

Phase 2 RESEARCH: Breast awareness, barriers and information needs of BAME/marginalised communities

Table 1. Fieldwork Jan-March 2019 (conducted by Sadia Habib & Manveet Basra Breast Cancer Now) n=36

Method of data collection	Ethnicity	Location	Language delivery	Number of participants	Age breakdown (25yrs+)
Focus group 1	Pakistani, Arab, Somali, Bengali	Sheffield	English	8	25-68
Focus group 2	Pakistani, Polish, Ukraine, French Canadian, White, Irish	Bradford	English	13	25-83
Focus group 3	White, Argentinian, Spanish, Egyptian, Indian	London	English	11	25-68
Interviews: One-to-one Face-to-face	Pakistani, Pashtun	Sheffield Bradford	English Urdu Punjabi	4	25-69

Summary of the key findings

Knowledge of signs and symptoms

- The top 5 symptoms of breast cancer were selected by over 70% of the participants; A lump, change in skin texture, changes to the nipple, a swelling in the armpit/collarbone and discharge from the nipple.
- Only 14% of women are checking on a monthly basis and 25% are checking weekly so 39% in total, which is below the UK average. 50% do not check regularly whilst 11% never check at all.
- 58% felt very confident or fairly confident in noticing a change, whilst 20% felt slightly or no confidence at all and 22% reporting they did not know their confidence levels. We need to do more work to push up the numbers to enable women to be become more confident at noticing a change.

Accessing information

- 50% would look for information and advice from their GP practice, 44% from Google and 19% from family and friends.
- People thought the best way to reach customers with breast awareness was via the following means: Back of receipts, at the till, home delivery, **breast awareness sessions**, leaflets, labels, radio, TV, banners and busses, use labels on smart-price brand, posters in different language, monthly magazine, **hire trained bilingual workers**, toiletries section, **pop-up gazebo/tent**, site-wide banner, text message, **mobile bus, in-house advice with a private area, pharmacy**, video in a private area. Highlights in bold indicate many preferred face to face interventions.
- Quotes from participants when asked how they feel about receiving information from (supermarket):

"I would feel good receiving information from (supermarket name) because no other supermarket is doing this. I am sure lots of people would happily receive this"

"Very happy. I am pleased (supermarket name) is trying to find out views and engage with women from BAME communities"

- The top 3 preferences on ways to receive information from (supermarket) were: 1) Breast awareness sessions, 2) face to face e.g. Nurse, 3) in my local supermarket.

Barriers to awareness

Barrier type	Reported by participants
Psychological	Too scared to check; worried about what may be found Embarrassment, shame, modesty Not important to check Denial – it can't happen to me
Literacy/Accessibility	Lack of culturally and linguistically appropriate information Most information is in English, not everyone can understand it Online information not accessed by everyone; older women Those not able to read
Cultural	Perception of role of women; health not a priority Cultural upbringing (social taboos related to breasts, particularly amongst South Asian community) Beliefs about cancer and fatalism
Practical/knowledge	Don't know how to check, which areas to check, what symptoms to check Lack of awareness of risk Too busy to make time – side lined importance Lack of understanding of the benefits of early detection

"I'd rather not check to find something that I don't know what it is. For me as well, my doctor is not very great, and when I do go, I kind of do get brushed off. It's like you're in, you don't even sit down, okay next patient's coming in."

"You've got people that wouldn't actually get out into communities that don't know who they can tell. They're stuck at home. Or, you've got people with different disabilities, how do they explain things?."

"Language barriers and not understanding the importance of breast cancer. And maybe a little bit of body shaming. So, like you're touching yourself. That kind of thing. There'll be people not understanding what the reasons are, how to do it, and why to do it."

"It's a cultural thing. I remember long time ago, when your breasts are coming in your teenage years, you see family members saying don't wear tight things, it's like your breasts are something to be ashamed of and you are told not to look at this area (the breasts) and make sure you cover the area and so."

