

## **Mosaic Community Trust – Breast Cancer Session**

**16<sup>th</sup> March 2022**

On 16<sup>th</sup> March 2022, we attended the Mosaic Community Trust to undertake a session on breast cancer with the women's group. The session was attended by Soh-Yon Park (Researcher at the Institute of Global Health Innovation), Madhu Agrawal (facilitator for the session; previously Breast Cancer Nurse Specialist, and now Macmillan Cancer Information and Support Manager), and Halle Johnson (Public Involvement Officer at the Patient Experience Research Centre). 18 women of diverse ages and backgrounds (including African, Middle Eastern and South East Asian) attended the session.

The session was developed and hosted by Mosaic in collaboration with Soh-Yon Park (Researcher at the Institute of Global Health Innovation), Madhu Agrawal (facilitator for the session; previously Breast Cancer Nurse Specialist, and now Macmillan Cancer Information and Support Manager), and Halle Johnson (Public Involvement Officer at the Patient Experience Research Centre).

The purpose of the session was to:

- Understand current perceptions & experiences of breast cancer from the local community
- De-bunk current myths held by the community about breast cancer and increase awareness of what breast cancer (it's symptoms, who it affects and treatment options) and breast cancer screening actually is
- Educate community members on how to check their own breasts and what signs and symptoms to look out for

### **Format of the session:**

The session covered four main areas:

1. What breast cancer is and what the symptoms are
2. Breast screening processes in the NHS and what happens if you get an abnormal result
3. Treatment options for breast cancer
4. Breast awareness (including how to check your own breasts for symptoms).

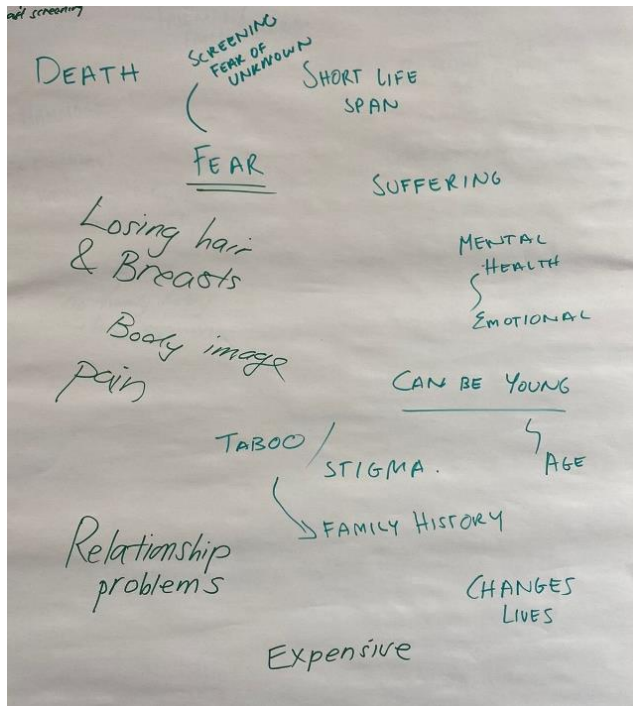
Throughout the session the community were invited to share their own perceptions of breast cancer as well as their own, and their family and friends, experiences related to this topic. Throughout the session we sat around in a circle and using a flip chart wrote down key comments/thoughts from the women as a means of taking notes without being too intrusive.

At the start of the session two open ended questions were posed, this was a good way to understand the women's current views about breast cancer and opened up the conversation about this topic. The questions and responses are provided below:

- ***What does cancer mean to you?***

Overall, there were many fears about cancer, with one woman highlighting that she had been told by her family that 'if you talk about cancer, you get cancer'

