

# Additional Resources



Scan this QR code to access online tools and resources. This includes information on cancer clinical trials and how to join one.



# Contact Details

📞 07887492172

✉ [bartshealth.trialsbreastcarenurse@nhs.net](mailto:bartshealth.trialsbreastcarenurse@nhs.net)

# Acknowledgements

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. The project aims to increase representation, improve patient retention, and generate evidence to support improved recruitment of ethnic minority patients.

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.

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# A guide for UK healthcare professionals: inclusive practices in breast cancer clinical trials

## CONTACT DETAILS:

📞 07887492172

✉ [bartshealth.trialsbreastcarenurse@nhs.net](mailto:bartshealth.trialsbreastcarenurse@nhs.net)

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# Context

## Health inequities in breast cancer

Breast cancer is the most common cancer in the UK.<sup>1</sup> It is also one of the primary cancers that affect people from African, Caribbean, and South Asian communities.

African, Caribbean, and South Asian people are more likely to be diagnosed later with more advanced-stage cancer.<sup>2</sup> They are also more likely to be diagnosed with breast cancer types that are more difficult to treat:

- African and Caribbean people are up to twice as likely as White British people in England to receive a late-stage diagnosis for some cancers.<sup>3</sup>
- South Asian people, including Indians, Bangladeshis, and Pakistanis, are at higher risk of being diagnosed with late-stage breast cancers.<sup>4</sup>

Though they have fewer breast cancer cases than the white population, African, Caribbean, and South Asian people are at greater risk of being diagnosed with breast cancers that are more difficult to treat.<sup>4</sup>

## Under-representation in clinical trials

It is important to include people from different ethnic backgrounds in health research. People have different health needs, and their bodies can react to treatments in different ways. By including all groups, we can make better treatments that work for everyone.

We must also acknowledge that clinical trials have historically under-represented African, Caribbean, and South Asian people.<sup>5</sup> They still do so in the UK today. In the past, there have been serious injustices, like the Tuskegee Experiment, which misled and denied treatment to African American men with syphilis.<sup>6</sup> These actions caused harm and broke trust in the medical system. It is important to remember these past mistakes, as they help ensure today's health research is ethical, respectful, and transparent. Everyone should benefit fairly.



Therefore, more African, Caribbean, and South Asian people need to participate in clinical trials. This will help us learn about hard-to-treat cancers in these communities and create better treatments. This booklet gives clear information to help people decide whether to take part in clinical trials.<sup>7</sup>

## Improving your own practice to increase diverse recruitment to breast cancer clinical trials

This booklet, and the partners who developed it, aim to provide information and guidance to healthcare professionals so that they can empower and support African, Caribbean, and South Asian people to take part in breast cancer clinical trials. We strongly advise that alongside this booklet you:

- Learn and build awareness about the cultural, social, and economic factors that prevent African, Caribbean, and South Asian communities from joining clinical trials.
- Make your practice culturally competent.
- Use language and materials that are respectful and accessible to diverse populations.
- Offer translation services and culturally relevant resources to make participation easier.
- Acknowledge historical and ongoing mistrust of the healthcare system. Be ready to discuss these issues openly.
- Rebuild trust by being accurate and transparent.



# Engagement checklist

Here are some guidelines on patient engagement and inclusive behaviours. Review the following points, and use them as a guide when interacting with people from African, Caribbean and South Asian communities.

- ☐ Take time to understand the patient’s cultural background. Their traditions, beliefs, and values may affect their healthcare decisions.
- ☐ Do not dismiss or trivialise these beliefs, even if they seem irrelevant to the trial. Learn about and respect these perspectives. Acknowledge any areas where your knowledge may be limited.
- ☐ Consider each patient’s unique background, experiences, and needs. Personalise your engagement to reflect their unique circumstance. Avoid using a one-size-fits-all approach.
- ☐ Use written, verbal, and visual information to suit different preferences and literacy levels. Providing information in the patient’s preferred language is also recommended.



