‘Unseen, Unheard: Improving Black women's experience and outcome around breast cancer’

Meeting Notes

February 2026

Background

Driven by national and local data and insight for Dorset, Hampshire and the Isle of Wight about Black women’s poorer experiences of breast cancer diagnosis, treatment and care, Wessex Cancer Alliance (WCA) met with local Black women (both survivors and community members), primary and secondary care, and community support organisations (see Appendix A) to discuss these differences in outcomes. The intention was to identify some priority areas to collectively address.

The national and local picture

Wessex Cancer Alliance presented the following national and local intelligence:

Cancer diagnosis

A national study by Fry et al., 2023 suggests that African, Caribbean, and Asian women with breast cancer are more likely to receive a late-stage diagnosis compared to their White British counterparts, a disparity that may be partly explained by higher levels of cancer fatalism observed among ethnic minority women (Vrinten et al., 2016).

These disparities may be attributed to a combination of factors, such as limited symptom awareness, restricted access to breast cancer education and treatment services, cultural stigma, and feelings of embarrassment (Niksic et al., 2016; Marlow et al., 2012). Additional barriers, including language difficulties and challenges in securing timely appointments, further contribute to delayed care, with evidence showing that patients from Mixed, Black, and Asian backgrounds are more likely to attend three or more GP consultations before receiving specialist referrals (Lyratzopoulos et al., 2013).

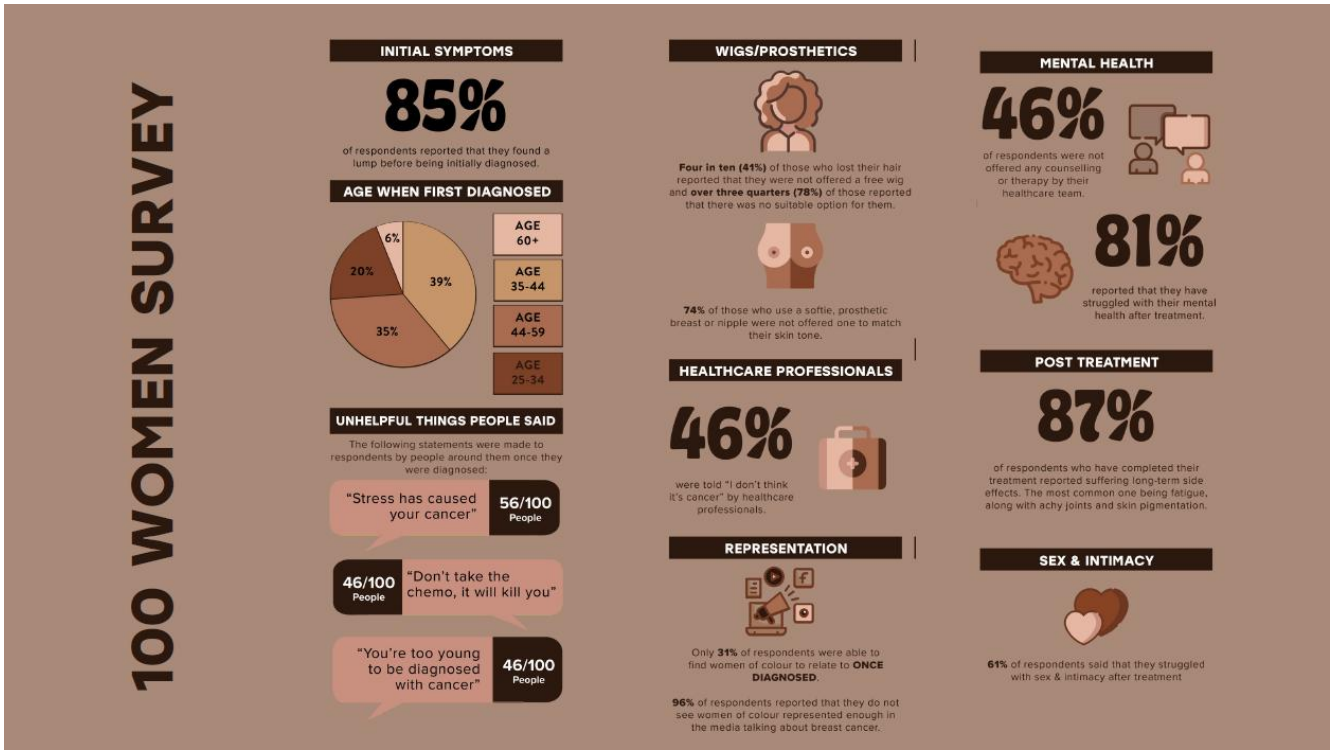
Furthermore, some Black women are more likely to present with hormone receptor–negative breast cancer, including the more aggressive triple-negative subtype, which is associated with poorer prognostic outcomes. (Copson et al., 2013 and Jack et al., 2013).

