



Manchester Health & Care
Commissioning

A partnership between
Manchester City Council
and NHS Manchester CCG

Community Engagement Research Project

**Barriers to cervical screening amongst Ethnic Minority
women aged 25-64 in north Manchester**

**Commissioned by
Manchester Health & Care Commissioning**

research undertaken by



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Executive summary

Every year in the UK, around 3,200 women will be diagnosed with cervical cancer. It is the most common cancer in women under 35. The NHS Cervical Screening Programme prevents 75% of cervical cancers, saving 5,000 lives in the UK each year, but over the past five years, 3.7 million women have not attended. Research shows that women from Minority Ethnic and disadvantaged communities are less likely to attend.

Manchester has a very diverse population with one third (33.5%) identifying as Black, Asian and Ethnic Minority (BAME) origin. The average life expectancy of women is 79.9 years compared to the England average of 83.3 years. Under the Index of Multiple Deprivation 2015, poverty indicators have ranked Manchester as the 5th most deprived district in England. It is also the poorest performing in terms of cervical screening compared to nine other districts in Greater Manchester with coverage at 63.9% (down from the previous year 64.8%). This is much lower than overall coverage in the North West, which stands at 72.0%.

Commissioned by Manchester Health & Care Commissioning and conducted by Jo's Cervical Cancer Trust, this research aimed to explore barriers to, and ways to improve, the uptake of cervical screening among BAME women in north Manchester.

To undertake this research, we used both qualitative and quantitative data using three focus groups and an online survey to gather data and offer a richer and hopefully true account of the issues within BAME communities.

In total 153 people took part in this research, 86 from BAME communities. Three focus groups were conducted with Pakistani (10), Indian (7) and Bangladeshi (10) women, and an online survey was completed by 126 comprising of 59 BAME: 67 white women.

"I put off having a smear because of pain and embarrassment. I had my first one, it was really bad (pain). I know I should go regularly but I don't cope well with pain because of past issues."

Comment from a BAME survey respondent

The online survey data revealed that 56.1% of BAME women delayed an invitation to screening with 15.8% delaying by more than three years. Less white women (34.6%) compared to BAME women (56.1%) have delayed attending. Common barriers across both BAME and white women were; they put off going, they forget the appointment and concerns about the test being painful.

The data shows a lack of knowledge about signs of cervical cancer and what a smear test is for. It also highlights the need to tackle barriers such as fear of pain, embarrassment, previous bad experiences, childcare and difficulty in getting a GP appointment.

Key findings from the focus groups showed that among women who attended:

- All had heard of cervical cancer
- All knew it can be a dangerous and fatal condition
- All agreed that early detection was important

Whilst all Bangladeshi and Indian women believed that cervical cancer can be treated, 30% of Pakistani women disagreed. Despite this, Indian and Pakistani women had better levels of awareness about what cervical cancer is compared to Bangladeshi women:

“It is cancer of the cervix”

“It’s a silent killer”

“What do I know about it? I know I should have it (smear test) because they say it eliminates cancers if they are lurking around. It’s just a good MOT check to make sure everything is fine”

“I know it is dangerous”

Below we list key recommendations based on the research.

1. GP Practice engagement to improve coverage

Our online data showed 48% of BAME and 42% of white women would prefer to have their smear test done by a woman at their GP surgery. Other published research has shown that women are more inclined to attend when reminded or prompted by GP practice staff.

GP practices need to be proactive in encouraging women to attend and consider the different methods for women to receive the information. Women wanted information in the form of:

- A leaflet
- A healthcare professional delivering information
- An email
- A text message

There is a need for an approach that provides both face to face and formal written information.

Women wanted open dialogue about cervical screening with their GP:

“I felt embarrassed but I discussed it with my GP. The GP said to me you shouldn’t find the test painful and it is a female nurse who will carry out the test on you. The next time I got my letter, I went for my smear test and it turned out fine (results)”

Comment from a focus group attendee

There was a consensus across all three focus groups that general health checks should include opportunistic offerings of smear tests for those overdue:

“If you have an appointment where they can check everything, you are more inclined to have it done. You have your blood pressure done, your eyes (checked), having this done and having that done, so you might as well have your smear test done”

Comment from a focus group attendee

2. Accessible services for cervical screening

BAME and white women highlighted issues around the availability of appointments at convenient times and the need for out of hours services, particularly for those who work during the day. GPs can play a proactive role in informing patients of extended hours services at the practice.

3. Increasing community education and engagement

We recommend that NHS Manchester CCG work strategically within the locality of the GP practice on community engagement with local organisations, residents, pharmacies, community centres, clubs, mother and toddler groups, and health & wellbeing neighbourhood workers via trained community cancer champions.

Community engagement via face to face discussions is critical to the success of raising awareness:

“Get out there and reach out, get into the communities out there. Face to face works. Leaflets won’t help. They are a waste of resources. If you have to use letters, then persistence is required for this”

“I think openness will help break barriers. Not in bigger groups but in smaller groups, face to face discussions work”

Comment from focus group attendees

4. Resources and people needed to increase community engagement

A combined approach is favoured to improve long-term awareness, including posters or leaflets in appropriate languages and visual tools such as videos and the use of South Asian TV and radio channels. Jo’s Cervical Cancer Trust has a range of posters, printed resources and translated films that be utilised by community group and GP surgeries:

<https://www.jostrust.org.uk/resources/materials/information>

The focus groups wanted to know, through clear and simple messages:

- The purpose of a smear test
- The process of having a smear test
- What cell abnormalities mean in relation to the development of cervical cancer
- The risk of not attending a smear test
- Risk factors, especially factual information on HPV.

Language and literacy barriers were a common theme across all three groups and it was clear that there is a need to deliver messages in a culturally and linguistically appropriate manner and environment, particularly using face to face settings.

5. Community cancer champions

Utilising local residents as cancer champions, who are ideally placed within communities, provides the opportunity for women to engage with someone familiar from the community or someone they relate to.

6. Soft intelligence information/data sharing

Work closely with the Screening and Immunisation teams to feedback discussions on barriers to screening faced by women. This will improve understanding of the ever-evolving barriers within certain communities and enable teams to assess approaches used in service designs, provisions and delivery.

1. Background

Every year in the UK, around 3,200 women will be diagnosed with cervical cancer and it is the most common cancer in women aged 35 and under. The NHS Cervical Screening Programme saves 5,000 lives in the UK each year but over the past five years, 3.7 million women have not attended cervical screening. The latest statistics show attendance of cervical screening in England is the lowest for two decades. Coverage has fallen from 72.7% to 72% in the last year with over 1.2 million women not taking up their invitation¹. It is now the lowest it has been for 20 years having fallen across every age group and almost every local authority in England.

- Coverage in women aged 25-49 has dropped to below 70% for the first time and it is now at 69.6%, down from 73.7% in 2011
- Coverage among 25-29 year olds has fallen by 1.2% to just 62.1%
- The highest fall was among 60-64 year olds, decreasing by 1.4% to 69.7%
- Three age groups now have coverage below 70%: 25-29 year olds, 30-34 year olds and 60-64 year olds
- Almost a third of local authorities (45 of 150) achieved coverage of less than 70%.

Women from Minority Ethnic and disadvantaged communities are less likely to attend cervical screening. The data highlighted below shows the bulk of evidence currently available on these two cohorts:

1.1. Black, Asian and Minority Ethnic (BAME) Women

We know from National Cancer Intelligence Network (NCIN) data that women from BAME backgrounds have one of the highest levels of non-attendance of cervical screening. There are significant barriers to screening for this group, including cultural barriers and a lack of knowledge within the community², and significantly poor health literacy. Poor health literacy (the ability to understand one's own health needs and make sound health decisions) is strongly associated with factors including being born outside of the UK and having English as a second language. It is estimated that seven million adults (20%) in the UK cannot read or understand simple instructions or labels such as those found on medicine bottles.³

Research undertaken by the charity underlined the need within this group for easy-to-understand information on cervical screening, as there was a general lack of understanding about the key facts:

- In a YouGov survey with a sample size of 1179 white women and 1177 BAME women aged 20-65, just over half (53%) of the BAME women surveyed thought screening was a necessary health test compared to 67% of white women
- 78% of BME women and just 70% of Asian women knew what a cervical screening test is for, compared to 91% of white women

¹ Data taken from NHS Digital: <https://digital.nhs.uk/catalogue/PUB30134> 09.11.17

² Marlow LAV, Waller J, Wardle J. 2015. *Barriers to cervical cancer screening among ethnic minority women: a qualitative study*. J Fam Plann Reprod Health Care

³ Manning D, Dickens C 2006. *'Health literacy: More choice, but do cancer patients have the skills to decide?'*, European Journal of Cancer Care

- Twice as many BAME women (30% BAME compared to 14% white) said they would like a better understanding of the test before attending
- 51% of BAME women wanted a more detailed explanation of what the risks were if they didn't attend, compared to 32% of white women
- A third more BAME women of screening age (12%) compared to white women (8%) said they had never attended a cervical screening appointment
- Additionally, we know that the incidence of cervical cancer is up to twice as high among older Asian women⁴
- In 2015, Jo's Cervical Cancer Trust conducted BAME focus group work in partnership with the Community Health and Learning Foundation, the UK's leading health literacy organisation. Some focus group participants said that they struggled with reading health information and that complex written information is not seen as a substitute for the spoken word. There was also a low understanding of the link between cervical screening and cervical cancer.

1.2. Disadvantaged communities

There is evidence that both incidence and mortality are higher in those living in the most deprived areas of the UK. As well as the factors above, including poor health literacy and a high proportion of BAME/immigrant populations with low access to healthcare, factors associated with living in deprivation (i.e. high incidence of smoking, earlier age of sexual activity, multiple partners, higher incidence of HIV) increase the risk of women in developing cervical cancer. In recent research, the charity found that:

- Screening has historically been lower in disadvantaged communities and barriers to screening include seeing the screening procedure as aversive and feeling less obligated to attend than women who reside in wealthier areas⁴
- Mortality could be twice as high among disadvantaged communities, and there are significant gaps in one and five-year survival rates between this group and the least deprived (a 6% gap in relative survival one-year after diagnosis and an 11% gap for five-year relative survival).⁵

1.3. Challenges in Manchester

Manchester has a very diverse population with one third (33.5%) of the population identifying as Black, Asian and Ethnic Minority (BAME) origin. The average life expectancy of women is 79.9 years compared to the England average of 83.3 years. Under the Index of Multiple Deprivation 2015, poverty indicators have ranked Manchester as the 5th most deprived district in England⁶. It is also the poorest performing in terms of cervical screening compared to nine other districts in Greater Manchester⁷ with coverage at 63.9%

⁴ Webb et al., 'Uptake for cervical screening by ethnicity and place-of-birth: a population-based cross-sectional study', Journal of Public Health, Vol. 26, No.3, 2004

⁵ Profile of Cervical Cancer, 2012

⁶ Public Intelligence Populations Publications. A01 Manchester factsheet, 2017.

http://www.manchester.gov.uk/downloads/download/4220/corporate_research_and_intelligence_population_publications Accessed 20.12.17

⁷ Cancer Services, Public Health Profiles. Demographics, Screening, Diagnostics. <https://fingertips.phe.org.uk/profile/cancerservices/data#page/0> Accessed 20.12.17

(down from the previous year 64.8%). This is much lower than overall coverage in the North West, which is 72.0%.

