs of individual patients and examples included: flexible appointment times to suit their preference, extended appointments allowing additional time where this is helpful, encouraging a chaperone to attend with the patient, the Nurse can carry out home visits two afternoons per week where patients have mobility difficulties.

The Nurse explains why Cervical screening is important, what it involves and demonstrates the equipment used. The Nurse checks the patients' understanding and asks if they have any fears about the process.

The Nurse told Expect the Best that she looks for accessible resources online to share with patients with Learning Disabilities and their support.

The Nurse has met with a Community Learning Disabilities Nurse and meets with the Practice Doctors to share knowledge and best practice.

Being a small Practice, the Nurse expressed that they know their patients well. Every patient with a Learning Disability has an Annual Health Check. Surgery has an “alert check-up system” for each patient so doctors/nurse can see if anything needs acting on.

Written results are sent the patient and to the Surgery so the Doctor or Nurse can follow up where necessary e.g. if screening needs repeating or if a follow up at the hospital is necessary.

### Identified Barriers

Patients receive initial letter from National Screening Service and is not offered in an accessible format.

Where a patient is in a wheelchair, they may have to refer the patient to an alternative place e.g. gynaecologist in hospital setting. This is to allow for the fact that the plinth at the Surgery does not go up and down so may be difficult for wheelchair user to access.

## Survey Findings

### Cervical Screening

Most responses were from women aged between 25-49 years who should be invited for screening every 3 years. Those who completed the survey had a range of mild, moderate and complex learning disabilities, Asperger’s or Autism as well as specific needs such as mental health support needs, Down’s Syndrome and Epilepsy.

50% answered that they had not had a smear test in the last 3 years and just 35% of those who were eligible answered that they had.

Those who rated their experience as good told us that having support from another person helped them, that the kindness of the Nurse made a difference and seeing the equipment to be used helped. From an opposite perspective, for one respondent seeing the equipment made them feel very scared and more reluctant to go through with it.

For those who were invited to go for the screening but did not attend, their joint top three reasons were feeling worried or scared about the test, feeling embarrassed and thinking that the test would be painful. Some women also stated that they are not sexually active and, as a result, one woman had been advised to ignore the invitation letter by their GP.

The results showed that having support from another person at the test would help, followed by having a better understanding the test and more time with the Nurse.

Most women said they had not seen any easy read information about the smear test or about Cervical Cancer and while a high percentage had been for an annual health check with their GP, they had not discussed cervical screening.

## **Breast Screening**

There were very few responses to the survey but those who answered had mixed experiences of breast screening. Those who had a good experience said that the Nurse was nice and explained things, that the screening didn't take long and was conveniently located to home.

While another said they were unable to use their local mobile unit and that it is not easy to travel to the local hospital. Respondents told us that having support from another person would make it easier for them to complete the screening and having support to read the appointment letter. Some women had seen easy read information about breast screening but less had seen any easy read information about breast Cancer.

## **Bowel Screening**

The Bowel Cancer screening survey was answered by a mixture of men and women, who mostly considered themselves to have mild learning disabilities and many had mobility and support needs which can be associated with the age range of 60-75 years for those eligible for screening.

Of those who were sent a home testing kit, 55% said they completed it and a large majority had advice or support from a health professional, Carer or spouse to understand and complete the test. Comments included that it was not pleasant, it was fiddly, people felt embarrassed, it was difficult to understand but some found the pictures on the leaflet helpful.

For those who were sent a test but did not complete it, we heard that they did not understand the test and did not want to touch faeces to complete the test. Largely people told us that having support from another person would make it easier for them to do the test, followed by understanding the test and having easier instructions to follow.

Only 10% of people had seen any easy read information about bowel Cancer or bowel screening. Just 30% of people reported having been to an annual health check with their GP in the last year of which 11% recall having talked about bowel screening.

## Case Studies

The following case studies have been provided by Barnet residents. For anonymity, the names of individuals have been changed.

### Case Study 1

Emma is a 43-year-old woman with mild Learning Disabilities. She has no physical disabilities and lives in a Supported Living service describing her support needs to include making sure she is looking after herself, not getting stressed, support going out and to maintain a routine.

Emma attempted to have a smear test within the last 3 years and described her experience of this as being bad. She advised that she had spoken to the Nurse about the test prior to the appointment but when she entered the room, the instruments were being prepared for the examination and she said *“that put me off. My mind was totally out of the window. I got really shaky and scared and felt like something wasn’t going to go. The thought of it (the speculum) being in me was something completely different”*.

Emma said that deterrents for having the test were that she had been scared and thought it would be painful, adding that it can be embarrassing. When asked to consider what she thought would make it easier she answered, ‘having support from another person’ and said that was important to her to have someone there, to be able to speak to her Carer who knows her well to reassure her and make her feel better. She was also able to identify that listening to certain kinds of music and to dim the lights help her to relax when she is feeling stressed and agreed she might have liked to have been offered this during the test. She also uses a self-soothing method of closing her eyes and telling herself it will be ok as a way to keep calm.

Emma said that she had been shown easy read materials about the smear test but didn’t know if she had seen information about Cervical Cancer. Emma had an Annual Health Review in August 2017 and the Lead Learning Disabilities Nurse confirmed that they discussed screening and how to carry out self-checks.

