The barriers to cervical screening for South Asian women aged 25-49 in North Kirklees.

Published August 2014

Shabana Ali

Healthwatch Kirklees
Unit 11/12 Empire House
Wakefield Road
Dewsbury
WF12 8DJ
Tel: 01924 450379
Email: info@healthwatchkirklees.co.uk
# Table of Contents

About Healthwatch Kirklees .................................................................................. 3

Background ........................................................................................................ 4
  Previous Campaign ......................................................................................... 4

Benefits of cervical screening ......................................................................... 5

Terminology ......................................................................................................... 5

Aims & Objectives ............................................................................................... 6

What did we do? ................................................................................................... 7
  Profile of respondents ...................................................................................... 7

Ethical considerations ......................................................................................... 8

Key insights from the interviews ....................................................................... 9
  “I don’t feel at risk” ......................................................................................... 9
  Fear of pain ....................................................................................................... 9
  Fatalistic Attitude .............................................................................................. 10
  Abnormal Results .............................................................................................. 10

Motivators ........................................................................................................... 11

Motivators for women who had attended a smear test ................................ 11
  Intention ........................................................................................................... 11
  Education and Knowledge ............................................................................. 11
  Value Health .................................................................................................... 12
  GP recommendation ........................................................................................ 12

Motivators for those who had not attended a smear test .......................... 13
  Leaflets ............................................................................................................ 13
  Education on importance of cervical screening ............................................. 13
  Friends and family/ Community Champions ............................................... 13

A professional’s perspective ................................................................................. 15

Chandni Clinic - Women only clinic ................................................................. 15

Conclusions and recommendations ............................................................... 16
  1. Using radio/TV media to present information ........................................... 16
  2. Developing a programme of health events for minority communities ... 17
  3. GP Information sent to patients ................................................................. 17
  4. Community Champions ............................................................................. 17

References .......................................................................................................... 19
About Healthwatch Kirklees

Our health and social care system is going through massive change. The voices of people who use health and social care services need to be clearly heard and valued by decision makers. That’s our role. Healthwatch Kirklees is here to gather and represent the views of adults, young people and children living or using services in Kirklees. We want to know what’s working well and what needs to be changed.

By working in partnership with North Kirklees Clinical Commissioning Group we aim to help the NHS understand what patients are saying about NHS services in our area. It’s crucial that patient experiences and insights help the CCG commission services that better meet the needs of our population.

Our voice is your voice. Every voice counts when it comes to shaping the future of health and social care, and when it comes to improving it for today. Everything that local Healthwatch does will bring the voice and influence of local people to the development and delivery of local services.

Healthwatch Kirklees - Aims and objective - 2014
Background

Cancer is now one of the leading health challenges in the UK with one in three people expected to develop some form of cancer in their lifetime. Cervical cancer is the most common cancer in females under 35 in the UK, over three-quarters of all new cases of cervical cancer are diagnosed in women aged 25-64 years (Cancer Research UK, 2014). Cervical cancer is caused by the Human papillomavirus (HPV). This virus can be transmitted through sexual contact.

Early detection and treatment of changes in the cells of the cervix can prevent a cervical cancer developing. The best way to detect changes in the cells of the cervix is by having regular smear tests (Cervical Check).

With the declining number of women attending cervical cancer screening it is feared that this will result in an increase of women being diagnosed with cervical cancer. According to research commissioned by Jo’s Cervical Cancer Trust women aged 25-29 and 60-64 are least likely to attend an appointment for cervical screening, with only one in three younger women and more than one in four of the older group not turning up.

“Yorkshire and Humber cervical screening uptake figures show Hull 72% followed by Wakefield and Sheffield. Bradford 72.3% and Kirklees was best uptake with 76.6%.” Jo’s Cervical Trust

Previous Campaign

In April 2013 a social marketing approach was used to increase uptake of cervical screening in women aged 25-34 years of age.

The project was led by Yorkshire Cancer Network and involved:
- NHS Bradford and Airedale
- NHS Kirklees
- NHS Calderdale
- NHS Leeds
- NHS Wakefield District
- NHS Hull

The aim of the project was to:
- Define which groups of women were more prone to poor attendance
- Understand the barriers to cervical screening
- Develop and pre-test ideas for improving the way local screening services are promoted and organised- drawing closely on insights gained from local women.

