



**Cervical Cancer Screening  
Project**

Report June 2020

**ANSWER  
CANCER**

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## Introduction

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This report details the findings of a major piece of engagement on cervical cancer screening and related experiences in Bolton. The work was conducted between July 2019 – February 2020.

We wish to say thank you to the many people that supported the project; those that helped co-ordinate sessions and focus groups, promote the work and support in many ways.

Thanks to the many people that have given us their views and shared personal experiences; attendees at sessions and focus groups, those that responded to surveys, individuals that have contacted through our other channels such as social media, email and telephone.

### Background to the project - Bolton

Healthwatch Bolton consulted on potential health and wellbeing activity for 2019-2020 and members voted 'prevention and screening' as a topic. We had the contribution of 200 people.

We decided to engage with women from a variety of sections of the community to deliver information and engagement sessions based around cervical screening. The general aim of the project was to establish what is and is not known by local people in Bolton about cervical screening. In addition, we hoped to highlight potential community cancer champions, which will ensure the work of increasing participation in cervical screening is sustainable.

The latest statistics for screening uptake in Bolton are:

- Breast - 68.9%
- Bowel - 54%
- Cervical 25-49 - 67.2%
- Cervical 50-64 - 75.9%

*\* as advised by Bolton Clinical Commissioning Group (March, 2019)*

Although uptake for cervical screening appears highest, it is actually, the one area where uptake is falling year upon year. Therefore, we felt we should focus our engagement on cervical screening in the hope of having most impact.

### Background to the project – Greater Manchester

Answer Cancer is the Greater Manchester Screening and Engagement Programme. It is commissioned through Greater Manchester Health and Social Care Partnership. Its aim is to provide a coordinated cancer screening prevention and screening awareness engagement programme across Greater Manchester.

The Answer Cancer Programme is a partnership between Salford CVS, BHA for Equality, Unique Improvements and Voluntary Sector North West.

The programme focuses on priority areas and communities, using a diverse range of approaches and interventions, by means of a community development and social movement approach. The programme stimulates a community-upwards, grass roots approach, where communities come together to improve the health of each other, independently of formal service structures.

In year one of the programme, five priority localities across Greater Manchester were identified where cancer screening uptake was particularly low. Bolton was one of these priority localities. In addition, communities of identity - who span geographies - are also a priority. These include Black, Asian and Minority Ethnic (BAME) communities, LGBT+ communities, carers, people with disabilities and communities living in lower socio-economic areas.

Answer Cancer delivers awareness raising sessions to communities, and utilises Answer Cancer Champions to increase awareness raising of Breast, Bowel and Cervical screening within communities. We offer a small grants scheme to support activity by community groups in raising awareness of cancer screening programmes, also offer a variety of training courses to upskill Answer Cancer Champions and those seeking to improve their knowledge on cancer, and offer support around evaluating activities which are delivered.

Through conversations between Healthwatch and Answer Cancer, an opportunity for joint delivery sessions was identified for Bolton. It was felt that engagement across communities - which would aim to include support from various stakeholders, would allow us to reach out to a wide range of people in Bolton. This would enable us to collate data which would be able to feed into both Bolton and Greater Manchester level Public Health, clinical commissioning group, council and primary care.

The project hoped to raise awareness and an increased appetite for continued awareness raising around cervical screening throughout various community groups in Bolton. A number of groups who participated in the project focus groups were successful in securing funding through Answer Cancer - to recruit Answer Cancer Champions and raise awareness on Breast, Bowel and Cervical screening which will help ensure the work we start is sustainable.

The Answer Cancer team will be continuing their work over the next three years and will be writing an evaluation report the following year. This ensures we will be able to see any impact from the project itself in combination with other work around screening in Bolton.

We will use the findings to provide recommendations to the Local Authority and Clinical Commissioning Group commissioners, public health, Greater Manchester Health and Social Care Partnership and Voluntary Community Services, as to how to increase uptake of cervical screening.

## Recommendations

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- Offer more flexible appointment times and locations to women. For some women, having a bad experience of a smear test due to factors such as attitude of staff, unpleasant environment, procedure not being explained properly etc, can all contribute to whether a woman will return for future smears. Care and consideration need to be embedded in the screening procedure to ensure it is as good an experience as possible.
- Increase education and understanding of cervical cancer, smear tests and particularly around the Human Papilloma Virus. Educate girls early in school so that screening is a 'normal' part of life and something that should be valued. Also raise awareness in communities on the needs of young women and men to have the HPV injection.
- Work closely with women from BAME communities who do not attend smear tests for cultural and religious reasons. Work to have a continuous dialogue with these communities to understand what can be put in place to encourage screening uptake.
- Highlight the need for unmarried women from BAME communities to still attend cervical screening.
- Educate men in the community into the need for women to attend cervical screening – so women can be supported to attend.
- Ensure health professionals understand why some women greatly fear a smear test, why they may fear it and work towards allaying fear e.g. Videos to show what happens, equipment used etc.
- Ensure female health practitioners are available to do the smear tests and ensure women are treated with patience, dignity and kindness.
- Ensure accessible literature is available particularly in areas of high footfall. Work with groups that are not attending screening to understand why e.g. those with a learning disability.
- Ensure literature includes the right to choose whether to have a test or not and also, if there are things in place to make women more comfortable such as different sized speculums.
- Work to ensure women receive a more personalised approach to smear testing and work to ensure women with disabilities get the same opportunities to be screened. Women with a learning disability should be invited for a smear with extra encouragement and information provided to ensure they attend.