Barriers to reporting symptoms to a GP

Barrier type	Reported by participants
Psychological	Patient delay: too scared to report symptom Worried about what may be found (cancer) Worried about others if diagnosed Fear of treatment and side effects
Literacy	Language barrier in explaining breast problem Not knowing that a symptom needs to be reported due to lack of linguistically appropriate information Those not able to read
Cultural	Embarrassment; seeing a male GP
Practical	Too busy to make time – priority low Difficult to get an appointment – adds delay Other things to worry about – multiple problems in life Transport, disability, distance
Services	GP services stretched, lack of appointments, dismissiveness

“It’s not like before; you don’t get the same doctor or nurse all the time. The big problem is getting an appointment. It is so hard to get an appointment.”

“My mum had cancer, she didn’t go to the doctor and thought to wait it out. She said ‘I don’t need to go, they won’t do anything anyway’ she was scared of treatment, losing hair, pain, chemo. The thought of chemo puts people off from going to the GP.”

“The biggest fear in my life is I will lose my breast and I will miss my feminine side. I love my breasts and if I find out I had breast cancer, and they remove it they will remove breasts and I want to avoid that.”

“I encouraged a lady once to attend a breast cancer talk and her response was; cancer comes from God’s will. Doctors cannot stop it. If it is fate, it will come, so if I die, I die.”

“A problem in the Asian community is, we don’t understand about the stages of breast cancer for example early stage and survival rates and so on. We think it means dying.”

“We women are so amazing, we have so many role, a mother, wife, sister whatever it is we have so many people depending on us, so for someone to go to their doctor thinking they have something life threatening, they might not go because they will think who will look after my children.”

Barriers to breast screening

Barrier type	Reported by participants
Psychological	Fear of cancer; worried about what may be found Bad experience and pain Embarrassment, shame
Literacy	Lack of culturally and linguistically appropriate information Not being able to read
Cultural/Societal	Perception of role of women; health not a priority, family first Lack of positivity; fatalism, lack of success stories Fear of being seen by male technicians
Knowledge	Too busy to make time – side lined importance Lack of understanding of the procedure Not important enough to attend
Services	Hospital setting
Practical	Travel, distance & procedure time Nobody to go with – lack of support Too busy; health not a priority

“If you’ve got children, or a partner, or the house and all these kinds of things, you do think it’s five hours of my day, (it) is going to be wasted going on trips to the hospital.”

“I think embarrassment. You don’t know who’s going to be there, who you’re going to have to be taking your clothes off in front of.”

“Women think about everybody else except themselves. We put ourselves on the backburner.”

“There’s women who think if I go to the hospital and they do check me, I WILL get cancer. Because when they are pressing my breast in this thing, when I go there I am well, but I come back ill! They started (all this) on me because I was alright before! So, there is a lack of understanding.”

Moving forward – next steps

- **Breast checking:** with over 50% not checking regularly and 11% not checking at all, encouraging women to check should be at the forefront of campaigns.
- **Symptom awareness:** Overall, knowledge levels of the symptoms were better than anticipated. However, more work needs to be done around overall symptom awareness particularly a change in size and shape, redness or a rash on the skin/nipple.
- **Raise confidence levels:** 42% felt slightly or no confidence at all with some not knowing their confidence levels at noticing a change.
- **Tackling barriers:** More than 50% reported they would tell their GP or a practice nurse first, however the barriers faced in reporting a change needs addressing. Offering information in a culturally and linguistically appropriate environment was a key theme amongst South Asian communities as a solution to breaking down complex barriers.
- **Intervention design:** Face to face interventions preferred. Appropriate resources and methods need to be in place to encourage engagement and buy-in to participate.
- **Campaigning better** with inclusivity at the forefront. Integrating channels and mechanisms to reach out to these groups within an overall campaign. Deliver within the communities and use role models to express positive experiences.