The campaign used methods such as clinician training, primary care engagement, community engagement and a poster campaign. The impact of the campaign was a
37% increase in the number of women attending smear testing in 2013 compared to 2012.
In addition, the Contraception & Sexual Health (CaSH) clinic in Kirklees reported a 61% uplift in number of cervical screening appointments in the campaign period, compared with the same period in 2012.

Benefits of cervical screening

- Cervical screening reduces the risk of developing cervical cancer.
- The number of women who develop cervical cancer has halved since the 1980s due to most women regularly attending cervical checks.
- Cervical cancer is now an uncommon illness in the UK due to regular screening.
- NHS cervical screening saves around 5,000 lives a year in England.

Terminology

The correct name for the procedure is a cervical screening test. However, the initial insight showed that women understand - and respond better - to the term “smear test”. This report therefore uses this terminology to ensure the message is clear.
Aims & Objectives

We agreed to help North Kirklees Clinical Commissioning Group (NKCCG) to understand why screening rates for South Asian Women living in Kirklees were lower than in other areas, and how they might be increased. We spoke to women in North Kirklees with the aims:

- To identify what or who influences South Asian women to access or avoid cervical screening, in particular barriers to accessing screening.
- To explore ways to improve uptake of cervical screening among South Asian women living in North Kirklees.

Our objectives were:

- To determine South Asian women’s understanding and perception of cancer and their knowledge of their own susceptibility to particular cancers.
- To ascertain this community’s knowledge of the existence of cervical screening services.
- To investigate and describe some of the factors that act as barriers to effective uptake of cervical cancer screening services among South Asian women living in North Kirklees.
- To establish what kind of intervention would be acceptable, appropriate and desired by this community to motivate them to access cervical screening.
- To understand the healthcare professionals’ perceptions of the barriers, for the South Asian women for whom they care.

The information obtained may contribute to current understanding of the reasons why South Asian women do not attend the recommended screening.
What did we do?

Shabana Ali, Healthwatch Kirklees Advisor, contacted local community organisations who support South Asian women and requested to speak with their clients about cervical screening. Arrangements were made to speak with women at:

- Sitara Project at Batley Baths and Recreation Centre
- Milen Care Day Centre
- Dewsbury Moor and Scout Hill Children’s Centre
- Ravensthorpe Children’s Centre
- Savile Town Children’s Centre
- Ladies Coffee Morning at Al-Huda Zawiya

Semi-structured interviews were completed with 20 women using an interview guide (see Appendix A).

The intention was to audio record the interviews and make detailed notes, however due to most of the participants not feeling comfortable with having their interview recorded we only used detailed notes.

We completed a thematic analysis of the interview data. This is the most commonly used method for qualitative exploration, therefore we used this method to analyse our insight findings from the semi-structured interviews.

Data analyses was undertaken by reading through the notes and identifying themes. Re-occurring themes from our findings have been presented in this report.

Profile of respondents

Women were not required to provide information about their age or ethnicity, but were asked for their age, ethnic background and whether or not they were born in the UK:

<table>
<thead>
<tr>
<th>Age</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of respondents</td>
<td>14</td>
<td>4</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnic background</th>
<th>Pakistani</th>
<th>Indian</th>
<th>Bangladeshi</th>
<th>Bengali</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of respondents</td>
<td>8</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

8 of the women who were interviewed said that they had been born in the UK.
Ethical considerations

We applied ethically sound data collection procedures to all participants in the insight.

- Participants made a voluntary decision about whether or not they wanted to take part in the insight. They were informed verbally and in writing that participation is strictly voluntary and they can withdraw participation at any time.
- All participants were informed of the purpose of the insight, what their participation will involve, how their confidentiality will be protected and how any information they provide will be used and stored. Participants were also informed about the benefits of taking part and who will have access to their information. To document that participants have given informed consent they were asked to sign a consent form, however not all the participants felt comfortable signing the form, in such instance verbal consent was necessary.
- All data we collected was anonymised.
- A copy of the Healthwatch Kirklees’ confidentiality policy was also made available to all participants.
Key insights from the interviews

We have identified the themes below which were identified in the interviews.

“I don’t feel at risk”

Women who were unmarried felt that they did not need a cervical smear test.

“I would be more likely to go for a smear test if I felt that there was something wrong or if I was married.”

“I have been invited for a smear test but I didn’t go. The reason I did not attend was because I am not married and I don’t feel that I need it.”

Some women also held the view that they did not need to have a smear test if they had only one partner.

“I don’t want to have one. I don’t feel I need it. I’ve only got one partner (husband) so I don’t feel I’m at a high risk of getting cervical cancer.”