- Be more understanding around the difficulties women may have in making appointments taking into account timings around women’s menstrual cycles. Consider extra training for staff booking appointments.
- Be mindful that some women have suffered sexual abuse and therefore work towards putting measures in place to help and encourage these women to have a smear.
- Commissioner’s employ a Cancer Screening Improvement Lead for Greater Manchester focusing on cervical screening to improve uptake and address barriers for women accessing services. Mirroring approaches for Breast and Bowel Improvement leads

## Summary of findings

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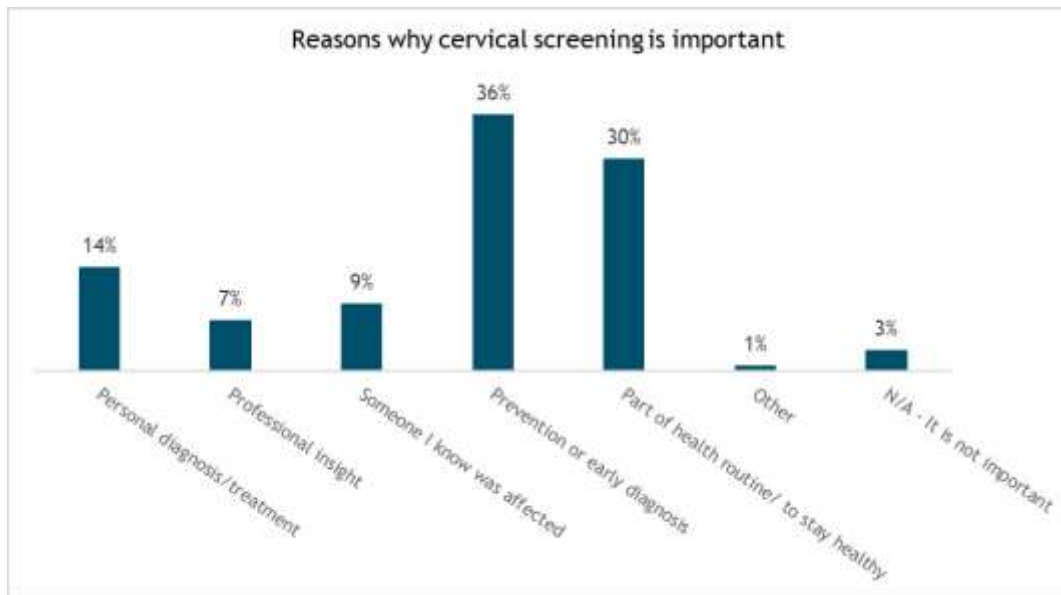
### Survey work

This section focuses on the results from the survey work. Details of the demographics can be found at the end of the report.

Each section presents the overall theme of the question topic area within the survey. Selected quotes are used when free comment boxes were present. Note that this is only a small selection of quotes intended to be representative or highlight key opinions overall.

### General

- When asked ‘how important is cervical screening to you?’ The majority of people felt it was ‘very important’ 78% (1004). Other responses included ‘quite important’ 12% (158), ‘A bit’ 5% (61), Not at all 5% (69). A total 90 people did not respond.
- A follow up question investigated the ‘reasons why’ people thought screening was important. As can be seen in the chart below, ‘prevention or early diagnosis’ 880 (36%) and ‘part of health routine/to stay healthy’ 728 (30%) were the most important reasons given.



*\*Respondents were allowed multiple selections in this question, the total responses were therefore 2466*

- When asked if 'you or someone you know had been affected by screening results?' there was a near even split between 'yes' 668 (52%) and 'no' 624 (48%). A total 90 people did not respond.

- In the follow up question whether 'this impacted on how important you feel cervical screening is to you?' most said 'yes' 557 (43%). The other answers included 'no' 144 (11%), 'not sure' 85 (7%), 'n/a' 506 (39%). A total 90 people did not respond.

### **The importance of screening**

"We are so lucky to have a free NHS, and to have free screening for this and other conditions."

"It is important to also recognise that some people find the smear test anxiety provoking and logistically difficult particularly if they suffer from vaginismus. There is a lack of awareness and assistance for this condition and people feel shame associated with it. The blood test would be amazing for people like this. One of my daughters would love this option as she suffers from vaginismus. She is one of the people overdue a test because of her condition and it worries me."

"I am aware that my lifetime risk of cervical cancer stands at 0.7% with the chance of unnecessary interventions brought about by cervical screening being very high. With that in mind, the risk vs the benefits, I'm happy with my very low risk and choose not to screen."

"I urge every woman to have their smear. I did, pre-cancerous cells were found and I was treated. I'm not sure what the consequences would have been had I not booked that smear. Part of my role now is looking after women who have smears, have treatment and unfortunately don't make it. EARLY DIAGNOSIS IS KEY AND IT'S REALLY NOT THAT SCARY"

### **Why screening is important**

"I think it's important for every woman to have their smear test. I honestly don't understand the reasons why women choose not to go. I'll be nervous the first time I get mine (in five years) however I'd be even more nervous having cancer treatment."

"The NHS is strapped for cash yet millions are spent on screening/treating healthy people with no symptoms, plus money on all these awareness campaigns is ridiculous. Let us not forget that screening is a choice, it is elective & a personal decision. Your target to screen everyone is 80% & this negates consent or informed choice!"

"Why would you not think it is important? Cancer affects 1 in 3 of us now and it does not discriminate so everyone has the potential to be affected."

### **How people were affected by screening**

"I know two people who had false positive results and have been traumatised as a result of this. They had nothing wrong with them but due to a false reading they have suffered greatly."

"Close friend, was caught early, treated and OK. Going under monitoring now."



## Understanding

- When asked 'were you aware that this is the purpose of a cervical screening' having been given a statement that explains the screening, a majority said 'yes' 1246 (96%), with a smaller number stating 'no' 46 (4%). A total 90 people did not respond.
- When asked 'do you know where to get information about cervical screening?' once again a majority said 'yes' 1178 (91%), with those saying 'no' 114 (9%). A total 90 people did not respond.
- People were also asked 'did you previously know how often you will be invited for a cervical screening?' Most respondents said 'yes' 1079 (84%) to the question, a minority said 'no' 213 (16%). A total 90 people did not respond.

