Artificial intelligence (AI) and breast cancer diagnosis

Discussions with Women from African and Caribbean Heritage

Acknowledgements:

Black Women Rising for introducing us to a remarkable group of women and providing the cover picture for this report.

To the women who shared their stories and thoughts within this report – without you we could not do what we do.

Contents

1. Background

There are around 56,400 new cases of breast cancer in the UK every year. This makes it the most common cancer in women[i]. There are several tests that can help clinicians to diagnose breast cancer, including breast examination, mammograms, ultrasound scans, and biopsies. A breast biopsy involves taking a sample of tissue from the breast and a specialist doctor, a pathologist, looking at it with a microscope. The pathologist decides if they can see any cancer cells in the sample. This helps decide if further tests or treatments are needed. To ensure patients receive test results quickly, it is recommended that breast biopsies are reported on within five working days[ii].

Ibex Medical Analytics (Ibex) have developed an Artificial Intelligence (AI) tool called Ibex Breast to help identify cancer in breast tissue samples. Ibex Breast can be used to support pathologists identify cancer cells. It can be used in two ways:

- as a "a decision support tool" - looking at samples before the pathologist and highlighting abnormal cells
- "a second read tool" - checking samples already looked at by the pathologist.

The pathologist's final report uses their own assessment, supported by the AI tool. Ibex Breast can also help identify markers, which can help decide which treatment, or combinations of treatments, are likely to be most effective for individual patients.

Ibex has been awarded a government-backed research grant to look at how Ibex Breast might be used in the NHS. Health Innovation Oxford and Thames Valley (HIOTV)[iii] are collaborators on this grant. The research plans to review 7,000 breast biopsy samples: the first 1,000 samples analysed as a "second read tool", and the next 6,000 as a "decision support tool".

HIOTV are leading the patient and public aspect of the research, focusing on understanding the views and experiences of marginalised, or seldom heard, patient groups. This report covers the findings of discussions with women from African and Caribbean heritage.

2. Methodology

Participants

Women from African and Caribbean heritage were contacted through the charities Black Women Rising[iv] and Breast Cancer Now[v]. Women were asked to contact HIOTV if they were interested in participating in the project. Women who contacted HIOTV (n=8) received an email of thanks and an invitation for a short on-line or telephone call to introduce them to a member of the project team and discuss opportunities for involvement. Six women responded to the email, and each attended a short introductory meeting. Following these discussions women were asked to participate in either a group discussion or to undertake a one-to-one, semi-structured interview. In February 2025,

four women took part in a group discussion, and one in an individual interview. One woman was undergoing chemotherapy and so was unable to take part.

Aim

The aim of discussions was to understand the views and experience of women from African and Caribbean heritage who had received a breast cancer diagnosis, in particular:

- their experience of diagnosis, care and treatment
- the views on the potential use of AI, such as Ibex Breast, in the diagnosis of breast cancer, including what might be required to trust an AI diagnostic tool.

Process

A briefing paper was sent to participants one week before the group discussion. The questions used for both the group discussion and individual interview are found in appendix 1. The psychological wellbeing of attendees/interviewees was a key concern. All women were reminded that they could choose not to participate at any point in time. Within the group setting, a member of the HIOTV Team was present to support via telephone should the need arise. Women were sent a follow-up thank-you email, with details on how they could claim reimbursement for participating.

3. Findings

Individual journeys

The women started discussion by sharing their journey of receiving a diagnosis and being treated for breast cancer. They described what was important to them, what had worked and what did not. Everyone agreed that each woman's journey, regardless of race or colour, needed to be seen as individual. Importantly, this individuality needed to be reflected in the way in which each woman was cared for and treated.

Empathy in screening

All participants had different experiences of screening, two having access to private medical care. Some women were diagnosed through routine screening, others self-identification and one through a concerned GP consultation. During the initial screening process several participants felt that the screening staff maybe de-sensitised to the concerns and experience of women attending.

"I was getting agitated as they were pulling me around and they weren't receptive to calming me down. They do it all the time and they lost humanity."