### Case Study 2

Claire is a 66-year-old woman with mild Learning Disabilities and Autism and no physical disabilities. Claire lives in a Supported Living Service and has been supported by her main Carer for 14 years. Claire last had a smear test at the GP surgery in 2001 which was negative in result. In subsequent years, as she became due for the smear test, there were concerns about a deterioration in her communication, level of understanding and therefore her ability to consent to the test and she expressed a refusal to have the smear test.

Claire was supported to attend an Annual Health Review with the Lead Learning Disability Nurse in November 2017 with her main Carer and eligibility for cervical screening was discussed.

### Case Study 3

Gary is a 68-year-old man who has a mild learning disability and lives with his wife who also has a learning disability and they both receive outreach support.

In 2003, when Gary was just 53 years old, he was diagnosed with Bowel Cancer and had surgery as a result. At the time he wasn't eligible in terms of his age for Bowel Cancer screening. His Support Worker at the time reported that he ate a poor diet and had a history of ongoing bowel issues that suddenly deteriorated. The hygiene levels within the home bathroom were noticeably worse which lead the Support Worker to ask questions and prompt Gary to seek advice from his GP.

Gary recalled *"I used to get pain in my belly, it would come and go. I went to the Barnet General Hospital with my Support Worker at the time, they diagnosed me and the next day I had an operation. I was told what was going to happen, I was awake and it didn't hurt. My wife was there, it was upsetting for her as well. I didn't think I would get it but I did"*.

### Feedback on Easy Read Materials

Those in attendance at the Women's Cancer Screening Forum and some individuals who were supported individually were supported to look through an Easy Read booklet from Jo's Trust entitled 'Having a Smear Test. What is it about?' and were shown 'The Smear Test Film' co-produced by Jo's Trust, Public Health England and women who have Learning Disabilities.

Feedback on what people learned about Cervical Cancer:

*"It helped me in a small way about Cervical Cancer"*

*"It is when you change some of the cells of your body"*

*"I found it helpful"*

*"Lots of women died from it"*

*"I think I understand now why it is important to have it. It's given me an idea that I should try and have one. I think it's important, it will save your life"*

Feedback on what was learned about smear tests:

*"Little bits about the women's problems and the smear test"*

*"How it is done and what it involves"*

*“It is important to have a smear test”*

*“It showed us how it was done”*

*“It was good seeing the equipment, the plastic speculum”*

*“I learned that you can have a smear test if you are not sexually active”*

The easy guide to Breast Screening produced by the NHS and Public Health England published in February 2018 was shown to participants who shared the following feedback:

*“The photos of the machines were helpful, it was all helpful”*

*“I found out how to check my breasts”*

*“I didn’t know you don’t go to the Doctors for breast screening”*

*“I learned that it (Breast Cancer) can spread”*

The easy read Bowel Cancer and Bowel Screening booklet by Liverpool Community NHS Health Trust in 2014 was shown and the following feedback received:

*“It helped”* and *“It helped to remember”*

*“I learned what it actually is, the polyps and the symptoms”*

4 participants commented on the information about healthy diet in order to reduce risks *“I didn’t know about all these vegetables”*, *“I didn’t know about the diet”* and another said *“it’s helpful to know”*

*“I didn’t know that more men get Bowel Cancer than women”*

*“I didn’t know that blood in the toilet can be a sign”*

*“I didn’t realise it was (stool samples) 3 days in a row, I just did it when I could”*

## **Recommendations**

Expect the Best make the following recommendations in order to more effectively engage patients with learning disabilities with Cancer screening and to impact on better health outcomes, in line with the aims of this project for this.

1. For best practice identified within the GP surgeries to be shared in order that this to be replicated.
2. Specialist support via the Community Learning Disability Team to be encouraged within GP surgeries in order to improve practice and improve engagement.
3. GP surgeries to access Easy Read information to support the understanding of Breast, Bowel and Cervical Cancers.

<https://www.jostrust.org.uk/shop/cervical-screening-and-cervical-abnormalities/easyread-booklet-having-smear-test-what-it-about>

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/675924/Breast\\_screening\\_easy\\_guide.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/675924/Breast_screening_easy_guide.pdf)

<https://www.merseycare.nhs.uk/media/3671/bowel-cancer-screening.pdf>

<https://www.macmillan.org.uk/information-and-support/resources-and-publications/other-formats/easy-read.html>

4. The following Cancer Screening Good Practice Guide for Primary Care to be circulated, which includes a section on ‘people with additional needs’:

<https://www.healthylondon.org/resource/good-practice-screening-guide-breast-cervical-bowel/>

5. Support Providers and Parents and Carers would benefit from additional training or awareness raising on the signs and symptoms of Cancers, in order that they can effectively support people with learning disabilities whom they support to flag health concerns in a timely manner.