### **Awareness of the importance of screening**

"It is only ever one sided not full balanced information is given."

"Many people think screening is done to detect cancer and I feel this is one of the reasons women are scared to attend. There is a definite lack of education about screening as it's a taboo subject people just don't want to talk about especially when it's related to cervical. I also think that many cultures also find this subject difficult to discuss and therefore it remains hidden."

### **Awareness of access to information about screening**

"Jo's Trust Cervical Cancer website is much better than the NHS. It acknowledges that testing can be a bad experience and gives advice to people who find the test difficult. It is less biased and more detailed than NHS information and makes it clear that testing is optional and you can opt out."

"It is a bit hit and miss in Bolton. Miscommunication with the GP practice. Much more organised when it was national screening."

"Jo's Cancer Trust, Cancer Research UK, generic websites, GP, nurse."

### **The frequency of invitations**

"It is utterly shameful that women under the age of 25 aren't invited for screenings. I was 20 years old when it was discovered that I had abnormal cells. Had I not had the screening, I could have developed cancer. Screening should be routinely offered to all women over the age of 16, and also on demand for anyone who asks for it."

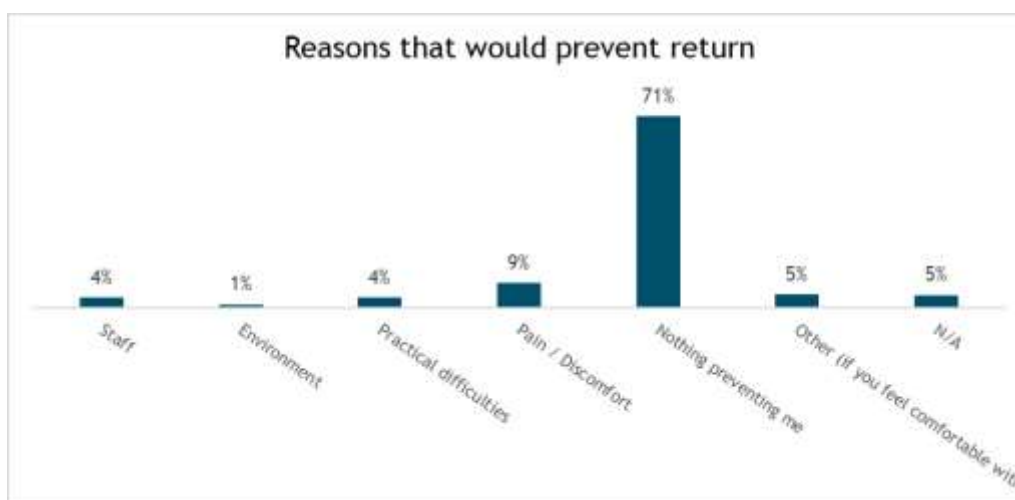
"Being 49 I would still prefer to be screened every 3 years."

"Yes although I would prefer it to be offered more often. The schedule seems like a long time when it could save your life. But I understand the service is pushed as it is."

"I am aware, however, as I've opted out of screening by staying in writing under GDPR, I do not give permission for my data to be processed for the purpose of health screening, it keeps any GP consultations on topic and removes me from the QOF list."

## Experience

- When asked 'have you been invited for a screening?' the majority of respondents said 'yes' 1142 (88%), of those that selected 'no' 61 (5%) were under the screening age, 44 (3%) were over the screening age. There were 45 (3%) of responses that said no for an 'other' reason. A total 90 people did not respond.
- When asked how 'did you feel when you received the information?' most respondents said 'positive' 490 (44%). Other responses included 'neutral' 209 (19%), 'negative' 77 (7%), necessary 272 (24%), n/a 26 (2%) and other 40 (4%). A total 268 did not respond.
- People were also asked if they had 'attended a screening?' to which the majority said 'yes' 1043 (94%). A smaller number said 'no' 71 (6). A total 268 people did not respond.
- A follow up question asked 'was there anything about your experience that would prevent you from going again?' the most popular response was 'nothing preventing me' 700 (71%), the second most popular response was 'pain/discomfort 92 (9%).



*\*Respondents that has attended screening were asked to respond, total responses were therefore 983*

- When asked if there was 'anything about your screening experience that has encouraged or motivated you to attend further screening?' the responses were nearly evenly split between 'yes' 387 (42%) and 'no' 525 (58%). A total 470 people did not respond.
- People were asked a follow up question 'were there any positives to your experience of screening?' the most popular answers were 'reassurance/a clear result' 571 (36%) and 'it was quick/easy' 522 (33%). Other responses were 'the staff' 313 (20%), 'diagnosis/treatment' 118 (7%), 'no' 71 (4%) and 'other' 7 (<0%).
- Those that had not attended a screening were asked the question 'if you have not attended, what are the reasons behind this?'. The responses included, 'made an informed choice' 22 (2%), 'practical reasons' 20 (2%), 'pain, embarrassment, discomfort' 43 (4%), 'too old/young' 3 (<0%), 'cultural reasons' 7 (1%), 'don't believe relevant to me' 6 (<1%), 'other' 71 (7%) and 'n/a' 764 (79%).

### **Invitation to screening**

“I am 60 and concerned that in a few years they will stop for my age!”

“Had regular screening until had hysterectomy.”

“I was told that due to the complications of accessing the service as a wheelchair user that I would not be called back, even though I am within the age bracket.”

### **After invited screening**

“But I didn’t feel positive going, feel too conservative to attend GP for a check -up due to fear and embarrassment.”

“The letter assumed that I had no choice or rights over my own body, and that my body was the property of the NHS. The letter gave me no right to reply or decline the invitation, which it should have done, by law. I was very angry that initially I was not given any opportunity to decline. It was only much later that I found out I could opt out. The letters are bullying and coercion.”