"I was there all afternoon, and no-one told me what was happening."

The challenge of communication and information

During screening and diagnosis some participants were told not to "Google" and others chose to immerse themselves in as much information they could. One participant felt:

"overwhelmed with education that is not properly categorised into specific diagnosis."

This prompted a discussion around education and campaigns more generally. Most participants felt that the breast cancer information they had seen might give people a misleading narrative. It might make *"all women feel like they are going to have the same journey."* Breast cancer could be treated more as an umbrella term:

"it's like a Russian doll set where one box fits within another, my breast cancer is a box within a box, within another box."

(the umbrella term breast cancer being the largest Russian doll).

There were a variety of thoughts about what information women received and what they thought was useful. One participant shared the need to be in control of her treatment plan, have all the information and make joint decisions. Another felt rushed into their treatment.

"I felt rushed into my treatment, I said yes to everything which is not like me. My daughter suggested to postpone for one week which was a special time with family to prepare. You could have six months to decide if it's not going to change the outcomes."

One participant noted that an information video rather than lots of leaflets was useful.

"The oncologist was lovely and gave me access to a radiotherapy video which gave me an understanding of how it works, I was put at ease and knew what was going to happen."

Another participant felt that the relationship between them and their consultant was very clinical. There was *"no real explanation about the cancer itself, just what was going to happen to you."*

Two of the participants had triple negative breast cancer and felt it was important to *"sit with those (women) who have a triple negative diagnosis"*. They felt that the Macmillan website said no positive thing about triple negative breast cancer.

Most participants noted how the charity Black Women Rising has been a great support, being with women of similar culture and going through breast cancer together.

"It made me feel like I was not alone."

Communities, clinicians and understanding of risk

There was consensus that there is a lack of understanding about ethnic diversity and health within public campaigns and screening programmes. One participant highlighted that *"black women tend to get diagnosed younger and are more at risk of triple negative breast cancer."* It was noted that there is a lot more targeted publicity around diversity and prostate cancer.

One participant shared her experience that she was told her mammogram was "*all fine*." She asked if they thought that she had "*dense breast tissue*." An MRI was then carried out which raised concern and subsequently a diagnosis of triple negative breast cancer was made.

Some women felt that assumptions might be made by clinicians, researchers, and members of the public. A feeling that they maybe *"de-sensitised to black health"* and may not know about differences in pathology and outcome for black women. For example, an assumption that all breast tissue is the same, whereas women from African and Caribbean heritage may have more dense tissue. Some suggested that maybe there needed to be a different approach to screening for women from different ethnic backgrounds. Alongside this, participants felt that there was little understanding in their communities about the specific risks for black women in relation to breast cancer.

Cultural assumptions and sensitivity

Two participants felt that their GP was dismissive of their concerns. One had private medical care through their employer so requested further screening. One participant felt that *"some doctors think that we feel less pain, and everyone thinks you are a strong black woman"*. The truth is that *"you want someone to be strong for you."* One participant shared that perceptions of friends, family and work colleagues were that she looked good. Her reality was *"I don't go pale, I'm tired and I ache everywhere."*

AI and the speed of diagnosis

Women had had different experiences of waiting for results. One participant felt that the waiting time for results needed to be improved *"you are on high alert as dealing with this illness, so many thoughts going through your mind."* Another participant shared that they felt they received their results and diagnosis quickly and thought it could not have been any quicker. However, she said that *"whether it took a day or a month, it's still stressful."* Overall, there was a positive feeling that technology providing a quicker diagnosis would a good thing.

"With the rising cases it's important that women who have a diagnosis are diagnosed quickly so that they have time to think about choices."

"Some women I've spoken to have had a misdiagnosis. Having an extra set of eyes and being able to have a quicker diagnosis is what people want."