“I don’t think I’ll attend another screening because I’ve had kids now so I don’t feel that I’m at risk of any disease down there. If I felt that something was wrong or if I had any symptoms then I would see my GP.”

“I’ve spoken to other female family members and friends and most don’t go for smear tests. Many say that it’s only for women who have more than one partner.”

Fear of pain

Fear and anxiety surrounding ideas of pain, discomfort and a potential cancer diagnosis greatly contributed to a screening defiance.

Some women reported experiencing pain and discomfort after the smear test.

“I felt nervous that it would be painful. I found it painful and uncomfortable. It put me off going again. After the test I had some discomfort for a few hours, I didn’t like the feeling.”

“The smear test was really painful and I had a lot of discharge for a few days after.”
Fatalistic Attitude

A fear of receiving a cancer diagnosis was identified as a key barrier to cervical screening. Some women held the view that by having the smear test they would be tempting fate and believed that if it was in their destiny to get cancer then nothing could prevent that.

“I believe if you are destined to get ill then nothing will prevent that. It’s better to not know and live a happy life even if it is short, than to know and die faster.”

“I know that it is to detect cancer and can help identify and cure the disease quicker, but I believe that whatever is destined will happen to you regardless of how many tests you have.”

The fear mentioned above can place women in high states of anxiety, and as a result, many women fail to attend for a cervical screening.

Abnormal Results

The time between having a smear test and receiving abnormal results was also deemed to be a barrier.

A reoccurring barrier to cervical screening was waiting for results. Many women expressed their concerns around their experiences of waiting for cervical screening results and felt that delays in receiving results made the process more stressful.

Another barrier identified was the possibility that abnormal cell results meant unfavourable cancerous results and would lead to further cervical smears.

“I have had my sister go through stress. She had a smear test and the results came back abnormal twice and she was extremely stressed. Her letter arrived on Fridays which made it worse as on Saturday and Sunday she was not able to call anyone for advice.”
Motivators

Our insight complements other pieces of research in understanding the low uptake rate among South Asian women. However in comparison to most studies which tend to focus exclusively on understanding the barriers to cervical screening, our insight examines the potential motivators that could help increase the uptake rates of cervical screening among South Asian women.

The women who had been for their smear tests were asked “What do you think would motivate women to attend a smear test”?

Motivators for women who had attended a smear test

Intention

Intention to attend a smear test emerged as a key concept and strong predictor of actual attendance.

“The women who care about their health will attend regardless of whether you send them invitation letters or not.”

“Some women will never go for a smear test no matter how many shock tactics you use.”

“I don’t think the NHS can do anything as the women need to have the intention first.”

Education and Knowledge

Our findings support the health belief model; the women’s knowledge of cervical cancer correlates with attendance to cervical screening.

The knowledge level about cervical cancer was low among the women who had not been for a smear test, whereas women who had attended screenings had a higher knowledge level. Below are comments from women who have attended:

“I think people who are aware of the benefits of cervical screening are more likely to attend.”

“I think the NHS should send letters to them in Urdu or whatever language they can understand, so that they can gain information themselves. Many don’t understand what the test is for so they don’t bother with it. It’s such a taboo topic in our community, you cannot talk about it openly as it is seen as being promiscuous.”
“I know what cervical cancer is so I understand the importance of having a smear test.”

“More education is needed for women who do not understand the benefits of smear tests. Early diagnosis is better than late treatment.”

Value Health

“I care about my health and want to be on the safe side so I make sure I attend appointments.”

“I went for the smear test because I want to look after my health.”

“I will go for it again when they call me. I think it’s important to be healthy and aware of bodily changes. I’d rather have a 2 minute test than get ill and have intrusive treatment.”

“I will attend another screening as I want to be healthy.”

GP recommendation

GP recommendation was found to be a major facilitator of cervical screening adherence.

“I attended because I was advised by my GP to have one.”

“I received a letter from my GP inviting me for a smear test.”

“It was the constant reminders and the information leaflet that motivated me to attend.”

“GPs are the only people women will listen to. If the GP explained and ordered them to go then they will definitely go. When GPs say something is important women from abroad are more likely to listen to them.”

“I only attended because my GP said I should.”
Motivators for those who had not attended a smear test

The women who had not been for a smear test were asked “What can the NHS do to encourage you to attend a smear test”?

Leaflets

Some of the responses were about the design of the leaflets, the preferred language and the timing of invitations being sent out.

“I think they (NHS) should make the leaflets less boring. They also look serious and depressing.”