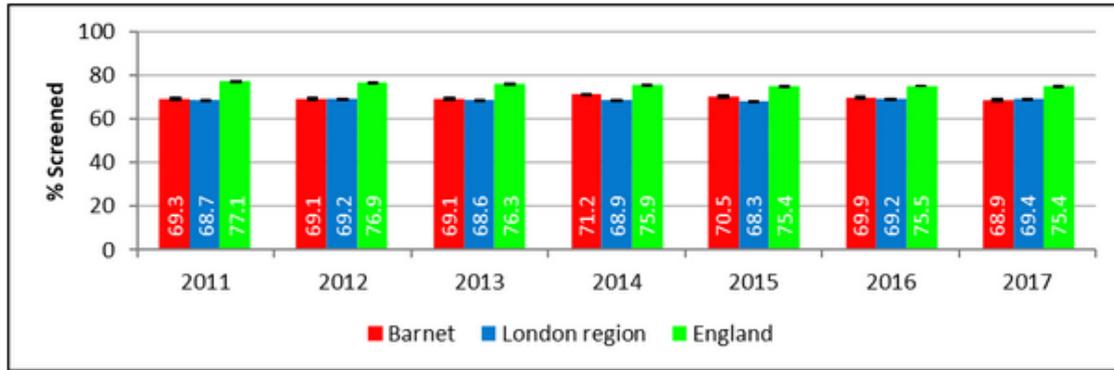
MacMillan offer some training on general Cancer awareness as well as specific types of Cancers, living with Cancer and Palliative Care. Their training programme can be found via their website:

<https://learnzone.org.uk/professionals/>

<https://learnzone.org.uk/public/>

## Action Plan

The Barnet Joint Strategic Needs Assessment identifies that Cancers are within the leading three causes of deaths for men and women in Barnet. It also highlights that, within the general population of the borough, Cancer screening coverage for Barnet was significantly worse than the national average for bowel, breast and cervical Cancers between 2015 and 2017.



Source: Public Health England, Public Health Outcomes Framework.

Expect the Best conclude that there are major barriers to engaging with both health services and with people with Learning Disabilities themselves on the issue of Cancer Screening. However, to make changes towards stronger engagement, this must be driven by health services. We would like to see this issue raised within the CCG and the Health and Wellbeing Board to consider how improvements can be made and to seek a multi-agency commitment from health services and commissioning within Barnet to take this forward.

Aim:

What do we want to achieve	Lead	Achieved by	BRAG	Comments
1. To provide information for people with learning disabilities and family carers about cancer, cancer screenings and lifestyle changes				
2.1 To make available to service providers the above information				
2.2 To adapt for providers local Public Health information in a pack				
3. To hold a workshop for service providers to raise awareness of cancer, cancer screening and lifestyle changes				
4.1 To provide awareness training for staff at breast-screening clinics, including information and Easyread material				

<b>What do we want to achieve</b>	<b>Lead</b>	<b>Achieved by</b>	<b>BRAG</b>	<b>Comments</b>
4.2 To produce Easyread invitations to screenings				
4.3 To review GPs' list of people to invite for screening to make sure they include people with learning disabilities				
4.4 To support GPs regarding MCA and best decision-making for cancer screening				
5. Work with the Care Quality Team to repeat the survey of providers				
6. Repeat the focus group for people with learning disabilities and update the local case studies				
7. To create a specific section on cancer and cancer prevention in My Health Matters				
8. To ensure there is a link with cancer and cancer screening in the Annual Health Checks				

<b>What do we want to achieve</b>	<b>Lead</b>	<b>Achieved by</b>	<b>BRAG</b>	<b>Comments</b>
9. To update the prevalence rates for people with learning disabilities in Barnet				

## Surveys

### Bowel Cancer Survey

**Cancer Screenings Project**  
**Questionnaire – Bowel Cancer Screening**




**1. Are you answering these questions about:**

	Please tick
 Yourself	<input type="checkbox"/>
 A relative you care for	<input type="checkbox"/>
 someone you support professionally	<input type="checkbox"/>
 Other (please tell us)	<input type="checkbox"/>

**2. What is your gender?**

 Male	<input type="checkbox"/>
 Female	<input type="checkbox"/>
 Transgender	<input type="checkbox"/>

**3. How old are you?**

 60-75	<input type="checkbox"/>
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**4. Do you consider yourself to have:**

 Mild Learning Disabilities	<input type="checkbox"/>
Moderate Learning Disabilities	<input type="checkbox"/>
Severe or profound Learning Disabilities	<input type="checkbox"/>
Autism or Aspergers	<input type="checkbox"/>
None	<input type="checkbox"/>
Don't know	<input type="checkbox"/>
Other (please tell us what)	<input type="checkbox"/>

**5. Do you have any physical disabilities?**

	<input type="checkbox"/>
 Yes	<input type="checkbox"/>
 No	<input type="checkbox"/>

**6. Do you have any support needs? e.g. a mobility aid, a wheelchair or communication needs**

 Yes (Please tell us more)	<input type="checkbox"/>
 No	<input type="checkbox"/>

**7. Have you been sent a home testing kit for bowel cancer screening in the last 2 years?**

 Yes	<input type="checkbox"/>
 No	<input type="checkbox"/>

**8. Did you complete the home testing kit?**

 Yes	<input type="checkbox"/>
 No	<input type="checkbox"/>

**9. If you said yes – what was it like to complete the home testing kit?**

<input type="text"/>	<input type="checkbox"/>
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**10. Did you have support to complete the test?**

 Yes – Please explain:	<input type="checkbox"/>
 No	<input type="checkbox"/>

**11. If you did not complete the test, please tell us why not**

<input type="text"/>	<input type="checkbox"/>
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	<b>12. What would make it easier for you to complete the test?</b>	
	Understanding the test better	
	Having support from another person	
	Easier instructions about the test	
	Other (please tell us)	

	<b>13. Were you shown any easy read information about bowel cancer screening?</b>	
	Yes	
	No	
	Don't Know	

	<b>14. Have you seen any easy read information about bowel cancer?</b>	
	Yes	
	No	
	Don't Know	

	<b>15. Have you been to an Annual Health Check with your GP in the last year?</b>	
	Yes	
	No	
	Don't Know	

	<b>16. If yes, did you talk about bowel cancer screenings at the annual health check?</b>	
	Yes	
	No	
	Don't Know	

**(For Focus Group only)**  
 Now we will look at some Easy Read Information about Bowel Cancer and smear tests.  
 We would like to know what you think and if it has helped you at all.