### **Barriers to prevent going**

“After my previous experience of screening and a subsequent sexual assault, I do not trust staff to treat me in a compassionate manner.”

“Appointment is during work time, so need to take time off work.”

“They forced the speculum into my body without my consent, I didn't get to choose.”

“Disgusted in hygiene practices with staff telling me they reuse the sheets they place on top of you as they don’t have enough for a fresh one for each new patient.”

“Very traumatic for me due to sexual assault.”

“I was seen by a male doctor which I wasn't comfortable with, when I asked for a female nurse there weren't any available.”

### **Motivate to return**

“Quick simple procedure - took about 10 mins from going into the room to coming out.”

“I feel really grateful and blessed that I live in a country and a time where this test is available to protect my health and well-being.”

“The procedure was quick and pretty much painless. The nurse was friendly and professional, and explained everything to me beforehand so I felt more relaxed.”

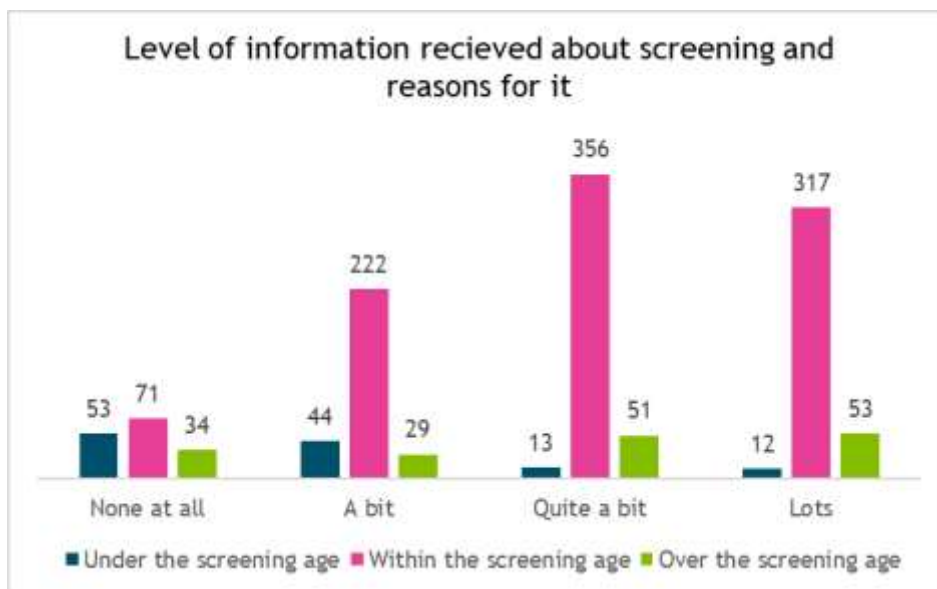
“I always go to my screening - it had never been a problem for me to attend and I have never had a bad experience in all my years of attending. The service is amazing and caught my pre-cancerous cells last year.”

### **Positives**

“The only positive thing is when you get the all clear (or an early diagnosis which could be life saving).”

## Knowledge

- People were asked to estimate the level of information they had received based on their age related to the screening programme 'How much information have you been given/told about the screening process and reasons for it?'. The chart below summarises the range of answers and suggests that those within the target range are most informed.



*\*The chart is based on number of responses for each option, there were 1255 responses in total.*

- Those below the screening age were asked 'have you had your human papillomavirus (HPV) vaccine?'. Responses were fairly even with 'yes' 62 (46%) and 'no' 72 (54%).
- When asked 'The HPV vaccine helps protect against cancers caused by HPV - Were you aware that this is the purpose of the HPV vaccine?' people mostly knew this was the case 'yes' 673 (62%), 'no' 421 (38%). A total 288 people did not respond.
- When asked 'From September 2019 in England, girls and boys aged 12 to 13 years will be routinely offered the first HPV vaccination when they're in school Year 8. The second dose is normally offered 6 to 12 months after the first (in school Year 8 or Year 9). - Were you aware of the above?' slightly more people did not know about this 'no' 605 (55%), 'yes' 489 (45%). A total 288 people did not respond.

### **The location of information**

“The letter you get from NHS with the invite to book an appt has info in the letter and a leaflet which are good.”

“I was told about this at Changing Life Directions well-being group. I was explained in Urdu and talked with other ladies.”

“Firstly, I had an information on the letter (invitation), secondly on my appointment I was been informed about the time of waiting for the result and the nurse gave me the additional leaflet to read.”

### **Information on HPV**

“In professional role/public health induction.”

“My sister had the vaccine at school and I researched it for her.”

“Information in the media, online and through information leaflets.”

“Via child’s school leaflet”

### **Awareness of school tests**

“More information would be helpful out there in doctors surgeries.”

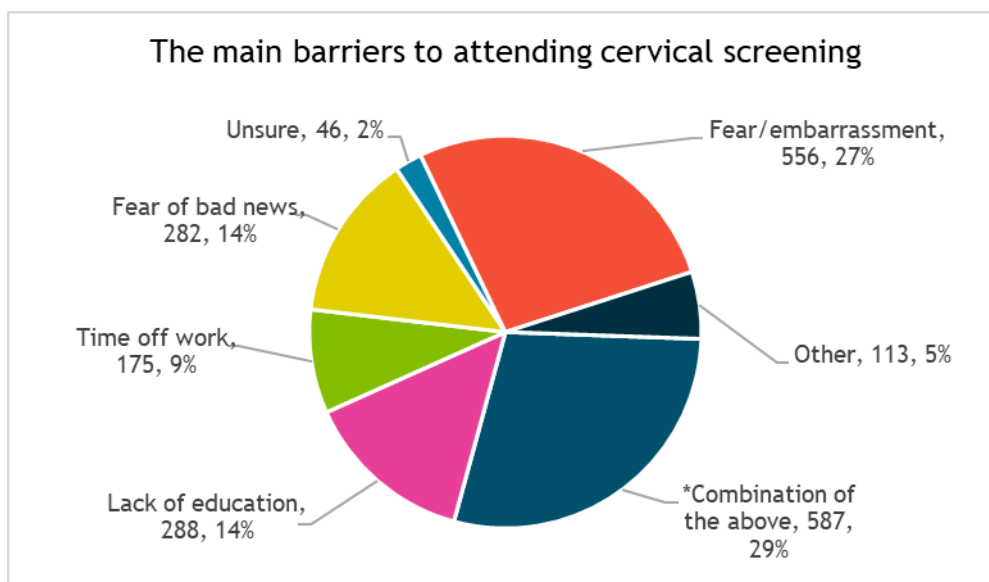
“Why stop at 25 years? Surely this would be safer to continue to offer the vaccine for longer.”