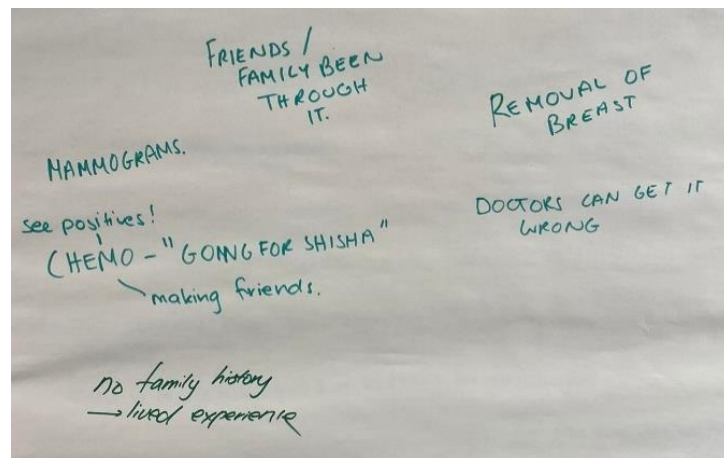
Others believed that if someone in your family had cancer, you would also get cancer



This 'fear of the unknown' and negative perceptions of cancer led to 12/18 (two-thirds) of the women saying that they would not attend their breast screening appointment when invited.

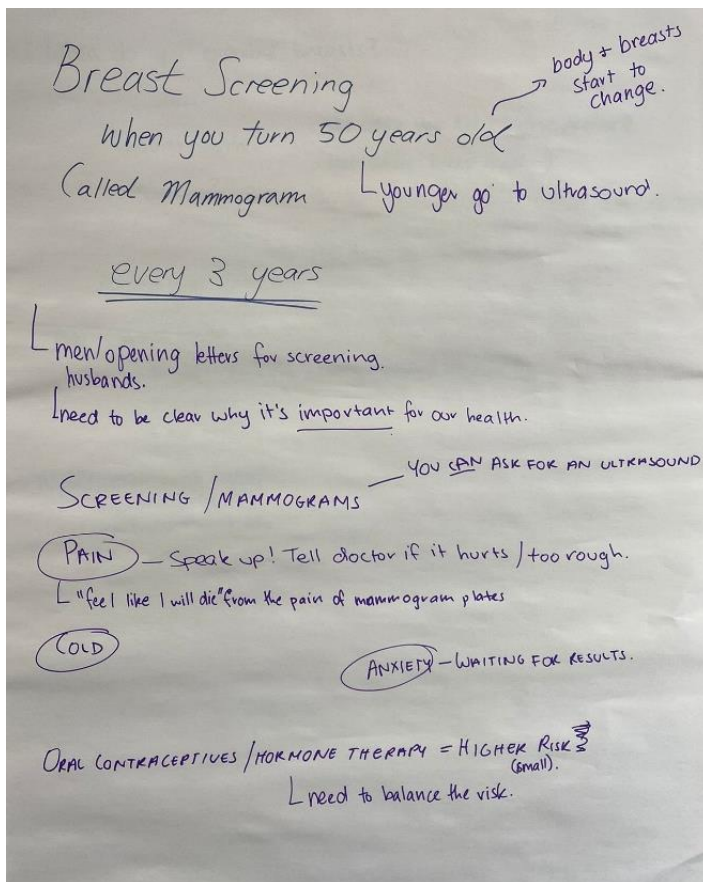
- **How much do you know about breast cancer?**

When answering this question, many of the women drew on experiences from family/friends who had been diagnosed with breast cancer (or cancer). One woman had recently experienced breast cancer herself, being diagnosed at the start of the pandemic and then undergoing chemotherapy, a mastectomy and radiotherapy. While she had a bad experience of diagnosis, with her GP sending her back with antibiotics on two occasions claiming that it was 'just an infection', she shared her positive outlook of going through treatment with the support of her friends/family and her faith. She provided an anecdote during the session where she talked about going to chemotherapy with her friends and family as 'going for shisha' and how she saw it as a social opportunity to 'make friends' with the nurses and other patients.



After the open questions and discussion further information was provided on breast screening and awareness, with women encouraged to ask any questions or share any experiences relating to these.

