NHS
Wessex
Cancer Alliance

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

Meeting Notes from April 2026

Welcome and introductions

Dr Mary Udo, chair of the meeting, welcomed everyone to the meeting and explained the propose of the meeting was to:

- Bring together patients, community members, clinicians and healthcare colleagues to discuss the differences in breast cancer diagnosis, experiences and outcomes of local Black and Asian women
- Confirm priority areas for action and how to take these forward.

Mary started the meeting by inviting a new member of the group to describe her experience of getting a diagnosis, who said that it was a conversation with her daughter that encouraged to get her symptoms checked.

Summary of community insights

Building on the insights shared at the first meeting about these issues, community reps and patients continued to share their experiences of talking about cancer with friends, family and communities. Here is a summary of that insight and this highlights how specific approaches are needed according to the audience.

- Some people may not wish to know they have cancer or are afraid to find out, or don’t think they can even get it.
- Many Asian women don’t talk about cancer, especially if they are older.
- Experiences of support from friends and family vary from person to person. Whereas some may not wish to talk about cancer, for others close family members can encourage women to get themselves checked.
- Sometimes minority ethnic women deprioritise their own health because they are busy looking after others and have weighty caring responsibilities.
- If cancer is known to have affected a family member this may have wider family implications, for example, marriage prospects for the person’s child.
- People from Black African communities can die without close family and friends not knowing what they have died of. Community members said they often didn’t understand why this is not share but perhaps this is because of stigma and embarrassment.

- Some people think they cannot get certain diseases, like breast and other cancers, so they need to be informed that they can.
- Wives of pastors and minsters can be helpful ways of reaching Christian communities.
- Some Caribbean people who have had breast cancer in their family talk about this openly. The issue for them can be that health professionals do not take them seriously and listen to what they are being told by the person. These historical poor experiences of care can mean continued mistrust of health services and influence whether someone does or doesn't seek help, even if it hurts them in the long term.
- It shouldn't be the responsibility of people to adjust how they talk to their doctor. Clinicians need to listen better.
- A number of people described how community champions who are part of a community are one of the most effective ways to convey messages.
- Just being open and talking about cancer can make a difference to people, you never know who you might help.

After the meeting Amara offered further useful reflections in her blog to which the Alliance reposted and replied.

Relevant updates since the last meeting

- **The Portsmouth 'Pathfinder Project' has been launched** as a pilot. As well as an App, Dr Tasmia Tahmid will be setting up roving 'community drop ins' for those unable to use the App. These will be to talk to women about any early concerns they have, provide them with information and signposting, and encourage them to seek help via the GP where appropriate.

  Tasmia is looking for additional funding to extend the project, for example, to cover more languages and pay two community volunteers, whose role is to do community outreach, raising awareness and encouraging people to use the App. It was suggestion to coproduce information about this new service with community members so they can full understand what's on offer. **Action:** Sue to put Marcia in touch with Tasmia so she can find out more.

- **Maggie's held a successful Multi-Faith Day at their Southampton Centre** on the 22nd of April. A number of faith leaders and community members came and the Centre shared what services and support that are able to offer.

- **Wessex Cancer Support are developing a funding application with Dorset Race Equality Council to explore with Black and minority ethnic cancer patients their support needs,** including engagement to understand the issues and to have a worker who could support developments.

- **Bournemouth University and the Alliance are exploring National Institute for Health Research funding around women's health to potentially evaluate this project.**

- **Communities Against Cancer have recruited 17 Community Well-Being Champions.** They are from a range of communities across Dorset, Hampshire and Isle of Wight. With a small amount of grant funding, they are given support by Action Hampshire and Wessex Cancer Alliance to do awareness raising activities, based on trusted information, in ways that suits their communities. Examples include community radio stations, faith-based community awareness raising, or activities via workplaces.

  Action: Sue to talk to Amara about the Communities Against Cancer Champions, and invite Action Hampshire to showcase this at our next meeting.

- **Dorset Breast Screening Unit have filmed a breast self-check video using a beach ball,** that is discreet and doesn't use anatomical parts. Sue shared it with community members straight after the meeting. **Action:** Sue will send the video link out for further comments.

- **The Dorset Insight and Information System team have re-run the ethnicity data and there has been no improvement so far but the team are looking to this and having further discussions.** We will add this to our project action plan.

- **Anastasia said the Hampshire and Isle of Wight Healthcare Foundation Trust are in the early stages of exploring how to support community members to advocate for themselves.** Sue and the Alliance would be interested in exploring how they can support this approach.

- **Sue said she had been exploring existing cultural awareness training related to cancer,** and is sharing these on our Workforce website. Our workforce team are also looking at options via other Cancer Alliances.