	Manchester	North West
25-49 year olds	61.6%	70.1%
50-64 year olds	71.8%	76.0%
Coverage overall	63.9%	72.0%

Table 1. Cervical screening coverage in Manchester

Manchester faces major challenges in the cancer arena⁸:

- Cancer outcomes in Manchester are the poorest in England, particularly in north Manchester where cancer incidence is the highest in England; followed by central Manchester which is the second highest
- High premature mortality rates
- Approximately one quarter of all cancer diagnoses in Manchester are made through emergency presentation. Such cases are often indicators of advanced disease that may not respond to treatment effectively
- Less than half of cancer diagnoses are at Stage 1 and 2. Early stage at diagnosis is one of the most important factors that affect cancer outcomes
- Late diagnosis of cancers with many patients diagnosed at a stage III or IV where successful treatment is less likely. Approximately half of all cancers in Manchester are diagnosed at stage III or IV
- Patient participation in National Cancer Screening Programmes – Manchester uptake for all three cancer programmes is lower than national minimum standards. NHS Right Care information suggests that if Manchester uptake rates were similar to comparable CCGs, an extra 9200 women could be screened for cervical cancer. Some of these people will have cancer that could be detected at an earlier stage (Health scrutiny committee, Oct 2016)
- Given smoking is a risk factor for cervical cancer - given smoking prevalence in Manchester (22.7%) remains higher than the national average (16.9%)
- One-year survival rates: North Manchester has shown significant improvement in survival but remain below the Greater Manchester and national average.

⁸ GM Cancer Report 2017. Manchester Joint Strategic Needs Assessment. Adults and older people. Chapter Physical Health. Topic Cancer

2. Research aims

This research has been commissioned by Manchester Health & Care Commissioning and conducted by Jo's Cervical Cancer Trust.

In this research we aimed to:

- Understand barriers to cervical screening within BAME communities in north Manchester area and in doing so explore women's knowledge, attitudes and beliefs about cervical cancer and cervical screening
- Identify approaches that work in disseminating health education messages/interventions to encourage uptake
- Identify appropriate forms of communication and information about the health of the cervix
- Produce a list of recommendations for future work.

2.1. Terminology

The correct name for the screening procedure is a cervical screening test but research and experiences show that women understand and respond better to the term "smear test"⁴. For this reason, the term "smear test" was used when conducting our research.

3. Methodology

During this research, we used both qualitative and quantitative methods: a combination of focus groups and an online survey allowed us to gather data and offer a richer and hopefully, a truer account of the issues being explored within BAME communities.

3.1. Focus groups

The use of focus groups allowed us to:

- Use group interactions to prompt participants
- Highlight community knowledge; allowing us to explore myths, misconceptions and barriers
- Gain detailed information about personal and group feelings, perceptions and opinion
- Safe environment allowing small groups of no more than ten to openly discuss sensitive issues
- Depersonalises: important when topic is the cervix
- Offer the opportunity to seek clarification.

A focus group questionnaire was devised to help structure the sessions and explore the following themes (see Appendix A):

- Awareness of cervical cancer
- Knowledge of risk factors
- Knowledge of symptoms
- Knowledge of cervical screening
- Barriers to screening (reasons for low uptake)

- Information needs (e.g. tailored messages, terminology, imagery, content, other)
- Which interventions are appropriate to use in overcoming barriers
- Make recommendations.

Participants were recruited via our Manchester Public Health Engagement Coordinator, who connected with local community organisations that support BAME women and arranged to speak to their clients about cervical screening.

Using semi-structured interviews, we conducted three focus groups with 27 women from the following South Asian communities: Pakistani, Indian and Bangladeshi. All sessions were audio-recorded and detailed notes were taken by a note-taking moderator. The focus groups lasted between one hour and 1.5 hours. Discussions in Urdu and Punjabi were translated by the Public Health Engagement Coordinator and detailed notes were compiled to capture all the data. They were delivered in the appropriate language to remove the language barrier to participation and conducted in Urdu, Punjabi, English and Sylheti. An interpreter was used for the Bangladeshi women's group. We aimed to have a minimum of seven and a maximum of ten people per focus group. We offered a £10 shopping voucher as an incentive to attend the sessions.

All three groups were moderated by our Manchester Public Health Engagement Coordinator and women attending the group had mixed ability to read and write in own language/English and levels of acculturation.

For qualitative exploration, we used a thematic analysis approach of the interview data. This method enabled us to analyse the findings from these focus group sessions. At the end of each session, a cervical cancer and screening awareness workshop was delivered to each group, which also gave the opportunity to answer questions that had been raised by the women during the session.

3.2. Online Survey

We aimed to capture the views of women from a range of minority groups and run a paper version and an online survey hosted by survey monkey. The purpose of the survey was to help us better understand the awareness and knowledge of cervical screening, highlight community knowledge and experiences, identify misconceptions and barriers to screening uptake and understand what how people would like to receive information on cervical screening. It was designed to complement the focus group work. The survey was incentivised to encouraged participation with a £50 prize draw. It ran for almost six weeks from the 1 February to 12 March 2018.

3.3. Ethical considerations

All participants took part voluntarily. Information was requested about the following but on an optional basis:

- Gender
- Age range
- Ethnicity
- Locality

- Born in the UK/Not born in the UK
- Smoker/non-smoker

Ethically based data collection procedures were put into place for all participants. All participants were informed of the purpose of the study, what their participation would involve, the benefits of participation, how their confidentiality would be protected and how their information would be used to inform awareness and recommendations for future work and service provisions. A consent form was given to each participant to complete before providing any input. All data collected was anonymised.

4. Results

In total 153 people took part in this research and 86 of those were from BAME communities. Here we outline the results of the focus groups and survey.

Method of data collection	Ethnicity	Age 25-64	Location	Language	Numbers taking part	Age breakdown (years)
Focus Group 1	Pakistani	25-64	North Manchester	Urdu/Punjabi English	10	30-34: 1 45-54: 4 55-64: 5
Focus Group 2	Indian	25-64	North Manchester	Urdu/Hindi English	7	45-54: 4 55-64: 3
Focus Group 3	Bangladeshi	25-64	North, Central & South Manchester	Sylheti/English	10	30-34: 4 35-44: 5 45-54: 1
Online Survey	BAME and white women	25-64	Manchester/ North Manchester	English	126	

Table 1. Our research participants

4.1. Results from the focus groups

Key findings for women from South Asian communities about their knowledge of cervical cancer:

- All women in the sample had heard of cervical cancer
- All knew it can be a dangerous and fatal condition
- All agreed that early detection was important.

Whilst all Bangladeshi and Indian women believed that cervical cancer can be treated, 30% of Pakistani women disagreed. Despite this, Indian and Pakistani women, notably, had better levels of awareness about what cervical cancer is compared to Bangladeshi women:

“It is cancer of the cervix”

“It’s a silent killer”

“What do I know about it? I know I should have it (smear test) because they say it eliminates cancers if they are lurking around. It’s just a good MOT check to make sure everything is fine”

“I know it is dangerous”

“There has been a change in knowledge levels and how people think. Awareness helps because it is easy to dismiss symptoms for something else, like if you had back pain you may think it’s maybe because I lifted something heavy, whereas now we think it might be cancer so need to get checked out to get reassurance”

Amongst all Bangladeshi women, awareness is not matched by knowledge. Despite having heard of cervical cancer and all agreeing that it can be treated, with 50% thinking it can be prevented, none of the women knew what cervical cancer is and that it affects the cervix.

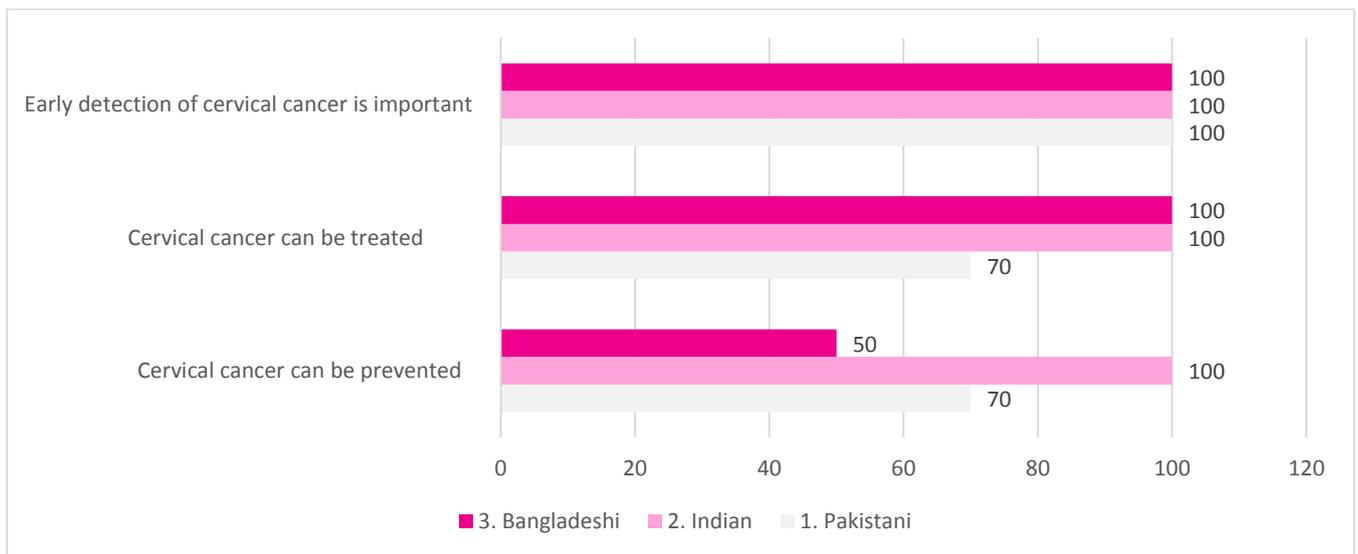


Figure 1. We asked participants in the focus groups if they agreed with the statements above.

4.1.1. Awareness of Human Papilloma Virus (HPV)

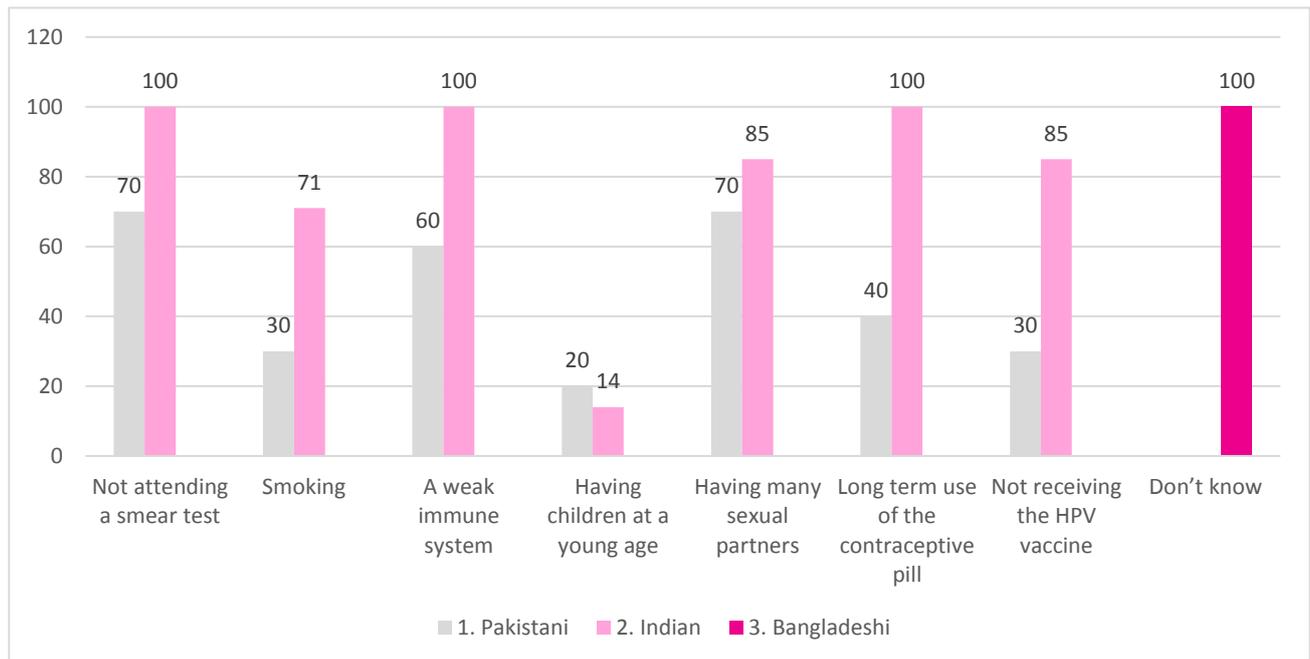
Awareness of HPV causing cervical cancer was extremely low amongst all South Asian women (96%), with many having never heard of the term ‘HPV’. The 4% who knew about HPV causing cervical cancer, were women from the Indian women’s focus group who had been informed about HPV due to the HPV vaccination programme.

