

Macmillan Cancer Support, Roche, and the NHS Race and Health Observatory (NHSRHO) are working in collaboration to address ethnic inequalities in breast cancer clinical trials. This project is being piloted at **Barts Health NHS Trust**. Materials will be shared with breast cancer patients at this site, supported by a newly hired clinical post funded by the project.

A special thank you to **Caribbean & African Health Network (CAHN)**, **South Asian Health Action (SAHA)**, and **Egality Health** for their invaluable contributions to community engagement with people with lived experience and the creation of supporting materials.

Where can I learn more?

Your **Clinical Nurse Specialist** can provide specialist advice, information, support and holistic care to patients diagnosed with breast cancer and their families, including specific guidance on clinical trials.

GET IN TOUCH TODAY!

☎ 07887492172

✉ bartshealth.trialsbreastcarenurse@nhs.net



Why Take Part in a Breast Cancer Clinical Trial?

Breast cancer is the most common cancer in the UK,¹ and one of the **primary cancers that affect people from African, Caribbean and South Asian communities**.

However, clinical trials have often excluded African, Caribbean, and South Asian people,² meaning these communities are not adequately represented in breast cancer research.

Representation matters. Differences in genetics, biology, and how people process drugs can affect how effective a treatment is. These factors vary among groups.

We need more people from our communities to take part in trials to improve our understanding of the more advanced and harder-to-treat cancers that affect us, and **develop better treatments**.³ Especially as we know our communities are already facing worse **health outcomes**:

- African and Caribbean people in England are twice as likely as white British people to get late-stage cancer diagnoses.⁴
- South Asians, including Indians, Bangladeshis, and Pakistanis, are more likely to be diagnosed with late-stage breast cancer.⁵
- African, Caribbean, and South Asian people face a higher risk of tougher-to-treat breast cancers.⁶



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CAHN
Caribbean & African Health Network



SOUTH ASIAN
HEALTH ACTION
For better health choices



egality
equality in health

Why should I take part in a trial?



WHY DOES IT MATTER?

- Breast cancer survival has doubled in the past 50 years.⁷ New treatments developed from clinical trials play an important role in increasing survival rates.
- African, Caribbean and South Asian people are more likely to receive a late-stage diagnosis⁴. They are also more likely to be diagnosed with more advanced-stage cancer, and cancers that are harder to treat.^{5,6}
- Yet in the UK only 4 in 10 people from ethnic communities would take part in a clinical trial, compared to 6 in 10 white people.³
- This stems from challenges within the health system rather than shortcomings within the communities.



WHAT COULD THIS LEAD TO?

By taking part, you can:

- Support researchers to improve early detection, enhance treatments, and increase survival rates. This will ultimately help advance outcomes for people living with breast cancer.
- Represent the African, Caribbean, and South Asian communities. This is critical to develop treatments that are safe and effective for our communities.
- Help reduce health inequalities and contribute to treatments for the advanced-stage and harder-to-treat breast cancers that affect our communities.

HOW DOES IT BENEFIT ME?

By taking part,

- You may gain access to treatments and medical research not yet available on the NHS.
- You may receive additional monitoring and care, which can lead to better management of your condition.
- You can learn more about breast cancer and its treatments. This can help you make more informed decisions about your health and wellness in the future.
- You can take an active role in your own healthcare journey. This can empower you to have more agency over your treatment decisions and be more involved in your health management.



HEAR IT FROM OTHERS!

"I think it's important for people to have those opportunities to be involved in trials. There's no need to be frightened because it can prolong your life."
- Sukhy



"Clinical trials are something that I would strongly encourage. I'm living proof that these things work for a period of time."
- Martina

Clinical Trial Process



This section sets out the process of a typical clinical trial. Details may vary across different trials.

STEP 1: UNDERSTANDING THE TRIAL



Clinical trials are research studies that test new treatments to see how well they work. They are essential for developing new ways to prevent, detect, and treat breast cancer. By participating in a clinical trial, you can help advance medical knowledge. You can also potentially benefit from new treatments.

STEP 2: ELIGIBILITY AND ENROLLMENT



Before joining a clinical trial, you must meet certain criteria to ensure the trial is safe and suitable for you. This may include factors like your age, type and stage of breast cancer, and previous treatments.

STEP 3: THE TREATMENT PLAN



Once enrolled, you will get a treatment plan outlining the specific procedures, medications, or treatments you will receive. This plan is designed based on the trial's goals and your medical condition.

STEP 4: MONITORING AND FOLLOW-UP



Throughout the trial, your health and response to the treatment will be carefully monitored. This helps ensure your safety and gathers important data about the treatment's effectiveness.

STEP 5: COMPLETION AND RESULTS



After completing the treatment phase, there will be a follow-up period to monitor your long-term health and gather final data. The results of the trial will contribute to medical knowledge and may lead to new treatments becoming available.