	<b>17. What did you learn about Bowel Cancer?</b>

	<b>18. What did you learn about bowel cancer home testing?</b>

	<b>19. Has this changed whether you would complete a home testing kit?</b>
	Yes
	No

# Breast Cancer Survey



**Cancer Screenings Project**  
Questionnaire  
- Breast Cancer Screening



Expect the Best  
The Cancer Research UK  
healthwatch  
Basset

1. Are you answering these questions about:		Please tick
	Yourself	<input type="checkbox"/>
	A relative you care for	<input type="checkbox"/>
	Someone you support professionally	<input type="checkbox"/>
	Other (please tell us)	<input type="checkbox"/>

2. How old are you?		Please tick
	50 - 69	<input type="checkbox"/>

3. Do you consider yourself to have:		Please tick
	Mild Learning Disabilities	<input type="checkbox"/>
	Moderate Learning Disabilities	<input type="checkbox"/>
	Severe or profound Learning Disabilities	<input type="checkbox"/>
	Autism or Aspergers	<input type="checkbox"/>
	None	<input type="checkbox"/>
	Don't Know	<input type="checkbox"/>
	Other (please tell us what)	<input type="checkbox"/>

4. Do you have any physical disabilities?		Please tick
		<input type="checkbox"/>
	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>

5. Do you have any support needs? e.g. a mobility aid, a wheelchair or communication needs		Please tick
		<input type="checkbox"/>
	Yes (Please tell us more)	<input type="checkbox"/>
	No	<input type="checkbox"/>

6. Have you been offered a breast cancer screening appointment in the last 5 years?		Please tick
		<input type="checkbox"/>
	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>

7. If you answered no, have you had a letter inviting you to a breast cancer screening in the last 5 years?		Please tick
		<input type="checkbox"/>
	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>

7. If you said yes, how would you rate your experience?		Please tick
	Excellent	<input type="checkbox"/>
	Good	<input type="checkbox"/>
	Ok	<input type="checkbox"/>
	Bad	<input type="checkbox"/>

10. If you were invited to a breast screening but did not go, please tell us why		Please tick
		<input type="checkbox"/>
	Worried or scared about the test	<input type="checkbox"/>
	Thought the test would be painful	<input type="checkbox"/>
	Do not understand what a smear test is	<input type="checkbox"/>
	Did not understand the letter	<input type="checkbox"/>
	Embarrassed about having the test	<input type="checkbox"/>
	Other - please tell us why	<input type="checkbox"/>

8. What made you choose this rating? What made it a good or bad experience		Please tick
		<input type="checkbox"/>
		<input type="checkbox"/>

	11. What would make it easier for you to complete the test?	
	Understanding the test better	
	Having support from another person	
	More time with the nurse doing the test	
	Other (please tell us)	

	12. Were you shown any easy read information about breast cancer screening?	
	Yes	
	No	
	Don't Know	

	13. Have you seen any easy read information about breast cancer?	
	Yes	
	No	
	Don't Know	

	14. Have you been to an Annual Health Check with your GP in the last year?	
	Yes	
	No	
	Don't Know	

	15. If yes, did you talk about breast cancer screenings at the annual health check?	
	Yes	
	No	
	Don't Know	



(For Focus Group only)

Now we will look at some Easy Read information about Breast Cancer and breast cancer screening.

We would like to know what you think and if it has helped you at all.

	16. What did you learn about breast cancer?

	17. What did you learn about breast cancer screening?

	18. Has this changed whether you would <u>attend</u> a breast cancer screening?
	Yes
	No

# Cervical Cancer Survey



Cancer Screenings Project  
Questionnaire – Smear Tests



1. Are you answering these questions about:		Please tick
	Yourself	
	A relative you care for	
	Someone you support professionally	
	Other (please tell us)	

2. How old are you?		
	18 – 24	
	25 – 49	
	49 or older	

3. Do you consider yourself to have:		
	Mild Learning Disabilities	
	Moderate Learning Disabilities	
	Severe or profound Learning Disabilities	
	Autism or Aspergers	
	None	
	Don't Know Other (please tell us what)	

4. Do you have any physical disabilities?		
	Yes	
	No	

5. Do you have any support needs? e.g. a mobility aid, a wheelchair or communication needs		
	Yes (Please tell us more)	
	No	

6. If you are 25 – 49 years old have you had a smear test in the last 3 years?		
	Yes	
	No	

7. If you are 49 years old or older have you had a cervical 'smear test' in the last 5 years?		
	Yes	
	No	

8. If you said yes – how would you rate your experience?		
	Excellent	
	Good	
	Ok	
	Bad	

9. What made you choose this rating? What made it a good or bad experience?		

10. If you answered no – Have you had a letter inviting you to have a smear test in the last 3 - 5 years?		
	Yes	
	No	

11. If you were invited to a smear test, but did not go, please tell us why		
	Worried or scared about the test	
	Thought the test would be painful	
	Do not understand what a smear test is	
	Did not understand the letter	