4.1.2. Knowledge of cervical cancer risk factors

All Bangladeshi women had no knowledge about any of the risk factors pertaining to cervical cancer. Overall, in comparison, Indian women had the strongest knowledge about risk factors, followed by Pakistani women having some knowledge about risk factors.

Figure 2. We asked focus group participants: which of the following do you think are risk factors for cervical cancer? Data is presented here in %.

There were misconceptions around risk factors existed across both Indian and Pakistani groups:



“Like they say that breastfeeding reduces the risk of breast cancer, as a Muslim, cleanliness of the private regions is important and not having sex during menstruation are ways we can reduce the risk and save ourselves from developing cervical cancer”

“I am not sure, but I have heard that if you do not have normal periods then that can cause cervical cancer”

“Fibroids” “Cysts” “Polyps”

“Maybe it’s the way you wipe yourself lower down”

4.1.3. Sexual behaviours as a risk factor

All Pakistani women believed that having sex during menstruation would increase the risk of cervical cancer and that certain sexual behaviours contributed to the development of cervical cancer. Religious beliefs also contributed to the perceptions of why someone would develop cervical cancer:

“Sexual intercourse during menstruation is not permitted in our religion. Maybe this is why it (cervical cancer) can become a punishment from God”

“I know a woman who used to have sex whilst on her period with her husband. Then she developed cancer. She suffered a lot and passed away despite having treatment but the treatment of those days is different to current treatment. This happened when I was not married myself so the awareness was really low, we didn’t have much information about it back then”

“Her husband had certain sexual behaviours that she did not like” (referring to a woman who had cervical cancer)

A number of issues came to light amongst both Indian and Pakistani women; the belief that certain sexual behaviours can cause cervical cancer, issues around sexual abuse in relationships and the cultural and religious barriers such as modesty in terms of the reluctance to seek help from a male GP.

4.1.4. Knowledge about the symptoms of cervical cancer

Alarming,ly, none of the Bangladeshi women knew about any of the symptoms for cervical cancer. In contrast, the majority of Indian women knew about all the symptoms. 100% were aware that an unusual vaginal discharge and post-menopausal bleeding could be a symptom, compared to 50% of Pakistani women, respectively.

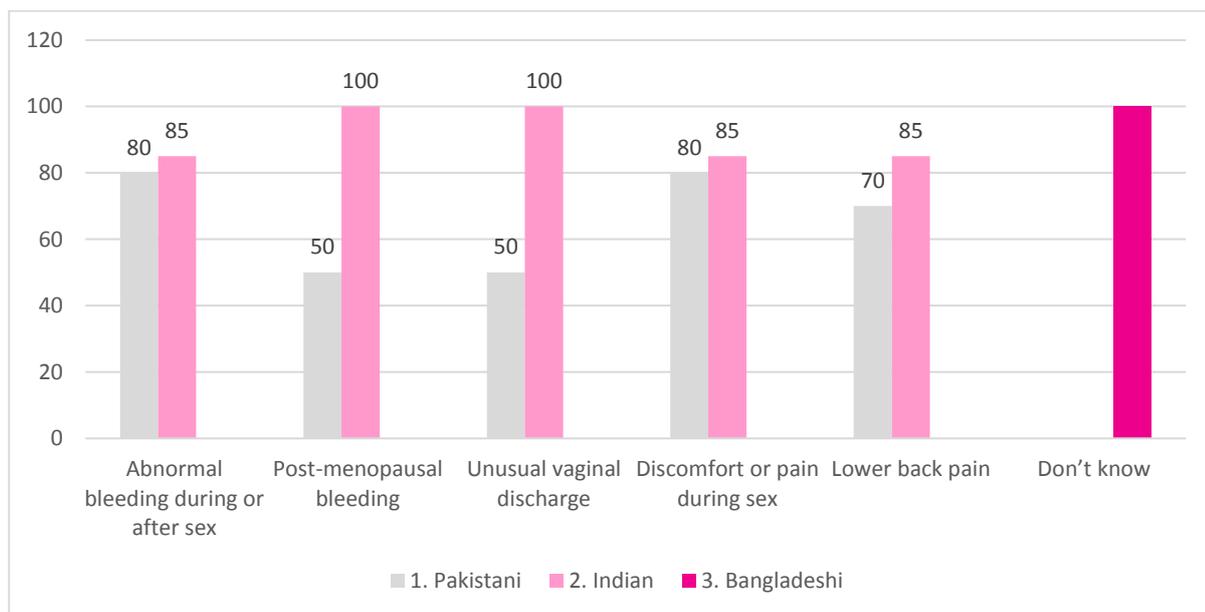


Figure 3. Focus groups were asked to identify symptoms of cervical cancer. Data give in %.

“That might be a risk factor for endometrial... rather than cervical cancer”

“I think that when you are having sexual intercourse, that (bleeding) might happen naturally. But if it is all the time, then it might be a symptom”

“No I never thought it (bleeding) was. I thought it could be the (sex) position”

“I had bleeding 5 years after my menopause. It was heavy bleeding too so I went to my GP. After further checks I was told that had you delayed seeking help, this could have turned into cancer. I had successful treatment for nine months and the bleeding stopped”

“I had pain during sexual intercourse and when my daughter explained this to my doctor it was then that I was diagnosed [with cervical cancer]. Thank God I am fine”

“Recurrent infection in the urine can be (a risk)”

4.1.5. Knowledge about cervical screening

From the women at our focus groups: 92% (25) of BAME women had attended for a smear test during their lives with 22% (6) having delayed attendance in the past. One woman delayed by 20 years.

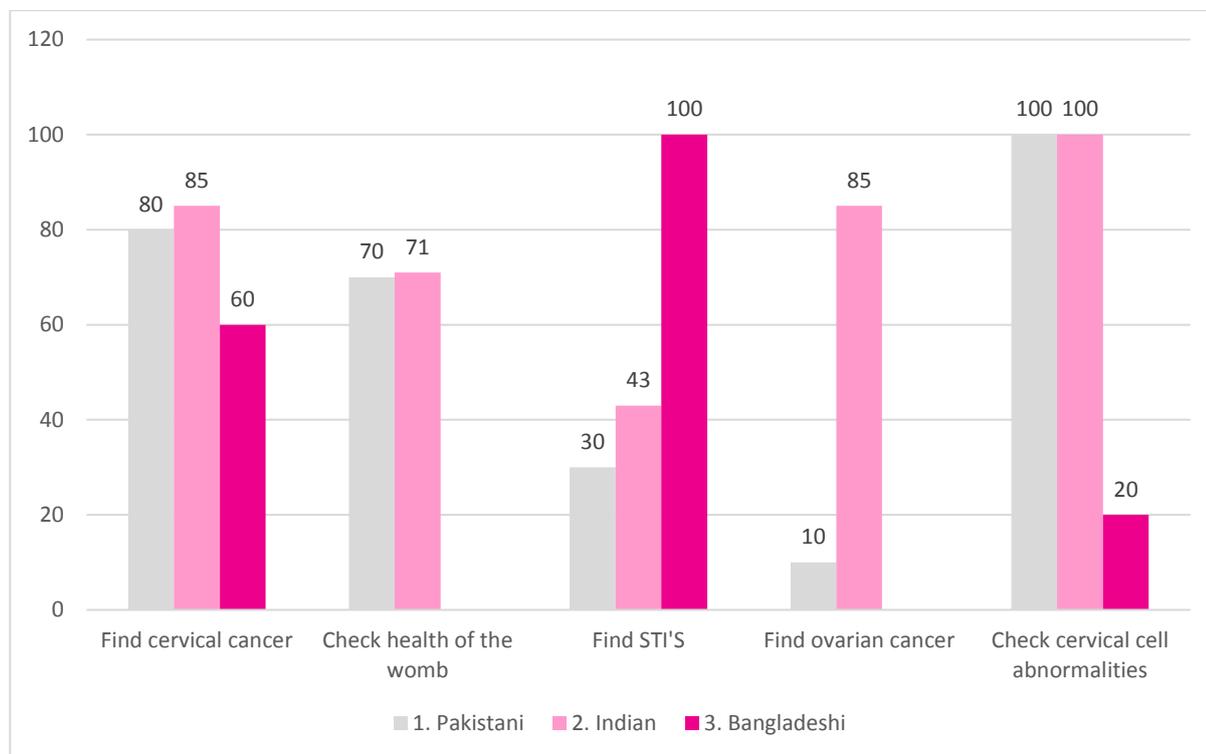


Figure 4. Focus groups were asked what they thought cervical screening (Smear tests) were for. Data given in %.

100% of Indian and Pakistani women knew that a smear test is done to check cervical cell abnormalities but only 20% of Bangladeshi women were aware. However, all women thought the test had other purposes too, for example, 85% of Indian women thought it could find ovarian cancer and all Bangladeshi women thought it checked for STI's. The majority of women also thought it was a test to find cervical cancer.

“I think a smear test is done to check the health of all parts of the reproductive organs”

“I know they take some cells from inside there (cervix) and that sample is sent off and you get your results”

“I never knew what a smear test was and what it was for. It was in a group discussion I learnt about it and realised I had never had a letter to invite me for a smear test”

“I think the test is for the early detection of cancer. One test can pick up quite a lot of things, that’s what I thought anyway” (referring to a smear test)

4.2. Reviewing the focus group discussions to understand barriers to cervical screening

In the following section, we analysis the discussions from the focus groups and highlight barriers to screening within five categories:

1. Accessibility
2. Psychological
3. Literacy
4. Cultural
5. Physical

4.2.1. Accessibility

Data from the online survey participants highlighted accessibility issues to cervical screening but the cohort of all three focus groups did not perceive this as a major barrier. We anticipated that this would be a barrier for women in the focus groups but this was not mentioned by any of them.

4.2.2. Psychological barriers

Psychological barriers ranged from embarrassment and shyness through to fear of cancer.