## Breast Screening:



An overview of the current breast screening programme through the NHS was given by Madhu.

Madhu highlighted what going to a breast screening mammogram would be like, that each experience may be different as each nurse is different, and that there will always be some pain/discomfort, but it shouldn't be excessive. She also explained that the plates used will often be cold. The discussion focused on ways in which women may feel comfortable to attend their screening appointment including:

- bringing a friend/family member to their mammogram appointment
- communicating to their nurse if they feel too much pain or if they are too rough
- asking their doctor to have an ultrasound instead of a mammogram if they would like.

One woman noted that her friend said 'I feel like I will die from the pain' from a

mammogram experience and noted that her friend said she would not go back for another due to the experience.

Questions/discussion points:

- Why is the age set at 50 years old, and what if you want a breast check earlier (especially if you have a family history)?
- Women highlighted that their husbands would open their letters first, so it would be important that they feel empowered to say to their husbands why they need to go to breast screening and why it's important to go.

## Examining your breasts:

After this discussion on breast screening, a conversation was started about breast examination. The women were asked when they thought they should examine their breasts, and then a practical demonstration was given by Madhu.

One of the women, who had had breast cancer herself, kindly volunteered to be a model for the demonstration, as she wanted to give back and ensure others knew the right way to check their breasts. As part of this session women were also shown print outs of different symptoms of possible breast cancer, women were given the choice to close their eyes or pass from seeing the images if they felt that this would be distressing for them.

Most of the women did not currently examine their breasts and were not aware of the correct way to do this or what to look/feel for. It was explained that women should examine their breasts once a month, and this should start from puberty. Madhu also explained that during menstruation, pregnancy and breast feeding, breasts become 'lumpy' so while women should continue to examine their breasts during this time, lumps during this time aren't often a cause for worry/concern.

The women were informed that they were looking for a small 'pea' sized lump, with women comparing this to a 'chickpea but smaller'

Many of the women felt that the shower/bath would be the best time for them to examine their breasts as this was the main time they had to themselves.

### **Treatment for breast cancer:**

As part of the discussion, Madhu highlighted the treatment options for breast cancer. As some of the women held views that 'if you get cancer, you will die' Madhu highlighted that with early identification 98% of breast cancers are cured, which was re-assuring to the group.

The process of going through chemotherapy, mastectomy and radiotherapy was shared. Including why chemotherapy can only be done every 3 weeks and how it works, with Madhu highlighting that it is a 'poison' which will kill the cancer, but also kill the other good cells in your body. Talking about mastectomy Madhu also highlighted that the doctors need to take a lot more area of tissue than just the lump as a precaution, as doctors cannot see to the human eye what the cancerous cells are and what aren't. One of the women, who had had a mastectomy showed the women her removed breast to educate others on what this would look like. She was asked how she had got through the treatment herself, to which she replied, 'with friends, family and faith'.

### **'Myths' that arose throughout the discussion:**

Throughout the morning a number of 'myths' around cancer and breast cancer emerged.

- If you talk about cancer, you get cancer (fear imposed by family)
- You can tell how high your hormone levels are by looking at body hair (e.g. lots of body hair = high testosterone)
- You shouldn't wear deodorant/perfume around your breast area/under your arms, as it will give you breast cancer
- Medicine (antidepressants) can cause breast cancer
- You will die if you get cancer

As part of debunking these myths, we discussed why these perceptions were not true, and highlighted some of the risk factors for breast cancer, many of which the women were not aware of. These included:

- Older age, with your risk increasing as you get older (especially for post-menopausal women). Age is getting younger though due to our lifestyle, so we need to exercise, eat well, and do 'what makes us happy' for a stress-free life.
- Some medication does increased risk slightly, this includes taking oral contraception or hormone replacement therapy, but you need to balance out the risks/benefits of taking these

- Large breasts, due to having more tissue available for cancers to grow
- Family history, having a mother, sister or daughter diagnosed with breast cancer increases the risk of breast cancer, but doesn't necessarily mean you will get cancer.