“This information should be shared more. I didn't get the vaccine because I was in the very first year it was given to schoolchildren and my mum wasn't convinced. Have recently felt worried that I didn't get the vaccine but didn't know: if I really needed it; if it was too late to get it; how I could get it, or whether it would cost me.”

“I was only aware that this was available to girls.”

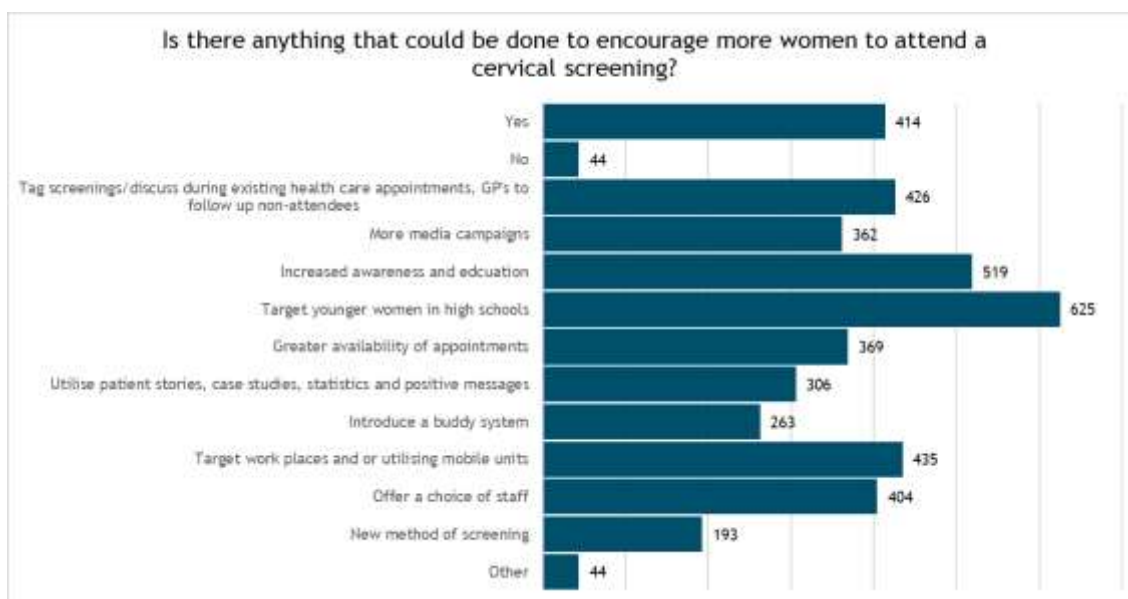
## Barriers

- People were asked 'What do you think the main barriers are for women attending cervical screenings?' from the responses 'combination of the above' 587 (29%) and 'fear/embarrassment' 556 (27%) were the main reasons. The chart below summarises the responses:



*\*Respondents were allowed multiple selections in this question, the total responses were therefore 2047*

- People were asked 'Is there anything that could be done to encourage more women to attend a cervical screening?' overall most of the possible options were popular, though 'Target younger women in high schools to prepare for future screenings' 625 (14%) and 'Increased awareness and education' 519 (12%) were the two most selected responses.



*\*Respondents were allowed multiple selections in this question, the total responses were therefore 4404*

- When asked 'Would it help to have the procedure explained first?' most people said 'yes' 914 (84%), a smaller number did say 'no' 180 (16%). A total 288 people did not respond.

#### **General comments on barriers to going**

"For all the women I know, the awful attitude of the staff that have treated them means they won't go back."

"People just put off doing things like this. I am really passionate about preventative health and I still put it off! It's just inertia - people need reminders. I normally leave letter in kitchen till I make appointment and it still takes me about 2 months!"

"In my opinion it is probably more that young women wish to close their minds to it, just like smokers do not want to think about lung cancer."

"Very embarrassing for some women to ask for time off work, especially male line manager in smaller organisations. A letter as evidence which just says required for a test without detail (maybe tear off strip) would help such women enormously. This test comes with a feeling of being a vulnerable female for some."

"It is not very nice, they don't want it, it is hard to get an appointment at the doctors, and you have to go through your menstrual cycle with the receptionist to try and coordinate the appointments available with the right time to do it. If you want it, this is a lot of faff, but you will do it. If not, it is all a pain in the derriere for something that is supposed to be routine."

"A lot of people hear the horrible experiences of the few people who struggle and think this is true for everybody. Also I have heard of people struggling to get appointments they are able to attend."

#### **Ideas on how to encourage attendance**

"I believe there are different size speculums. I have never been told or made aware of this before."

"Information in Urdu. No online appointments with GP."

"Make sure nurses/ doctors are female (most are). Age difference - young people who have not had children are much more likely to ignore/ defer appointments due to embarrassment/ comfort factors."