“It’s embarrassing. It’s just the thought of having anything down there done, when you are not having a baby. Having a baby you get something at the end of it but when you are having a smear test you don’t”

“Sometimes it’s because you feel embarrassed. That’s why I never used to attend for my smear test. I was very young as well at that time and I used to feel embarrassed, like, sticking your legs (up) like this and being poked! It’s due to the fear of pain too”

“Taking your clothes off in front of a stranger is also an issue”

“Shyness, that’s what stops me”

The presence of a male doctor also acted as a psychological barrier for women attending their appointment:

“Women get worried that it will be a man who will take a look inside (the vagina). I had a male who did that at a smear test so I didn’t go (again)”

“I went for a smear and it was a male doctor so I refused it and requested a female nurse “

Fear of the test and of cancer created much anxiety for our focus groups. The real fear of a negative outcome such as cancer from a smear test influences the decision not to attend:

“Some women have a suspicion that they might have something wrong so they don’t want to go. They don’t want to know if they have cancer, they don’t want to worry”

“They don’t know if there is going to be a cervical problem. They don’t know properly but worry about any bad news like cancer. They don’t want to find out, they don’t want to know if they will die or find out they are in the last stages of cancer. They say that my mum or my aunty, they didn’t do that (go for smear tests) so why do I need to do that? It’s denial”

“We women always become afraid of tests well before they take place, without thinking about whether the test is beneficial to us or not”

Upon reflection, 74% of the women thought a smear test was done to find cervical cancer. There was no knowledge about the incidence rates of abnormalities detected and how the cervical cancer progresses. This indicates that education is key; using factual, evidence-based information to better inform BAME women about the purpose of smear tests and the role of cervical cell abnormalities in the development of cervical cancer.

Family and friends can often be effective networks of support but the stigma around cancer itself can prevent someone affected by it to refrain from accessing that support.

“Previously no-one wanted to talk about cancer but now, there is at least one person in every family that has suffered from cancer. There are still families that don’t want to talk about cancer. I know from previous experiences my side of the family, even now they don’t want to talk about it”

“I wouldn’t necessarily say its religious or cultural but individual family barriers. It’s a barrier within a family when people can’t talk”

There was frustration noted across all three groups of women that the reluctance to talk about cancer openly had an impact on family and loved ones. It was voiced that talking about cancer was still a taboo and that it meant that some women were suffering in silence:

“My mum had cancer and I only found out after eight months of her having it. She had treatment and I didn’t even know (tearful). I couldn’t go to London to visit her because my kids had GCSE’s so I went down in the holidays and had the shock of my life. I am a talker and believe these things are what families need to know”

It was felt that cancer overall, as a term, was feared within South Asian communities.

4.2.3. Literacy barriers

Our focus groups reported that some women lack literacy skills to help them understand what a smear test is but also what the results mean:

“Sometimes women don’t know what’s being done to them”

“Women don’t attend because they don’t have the awareness of the importance of a smear test. They think they are being called just for another test without knowing the reason why and so think it’s not a priority and don’t attend. This is because they lack knowledge”

“Most women in our Bengali community don’t know what a smear test is. So they don’t know what happens”

“Some women have a language barrier. When they receive the letter, they do not understand what it says so don’t attend”

“I had a case where one woman got married and came from abroad, she was distressed that she could not conceive. I asked her how you know this. She said she got a letter from the doctor saying she was unable to conceive. I said to her that sounds impossible, where is the letter? Anyway, she bought the letter to me to read and I realised she was overdue

for a smear test by four years. It turned out her mother-in-law had told her the letter was about her being unable to conceive when in reality, the letter was the invite letter you get for a smear test. Confusion.”

4.2.4. Cultural barriers

Our focus groups talked about cultural stigma about HPV and cervical cancer and the quote below highlights the risk around the lack of appropriate awareness about HPV within BAME communities, with consequences which could set back the efforts placed into raising awareness of cervical cancer and increasing cervical screening uptake.

“It’s going to be frowned upon isn’t it? Because your automatic assumption is that somebody’s been... naughty. I’ve never really looked into it, if I’m honest with you, and now that you are saying this (about HPV), at the forefront of my mind, I’m saying oh my God she has got cervical cancer so she must have a numerous amount of partners somewhere. You know it’s just a thought that comes in front of your mind, even though it’s not true. It could be the man. Unless you delve into it, unless you have the knowledge about it, you are going to make assumptions, aren’t you?”

HPV is transmitted via sexual intercourse and genital to genital contact, which can give rise to the stigma that exists within communities resulting in the questioning of the sexual behaviour of an individual. The fear of negative judgements towards women affected by cervical cancer or abnormalities can instigate a cycle of fear and anxiety and the reluctance to access appropriate support. This fear is also a barrier to screening amongst younger, unmarried women within these communities.

Bangladeshi women highlighted that there was a stigma attached to being poorly within their community and that women health issues were often not discussed openly:

“Even when a women is pregnant in our community, you don’t discuss it and men only realise it (that they are pregnant) when they see their bellies getting bigger. I just think there’s a stigma attached to being quite poorly. Particularly with cancer and the fear attached to it”

“There are feelings in the community that someone may have sinned and they got cancer as a result”

“When people have that kind of cancer, cervical cancer, they try to hide it. They don’t want people to know”

4.2.4.1. Fatalism combined with stigma

“I would rather die of it than anybody know whilst I’m alive that I’ll die from cervical cancer. It’s a harsh truth. Who wants to be alive (whilst) being treated for cervical cancer and the world knowing about it? It is a scary thought so people are going to think well I’m not going to be tested. If I’m going to die I’m going to die”.

The above quote shows the dire need to increase knowledge and awareness about HPV and the unquestionable need to tackle the stigma related to HPV (due to its mode of transmission) and cervical cancer within South Asian communities.

4.2.4.2. Marital status

A common question arising across all three focus groups was about unmarried women and whether they needed to attend for a smear test. Some women stated that many unmarried women do not go for cervical screening in their community because they are sexually inactive. For South Asian women getting 'married' is a validation that they can now attend for a smear test without fear of judgement from others. However, consideration should be given to address the barriers faced by unmarried South Asian women who want to have a smear test but do not attend for reasons such as the fear of a negative outcome and consequently the risk of the community knowing about the outcome.

4.2.4.3. Health as a low priority

Across all three focus groups, women highlighted that health was not seen as a high priority by women in their communities. Their feedback conveyed that women traditionally played the role of a primary caregiver for both the family and the community and that this role often limited their ability to make their own health and wellbeing a priority:

“Sometimes women tend to ignore their health and put everybody else first and (have) no time for themselves”

“Women tend to pay more attention to their children and husbands but not themselves. If a husband is supposed to have a (medical) test, they are quick to ensure he attends”

“In many communities, because women are not ‘considered’, they don’t consider themselves as well. They are only there for their children, they’re only there as a wife, they are only there for that reason so they have very little time for themselves. So even if they have an abnormality or a discharge they will say ‘oh it doesn’t matter, it will go away’, I haven’t got time”

“I cancel doctors’ appointments due to sickness in my children, one is one year and other is five years old. My middle child is four years old and he is autistic. If I take half an hour for myself, I think maybe in this half an hour I can feed my children, they are more important, I can go another day. Lots of parents do that, I do that”

4.2.4.4. Influence of family members

“Sometimes, it is the husband who will tell you not to attend. He will say, “Why do you need to go? You are fine”.

All three groups highlighted that a lack of understanding and knowledge about cervical cancer amongst men existed widely and that the influence of their beliefs and perceptions contributed to the decision-making process of a women to attend for a smear test. It meant that due to a lack of knowledge, they were not fully informed of the risks and health

implications that can arise from not attending for a smear test, thus forming perceptions based on the little knowledge they had:

“There is the notion that if you have no problems, then there is no need to go. This happened to me. I was nearing my ninth month of pregnancy. I had no movement for two days. I told my husband and a close friend. They both told me don’t worry sometimes there can be no movement of the baby for two days. I believed and felt reassured. My husband said I was fine, not to worry and I would be ok. I felt sick and unwell and when my friend looked at me she told my husband to take me to the hospital. The doctor said if I had sought help sooner, I may have been able to save my baby”

“Some men feel uncomfortable knowing their wives will have to lay down in front of a stranger. Maybe to void the situation they will say, “You are fine, there is no need to go”

“A man may feel that his wife may be questioned about his fidelity, any relationships he may have outside of marriage to someone else. I know that’s one reason why men will tell their wives not to attend (for a smear test)”

However, some women from the Pakistani and Indian women’s group said that their husbands were supportive and encouraged them to seek help if they had a symptom.

Bangladeshi women collectively and strongly aired the view that the influence of elders in the community played a key part in the decision-making process to attend a smear test.

“Unfortunately we are told (by elders) what is so special about you? We have been through aches and pains, have had many children, so pull yourself together, there is nothing wrong with you, you are fine. That’s where the conversation ends. Subject closed”

“Some women’s opinion is that, you know, most of my relatives who are alive in old age, have many children but they don’t have any disease or cancer so why should I do that (have a smear) I am not at risk”

“My in- laws and aunt tell me not to go but that makes me feel more scared”

In contrast, there was no spontaneous mention of the influence of elders in the family amongst Pakistani and Indian women. This barrier indicates the need to target older people within the Bangladeshi community with educational behaviour change interventions. If their perceptions change, they are most likely to influence women positively in making the decision to have a smear test.

4.2.5. Physical barriers

Pain was mentioned spontaneously as a barrier across all three groups of women and that this prevented women from attending, especially if they had never attended for a smear test before:

“I am afraid of the pain, it’s not nice, is it?”

Other physical conditions also prevented women from attending as one Pakistani woman explained:

“I delayed attending for my smear test due to dizzy spells that I get when I get up after laying on my back”

And those who had attended, mentioned going for a repeat smear, or the thought of this, was a barrier:

“I have heard women say they have been many times for smear tests but they have not been able to take a sample so don't go”

4.3. Results from the online survey

126 respondents completed the survey: 99.2% (129) women and 1 preferred not to disclose. Our respondents come from: 52.7% (66) North; 20.7% (26) Central and 26.6% (36) South Manchester. Half (53.2% (67)) people identified themselves as white English/ Welsh/ Scottish / Northern Irish, 46.8% (59) from BAME communities.

Only 40% (44) of respondents always attend cervical screening when invited. One in ten (9.2% - 10) of those responding had never attended screening with almost half (45.9%) delaying their invitation to attend. 4.6% (5) had never been invited to screening. Half (50.5%) of responders that had delayed attending stated that they attended within six months of receiving the letter. 11% delayed attendance for more than three years.

The top three reasons for not attending were:

- I kept putting it off - 31.7% (19)
- I forgot all about it – 21.7% (13)
- I was worried it would be painful – 23.3% (14)

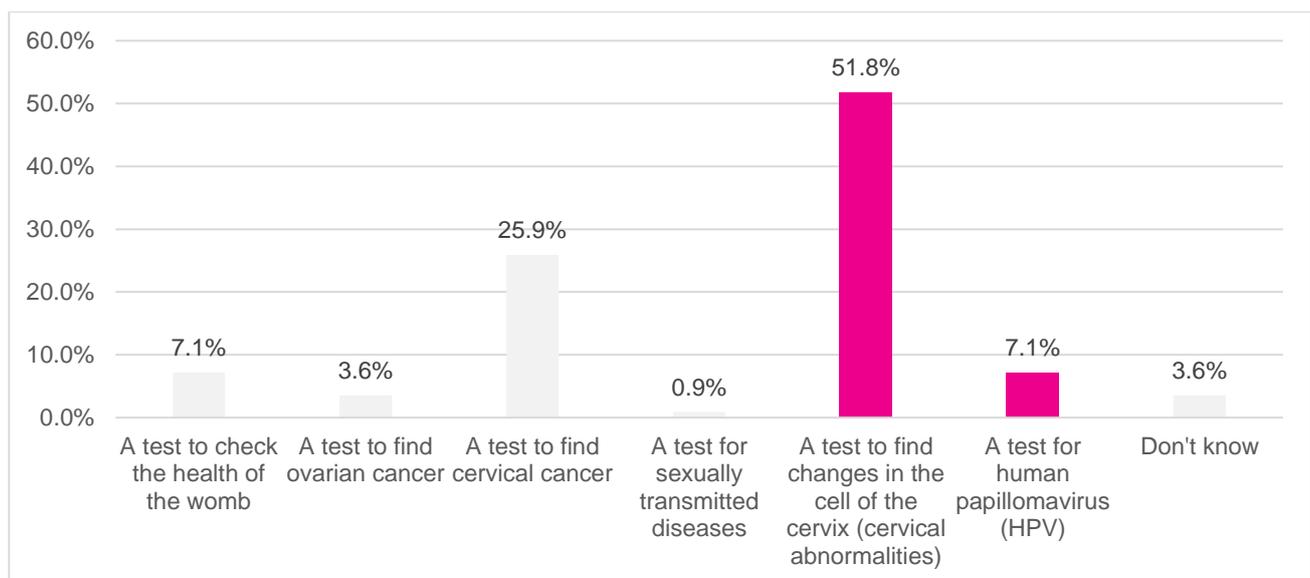


Figure 5, What our respondents think cervical screening is for (all data 115 responses, 14 skipped)

4.3.1. Survey data from women from BAME communities

59 responders were from BAME communities with one third of women aged between 25 and 45.