“I can only read Urdu so I would prefer information in Urdu.”

“The NHS should send letters only when you’re sexually active.”

“I can’t think of anything that will make me go. I think the NHS should not send letters saying that the results are abnormal, they should see you in person. It’s so worrying when you get told that something isn’t normal. The NHS should only send letters confirming the results are clear.”

Education on importance of cervical screening

Some comments made were:

“I think women need knowledge about the importance of cervical screening and the risk of not having one. Women need to learn how to relax their bodies, I think nurses should spend more time relaxing the women who are having it for the first time. If it is painful the first time then most women will not want to attend.”

“I think women need educating that cancer can affect them at any time and having a smear test can save them from intrusive treatment or save their lives.”

“I can’t think of anything that the NHS can do to encourage women to attend for a smear test. I think women should be given all the information and then allowed to make their own choice.”

Friends and family/ Community Champions

It was clear from conversations that people require information about cancer in different ways.

The women interviewed were asked “Is there anyone else that could encourage you to attend a smear test?”
The comments demonstrate how family can not only motivate but also pose as barrier. Some women told us that the older family members still held false myths about smear tests and had some influence on whether they should attend for a test or not.

Some comments were:

“I’m not sure how the NHS can encourage women to attend for a smear test. I think there needs to be more information that is targeted at the older women as they have a lot of influence over their daughters and daughter-in-laws. Some girls might need a smear test but they won’t attend because they are worried their parents will think they’ve been up to no good. It depends on the family and how cultural or educated they are.”

“The NHS should promote issues such as smear testing in a way that women do not feel offended. They should speak to the religious leaders who can encourage women to have a smear test as a way to prevent cancer.”

“If I had any symptoms and my GP told me to have one then I will. If cervical cancer is really an issue in the Asian community then they (NHS) should make people aware.”
A professional’s perspective

Chandni Clinic - Women only clinic

Chandni Clinic is a women only clinic which enables women from hard to reach communities to talk confidently about sexual health with a female doctor in their own language.

Based in the Dewsbury and District Hospital and run by staff from The Mid Yorkshire Hospitals NHS Trust, the clinic was set up following a survey stating 70% of women from Asian backgrounds had no concept of sexual health and the services available to support them.

The clinic is run by Dr Jabeen who can speak a number of languages including Urdu and Gujarati and has played a significant role in establishing the programme; translating leaflets, visiting mosques and generally building up trust with local communities.

We met with Dr Jabeen who shared with us her experience of work on the education of cervical screening, which she does as part of her gynecological and sexual health awareness programme.

Dr Jabeen has developed her own model of health education programme. When she visits women’s groups she takes her sample cervical screening kit with her so that she can show the women what the brush looks like, they are made to feel it and then using pictures of a uterus and cervix, she explains where the brush is supposed to go. One of the important myths about cervical screening amongst the South Asian women is that it may damage the anatomy of the cervix or uterus which may result in infertility, to combat this fear Dr Jabeen uses pictures and explains the basic anatomy.

Dr Jabeen told us that she has identified many patients who have never had a cervical screening. Although most agree to have one after she has used her model of explanation, Dr Jabeen finds that most will never attend their GP for it. The women do request Dr Jabeen for a smear test but apart from exceptional cases (those presenting concerning symptoms, but have never had a smear test) this is not always possible due to the lack of funding.

Dr Jabeen believes that it is important that services such as Chandni Clinic are identified as they are specifically designed to address all main barriers for South Asian women, such as language, female clinician and privacy.
Conclusions and recommendations

Although the interviews highlighted many barriers to cervical screening, they have also identified several factors which are crucial for improving attendance.

One of the reoccurring themes was that many women felt that they were “not at risk” of cervical cancer, therefore were not fully aware of the screening programmes and their purpose. Although marketing campaigns in relation to cervical screening and cervical cancer awareness have/are being carried out, they are not reaching all communities. Some communities not being reached are likely to be those who currently have the least access to knowledge and information relating to cervical cancer.

As women from the South Asian communities have a lower uptake of available screening it is of high importance that the marketing and communication strategies are adapted to better meet the needs of more diverse communities.

From our insight and public engagement, Healthwatch Kirklees has identified certain recommendations which will improve the good work that is currently being carried out by the NHS in order to raise the awareness of cancer screening services in Kirklees.

These recommendations, when applied, will also break down some barriers for women from ethnic minority communities to access information relating to cervical cancer in order for them to be able to monitor their own health needs more effectively.