	Embarrassed about having the test	
	Other – please tell us why	

	<b>12. What would make it easier for you to go for a smear test?</b>	
	Understanding the test better	
	Having support from another person	
	More time with the nurse doing the test	
	Other (please tell us)	

	<b>13. Were you shown any easy read information about having a smear test?</b>	
	Yes	
	No	
	Don't Know	

	<b>14. Have you seen any easy read information about Cervical Cancer?</b>	
	Yes	
	No	
	Don't Know	

	<b>15. Have you been to an Annual Health Check with your GP in the last year?</b>	
	Yes	
	No	
	Don't Know	

	<b>16. If yes, did you talk about the smear test at the annual health check?</b>	
	Yes	
	No	
	Don't Know	

 **(For Focus Group only)**  
 Now we will look at some Easy Read information about Cervical Cancer and smear tests. We would like to know what you think and if it has helped you at all.

	<b>17. What did you learn about Cervical Cancer?</b>

	<b>18. What did you learn about smear tests?</b>

	<b>19. Has this changed whether you would attend a smear test?</b>
	Yes
	No



## Appendix: High risk groups – barriers to accessing cervical cancer screening and best practice



### Barriers facing BME women

The problem: **1/3 more** eligible BME women have never had cervical screening compared with white women

Reasons for this include:

- **Low awareness** of what cervical cancer is, risk factors (including HPV), symptoms or the test's purpose
- **Cultural barriers** including stigma around cancer, fatalism
- **Marital status** – it may be considered unnecessary for unmarried women by relatives/elders; sexual activity before marriage is taboo and may not be disclosed
- **Embarrassment and fear** about the test itself
- Embarrassment about the presence of a male doctor
- Fear about a negative outcome
- **Literacy and language barriers** affecting understanding of written invitations

(From research undertaken by Jo's Trust. April 2018.)

BME women

Younger women

LGBT+ people with a cervix

Women from deprived areas

Women with disabilities

Survivors of sexual violence



## What works in reaching BME women?

- Simple English and/or materials translated into people's own language
- Trusted messengers from within their local community
- Engagement through community leaders, faith groups, religious leaders to increase understanding and break down stigma
- E.g. programme run by VBME-Trafford - cervical screening liaison worker (Aliya) who went into local BME shops/businesses, worked with community leaders and called women directly



## Case study – 6-week programme by VBME-Trafford



- Materials developed & translated
- Community outreach - faith groups, BME community groups & ESOL classes, schools, community centres & libraries, local businesses
- Directly contacting women who had not responded to screening invitations by phone



## VBME-Trafford programme

- Project led by BME Health Liaison Worker Aliya Bukhari, helped by her cultural + linguistic skills
- 1 in 4 women declined to book when contacted by phone
- Targets set for March 2015: 100

Outcome	Number of women
Total Appointments Booked	107
Total Appointments Attended	72
Appointments did not attend (DNA)	35
Number of women overdue by 5 years +	19
Number of women lesbian or bisexual	3

Many women were booked for April 2015 and are therefore not included in these figures.

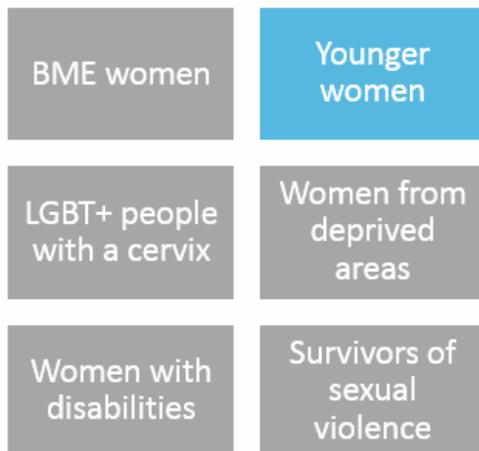


## Barriers facing younger women

**1 in 3** women aged 25-29 skip screening (vs 1 in 4 on ave.)

In a recent survey by Jo's Trust:

- **Lack of knowledge and understanding** - 61% of women aged 25 to 35 were unaware they were in the highest-risk group for cervical cancer, a quarter didn't think they needed to go as they were healthy. Over 1/3 believed screening doesn't reduce your cancer risk.
- **Body image and embarrassment** - 35% of all women reported being embarrassed to attend because of their body shape (50% of non-attenders). 48% of non-attenders had concerns over the appearance of the vulva and 54% about whether they smelled 'normal'; 31% said they wouldn't go if they hadn't shaved/waxed their bikini area
- **Accessibility barriers** - 35% wouldn't go if they had to take time off work, 16% wouldn't miss the gym for it. 26% said it's too hard to make an appointment
- **Fear of the 'unknown'** coupled with others' 'horror stories' (Farrington, April 2010)



## What works in reaching younger women?

- Addressing knowledge gaps to explain the test's relevance and benefits, including that they are in a particularly high-risk group
- Making it easier to book an appointment, including evening/out-of-hours appointments
- Younger women are more likely to get health-related information online and use social media



## Barriers facing women from deprived areas

The problem: 1 in 2 women from the most deprived parts of the UK do not attend cervical screening

In a 2011 study based in an area of social deprivation:

- **Practical issues** such as the timing of the appointments, lack of time and having to find childcare were identified as important barriers to screening.
- **Knowledge** of cervical cancer including associated risks and preventative factors was extremely limited.
- **Negative previous experiences** of cervical screening, with feelings of 'fear', 'embarrassment' and feeling 'stigmatised'

BME women

Younger women

LGBT people with a cervix

Women from deprived areas

Women with disabilities

Survivors of sexual violence

Logan, L., & Mollifpatrick, S. (2011). Exploring women's knowledge, experiences and perceptions of cervical cancer screening in an area of social deprivation. *European Journal of Cancer Care*, 20(6), 720-727.