- The largest groups collected were: 17% (10) were from Pakistani communities, 15.3% (9) from African heritage, 13.6% (8) Other Black/African/Caribbean and 8.5% (5) Caribbean (See Figure 6).
- Over one in ten (11.9%) smoke
- 32.2% born outside of the UK
- Most live in North Manchester 57.6% (34) with 22.0% (13) in Central and 20.3% (12) South Manchester.

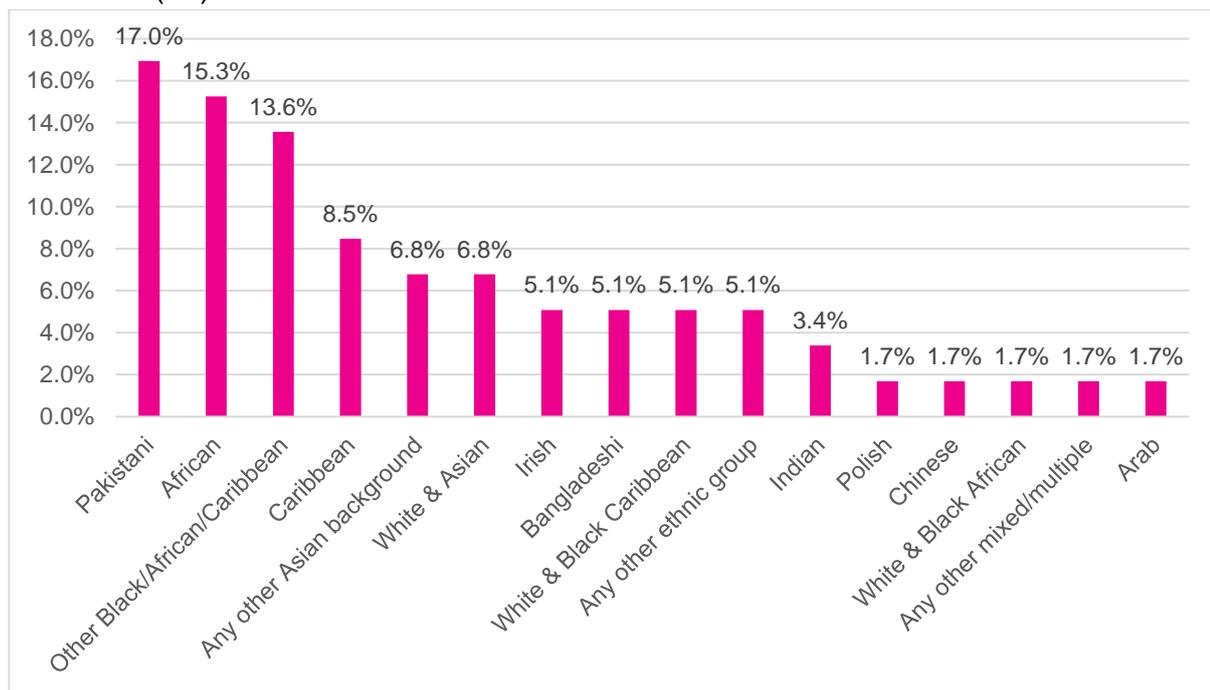


Figure 6. Breakdown of ethnicity of respondents

For those living in north Manchester there was good distribution across the region with most responders from: City centre, Crumpsall and Moston.

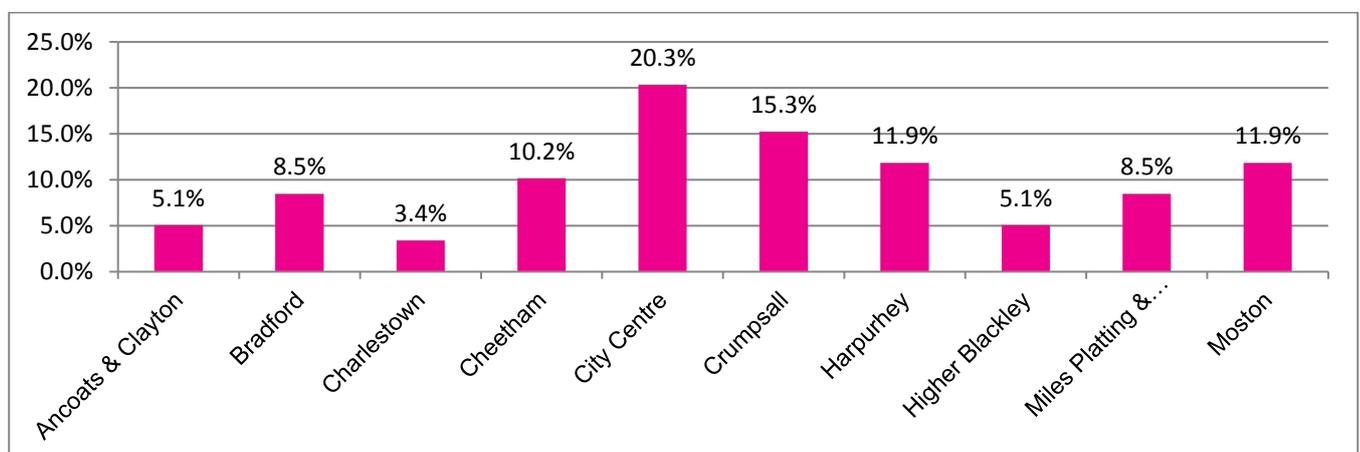


Figure 7. Breakdown of those living in North Manchester

4.4. Comparisons between BAME and white women

Our BAME respondents were slightly older than the white respondents (see Table2). Slightly more women smoked in the white cohort (13.4%) versus the BAME data (11.9%)

More women from BAME groups were born outside of the UK (32.5%) versus only 1.5% in the white women.

We had similar numbers of women from north and central Manchester but double the number of white women from south Manchester.

4.4.1. Knowledge of risk factors and symptoms of cervical cancer

Knowledge of the signs of cervical cancer varied by ethnicity. Overall, BAME women showed lower levels of knowledge of the signs of cervical cancer compared to white women.

- 81% of white women were aware that not attending for a smear test is a risk factor compared to 59% of BAME women
- 74% of white women were aware that infection with the HPV virus is a risk factor compared to 53% of BAME women
- 87% of white women felt that family history is a risk factor compared to 68% of BAME women. Family history plays no role in the risk of developing cervical cancer
- Only 29% of white women and 31% of BAME women knew that smoking is a risk factor for cervical cancer.

A similar pattern regarding the levels of knowledge about the risks of cervical cancer was identified in the knowledge of the signs of cervical cancer according to ethnicity. The knowledge around the signs for cervical cancer in white women was considerably higher compared to BAME women:

- 70% of white women thought that vaginal bleeding in between periods is a sign compared to only 51% of BAME women
- 65% of white women thought that comfort or pain during sex is a sign compared to 42% of BAME women
- 65% of white women thought that vaginal bleeding during or after sex is a sign compared to 49% BAME of women
- 22% of white women did not know any signs compared to 32% BAME women.

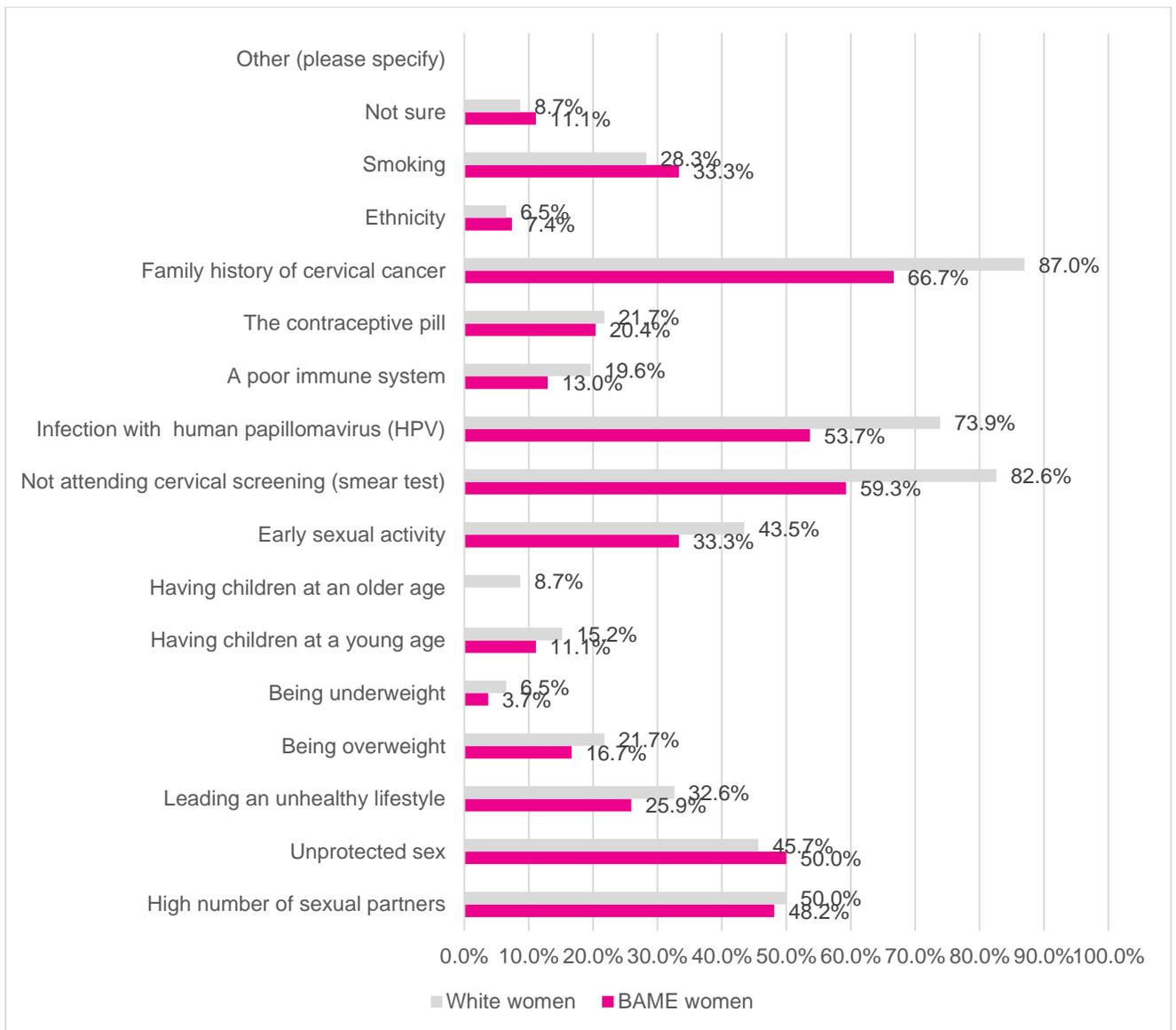


Figure 8. Online respondent's knowledge of risk factors associated with cervical cancer

