

Report

“Community insight work to better understand why defined groups of women do not access Breast and Cervical Cancer screening services in Preston”

October 2012

Aim:

To better understand the attitude and approach of women from BME background towards Breast and Cervical Cancer screening and other services in general in Preston.

Objectives:

- To explore the knowledge and patterns of uptake of cancer screening programmes in Preston.
- To identify barriers to access cancer screening programmes
- To make recommendations based on participant's feedback with a view to make improvements to the programme.

Sample:

This consisted of 87 women from BME backgrounds and were aged between 16 to 70 years. The category of 16-24 years was added even though it did not constitute part of our original proposal. This proved to be beneficial as the data collated from this age group showed a different mindset and perceived barriers which statutory agencies may want to address.

The participants were recruited from:

- Drop in clients at Preston Muslim Forum
- Women attending courses at Preston Muslim Forum
- Ramadan events at various locations
- Women attending other community centres

Locations:

- Al-Hidaaya Centre – St. Augustine Centre, Avenham
- Sisters for Sisters – St. James Street, Frenchwood
- Iqra Education Centre – Garstang Road
- Preston Muslim Forum – ESOL classes
- Maa-Bachcha Group - Hamaara Centre – Castleton Road

Rationale:

The questions were designed to be specific and relevant so that the respondents were able to relate and respond in a positive manner. Since the respondents were given one to one support to complete the questionnaires the aim was to bring out the pertinent information and thus avoiding any confusion on part of the respondents.

It was decided from the beginning not to post or e-mail the questionnaires to individuals or organisations and expecting them to complete in isolation and return. The one to one and group sessions enabled us to interact and trigger discussion. In the process we were able to learn about the condition and attitudes of the respondents.

Methodology:

- **Questionnaires:**

These were designed to extract basic information from the target group and were not intended to trigger discussion. The questionnaires were mainly to capture the knowledge and awareness of participants. The facilitator encouraged interviewees to complete the questionnaires and provided assistance to clarify or seek further explanation.

Questionnaires – Brief Analysis:

16 to 24 years:

- 100% respondents said they know what breast cancer is and its signs and symptoms.
- 88% said they know what cervical cancer is – similar percentage also said that they do not know or are not sure of its signs and symptoms.
- 66% said they are aware of breast cancer screening programme
- 77% said they are aware of cervical cancer screening programme
- 44% said they do not know what smear is and did not had a smear test.
- 22% know what smear is but not had a smear test
- 33% said they know what smear is and had a smear test as well
- All of them were able to approach their GP/Nurse for smear test. 22% respondents however have not approached their GP/Nurse yet.

25-30 years:

- 70% respondents said they know what breast cancer is and its signs and symptoms.
- 40% said they know what cervical cancer is – 75% also said that they do not know or are not sure of its signs and symptoms.
- 50% said they are aware of breast cancer screening programme
- 15% said they are aware of cervical cancer screening programme
- 45% said they do not know what smear is and did not had a smear test.
- 15% know what smear is but not had a smear test
- 40% said they know what smear is and had a smear test as well

31-40 years:

- 100% respondents said they know what breast cancer is and its signs and symptoms.
- 85% said they know what cervical cancer is – 48% also said that they do not know or are not sure of its signs and symptoms.
- 80% said they are aware of breast cancer screening programme
- 75% said they are aware of cervical cancer screening programme
- 5% said they do not know what smear is and did not had a smear test.
- 15% know what smear is but not had a smear test
- 80% said they know what smear is and had a smear test as well

41-50 years:

- 100% respondents said they know what breast cancer is and its signs and symptoms.
- 72% said they know what cervical cancer is – 77% also said that they do not know or are not sure of its signs and symptoms.
- 95% said they are aware of breast cancer screening programme
- 40% said they are aware of cervical cancer screening programme
- 25% said they do not know what smear is and did not had a smear test.
- 15% know what smear is but not had a smear test
- 55% said they know what smear is and had a smear test as well

51-60 years:

- 80% respondents said they know what breast cancer is and its signs and symptoms.
- 40% said they know what cervical cancer is – 80% also said that they do not know or are not sure of its signs and symptoms.
- 80% said they are aware of breast cancer screening programme
- 60% said they are aware of cervical cancer screening programme
- 20% said they do not know what smear is and did not had a smear test.
- 80% said they know what smear is and had a smear test as well

61-70 years:

- 85% respondents said they know what breast cancer is and its signs and symptoms.
- 35% said they know what cervical cancer is – 70% also said that they do not know or are not sure of its signs and symptoms.
- 100% said they are aware of breast cancer screening programme
- 65% said they are aware of cervical cancer screening programme
- 20% said they do not know what smear is and did not had a smear test.
- 15% know DO NOT know what smear is but had a smear test
- 65% said they know what smear is and had a smear test as well

Following were some of the other concerns expressed in questionnaires:

- Receptionists do not provide enough information and always send it to doctor.
- embarrassment-unease approaching male doctor
- no information available in Urdu/Gujarati
- The only awareness of signs and symptoms for breast cancer was lumps.
- Do not know when to go for these tests
- Had a smear test but was not told that it was to identify cervical cancer
- 100% would like a female nurse from start to finish.
- Majority did not know what and where the Cervix was.

- **Group Work:**

This was arranged mainly with those who responded to the questionnaires. This was considered the most appropriate method to explore the attitudes and experiences of participants, as it enabled them to interact through discussion and anecdotes. The group work was carried out at various locations and the finding reflects the experiences of services from the different wards of Preston. The ward data however is highlighted only as a snapshot and the emphasis remains on the age group. The facilitator provided clear explanation of the purpose of the exercise and helped people feel at ease and facilitated interaction between group members through asking open ended question which were based on participant's perception and responses.