  Comments were made about unless training is made mandatory GPs and others won't do it as they have some much to do. Tamzen suggested she could do a health inequalities webinar with GP receptionists, and to speak to the ICB about including this in a Target Session, attended by many GPs.

- **Most of the Wessex Hospital Trusts are keen to show the Unseen Unheard film to their workforce and are planning this for the Autumn.** This includes HHFT, Portsmouth, Dorset and University Hospital Dorset

(Bournemouth, Christchurch and Poole) and Southampton have also been offered this. The Alliance can support these events, with practicalities and also has a small budget e.g. for refreshments etc. **Action:** Maggie's to host a Southampton showing of Unseen Unheard and invite clinicians. Sue said Helena Boyce may be happy to support.

Other issues that arose from the discussions

A question was asked as to whether the breast screening age criteria will be reduced as more people are getting diagnosed at an earlier age. Mary explained that this may happen in time but not immediately, so we need to continue to make people breast aware.

We talked about the need for communities and health professionals to work together to bring about change, as well as the responsibility the NHS has to challenge previous practice and continue to improve.

Anastasia shared her frustration at the continued low availability of appropriate wigs for Black cancer patients in light of the number of suppliers producing and selling wigs for this market. There is a need to increase the diversity of suppliers able to provide wigs to offer better choice and dignity.

Community members continued to advocate for culturally appropriate breast cancer awareness raising with and in communities. This includes media opportunities - enabling people with lived experiences to share their stories in a psychologically safe way. If people are willing to get involved and be filmed, we can arrange the appropriate training and support as well as set up filming. **Action:** to let Sue know.

Emerging actions

Set out an action plan (including why we have identified the issue) for each element – based on last meeting's priorities and issued raised today, including:

- Data completeness
- Updates about the partner's projects as shared at this meeting
- Dorset REC/Wessex Cancer Support conversations on supporting people from minoritised communities who have cancer
- Follow up on improvements to wigs/ images / prosthetics
- Communities Against Cancer recommissioning to include the specific needs of Black and Asian women in specification
- Explore options for mandatory training across healthcare on cultural competency, attendance at Target GP training, training for reception/admin staff
- Organising and publicising Unseen, Unheard viewings
- Exploring how the Alliance can support the HIOW Foundation Trust Self-advocacy project
- Co-design approach to survivorship patient storytellers

- Work with community members on a genetic testing and family history approach that is culturally aware
- Consider what information could be published in the scientific/industry press.

Immediate next steps

The immediate next steps from this meeting will be to follow up on identified actions, including setting out an implementation plan. This will be shared for comments and we will start to deliver against these.

We will also organise a meeting of this Steering Group for September to review initial progress against the actions, as well as invite Action Hampshire to come and share more about the Communities Against Cancer Champions.

We will develop a Wessex Cancer Alliance webpage as way of sharing this work and consider further communications opportunities to promote it and awareness raising opportunities.

For more information, questions or to get involved contact:

Sue Newell, Wessex Cancer Alliance on Sue.Newell@wca.uhs.nhs.uk or 07961 062883.

Appendix A: Meeting participants and apologies

Dr Mary Udo	Meon Practice GP (Meeting Chair)
Shipa Ahmed-Khan	Equality Diversity and Inclusion lead, Portsmouth Hospital
Natasha Chikiwa	Community representative
Anne Cato	Community representative
Becky Foster	Southampton University
Gilly Howard-Jones	Maggie's Centre, Southampton
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
Lisa Young	Lead Clinical Nurse Specialist, Hampshire Hospitals
Suzanne Bannister	Wessex Cancer Support
Tamzen Hogben	Wessex Cancer Alliance GP Practice Manager Advisor
Marcia Hudson	Community representative
Gita Patel	Community representative
Bharti Patel	Community representative

Apologies

Stephanie Alderman	Breast Cancer Clinical Nurse Specialist, Southampton Hospital
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
Ali Keen	Lead Clinical Nurse Specialist, Southampton Hospital
Claire Smith	Lead Cancer Nurse, University Hospital Dorset
Linda Agyemang	Bournemouth University

Tasmia Tahmid	Locum Breast Surgeon and Tasmia Asif Cancer Hospital and Research Centre CIC
Reeta Kerai	Dorset Breast Cancer Screening Unit
Barbara Hudson-Owen	Community representative
Christine Glew	Wessex Cancer Alliance GP Advisor
Jill Ghanouni	Sea City GP Partnership
Edit Galambos	Lead Clinical Nurse Specialist, Portsmouth Hospital
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