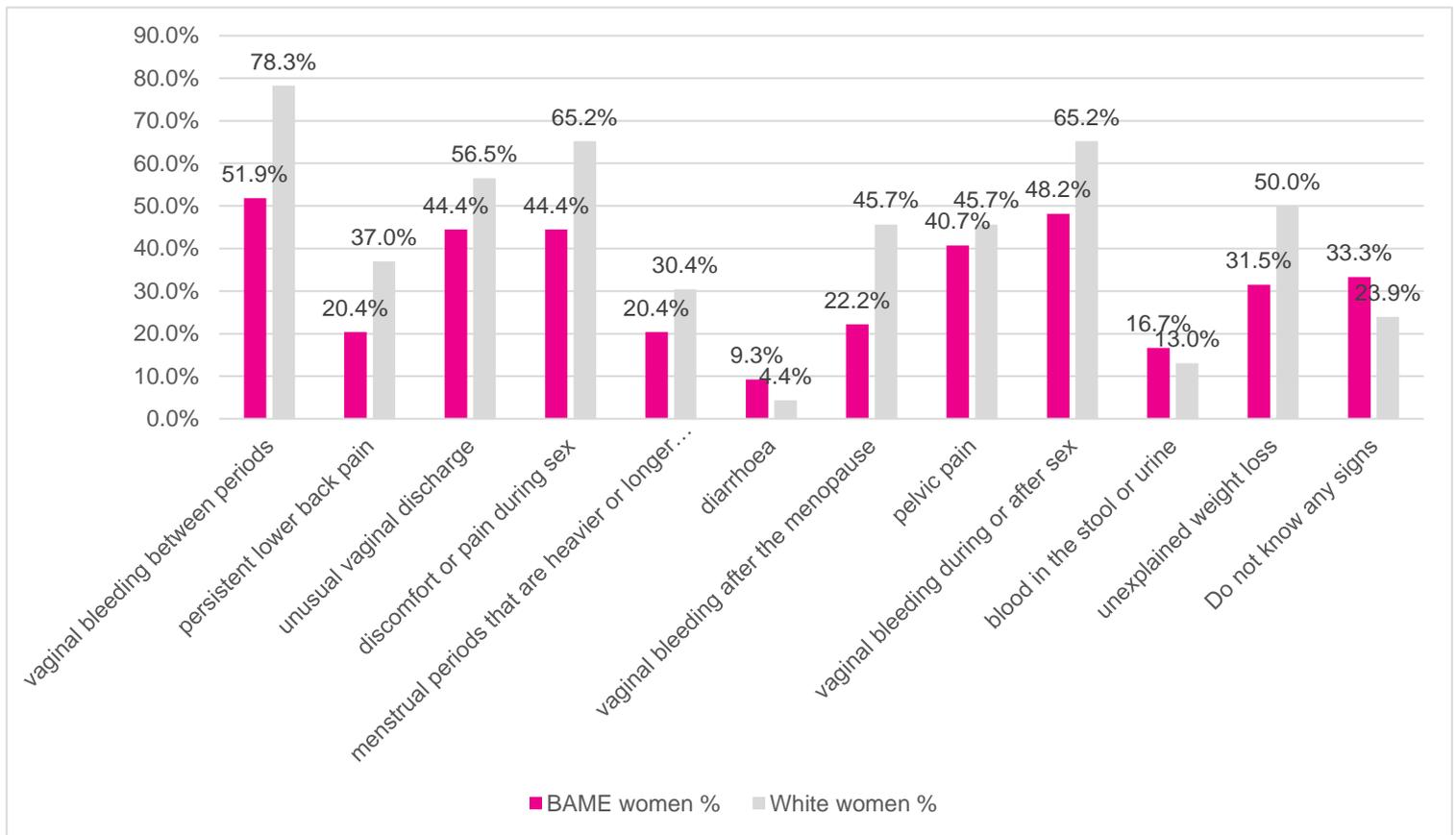


Figure 9. Online respondent's identification of signs of cervical cancer. Data given in %.

4.4.2. Cervical screening knowledge

Knowledge of cervical screening varies by ethnicity with two thirds (66.7%) of white women identifying cervical screening as a test to find changes in the cells of the cervix, compared to 37.9% of BAME women.

"I delayed smear tests until I had time to go due to work and raising children. My last smear found abnormalities so I don't delay anymore. I used to think it won't affect me and that it doesn't affect my community, but now I know it can. Women need to attend. It can happen to anyone."

Comment from a BAME survey respondent

Higher numbers of women (32.8%) from BAME groups compared to 18.5% of white women thought the test was done to find cervical cancer.

No white women:

- Thought the test was to find ovarian cancer but 7% of BAME women did
- Didn't know that screening identifies abnormal cervical cells but 7% BAME were unsure about what the test does.

“My health has been good 'down there' so I never thought it was important for me (to attend) but I attend anyway because my GP keeps reminding me.”

Comment from a BAME survey respondent

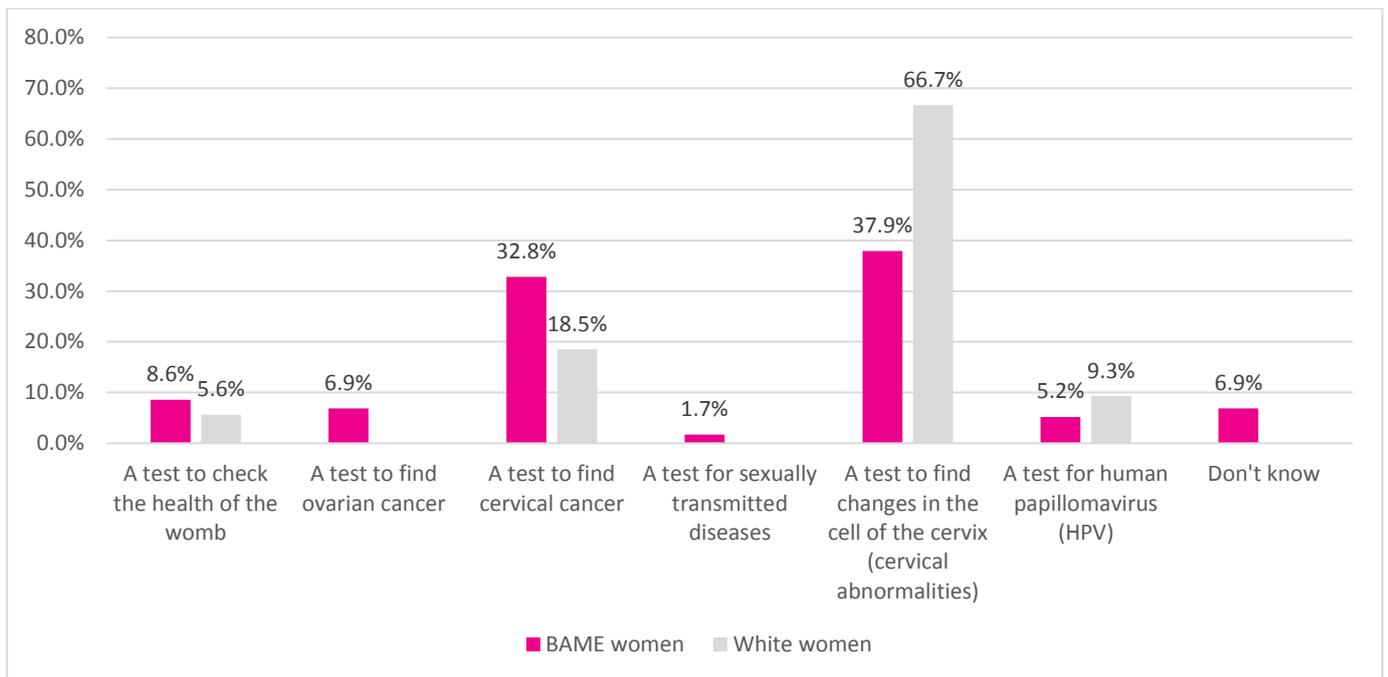


Figure 10. What do women think cervical screening is for (BAME vs white women)

“I don't want to know about the results because it scares me (cancer). My friends have had it done and one of them got bad news. I don't want to think about it.”

Comment from a BAME survey respondent

	BAME Only	White British ONLY
Respondent numbers	59	67
Gender	98.3% (58) female and 1.7% (1) did not disclose	100% female
Age	62.7% of women were under 45 but within screening age. Only 7% were under 24 <ul style="list-style-type: none"> • 6.8% (4) - Under 24 • 17% (10) - 25-29 • 18.6% (11) - 30-34 • 27.1% (16) - 35-44 • 17% (10) - 45-54 • 13.6% (8) - 55- 64 	70.3% are under 45. Only 6% under 24. <ul style="list-style-type: none"> • 6.0% (4) - Under 24 • 30.0% (20) - 25-29 • 19.4% (13) - 30-34 • 20.9% (14) - 35-44 • 13.4% (9) - 45-54 • 10.5% (7) - 55- 64
Ethnicity	Respondents were from the following communities: <ul style="list-style-type: none"> • 17% (10) – Pakistani • 15.3% (9) – African • 13.6% (8) – Other Black/African/Caribbean • 8.5% (5) – Caribbean • 6.8% (4) - Any other Asian background • 6.8% (4) – White Asian • 5.1% (3) – Irish • 5.1% (3) – Bangladeshi • 5.1% (3) – White & Black Caribbean • 5.1% (3) – Any other ethnic group • 3.4% (2) - Indian • 1.7% (1) - Polish • 1.7% (1) - Chinese • 1.7% (1) - White & Black African • 1.7% (1) - Any other mixed/multiple • 1.7% (1) – Arab 	100% English/ Welsh/ Scottish / Northern Irish
Smokers?	<ul style="list-style-type: none"> • 11.9% (7) smoke • 84.8% (50) do not smoke • 3.4% (2) did not disclose 	<ul style="list-style-type: none"> • 13.4% (9) smoke • 82.1% (55) do not smoke • 4.5% (3) did not disclose
Born in the UK	<ul style="list-style-type: none"> • 67.8% (40) – born in UK • 32.2% (19) – born outside the UK 	<ul style="list-style-type: none"> • 98.5% (34) – born in UK • 1.5% (1) – born outside the UK
Location in Manchester	<ul style="list-style-type: none"> • 57.6% (34) North • 22.0% (13) Central • 20.3% (12) South Manchester 	<ul style="list-style-type: none"> • 47.8% (32) North • 19.4% (13) Central • 32.8% (22) South Manchester

Table 2. Online survey data showing the difference between BAME and White women

4.4.3. Differences in cervical screening attendance

There was a small difference of 0.8% between respondents who had never attended - 8.8% BAME versus 9.6% white - however this is not statistically significant.

“I put off having a smear because of pain and embarrassment. I had my first one, it was really bad (pain). I know I should go regularly but I don't cope well with pain because of past issues.”

Comment from a BAME survey respondent

Less white women (34.6%) compared to BAME women (56.1%) have delayed attending cervical screening.