Group work – Feedback:

- All of the participants were aware that Cancer is a serious disease.
- 16-24 years old questioned that since jabs only protects them from four illness, is it worth going through as jabs makes them sick. This age group was also under the impression that it is not relevant for them and more suited to older people.
- Some older ladies (51 to 65 years old) saw cervical screening important to younger women only.
- Those who have accessed the services found the experience unpleasant and uncomfortable.
- There was no inhibition linked to religious/culture practices if it was done by female nurse.
- The literacy barriers for some deprives them of accessing information and services
- Hygiene issue was highlighted as there was perception of 'un-cleanliness' attached to it for the stricter religiously inclined ladies.
- No publicity/leaflets in doctors surgeries especially in Urdu/Guajarati
- No equivalent word for cervical cancer in Urdu or Gujarati
- Unhelpful attitude of receptionists
- Overwhelming majority of women identified lump as the only sign of breast cancer. They were however unsure of self-examination.
- NHS Cancer Screening leaflets at the surgeries do not mention signs and symptoms for cervical cancer.
- Some of the women did not relate smear test with cervical cancer.
- Some of those who took smear test were not explained the link between the test and cervical cancer.
- Not aware of mobile surgeries (port cabins)

Observation:

The visits carried out by the project worker to four GP surgeries in Deepdale, Frenchwood and Fishwick revealed the following:

- Insufficient publicity material
- Inappropriate publicity material
- Unhelpful attitude of GPs receptionist
- No visible display of Cancer Screening Programme information.

Conclusion:

This community based qualitative study has revealed some of the reasons and attitudes behind low uptake of cancer screening services. The barriers included poor health knowledge, unhelpful and complacent attitude of health professionals, language, communication strategy of NHS, lack of ground level health workers amongst others.

Developing stronger links with the community through ground level and bilingual health workers was one of the needs highlighted in order to raise awareness and increase uptake of services.

Recommendations based on participants feedback:

- The generic letters sent by NHS gets misplaced or are forgotten.
- Need contacting by phone – may be a follow up from an Asian worker.
- Appointment system would work.
- GPs need to be more pro-active
- More community based education and awareness is needed.
- Explaining the procedures and education to patients would make them more confident
- GP's, GPs receptionists and health professionals to be educated in culture beliefs, customs, language needs and communication skills.

Next Steps:

The project has enabled PMF to enhance the knowledge related to Breast and Cervical Cancer and especially the screening programme. Due to success of the project we intend to deliver the following on an on-going basis:

- Provide advice, sign posting, and practical support to women with cancer queries.
- Provide assistance to tackle any barriers they may perceive/face.
- Ensure that women in need and those who are entitled receive the services.
- Representing issues identified by BME women and liaising with health agencies.
- Assist health agencies to promote the message of Cancer related programmes.
- Develop meaningful partnership with health agencies and professionals to address wider issues related to cancer in a holistic way.

Presentation event on 23 October 2012:

The presentation event arranged as part of the project proved very beneficial in raising awareness and providing opportunities to ladies to seek clarification regarding breast and cervical cancer. The event attended by 23 women was held at the Hamaara Centre and delivered by Kerry Crooks from NHS Central Lancashire.

The event covered topics such as:

- What is cervix and breasts
- Symptoms of cervical and breast cancer
- Importance of attending screening programme
- What happens during screening appointments
- HPP vaccine
- Side effects and raised awareness to tackle issues at early stages



Event Evaluation:

In light of the fact that since the ladies went through the process of completing questionnaire, it was decided to evaluate the presentation informally and verbally. This was done on the day – face to face and follow up – through telephone. All participants agreed:

- The session was very informative and interesting.
- They are now more aware of breast and cervical cancer
- They would like further support
- They would access PMF to seek any further advice.

- **GPs presentation on 7th November**



The above session was not organised by Preston Muslim Forum and did not constitute as part of the project. We however decided to attend and contribute in order to hear the views of health professionals and exchange our concerns highlighted by women. The project workers found the session informative which they hope to feed back to the women who participated.

Following are some of the points highlighted by the health professionals who attended:

- GPs do send the reminders for smear test but the response received is negligible.
- Waste of time as they do not attend and do not listen to advice.
- Cultural and religious barriers do play part in low intake
- Community and Religious leaders should take responsibility to advice and encourage women to attend screening programmes and tests for early detection.
- The attitude is consistent amongst some non-BME women as well.
- Cannot see what anything different could be done.
- May need shock tactics similar to smoking advertisement.
- The issue can be only be tackled when all agencies and community work together.
- The fear factor cannot be under estimated and is quite understandable.

The GPs however were forthcoming and as a general consensus agreed to re-visit their procedures in order to increase the uptake of cancer screening programme.

All Wards = Total 87

Age Group	Ribbleton	Fishwick	Deepdale	St.Matts	Frenchwood/ Avenham	Other
16-24	3	1	1	1	2	1
25-30	2	2	5	1	0	3
31-40	4	3	3	5	6	2
41-50	3	3	6	2	3	1
51-60	3	2	2	2	1	0
61-70	1	3	5	2	3	0
Total	16	14	22	13	15	7

All Ages:

Age Group	No. of participants
61-70 years	14
51-60 years	10
41-50 years	18
31-40 years	23
25-30 years	13
16-24 years	9
Total	87