## Barriers facing LGBT people

The problem: **Half** of all eligible gay or bisexual women have never had a smear test

- In a 2011 survey, 37% of gay and bisexual women questioned had been **informed (incorrectly) by a health professional that cervical screening is not required if not having sex with men**
- Many LGBT women have had **negative experiences of healthcare** which can create a further barrier to accessing screening – in a survey of LGBT women, 36% said a doctor or nurse had assumed they were heterosexual.
- **52% cited embarrassment or fear** as reasons why they had not undergone screening in an Australian survey
- Trans men/non-binary people with a cervix are eligible but **will not routinely receive invitations to cervical screening** if registered as male with their GP practice, and may find cervical screening difficult psychologically



<https://www.bbc.co.uk/news/health-39230807>  
<https://www.nhs.uk/common-health-questions/sexual-health/should-trans-men-have-cervical-screening-tests/>

## What works in reaching LGBT women?

- Need for myth-busting because misinformation is prevalent
- Clear, evidence-based messages & information, from trusted messengers

Australia's '**The Inner Circle**' campaign is a good example of a campaign focused on improving understanding and awareness as well as uptake of cervical cancer screening amongst LGBT+ people who have a cervix

## Barriers facing women with disabilities

The problem: **only 19%** of women with LD have recently had a smear (vs 73% in the general population)

### Barriers facing women with learning disabilities:

- Low levels of understanding about cervical cancer, the test and its relevance in women with learning disabilities
- Literacy barriers
- Practical difficulties, especially if no carer available to assist with booking an appointment/accompanying to it
- People with autism or learning disabilities feel 30% less likely to be listened to by their GP.
- GPs may wrongly assume patients are not sexually active

### Barriers facing women with physical disabilities:

- Mobility barriers for some women with physical disabilities
- Body image barriers which can affect women both with and without disabilities may be more pronounced\*

BME women

Younger women

LGBT people with a cervix

Women from deprived areas

Women with disabilities

Survivors of sexual violence

<http://www.dimensions-uk.org/wp-content/uploads/MyGPandMe-Making-primary-car-fair-Dimensions.pdf>

\* e.g. Moin, V., Duvdevany, I., & Mazor, D. (2009). Sexual identity, body image and life satisfaction among women with and without physical disability. *Sexuality and Disability*, 27(2), 83-95.

## What works for women with disabilities?

PHE and Jo's Trust have produced an EasyRead written guide and a Smear Test Film, both with close input and feedback from women with LD

### Ways to reduce distress (advice from Cancer Research UK)

Taking all of the relevant risk factors into account, if the woman or her carer and doctor decide to do a cervical screening test there are ways of reducing distress:

- the woman needs to have a good explanation of what will happen
- they need to have someone with them who they know and trust
- a series of visits to the clinic beforehand to get to know the people involved

## Barriers facing women who have experienced sexual violence

- May not wish to disclose or have to recount what they have been through with a doctor/nurse, particularly one they have not met before
- May find anticipation of and/or the procedure itself (including power dynamics and concerns about feeling powerless to stop it) very difficult to manage
- Shame or believing that they do not deserve good health
- Embarrassment that there may be signs of damage, either from the attack or from coping mechanisms such as cutting and that they may be judged or might inadvertently disclose what happened
- Worries about how reactions to the examination, such as crying or dissociation, will be perceived or being judged



## Practical suggestions around cervical screening for women who have experienced rape/sexual assault (from Jo's Trust & the My Body Back Project)

- Double appointments to allow the patient more time both before and after the smear to recover their equilibrium.
- Booking an initial appointment to allow the patient to get to know the smear-taker, with reassurance that they don't have to have the smear test then.
- Bringing someone else as support or to serve as the patient's voice if they feel that they may lose it.
- Writing a letter (or ask a trusted person to), explaining their particular difficulties with having a smear and any specific dos and don'ts for the smear taker.

### Specialist services (eg. Rape Crisis and the My Body Back Clinic)

<https://www.jostrust.org.uk/blog/let%E2%80%99s-talk-about-it%E2%80%A6smear-tests-after-experiencing-sexual-violence>

## Barnet Learning Disabilities Service

### Lucy Little - Community Learning Disability Nurse

I commenced this project in January 2017 as part of my role as Health Promotion Lead within the Barnet Learning Disabilities Service.

I initially began with researching what the current National recommendations in relation to Cancer Screening were, I discovered the following:

**NHS National Bowel Screening Programme** - screening every 2 years to all men and women aged 60 to 74 (home testing kit).

**NHS National Breast Screening Programme** - screening every 3 years to all women aged 50 to 70, however so areas are offering from 47 years old and up to 73 years old.

**NHS National Cervical Screening Programme** - screening every 3 years to all women aged 25 to 49 and all women aged 50 to 64 every 5 years.