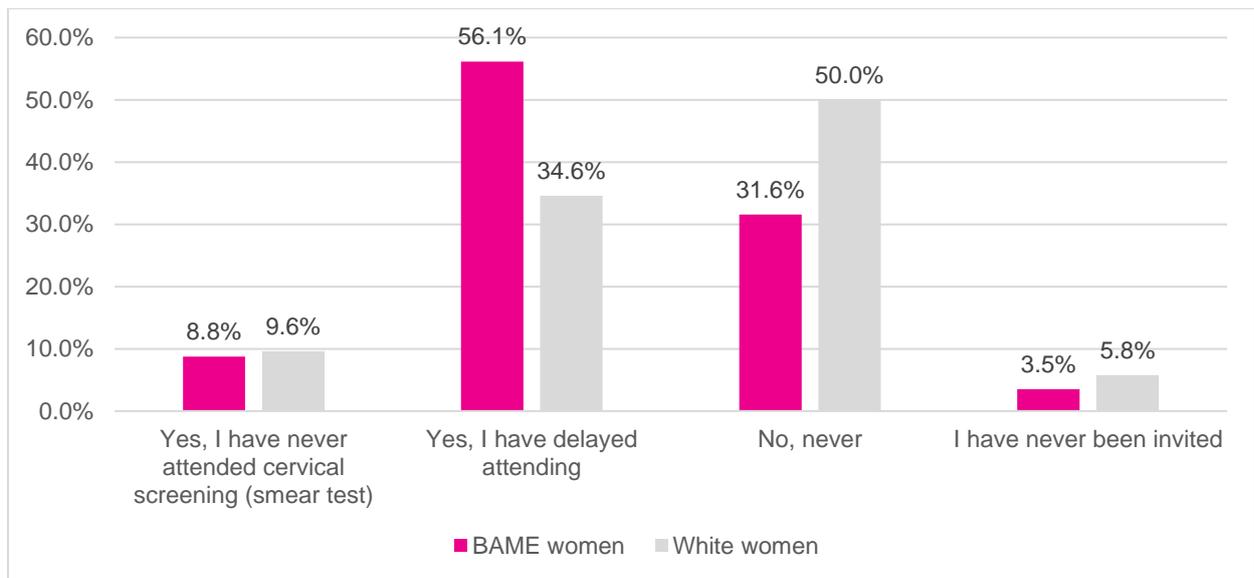


Figure 11. We asked respondents: Have you ever delayed your cervical screening (smear test)?

On average, most women irrespective of ethnicity, delayed for less than three months (31.6% BAME versus 42.3% white). But in the cohort that took this survey, 12.3% BAME women compared to 1.9% white women delayed between three and four years.

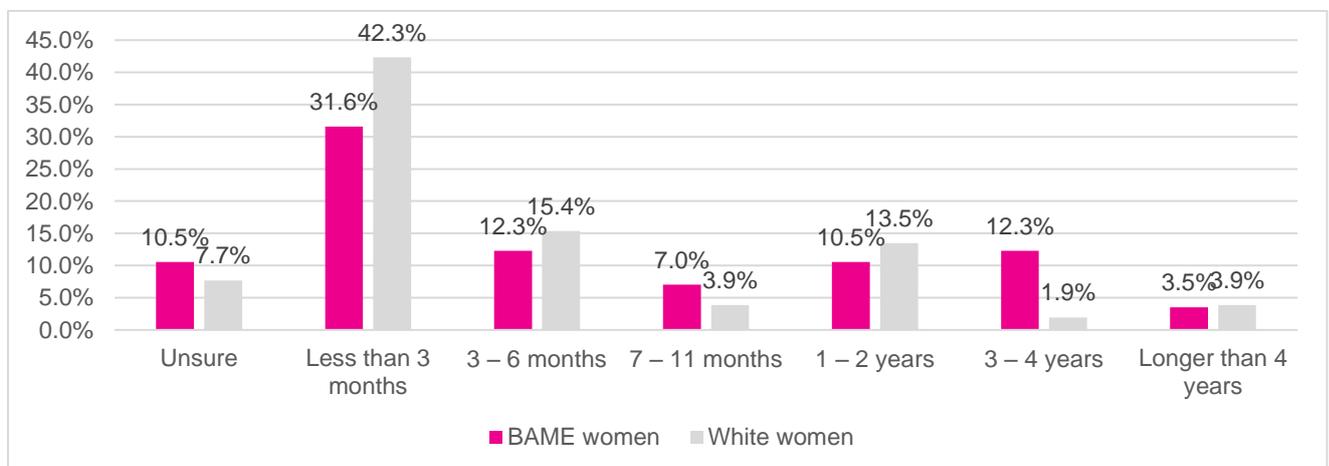


Figure 12. How long do women delay attending?

Women gave a variety of reasons for not attending with the most common reasons being:

- I kept putting it off
- I forgot all about it
- I was worried it would be painful.

Reasons for not attending	BAME women	White women
I kept putting it off	27.0%	39.1%
I forgot all about it	18.9%	26.1%
I was worried it would be painful	18.9%	30.4%
I was worried it would be embarrassing	16.2%	8.7%
I don't think it is important /relevant to me	10.8%	4.4%
I couldn't get time off work	8.1%	13.0%
I found it hard to book an appointment at a convenient time	16.2%	17.4%
I have had a previous bad experience when attending screening	8.1%	17.4%
I feel uncomfortable taking my clothes off in front of a stranger	8.1%	8.7%
I have found it hard to arrange childcare	8.1%	4.4%

Table 3. Reasons that online responders list for delaying attending (BAME vs White women). Data given in %.

“Terrible service from my GP surgery made it impossible - took time off work three times to attend smear test appointments and three times they were cancelled at last minute, on one occasion I was already the surgery when I was informed it had been cancelled. I simply gave up.”

Comment from a BAME survey respondent

Some BAME women listed reasons for delaying that the white women didn't:

“I've never been sexually active and don't think I need one until I am married. I checked with my GP who said it was ok to have one (smear test) when I get married. In my community, only married women go for smear tests.”

Comment from a BAME survey respondent

Reasons for not attending	BAME women	White women
I have not had sex recently so don't need to	8.1%	0.0%
Cervical cancer is rare in women of my ethnicity	10.8%	0.0%
I was worried about what the results would say	13.5%	0.0%
I'm not comfortable with how my genitals look	5.4%	0.0%
I worry that I have to get undressed in front of a male nurse/doctor	5.4%	0.0%
I would prefer not to know if there was something wrong	2.7%	4.4%
It's fate if I get cancer, it's God's will	2.7%	0.0%

Table 4. Reasons that online responders list for delaying attending (only BAME reasons). Data given in %.

4.4.4. Accessibility

Half of women wanted to make an appointment with their registered GP surgery (48.2% BAME versus 42.3% White women). More BAME women (19.6%) wanted to be sent an appointment time by their GP compared to white women (15.4%).

“I used to work night shifts so it was difficult to find time to go for a smear, then I had my first child and put it off, then I had a day job and found it difficult to get childcare. Eventually I had one done but a good two years late.”

Comment from a BAME survey respondent

40% of white women would like the opportunity to take their own samples at home and have them sent off to be tested compared to 33.9% of BAME women.

One quarter of women would like to receive a text message to provide them with information about cervical screening (25% BAME versus 26.9% white women), around four out of ten would like health professional to deliver the information (35.7% BAME versus 38.5% white women) and half (50%) of white women want an email. (See Figure 13).

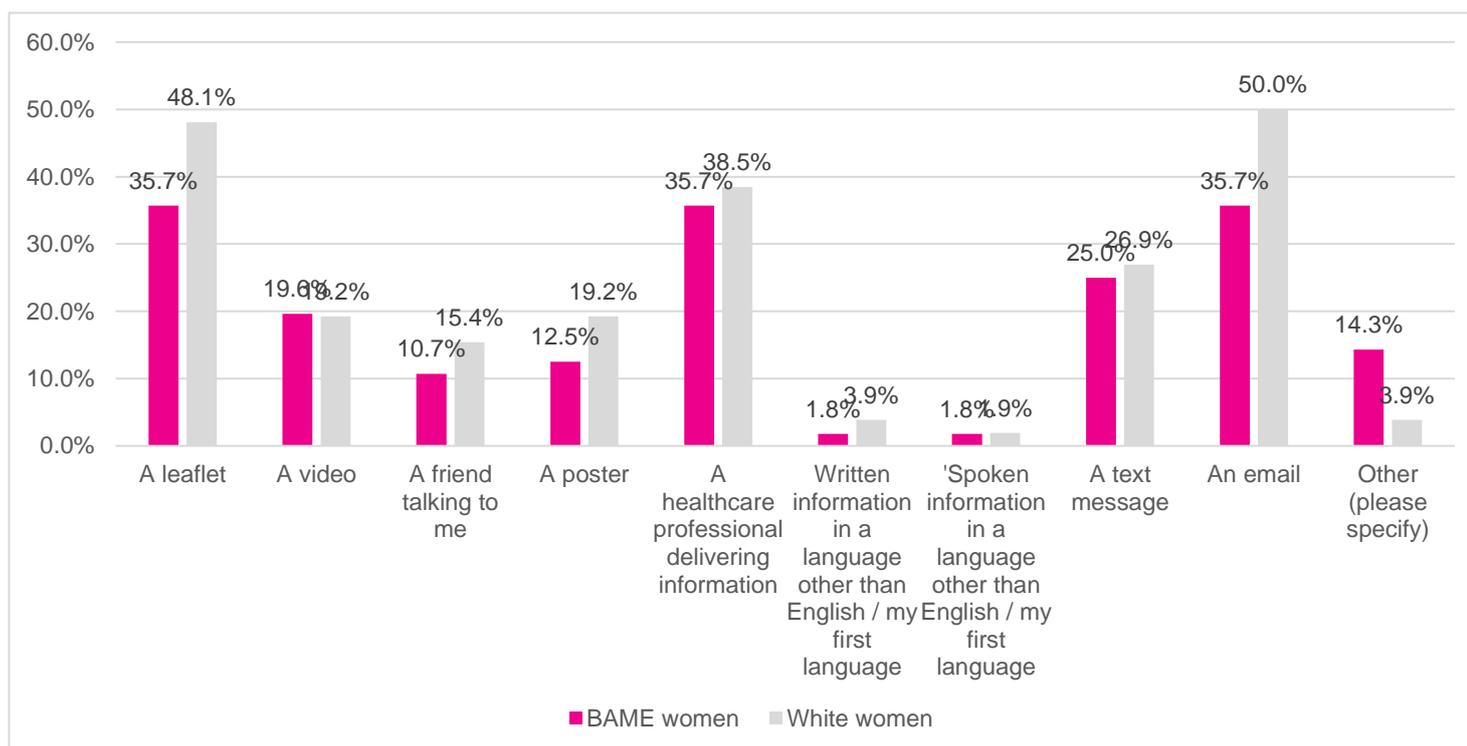


Figure 13. Online survey responders state how they would prefer to receive information about cervical screening

4.5. Online survey conclusions

The online survey data revealed that of the women that took our survey 56.1% of BAME women delayed an invitation to screening with 15.8% delaying by more than three years. Common barriers across both BAME and white women were; they put

off going for the test, they forget the appointment and women had concerns about the test being painful.

The data collected here shows there is a lack of knowledge about signs of cervical cancer and what a smear test is for. It also highlights the need to tackle barriers that prevent women from attending cervical screening such as fear of pain, embarrassment, previous bad experiences, childcare and difficulty in getting an appointment at their GP practice.

5. Overall findings and recommendations for overcoming barriers to cervical screening

The focus groups run as part of this research have provided rich data about what women think about cervical screening. The online survey complements the focus group survey to give a wider range of views. Below we list key recommendations based on the research conducted here and the views of BAME women.

5.1. GP Practice engagement to improve coverage

Our online data showed 48% of BAME and 42% of white women would prefer to have their smear test carried out by a woman at their GP surgery. Other published research has shown significant evidence that women are more inclined to attend for a smear test when reminded via text message or prompted by their GP practice staff⁹.

The Bangladeshi focus group felt that men in their community tend to take information given by a GP more seriously than any other source and that this was a one avenue for men to take on board the screening message:

“It can be done by a doctor giving men the information but not in a group work setting”

“It’s best to come from the GP maybe then the men will give it importance”

Comments from a focus group attendees

GP practices need to be proactive in encouraging women to attend for screening and consider the different methods to use for women to receive the information. Women from our survey wanted information in the form of:

- A leaflet
- A healthcare professional delivering information
- An email
- A text message.