### Concerns about Breast Cancer Screening and Treatment

- As part of this discussion several of the women reflected on their own or family/friends' experiences and concerns of having **delayed appointments** for breast screening follow-up, or **long waiting times for these**. With one lady saying she received a letter in January 2022, tried to book an appointment online and over the phone with no success, so gave up. Luckily her GP proactively booked one for her, after seeing she had not yet scheduled one, but this now isn't until April 2022. Another gave the example that her friend's breast cancer moved from a Stage 3 to Stage 4 while waiting for her treatment, which was extremely distressing. It was felt that this was a priority area which needed addressing, particularly because of the **anxiety/stress which occurs when waiting for appointments/treatment** which is heightened for this group, who already hold many fears around cancer, and which is exacerbated through family/friends who may think the woman is 'lying about not receiving the letter or hiding her results' when it's actually just the delay in receiving the results.
- A concern was also raised about **appointments being scheduled for other hospitals** (with more availability), which many said they would not attend, as they wanted to go somewhere that was familiar and close to home.
- Experiences of **GPs being dismissive about concerns around breast cancer** was raised. One woman noted that while she is under 50 years old (47 yo), her mum recently was diagnosed with breast cancer, and this raised concerns for her own health. She noted that despite communicating that she was anxious and stressed, and wanting to go for a screening appointment, the GP would not do this as she was under the age of screening programme. Madhu highlighted that if there is family history, and not getting checked is causing extreme anxiety/stress, then the doctor should refer them to the family history clinic.
- Overall, it was discussed that there is a massive gap between primary care and secondary care, women did not find remote consultations helpful, and many provided bad experiences with their GP. One woman noted that she thinks of going to see her GP as 'going to see my mother-in-law' as the GP always dismisses her symptoms saying 'oh no you don't have that, you have this', like her mother-in-law does. The women wanted their GPs to listen more and respond to their concerns.

### Key issues for clinical care:

- While education and empowerment are a first step to helping women understand why they should attend their screening appointment, we need to ensure that other barriers are removed, to ensure that they will return to future screening appointments, and attend any other appointments connected to their care. This involves:
  - reducing waiting time between appointments (especially important for this group, where anxiety and stress about cancer is heightened);
  - working alongside community partners who can provide holistic care and support, for instance if it's a long wait time for an appointment, treatment or results they can refer

- women to a community organisation (such as Mosaic) who can support them through anxiety, stress, and fear during that time.
- providing appointments in familiar environments (i.e., hospitals they have been to before and that are close to home)
- GPs need to be aware of cultural factors and perceptions feeding into fears/anxiety around cancer, and be flexible to individual's preferences for attending, for instance, an ultrasound instead of a mammogram, and for earlier screening if this is causing anxiety.

#### **Impacts from the session:**

- We were able to de-bunk myths currently held by members of the group about cancer and breast cancer and share risk factors with them, which they were not currently aware of
- At the end of the session, we posed the same question from the start of the session to the group: 'Would you go to your breast screening appointment when invited? At the start session 12 out of 18 women said they **would not** attend their screening appointment, however by the end all women left in the room (1 women had left, and some were preparing lunch) agreed that they **would** go to their screening appointment when invited.
- We raised key points and ways for the women to communicate with your GP about breast cancer worries/concerns, care and/or treatments. Including empowering women to:
  - use the word 'breast' (previously women who have been shy using this word said 'chest') in their communication
  - know they have the right to request a mammogram if they have any concerns regarding family history of breast cancer
  - know they have the right to request an ultrasound instead of a mammogram if they don't feel comfortable
- The insights from this session have been shared with the Imperial College Healthcare NHS Trust breast cancer screening team and the wider NHS London Breast Cancer Screening Programme team, as well as key researchers working in breast cancer across Imperial College, London. These insights have also fed into a project being led by the Institute for Global Health Innovation at Imperial College which is aiming to improve breast cancer care access and pathway for South Asian communities in London.