Whilst there are significant gaps in local data because ethnicity coding in health services is poor, in Wessex breast late-stage diagnosis was highest among Black or Black British patients (23.1%) and Asian or Asian British patients (17.1%), compared to White British women and other ethnic groups (Taylor, 2025). Improvements in ethnicity coding will ensure a more accurate picture of prevalence and differences in stage of diagnosis.

Local data also shows that breast cancer patients from minoritised ethnic groups are being diagnosed at slightly younger ages than white patients. There were no clear patterns related to deprivation, which appeared not to be a factor in diagnosis stage in our data, although future age standardisation of data sets may present a different picture.

Cancer care and support

There are also issues in terms of Black women's experiences of breast cancer care and support, as highlighted by Black Women Rising's survey of 100 women and their subsequent film Unseen Unheard, about six different women's experiences.



A summary of the issues include a lack of:

- Appropriate wigs and prosthetics
- Visibility in, and culturally appropriate, patient information
- Cultural awareness by breast care teams
- Psychological and / or peer support

WCA activities to date

At the meeting, Wessex Cancer Alliance shared the activities they have been undertaking or are currently exploring in relation to these issues. They are as follows:

- Engaging and raising awareness of breast cancer with local Black women's groups
- Reviewing local breast cancer diagnosis data
- Supporting local initiatives, such as showing of Unseen, Unheard film
- Sharing the Royal College of GPs online training aimed at improving breast cancer diagnosis in Black women
- Sharing our data and learning with Breast Clinical Advisory Group, Integrated Care Board and other colleagues to raise awareness of the differences in experiences to gather support this this work.
- Offering six 'Unseen, Unheard' film licences to hospital teams to plan local showings
- Working with Dorset Breast Screening Unit to produce an accessible breast examination video
- Looking to source a local supply of BRAVE – high-quality, visual decision-making aid for mastectomy patients.

Reflections and discussion

Following WCA's presentation, Dr Mary Udo, who was chairing the meeting, offered some reflections and invited others to. She said that what was presented was not surprising to her, and was keen to make sure we measure change of any interventions over time.

As well as addressing the data gap, addressing the cultural aspect would be a priority for her. Mary appreciates that her Black and Asian patients may come to her in fear and she does her utmost to make them feel comfortable to talk to her. Having survived breast cancer herself, she now feels she needs to be 'brutally honest' with her Black patients to encourage them to ask for help. It will be vital to support people to be able to self-advocate and that also means tackling unconscious bias in healthcare professionals and turning around long held beliefs in communities that they won't be listened and their viewpoint is not worthwhile.

Others offered their views that symptom recognition can be an issue. For example, when asked about skin changes, including redness and bruising, these may not show on darker skin tones. It was pointed out that it is difficult to self-advocate if you do not know what to look for, so community knowledge is important alongside cultural awareness in healthcare professionals.

There was a discussion about whether a younger women may be more confident to seek help and support, and whether a direct self-referral service may, like the recent North Hampshire pilot, work for Black and Asian women. The response was that possibly for some but not for those who may be less likely to access healthcare anyway, possibly from not knowing the system or not trusting the NHS.

A recommendation was made about health services coming out to where people feel safe and comfortable, offering food, and especially with health care colleagues who 'look like the community' they are engaging with. An example given was the 'Improving Black Health Outcomes' event in St Denys where hospital nurses came out to talk and do genetic screening at the local church. This however requires resourcing. Whilst using existing community groups is often the best way to do outreach, we need to consider those that do not access community groups or are isolated at home.

We were reminded that many Black people will have experienced trauma and this should inform our work with people and communities. Long-term consistent, bespoke messaging and approaches are needed to build trust with communities. Using translated information but also culturally sensitive information and interventions are necessary in places where communities gather, like churches. Information and the approach should be specific to that community.

Utilising the voice of the community and amplifying the lived experience of survivors to support the community can be very powerful. There could be specific training for carers/survivors around psychological safety, how to talk in groups to build their confidence to share their experiences. Survivors could be linked up with each other, if they wanted to, to also provide peer support to each other.

Dr Tasmia explained that her Community Interest Company was developing a new community based diagnostic service model for Black, Asian and women living in areas of deprivation in Portsmouth, to try and address some of the barriers to accessing primary care. This will include a community hub staffed by specialist clinicians and a low-tech App, both providing breast cancer awareness, help, advice and referrals into secondary care. A community coordinator will manage engagement with communities, promoting the Hub and what it does. Comments were shared that as this is being 'badged' as NHS, some people still may not trust it.

Finding safe spaces for the community is very important but consideration also needs to be given to the screening age of women. However, it is very unlikely there will be any changes to the national programme in the near future.

Whilst there are challenges to health services reaching some communities, there are ways it can be done, for example working with community connectors or representatives from communities. Going to places people feel safe. Providing food that meets people's dietary requirements etc, all helps to build trust. It's still

recognising that not everyone will be welcome in some communities but the most likely way to have success is to work with communities over time.

Another comment was made about us collectively needing communities to stand up so we need to encourage them to speak up. We also need to understand cultural sensitivities and address fear of cancer as this can affect people checking their own breasts. Strong faith in some communities may also build a belief that ‘cancer won’t happen to me’. We need to be clear that cancer is curable and that it can affect anyone from any background.