Although these were the National recommendations, I wanted to find out what was being offered to people with a Learning Disability in the London Borough of Barnet. In order for me to find this out, I decided to carry out some of my own research. I wrote letters to GP practices with attached questionnaires to be completed.

Initially in February 2017, I randomly selected 26 GP practices within the London Borough of Barnet and forwarded questionnaires to them to ascertain what Cancer Screening service they offer to people with a Learning Disability within their practice.

Having received only 4 responses back, I decided to send a further 35 in April 2017 (covering the rest of the GP practices that we have on our DES list).

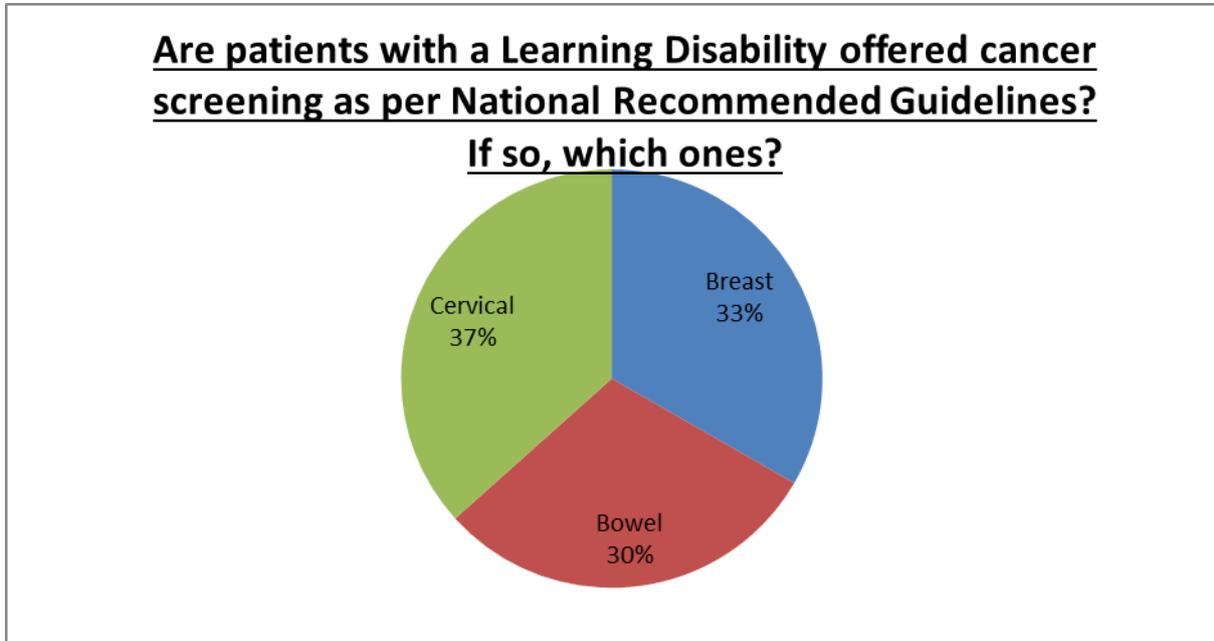
I received an additional 7 responses back, bringing the total of 11 GP practices with the London Borough of Barnet responded to the questionnaires I sent. To note - two were sent back with address no longer valid.

The questionnaires were made of 5 questions, giving the opportunity to answer “yes” or “no” with a selection of tick boxes too.

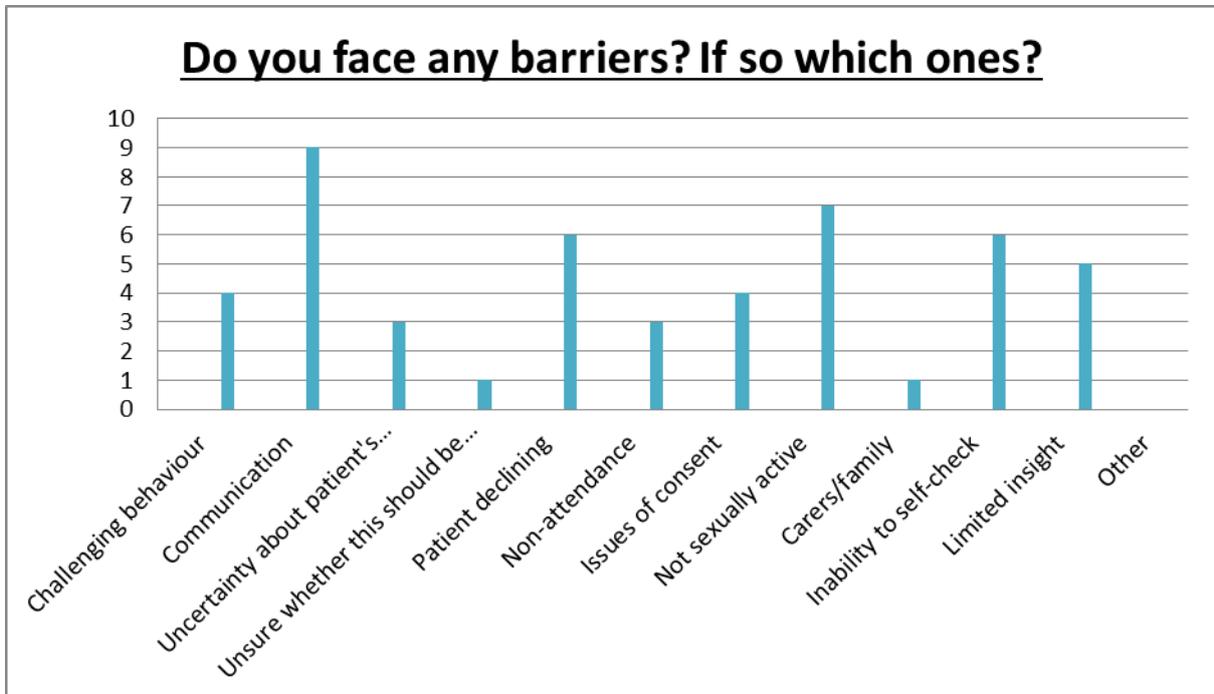
The questions were (including some comments made in response - in addition to tick box):