"Honesty about the screening, do not make women feel bad if they have not or cannot attend. Realise that sexual abuse can greatly affect the ability to have a cervical screening done, and that it is not comfortable for everyone."

#### **Whether having the test explained before is of use**

"For the initial appointment probably yes, but if the healthcare professional doing it is quick and does it pain free and makes it a positive experience it shouldn't need doing again."

"Please tell the woman that it is her choice whether or not to screen and explain limitations of screening/risks/harms."

## Own experiences

### Family and friends

#### **Young women**

“Many young women are hesitant and anxious coming for 1st ever smear. Some hear 'horror stories' from friends. Once they have actually had the smear test done they always say it was not as bad as they thought it would be.”

“I talk about it openly to my daughter.”

#### **Embarrassment**

“I think the procedure needs to be more welcoming. Some clinics aren't very inviting and don't realise how embarrassing the whole process is for some women.”

#### **Negative feelings**

“Before I had my first cervical screening, I had been told some awful stories about how bad it was. Thankfully it didn't prevent me from going but I can understand why it would put people off. It's a shame that other people are able to negative influence someone else going for their screening.”

“I think appointment availability is a big problem. We all know when our screening is due but the current system for arranging appointments isn't user friendly for working women. Late evening appointments, being able to book appointments several weeks in advance so can plan child care, time off work etc would make it so much easier & accessible.”

#### **The test itself**

“The whole experience of a screening is uncomfortable. If they took place in a nicer environment that may help.”

“Pain-free just a little discomfort but health benefits outweighs the negatives.”

“It's routine, largely painless, nothing to be embarrassed or scared about. It could save your life!”

#### **The test - staff**

“Some nurses are too rough (in a rush to get it done). I have an inverted cervix and they lose patience.”



## Personal stories

### **Embarrassment**

“I have never found it to be a problem. It is an uncomfortable feeling before entering the room, but dependant on the nurse, they can make you feel very comfortable.”

### **Negative feelings**

“It was the scariest thing I've done. Walking into the room was like walking dear row. I didn't feel this way because of bloody embarrassment. Please raise awareness for women who have suffered trauma.”

### **The test itself**

“Horrible. Degrading, unnecessary, destroyed my trust in the NHS. Opted out, private GP in future.”

“Quick and easy, absolutely nothing to worry about.”

“It is never nice to have a vaginal examination and is a bit embarrassing. You feel tense but have to try and relax. I have always had a lady doing the smear test. It is usually over very quickly without any fuss. It has never really hurt, more a slight discomfort, until this last time but I think that was due to changes brought on by the menopause. I have always had a positive experience.”

### **The test - staff**

“It's quick. The nurse is a professional so there so need to be embarrassed.”

“I've had 3 so far. All of them clear thankfully. The nurses were very pleasant and put me at ease. It is really nothing to worry about. They have seen alot of womens bits. All colours shapes sizes hairy or not etc...and it really wont bother them what it looks like as long as you have the screening.”

“Fantastic experience - at my local GP practise, lovely practise nurse who chatted to me throughout, who procedure took 2 minutes with no pain.”

## Focus group work

This presents the findings from focus group and engagement work. The comments gathered have been split into the views of general and mixed groups, in terms of ethnicity, and those groups from a BAME background.

A division has been used to allow the reader and the report to more clearly reflect the views of BAME people and contrast them with other groups. As in the survey, selected quotes have been used to demonstrate representative and specific views.

### General public and mixed groups

#### **What was already known?**

You get information from newspapers, GP's word of mouth, other people's experiences, some social media. - Several people in the group agreed with this sentiment

When I hear the word cancer I think: frightened, this is it, the end, life threatening, death sentence. The TV does not help as some TV series show people with cancer as fading away. - Several people in the group agreed with this sentiment

#### **What was new?**

"Shocked to hear the number of people being diagnosed and how much is link to lifestyle incl. diet"

Shocked at the low uptake for cervical screening - several people in the groups agreed with this sentiment

#### **The importance of screening**

Very important - several people in the groups agreed with this sentiment

"Do people now a days think stuff can be cured? Is this why they don't go for tests as they just think if I get something it can be cured."

#### **Have you attended?**

All attended regularly when called for - several people in the groups agreed with this sentiment

"I always go although I have delayed it a few times due to inconvenient appointments."

"I know someone who said she didn't go because she was gay and thought it wasn't relevant to her."

### **Encouraging you to attend**

“I think younger women don’t go because they are embarrassed and they think it is going to be painful because of what other people have said.”

“If we knew about the different sized speculums we would go.”

Make appointments easier to access e.g. mobile units in easy to reach locations - several people in the groups agreed with this sentiment

“Provide home test kits. They are convenient and women who find screening traumatic will prefer them. Also, if GPs have their screening targets removed they might speak to their patients honestly, including the harms of screening.”

### **Encouraging young people to attend**

Younger people are not interested - several people in the groups agreed with this sentiment

“Education should be done from age 14. I don’t think people know enough. I’ve never heard of HPV. I’ve learnt something today. My friend’s daughter is severely autistic and she wouldn’t understand what a smear is. She’s 27 and never been invited. I think it’s very much a fear issue. People are worried about what will happen and also fear that vaccines cause certain conditions e.g. autism. More needs to be done.”

“I was never allowed tests because my dad wouldn’t let me. I never had any sex education. I wasn’t allowed, so now I don’t know stuff. How can I make sure my children have the right information if I don’t know that what I was told by my parents was incorrect. It means I am just repeating the information I was given to them and that is potentially incorrect i.e. you only have a smear if you are having sex.”

“I think education should start in primary school. Girls are starting periods earlier now and how can they make informed choices without the knowledge. We are still such a prude culture and don’t talk about HPV and smears young enough because our children ‘aren’t having sex’ yet we are happy to let them go out in mini-skirts, mini tops, make up and dressed like mini me’s.”