Training AI and bias

All participants wanted transparency about how the AI software had been trained. It was important for them to be assured that a sufficiently diverse group of women and men were part of the training. Most of the women were aware that AI can produce discriminatory results if trained on biased data. They felt that, as black women already experience health inequity, they needed assurance that the AI had been trained inclusively. One participant noted that out of the five hospitals where the current research was being undertaken none are in London where a more diverse population may be found.

"I embrace change because it has to happen, and the world has to evolve. I'm sceptical as I know from the past if you have the wrong people putting in the data the data will be bias."

Information and AI

Information needs were discussed, and, dependent on what this current research finds, information for women and men should be tailored for specific groups and their potential risks and experiences. It was highlighted that information needs to be clear and concise to support those who are neurodiverse or have language barriers. All participants suggested that information given to patients needed make it clear that the AI is supporting

doctors, and that doctors will make the final decisions. There was no consensus on what information platforms were most appropriate but video links which could be socialised on black media platforms was thought to be a starting point.

4: Discussion

The need to process breast biopsies as quickly and accurately as possible to ensure treatment can be started promptly was clearly very important to all the women spoken to. If AI could help with this then it would be supported. However, women were also aware that the way in which AI is trained mattered if health inequalities were to be minimised, rather than exacerbated. This is in line with existing research eg the Institute of Global Health Innovation white paper that states AI could exacerbate existing health inequalities in minority ethnic groups[vi].

This sentiment exists against a background where, for some women and communities, there is mistrust in both the medical profession and in research. For people to trust Ibex Breast, or similar AI products, transparency in how the AI is developed and trained - on an appropriately diverse population of men and women - needs to be communicated. Transparency can help build bridges to reassurance and trust.

The way in which breast cancer is discussed in existing patient information maybe too generic. No one person is the same and within the Black Community there maybe difference in actual, and perceived, understanding of risk and outcomes. Ensuring that patient information and clinicians behaviours are not biased by stereotypes was seen to be essential. Harnessing specific media platforms e.g. Black Women Rising might help to dispel myths and promote understanding of breast cancer amongst black communities.

Appendix 1: Workshop Discussion Questions

What was your experience of receiving a breast cancer referral, triage and diagnosis process?

Objectives
To explore what the current pathway was like for women receiving a biopsy and what is important to them.

Prompt Questions

- What was important for you in the process of being referred to hospital with a suspected cancer?
- What was important to you whilst waiting to be seen?
- How did you feel about the information you were given to how your suspected cancer would be assessed and diagnosed?
- How do you think the process could be improved?

Views on introducing AI into the pathway to support diagnosis

Objectives
To explore participant's views on technology assisted diagnosis
To explore participants views on the benefits or risks associated with the use of digital technologies to support care and treatment.

Prompt Questions

- How do you feel about the possible introduction of technology and Artificial Intelligence in the referral and initial diagnosis process?
- What do you think could be the benefits of including technology like Ibex Breast?
- What concerns might you have about the introduction of technology like this?

Trust and design of product
Objectives
To explore what information participants feel they would like to know about the product in order to trust it and find it a reassuring product in their diagnosis process.
To explore how participants would like to be communicated with regarding this technology being used in the diagnosis process.
To gather feedback that will inform our patient infographic summaries, short videos and animations as well as FAQ sheets to explain the study findings.

Prompt Questions

- What information would you like to know about the technology, in order for you to feel you could trust its use in your diagnosis process?
- At what stage in your referral, diagnosis, triage process would you like this information to be given to you?
- How would you like this information communicated to you? By who? In what format?

Appendix 2: References and Endnotes

Alford, Nikita Rathod, 2022, AI could worsen health inequities for UK's minority ethnic groups (accessed 11th March 2025)

O'Brien et al, 2022, Addressing Racial and Ethnic Inequities in Data-driven Health Technologies (accessed 11th March 2025)

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[i] Breast cancer statistics | Cancer Research UK
[ii] Royal College of Pathologists
[iii] Health Innovation Oxford & Thames Valley
[iv] Black women rising
[v] Breast cancer now
[vi] AI could worsen health inequities for UK's minority ethnic groups - new report | Imperial News | Imperial College London