Our recommendations are:

1. Using radio/TV media to present information

It is evident that many people from South Asian communities regularly listen to interest/language specific radio stations. It is therefore recommended that NKCCG use these channels to promote their Cancer Screening Programmes and to raise awareness of cancer and its symptoms. Some recommended channels/ magazines are:

- Ramadan Radio (only on air during month of Ramadan)
- Sunrise Radio
- Awaaz
- Paighaam Magazine
- An-Nisa (women’s magazine)
2. Developing a programme of health events for minority communities

As some women explained that they feel they do not have enough access to information relating to the importance of cervical screening, it is recommended that NKCCG holds events to disseminate this information in an appropriate way. Since forming relationships with particular communities can be difficult and time consuming it is recommended that existing networks are tapped into for example:

- Children’s Centres - Stay and Play sessions, Baby Bistros
- Al-Hikmah Centre - Ladies ESOL classes, An-Nisa ladies group
- The Lighthouse Centre - Women’s wellbeing hub, Coffee morning
- Ravensthorpe Community Centre
- Pakistani and Kashmiri Welfare Society

3. GP Information sent to patients

For women who did attend their smear tests, GP recommendation was found to be a major facilitator of cervical screening adherence, which suggests that GPs need to take a proactive approach in encouraging their patients to attend screening.

In order to do this it is recommended that all information sent to patients from GP practices should be provided in the patient’s first language. This can be done at minimal cost by having standard letters translated into the preferred languages of their patients and stored as templates.

4. Community Champions

Although leaflets and the use of interpreters can be seen as a quick solution to communication barriers, our insight suggests that this is clearly not enough to increase the uptake rate among South Asian women. There is a need for regular community-based cancer awareness education, which is sensitive to religious and cultural needs. Interventions to increase uptake rates need to be more long-term and multiple in nature, tailored to the specific needs of the local community by, for example, developing close links with the community through Community Champions.

To improve uptake rates in Kirklees amongst South Asian females, we should focus on the personal moral responsibility, beliefs about the risks of cervical cancer and available treatments. Healthwatch Kirklees supports the idea of creating “Cancer champions” who could work within their own community groups.

The insight participants fully endorsed the creation of “Screening Champions” who could work within their own community groups.

Healthwatch Kirklees found that there were still many myths and incorrect beliefs held regarding cervical cancer.
For example;

“I’ve only got one partner (husband) so I don’t feel I’m at a high risk of getting cervical cancer.”

“I’ve had kids now so I don’t feel that I’m at risk of any disease down there.”

“I’m not married yet so I don’t need it yet.”

The role of a Screening Champion would be to bust the current myths about cervical cancer, provide factual and helpful information to their own communities to address the fears and misconceptions that women may have. This will empower women to take responsibility for their health in order to address it in a proactive way.

A programme of training and development will be needed to provide correct information and interpersonal skills for the champions.

Such as:

- Knowledge of Cervical cancer
- Knowledge about where cervical screening tests are carried out
- The types of treatment available for cervical cancer
- The effects of cancer on mental and physical health
- Effective listening and communication skills
- Knowing your boundaries and confidentiality

Community workers, housing support workers, ESOL teachers and other female community group leaders could be potential candidates for the role of a “Screening Champion”.
References


http://www2.kirklees.gov.uk/involve/entry.aspx?id=528
Appendix A

Cervical Screening Individual Interview Guide

Have you attended a smear test?
If Yes:

Feelings/Experience
What motivated you to attend? (Letter from GP, family member, prevention)
Feelings before attending screening
Where did the screening take place?
How was the experience of the screening? Travel, time off work?
Feelings after the screening
How did you feel you were treated by the staff?

Results
How quickly did you receive the results?
Were you offered advice/support regarding your results?

Future smear tests
Would you attend another screening?

Motivation
What could make it more likely for you to attend a smear test?
What can the NHS do to encourage you to attend a smear test?

Have you attended a smear test?
If No:

Feelings
How do you feel about having a smear test?
Explore feelings of embarrassment, fear, pain

Knowledge
Do you know what the smear test involves and what it’s for?
Have you been invited for a smear test?
Have you asked for a smear test?

Attending a smear test
Are you likely to attend a smear test if you’re invited? Why, why not?

Motivation
What would make it more likely that you would go for a smear test?
Is there anyone else that could encourage you to go? E.g. family member, friend, GP
What could the NHS do to encourage you to attend?

Post Natal Care-
What did you think about the post-natal care that you received?
Good? Bad? What would you like to see done differently?