“I’m 19 and don’t know anything about this. What you have told me today is the first time I have heard anything about smears, the HPV, process, treatments etc. I’m so glad I came because I would have been so scared and probably wouldn’t have gone when my letter came but now I will.”

### **Do you talk about screening?**

“Yes - I talked about it with having cervical cancer in our family. So other women know about going for screening”

“The ‘C’ word - you never say it in full so it’s not something I would talk about.”

“Yes. I nag to all my girlfriends because I have had cancer twice. I always encourage them to go and have even offered to go with them.”

### **Personal stories**

“...I had a normal routine smear this year which came back severe, therefore a biopsy was taken. The results changed my life and my personality forever. Cervical Cancer Stage 1b resulting in a radical hysterectomy and lymphnode removal. Luckily no lymphnodes were clear and no further treatment was required. Checks now for the next 5 years. The NHS are incredible and acted so quickly...”

“I’m going to a funeral this week. It’s the 4th one this year and all of them have died from cancer. Because of these experiences and my own dealings with cancer I find it easier to talk about it...”

“I was shocked that my sex life would be taken away from me without informed consent due to the lletz procedure. That’s why I don’t attend. Trauma and being let down by the system are key reasons.”

## BAME groups

### **What was already known**

It's not something that is spoken about much in our culture - several people in the groups agreed with this sentiment

It's hard to know much when we speak a different language to what the information is sent to you in - several people in the groups agreed with this sentiment

Cancer makes me think of: being scared - several people in the groups agreed with this sentiment

Our understanding is that there is nothing you can do about it - several people in the groups agreed with this sentiment

I've never got any information about cancer from TV or social media, we don't speak English - several people in the groups agreed with this sentiment

### **What was new**

Feel better knowing I can maybe leave a long skirt on to keep me covered up as long as the nurse can see what she needs to

Happy to hear that  $\frac{1}{2}$  of all people diagnosed with cancer survive for at least 10yrs. It's a good change from 40yrs ago - several people in the groups agreed with this sentiment

"It's good that you can ask for a specific nurse if you have one that makes you feel comfortable. I do that now because there is one nurse that talks to me throughout and it makes it so much better."

"I didn't realise that genetics only play a 2% chance in people getting cancer. You tend to hear people say 'well my brother had it etc.'"

### **The importance of screening**

"Very as 2 of my friends passed away that's why we are here today. I organised it to raise more awareness."

"You shouldn't tell people they have cancer because as soon as they hear that they shut off. They just leave it to God."

Some women more bothered about how they would be perceived by the doctor - several people in the groups agreed with this sentiment

### **Have you attended**

Main problem highlighted was that the women do not speak or read English therefore any letters they receive they cannot read - several people in the groups agreed with this sentiment

### **Encouraging you to attend**

Information in the right language - several people in the groups agreed with this sentiment

New method that is less uncomfortable and revealing - several people in the groups agreed with this sentiment

“Get rid of myths especially in our culture, like some parents won’t allow their children to have it done because to marry they have to be a virgin and they think that having this done will mean they are no longer a virgin.”

Confirmation that family GP’s are not going to tell parents if a child has been for their smear - very strict rules and many are told by their parents they cannot go as they are virgins (even if they are not) and worry that the GP will tell their family (some history that this has occurred before so a natural fear has arisen) - several people in the groups agreed with this sentiment

More education for younger women so they can educate parents - more youth clubs/groups so girls can learn - several people in the groups agreed with this sentiment

### **Encouraging young people to attend**

Not at all, I, well we didn’t know anything about it until today - several people in the groups agreed with this sentiment

“Not spoken about in mosques and if children go to Muslim schools it is not spoken about there either so the only information they get is from their parents and it depends how liberal or westernised they are as to what they believe or allow.”

Go into schools and talk more - several people in the groups agreed with this sentiment

### **Do you talk about screening**

“I’ve spoken to some of my friends because I have lost people.”

“Men definitely don’t talk about things and in certain cultures it’s even more of an issue especially if you are the only girl so they can’t talk to anyone.”

“Women in our culture aren’t meant to talk about things like that.”

### **Personal stories**

“Daughter had abnormal cells. After that I started attending my smears. We had been asking for a smear for years because she was under the screening age because she had lots of pain and other issue and the Dr just said she couldn’t have one and because she had 4 sons who were all healthy she would be fine.”

A number of women mentioned women and men who have died in the community from cancer - several people in the groups agreed with this sentiment

“...When asked would she send her unmarried daughter for a smear test she said “no because the community would talk and it would impact on the shame of the family and no one would marry her daughter.”

## Method

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### Methodology

Healthwatch worked with Answer Cancer and Bolton CVS to deliver information and engagement sessions. These sessions ensured we focused on raising awareness and developing individuals understanding around the process and importance of screening in the UK, as well as gathering views and experiences. The engagement sessions were centred on semi-structured group conversations, where we discussed a number of different topics such as: barriers to access, screening processes, communication, and fears.

Alongside Bolton CVS and Answer Cancer, we hosted a funding and engagement information session. This provided community groups the opportunity to find out more about the Answer Cancer grant that was available, including information about what being an Answer Cancer Champion would entail, what support Answer Cancer would provide in raising awareness on cancer screening, training offered, the application itself, and the process. We also highlighted the opportunity for groups to get involved further by signing up to an information and engagement session with their group.

We launched an online survey to allow us to capture their views and experiences of women who did not have the ability or desire to attend a group session.

Data was analysed on a quantitative and qualitative basis. The surveys provided us with both quantitative and qualitative data, with the group engagement sessions allowing for more conversational data.

### Who we spoke to

At the start of the project we aimed to speak to women from a variety of groups and ages including those from BAME, LGBTQ+, learning disabilities, physical disabilities, Eastern European, below screening age groups, lesbian women, trans women and men who have a uterus, and women with learning disabilities, we reached out but acknowledge there are some gaps in our engagement and these groups are not exhaustive.