1. Are patients with a Learning Disability offered cancer screening as per Nation Recommended Guidelines? If so, which ones?

*“Yes, as per national screening programme.”*



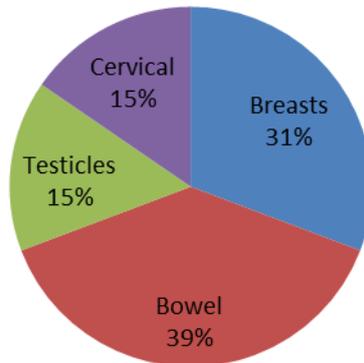
2. Do you face any barriers? If so which ones?



3. In your experience, do carers/families support with checking for abnormalities? If so, which areas? And how?

One comment written in response to this question was: *“not sure”*, another was *“help with discussion in surgery”*

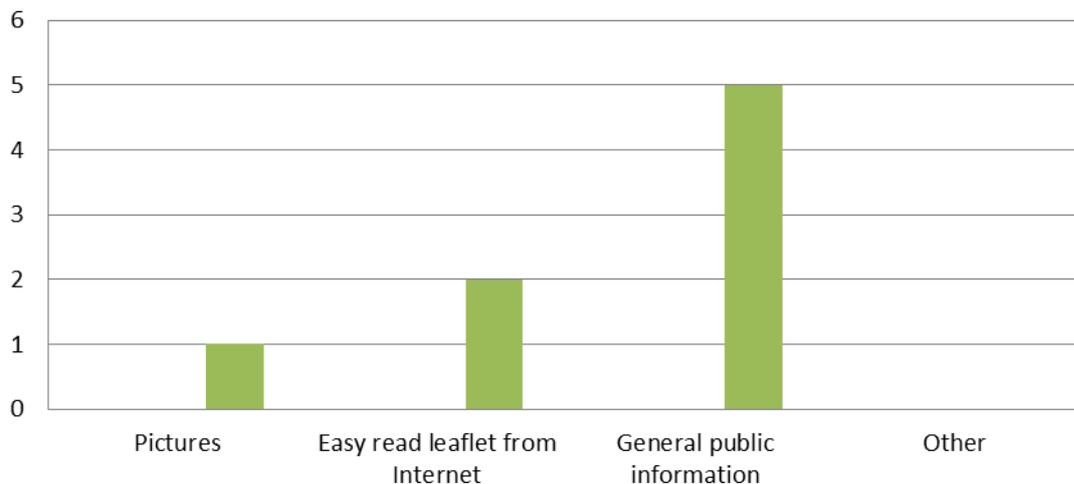
**In your experience, do carers/families support with checking for abnormalities? If so, which areas? And how?**



**4. Do you offer easy read information about cancer screening? If so, what does this information look like?**

One comment made in response to this question was; no, *“but can consider as future action”*

**Do you offer easy read information about cancer screening? If so, what does this information look like?**



**5. Is there any support your practice would like in regard to cancer screening and your patients with a Learning Disability?**

Comment written in response to this question included:

*“Written material to be able to give to patients/carers”*

*“Central support for ensuring these patients receive suitable literature and on practice LD list.”*



There was an additional question at the end, this was:

**6. How would you like to see the future in cancer screening for your patients with a Learning Disability?**

The comments made were:

*“Increased screening that is appropriate for the patient.”*

*“Formal invite tailored to those with LD.”*

*“I would like to see set up specialist clinics with mental health nurses who are trained to do checks for cancer abnormalities signs and symptoms. Patients will be familiar if they see same face each time. Even home visit to arrange them to be seen in their own environment.”*

*“Easy access and regular follow-up.”*

In addition to the questions, there were options to add additional comments throughout, as well as at the end of the questionnaire. The comments received were:

*“Only have 2 patients with learning difficulty - both very mild so probably not needing lots of input.”*

*“It would be good if there was additional support provided as often these patients require a lot more time in order to gain consent. Also, it is not always appropriate to do screening in the presence of carers.”*

Following the results received from the questionnaires to GP practices, I felt that more information needed to be gathered to find out what is going on from a care providers perspective around cancer screening.

At the beginning of October 2017, I wrote to 10 care providers within the London Borough of Barnet, in particular one service within each. I sent them a questionnaire to complete also.

I only received one response back of which did not provide me with enough detail or information.

Due to a change in role within the team, my cancer screening project came to an end and unfortunately no further data has been gathered or progress made.

Hopefully in the future, this project can be picked up again and continued.