Nursing colleagues gave examples of being invited out to a local Muslim women’s event to share awareness materials but it was still a shock to hear about their poor experiences of healthcare even now. They also reflected on lack of training for them specifically about cultural sensitivities about cancer. For example, nurses may not know that some people think that ‘cancer is catching’, which may mean that they do not ask the right questions of patients to be able to provide the right reassurance, support and care.

Training for all GP colleagues arose as an issue too. As well as training for GP, nurses and AHPs, receptionists need anti-racism training that challenges racial stereotypes to enable people to get appointments. On the issue of cultural awareness training, there may be learning from maternity services that could be explored.

In response to a health colleagues saying that it was upsetting that these issues are still going on, a breast cancer survivor expressed that these inequalities were not new, going back generations, and they should have been addressed. Others agreed and said that unfortunately they still do need addressing and action needs to be taken.

There was discussion about whether patients know they can have a chaperone for appointments and it may be helpful to have ‘cultural advocates’ that can accompany people. In Southampton, there are community champions for mental health services that volunteer to promote mental health in their area, aiming to bridge the gap between communities and services.

In terms asking about people’s ethnicity, it is not always made clear to patients why they are being asked and what it has to do the service they are accessing. It can be particularly difficult when community tensions are running high, as they are currently. Receptionists feel awkward asking and do not want to offend anyone so it would be helpful to have posters on the wall, making it clear why this is important.

Whilst the meeting ran out of time to talk in detail about people’s experiences of treatment and care, one particular issue was raised about access to hospital based personalised follow up according to individual’s needs. Some survivors were clearly struggling to access support for ongoing issues arising from their treatment, including

being called back by care teams, long waits for prosthetics and treatment induced menopause support. It felt like there needed to be further discussion about this.

Amara offered further insightful reflections after the meeting in her blog.

Priority themes

The priority themes that came out of the discussion for us to address were to:

- Address the ethnicity coding gap
- Provide cultural awareness training related to cancer to GP surgery and hospital staff
- Explore how we can support communities to self-advocate more effectively
- Continue to provide and expand culturally appropriate breast cancer awareness raising with and in communities
- Identify and share learning from the Portsmouth 'Pathfinder' model once it has been operating for a period of time.

Next steps

The immediate next steps are to share meeting notes and the presentation for participants' reflections, and then we will invite everyone to come back together to discuss taking forward the identified priorities in late April. As part of that discussion we will ask Black women with lived experience(s) of breast cancer to reflect on and share their experiences of treatment and care, or whether they would like to do this in a bespoke meeting with just them.

Contact details

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Appendix A: Meeting participants and apologies

Dr Mary Udo	Meon Practice GP (Meeting Chair)
Shipa Ahmed-Khan	Equality Diversity and Inclusion lead, Portsmouth Hospital
Linda Agyemang	Bournemouth University
Natasha Chikiwa	Community representative
Anne Cato	Community representative
Kathy Cooke	Workforce and Education Lead, Wessex Cancer Alliance
Nicola Duffield	Early Diagnosis Lead, Wessex Cancer Alliance
Debora Franchini	Lead Clinical Nurse Specialist, Hampshire Hospitals
Becky Foster	Southampton University
Edit Galambos	Lead Clinical Nurse Specialist, Portsmouth Hospital
Jill Ghanouni	Sea City GP Partnership
Christine Glew	Wessex Cancer Alliance GP Advisor
Gilly Howard-Jones	Maggie's Centre, Southampton
Barbara Hudson-Owen	Community representative
Reeta Kerai	Dorset Breast Cancer Screening Unit
Emma Leatherbarrow	Equality and Involvement Strategic Lead, Wessex Cancer Alliance
Anastasia Lungu-Mulenga	Hampshire and Isle of Wight Community Healthcare NHS Foundation Trust
Sue Newell	Involvement and Inclusion Lead, Wessex Cancer Alliance (Meeting organiser)
Amara Nnaji	Community representative
Nusirat Olayiwola	Community representative
Tasmia Tahmid	Locum Breast Surgeon and Tasmia Asif Cancer Hospital and Research Centre CIC
Lisa Young	Lead Clinical Nurse Specialist, Hampshire Hospitals

Apologies

Stephanie Alderman	Breast Cancer Clinical Nurse Specialist, Southampton Hospital
Suzanne Bannister	Wessex Cancer Support
Helena Boyce	Community representative

Claire Clayden-Lewis	Lead Breast Clinical Nurse Specialist, Hampshire Hospitals NHS Foundation Trust
Teresa Corbett	Wessex Cancer Alliance Personalised Care Lead
Goonj Johri	Breast Surgeon, Southampton Hospital
Ali Keen	Lead Clinical Nurse Specialist, Southampton Hospital
Shobhna Philips	Community Member
Claire Smith	Lead Cancer Nurse, University Hospital Dorset