Although cervical screening is not available to under 25's we also identified that we would like to speak to those from 16 years old. We wanted to establish young people's understanding of the screening process, as well as the HPV vaccine, with the hope of increasing awareness in preparation for their first screening invite.

In order to engage with as wide a community as possible we also attended various events including a mental health event held at Bolton University, Bolton Carers AGM and Information event, and Macmillan health and well-being event.

Throughout the length of the project it was challenging to identify and/or engage with particular communities such as those with learning difficulties, Eastern Europeans and those identifying as LGBTQ+ for a variety of reasons, and therefore the data is primarily from those of BAME and White British communities, as well as those with a caring responsibility.

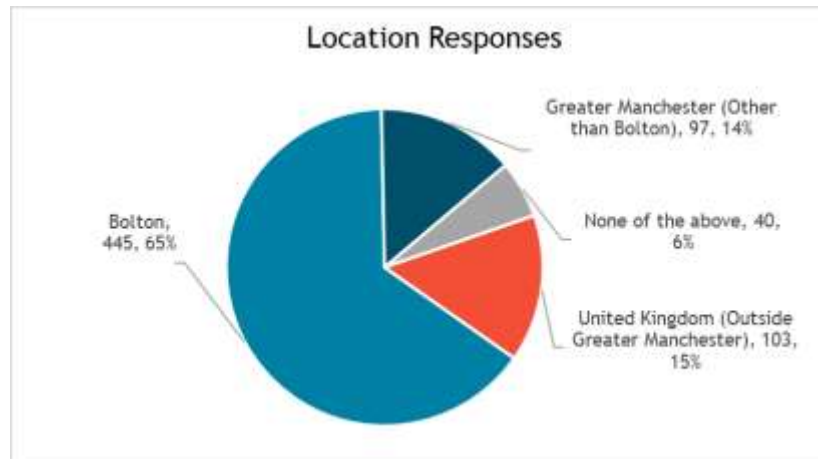
In addition to reaching out to specific community groups and attending public events, we opened up the project via survey monkey, meaning any member of the general public with experience or thoughts around cervical screening could participate.

We aimed to reach around 100 women via the information and engagement sessions and additional women via the online survey.

## Demographic details – related to survey work

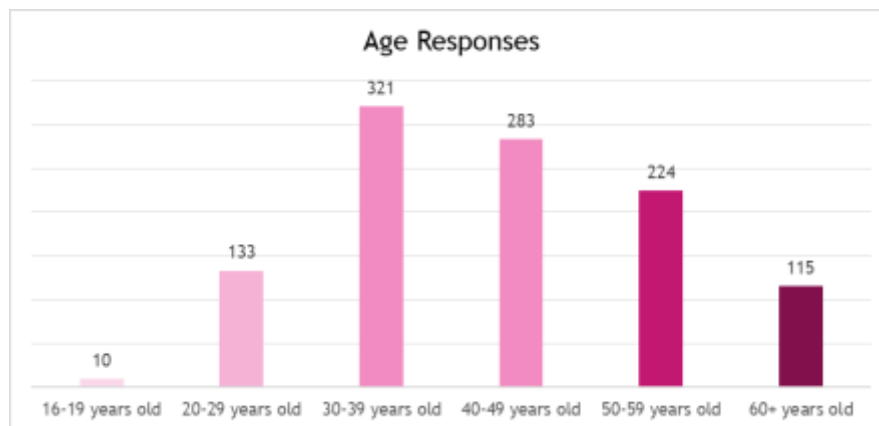
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Location:



*\*There were 685 responses to this question. 697 did not respond.*

Age:



*\*There were 1086 responses to this question. 296 did not respond.*

Gender:

- Considering the topic of the study the majority of respondents to the survey were female, 1071 (99%). There were a small number of other responses, with 2 non-binary (<0%), 5 male (<1%) and 5 prefer not to say (<1%). 299 did not respond to the question.

Sexuality:

- The majority of respondents identified as heterosexual/straight, 988 (91%). There were a number of other responses, with 28 bisexual (<3%), 14 lesbian (<1%), 3 gay (<0%) and 48 that prefer not to say (5%). 301 did not respond to the question.



Ethnicity:

- The majority of respondents identified as White/White other grouping, 909 (84%). The other responses were 140 BAME/mixed (<13%), 20 other (<2%) and 16 that prefer not to say (<1%). 297 did not respond to the question.
- *For this category there is a deeper breakdown but categories have been combined for clarity.*

Equalities monitoring:

- The following categories were also asked to identify and considered in this research - Disability, Religion, Carers, Unpaid carers, Pregnancy, Breastfeeding, Veterans.
- *For clarity these statistics have been retained, but do comprise part of the overall data.*

## Project details – related to group and engagement work

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| Engagement type | Details   |
|-----------------|---|
| Survey          | 1382 respondents.<br><i>A full demographic breakdown appears on page 23.</i>  |
| Focus groups    | 402 people engaged with.<br>13 focus groups.<br>4 general outreach events.<br>Social media – facebook/twitter<br>Standard channels – email/telephone<br><i>Demographic details were not collected in detail, but the ethnic background was noted.</i> |

## Contact details:

**ANSWER  
CANCER**

Email: [info@answercancergm.org.uk](mailto:info@answercancergm.org.uk)

Website [www.answercancergm.org.uk](http://www.answercancergm.org.uk)

Twitter: @AnswerCancerGM

**GMCA** GREATER  
MANCHESTER  
COMBINED  
AUTHORITY

  
in Greater Manchester

**healthwatch**  
Bolton

Email: [info@healthwatchbolton.co.uk](mailto:info@healthwatchbolton.co.uk)

Website: [www.healthwatchbolton.c.uk](http://www.healthwatchbolton.c.uk)