⁹ Huf et al 2017. Behavioural text message reminders to improve participation in cervical screening: a randomised controlled trial. The Lancet 390(S46).

There is a need for a joined-up approach that uses both face to face as well as formal written information.

Women from our focus groups wanted open dialogue about cervical screening with their GP:

“I felt embarrassed but I discussed it with my GP. The GP said to me you shouldn’t find the test painful and it is a female nurse who will carry out the test on you. The next time I got my letter, I went for my smear test and it turned out fine (results)”

Comment from a focus group attendee

There was a consensus across all three focus groups that general health checks should include opportunistic offerings of smear tests for those overdue:

“On the spot smear tests: sometimes it’s good to have a facility where when they are there (for something else), they can have it (smear test) done there, and that’s it, it’s done, especially for the chronic defaulters”

Comment from a focus group attendee

“In Manchester they used to have well woman’s clinics and you could have everything done including a smear test. But they stopped years ago. On the day, you didn’t have a choice because you were there and then they said, ‘right, why not have your smear test, too?’ and you’re there thinking well I’m here I might as well have the smear test done”

Comment from a focus group attendee

“If you have an appointment where they can check everything, you are more inclined to have it done. You have your blood pressure done, your eyes (checked), having this done and having that done, so you might as well have your smear test done”

Comment from a focus group attendee

5.2. Accessible services for cervical screening

BAME and white women highlighted issues around the availability of appointments at a time convenient to themselves and the need for out-of-hours services, particularly for those who work during the day. GPs can play a proactive role in informing patients of extended hours services that they can access via the practice.

5.3. Increasing community education and engagement

Increasing knowledge around signs and risks of cervical cancer. We recommend that Manchester CCG work strategically within the locality of the GP practice on community engagement with local organisations, residents, pharmacies, community centres, clubs, mother and toddler groups, and health & wellbeing neighbourhood workers via trained community cancer champions.

Community engagement via face to face discussions is critical to the success of raising awareness:

“Get out there and reach out, get into the communities out there. Face to face works. Leaflets won’t help. They are a waste of resources. If you have to use letters, then persistence is required for this”

“I think openness will help break barriers. Not in bigger groups but in smaller groups, face to face discussions work”

Comments from focus group attendees

5.3.1. The role of men and community education

All Pakistani, Indian and Bangladeshi women highlighted the need for men to be educated on cervical cancer and the importance of smear tests:

“I think there should be education of the men as well to encourage their women. Educating the men is important because if they know things then they might encourage the women to take up (smears) or look after themselves”

“Men should be taught about what cervical smear test is, why it’s important and that it’s for mothers, sister and wives, they should know this. It’s best to come from the GP maybe then the men will give it importance”

“It is very important for men to be educated about this. It is the woman who has to endure this illness, not the man. If men are educated, women’s health can improve drastically. If the husband is educated on these matters, he will be able to understand better about his wife’s health”

Comments from focus group attendees

The following methods of raising awareness and education amongst men in all three communities were recommended by the Pakistani and Indian women:

- **Screen TV adverts about cervical cancer and screening** - on news and sports channels. It was felt that men may become more aware and motivated to encourage women to attend for smear tests
- **Utilise Facebook** - The women highlighted that most of their husbands use Facebook and often discuss issues that they see on the social media platform and felt that this was an effective way to communicate the messages
- **Conduct live web casts on Facebook** - Some of the women stated that they watch live casts and learn about health issues, as do their husbands
- **Target workplaces** - Engage with men at their workplaces as one woman stated:

“Men do discuss a lot of things you know! My husband is a taxi driver he tells me a lot of things! So go to their workplaces or where you can find them such as Mosques, taxi ranks and Cash and Carry’s”

- **Men educating men** - It was felt that due to the sensitive nature of the topic of cervical cancer, using the approach of men educating men would work because women educating men would be ineffective:

“It all depends on funding but giving information to men at taxi ranks is one way to reach them. Get men to educate men on this. When a man tells another man something, they take on board the information better”

“Just like women talking to women is more effective about this topic, men talking to men about this will work better”

“Women are women and men are men when it comes to sensitive issues like this. For example, if a man was sat here telling us about cervical cancer and screening, we would not be comfortable or able to talk openly like this and we would not be able to ask questions either”

Comments from focus group attendees

5.3.2. Tackling barriers to uptake associated with communities

Discussions across all three focus groups raised the issue that women may not consider their health to be important and other people’s health come first such as their children, husbands etc. Making women’s health a priority amongst community groups is essential:

“Make women feel they are cared about and their health is important, because then, a woman actually feels she is being cared about. So, like a well-woman’s clinic the name says it ‘the well-woman’s clinic’. She will think somebody has put some thought into her, so somebody cares how she’s getting on and she’s going to think well I’m giving that half hour there (at the clinic) so I might as well have everything done”

Comment from a focus group attendee

Shame and embarrassment featured as important barriers that prevent women from South Asian communities from attending screening. Women across all groups thought that hard-hitting messages would encourage women to go:

“Tell women what will you do with this shame and embarrassment once you have cancer? Will you let shame and embarrassment take your life?”

“Tell women it only takes a few minutes, it can save your life”

However, some women felt that this may generate more anxiety and fear so messages need to be tactful and culturally and linguistically appropriate. Everyone agreed that there is a need to be more honest about health messages and that the

benefits of early diagnosis should be emphasised along with survival rates.

Yet, a diagnosis in the community acts as a motivator to realising the importance of a smear test:

“One of the ladies is saying that her 28 year-old sister died from cervical cancer so after that she has been going for her smear tests regularly. Her sister had two small children”

“When something like cervical cancer happens in the community, it’s at that time they think they should go for their smear test. That’s when they realise they have to do the smear test”

Comments from focus group attendees

5.3.3. Visual tools - Videos

Opinions about the use of visual aids, such as a smear test film, to raise awareness varied amongst the three groups. Pakistan and Indian women felt a video was a useful tool to use, but would need to be produced in the appropriate language:

“Explain to women the risks (of cervical cancer) and use tools like videos to explain this, like they show videos to children in schools to help them learn better”

“Like the bowel cancer campaign, it was done in multiple languages, and then they showed how to use the kit that comes through the door. A video is verbal information and visual too”

Comments from focus group attendees

However, the consensus amongst Bangladeshi women was that a video would prove useful in a group setting and if it was produced in their spoken language but not useful if the expectation was that they view it within the privacy of their own homes:

“Some women don’t know how to play a video and would not ask their child to show them how to use it because of the sensitive topic”

5.3.4. South Asian TV channels

All women felt that using South Asian TV channels as an avenue to raise awareness, would be a useful way to increase reach amongst women, especially those who spend a considerable amount of time within their homes.

5.3.5. Awareness posters

Pakistani women felt that a poster as opposed to a leaflet would be more useful and would need to be culturally and linguistically appropriate:

“Show a middle-aged South Asian woman and a young woman beside her, with an expression of sharing information/having a discussion. Let the poster encourage

women to attend by stating some simple cancer information and that it's an important test that can save your life"

"It needs to be sharp and simple like a caption that says 'do not miss your smear test appointment' or 'Be alert, be aware, be safe'"

"Have the poster in both languages because our younger women and girls cannot read Urdu, they read English, so make a poster appealing to both groups"

"Why not use an image of a woman wearing a headscarf? Something we can relate to"

Comments from focus group attendees

5.3.6. Overcoming the language barrier

Bangladeshi women highlighted that many of the women stay at home and are not as proactive in the community compared to other groups. They do not visit many places, apart from schools to pick up children and their GP practice. Thus, there is a real need to reach out to women within their homes. Women highlighted that face to face interventions were the preferred method of accessing information and improving knowledge, especially via GP practices:

"A GP knows everybody in the community, so if a GP writes a letter to say there is a talk on screening here and that it's important (to attend) that would work better. GP's have all the records of women so if they contact us and say there is a session, we would take it more seriously. Sessions should be held in Bengali (language) and avoid being held at school (drop and pick) times and school holidays."

"It would be useful to send the (invite) letter in Urdu, for women who cannot read English but can read Urdu."

Comments from focus group attendees

All Pakistani and Indian women agreed that a language barrier prevented women from attending their smear tests and suggested the following interventions:

"It would be useful to have information in both languages (Urdu and English) so it covers the younger and older women. You have to be careful with Urdu though as some of the terms used to describe some words can be complex and beyond our understanding"

"Do awareness sessions in spoken languages in places like temples, schools, work places"

Comments from focus group attendees

Pakistani women felt that for women who can read Urdu, the invite letter should be in the appropriate language and for those who are unable to read English or Urdu, the following methods were recommended:

“The best way would be to have a GP practice interpreter call these women and speak to them in Urdu when they are due for a smear test and book in an appointment at the same time. Not everyone can share the letter of invite with others and ask them to explain what it says”

“Verbal communication of information is better than a written form. Word of mouth is better than a letter. With a letter, you may end up binning it or putting it aside with the intention of reading it later but when someone is talking to you, your mind is paying attention to what they are saying so it registers better”

Comments from focus group attendees

All women felt that hearing about examples of case studies that had a positive outcome would encourage women to attend screening:

“Some women understand the importance, some don’t. I went to my neighbour who told me that she had lumps in her breasts and that they had grown. I made her understand the importance of seeking help by telling her you have small children you ought to go and get tests done for their sake. She went and had tests which showed early stage breast cancer. She had surgery. When I visited her, she said, “Had you not encouraged me to go and get checked, I may have not survived”

Comment from a focus group attendee

5.4. Resources and people needed to increase community engagement

A combined approach is favoured to improve long term awareness. Solutions such as posters or leaflets in appropriate languages help to increase the awareness of cervical cancer and uptake of cervical screening. Jo’s Cervical Cancer Trust has a range of posters, printed resources and online translated films that be utilised by community group and GP surgeries:

<https://www.jostrust.org.uk/resources/materials/information>

However, in addition our focus groups stated that they wanted to know, through clear and simple messages, the following:

- The purpose of a smear test
- The process of having a smear test
- What cell abnormalities mean in relation to the development of cervical cancer
- The risk of not attending a smear test
- Risk factors, especially factual information on HPV.

Language and literacy barriers were a common theme across all three groups. The solutions offered by the women highlighted a crucial need to deliver cervical screening messages in a culturally and linguistically appropriate manner and environment, particularly using face to face settings.

5.4.1. Community cancer champions

Local residents volunteering as cancer champions are ideally placed within communities to raise awareness about cervical screening amongst women, especially non-attenders. Women engage when they can interact with someone familiar from the community or someone that they can relate to thus leading to an increase in communication and engagement in key issues such as cervical cancer and screening. This would enable women to take control of their health more effectively.

The role of local community groups, keyworkers and leaders is pivotal to raising awareness and increasing screening uptake amongst BAME communities. They can also play an important role in tackling issues around health literacy. It is therefore vital to design and deliver interventions that are culturally and linguistically appropriate. Women are more likely to engage if the language barriers are removed and if the key worker implementing the delivery is of a similar cultural heritage or has a good knowledge of the cultural and religious barriers of the group of women being targeted. This enables the message of early detection and prevention to be absorbed effectively, enabling a positive health behaviour change.

5.5. Soft intelligence information/data sharing

There is need for all key stakeholders, including health care professionals, community groups and charities, who are conducting research or piloting new interventions to work closely with the Screening and Immunisation teams to feedback the discussions on barriers to screening faced by women. This will improve understanding of the ever-evolving barriers within certain communities and enable the teams to assess the approaches used in service designs, provisions and delivery.

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