What to expect from each step of the trial



STEP 1: UNDERSTANDING THE TRIAL

- Receive detailed information about the trial, including its purpose, procedures, risks, and benefits.
- Opportunity to ask questions and discuss any concerns at any point.



STEP 2: ELIGIBILITY AND ENROLLMENT

- A screening process that may involve medical history review, physical exams, and lab tests.
- If eligible, you will be asked to sign an informed consent form, which confirms your willingness to participate and understanding of the trial.
- It is your choice whether to consent to a trial.
- You can withdraw from the trial at any time.
- Participation in a clinical trial does not guarantee that the treatment being tested will be effective.

STEP 3: THE TREATMENT PLAN

- Regular visits to the hospital for treatments, tests, and check-ups. The frequency of the visits will depend on the particular treatment plan.
- You may receive the standard treatment for breast cancer, a new treatment being tested, or a combination of both.



STEP 4: MONITORING AND FOLLOW-UP

- Regular appointments for physical exams, blood tests, imaging scans etc.
- Report any side effects or changes in your health to the healthcare team.

STEP 5: COMPLETION AND RESULTS

- Continue to have check-ups and tests to assess your health after treatment. Complete questionnaires about your experience and quality of life.
- The trial team will share overall results with you, explaining what was learned from the study and any next steps.
- The trial team will keep you informed throughout the process.

Note: Clinical trials undergo a thorough assessment for risks. They must be reviewed and approved by an independent ethics committee and regulatory authority in the UK before they can start. This ensures patient safety before proceeding with research.



Sukhy's Story



My name is Sukhy. I'm 40 and I'm from West London. I'm a single mum with two children, so it was tough.

In 2019, I was diagnosed with primary breast cancer. I had a mastectomy with an implant, chemotherapy, and radiotherapy. Then I was on hormone therapy. I got the 'all clear' in March 2022. Unfortunately, in August 2022, I was diagnosed with secondary breast cancer.

I'd never seen anybody that looked like me that had breast cancer. Nobody in the community speaks about it, so it was really lonely.

"I think specifically as a secondary breast cancer patient, we don't really have anything to lose"

With my secondary diagnosis, it was a lot more difficult. I knew there were limited treatments and the prognosis is often not very good.

My nurse told me there might be trials available to me. I failed to get on the first two trials because I didn't qualify but, luckily, I managed to get on a trial. And it's working so far.

I'm all about the science and trying new things. With clinical trials, I think you're a lot more looked after. There are constant scans and tests and they make sure you're okay all the time. I have a constant contact that I can speak to whenever I need to.



Martina's Story



Hello, my name is Martina Warner. I'm 49 years old. I am a mother of three and I live with my partner.

In 2019, I was diagnosed with breast cancer cells. Unfortunately, it was triple negative cancer, which is one of the worst strains.

I'd finished my treatment, which consisted of chemotherapy then radiotherapy. And then about 18 months later, I started getting symptoms again and I found out that I had a tumour in my lung and liver. My next treatment was going to be intravenous chemotherapy. It was at that time that I decided to seek a second opinion.

"I'd like to see more of our community involved in trial drugs and to encourage us to be more involved."



I met a lady on a Facebook Group who was on a trial drug. I'd never heard of trial drugs before. I put forward my diagnosis to her, and she said trials were going on at Barts. I made the decision to go ahead with the trial drug.

I was given the right information by the professor. They answered all my questions. I did my research with a clinical nurse. They said trial drugs are actually monitored more closely than normal chemotherapy drugs. So, I felt safe and confident.

Frequently Asked Questions

FAQ

What decisions can I make in my treatment journey? Can I leave the trial if I change my mind?

You have full control over your treatment journey during the trial. You can decide to join, continue, or leave the trial at any time, especially if you experience change or have other concerns. Your participation is voluntary. Your health and well-being are prioritised throughout the process.

Will participating in a trial affect my overall treatment options?

Participation in a clinical trial should not negatively impact your overall treatment options. Before joining, discuss with your healthcare team how the trial fits into your broader treatment plan. They will ensure that you receive the best possible care, whether inside or outside the trial.

What are some potential risks that I should be aware of?

Participating in a clinical trial may involve some risks, including:

- Side effects which can range from mild to severe, depending on individual reactions
- The treatment may not be effective for you, even if it works for others
- There may be additional tests and visits to the clinic
- New treatments carry some uncertainty, as they are still being tested



Can someone come with me during trial visits for support?

Patients are generally allowed to have a companion during trial visits. However, policies can vary depending on the specific trial and the healthcare facility. Please speak to your healthcare professional for more details.

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Scan the QR code for more information on cancer clinical trials and how to take part.