- ☐ Give patients the time to express their concerns or ask questions without feeling rushed. Active listening shows respect and helps build trust.
- ☐ Proactively ask if the patient has any questions or concerns. Be mindful that they might not feel comfortable asking questions due to perceived power dynamics. Provide contact information for any follow-up questions.
- ☐ Avoid imposing your own beliefs or judgments on the patient. Offer information and support as needed but do not try to sway their decision with your views.
- ☐ Pay attention to non-verbal cues. They may show discomfort, confusion, or hesitation. These feelings may go unspoken. Address these cues with sensitivity.
- ☐ Use plain language and explain any necessary medical terms. Make sure your explanations are clear, especially if English is not their first language.





# Things patients (don't) ask

Create a space where patients feel comfortable asking about clinical trials. They may not know what to ask or feel nervous. Use the prompts below to guide discussions and encourage patients to share their concerns.

Purpose and Overview of the Trial

- What is the purpose of this clinical trial?
- How will the trial be conducted?
- How long will the trial last?
- How long do I have to decide about joining the trial?

Treatment and Care

- What kind of tests and treatments will I undergo?
- Will I get to choose my treatment, or will it be randomly assigned?
- Will I know which treatment I am receiving during the trial?
- Will participating in the trial affect my ongoing treatment or care?
- Will I need to make any changes to my lifestyle during the trial?
- Where and how will the tests and treatments take place?
- Will my GP be involved in my care during the trial?

Benefits and Risks

- What are the potential benefits?
- What are the potential risks?

Rights and Participation

- What happens if I decide not to participate or if I want to leave the trial?
- How and when will I be informed about the trial results?
- Will I incur any financial costs?

Confidentiality and Oversight

- How will my medical information be used and protected?
- Who oversees my care during the trial?



# FAQs - Barriers & Facilitators

What are some identified barriers that make clinical trials inaccessible for people from diverse communities? What facilitators can improve accessibility?

	Barrier	Facilitator
Mistrust and Historical Malpractice	People from diverse ethnic backgrounds may rightly have deep-rooted mistrust towards clinical trials. This is due to past unethical practices and mistreatment in the healthcare system. <sup>5,8</sup>	Trust-building actions are essential. Healthcare professionals should actively engage with patients. They should give clear, transparent information, and acknowledge past wrongs to help rebuild trust.
Racism and Discrimination in the Health System	Systemic racism and discrimination exist in the NHS. <sup>9</sup> They can create an unwelcoming environment for patients from diverse communities. This discourages them from participating in clinical trials.	Anti-bias training for healthcare professionals can help. It may encourage them to explore and address their own prejudices. This can help them to create a more inclusive and supportive environment for the patients.
Communication and Engagement	There is often poor communication about the potential benefits of joining clinical trials, for individuals and their communities. <sup>7</sup>	Healthcare professionals should clearly communicate the benefits of clinical trials. They should emphasise how participation can advance medicine and may improve future patients' outcomes in their community.
Information Delivery	Complex medical information can be difficult to understand. <sup>10</sup> This is especially true if it is not culturally sensitive or accessible.	Using simple language and different communication forms (e.g., written, verbal, visual) can help. Staggering the delivery of information can also help. This will make sure patients fully understand the trial and make informed decisions. Provide information in the patient's preferred language.



## 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.



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.

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

I'll be honest, the paperwork that they give you is not so easy to understand. I think there's quite a lot of science-speak there, but my team is amazing.

They were willing to explain anything that I didn't understand. They told me how the treatment works and answered my questions about side effects.

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

## Anjali wants you to know...

Hi, I'm Anjali. I'm the Lead Clinical Trials Practitioner for breast cancer at Barts Health in London. My role is to oversee all patients on clinical trials, specifically within breast cancer. I'm their point of contact and their caregiver throughout their cancer journey.

If a patient ever feels like they don't want to continue, we remind them that their consent is entirely optional. They can withdraw at any point.

Every part of your cancer journey and clinical trial journey is your choice.

***"Patients from different communities taking part in clinical trials will allow us to develop better and more personalised treatments."***

Clinical trials give patients access to treatments that they wouldn't necessarily get otherwise. It's about giving patients control of their own cancer journey.

The purpose of clinical trials is to try to find new treatments that can be effective. Cancer's constantly developing. So developing cancer treatments alongside that is the main purpose of clinical trials.

Involving patients from diverse communities is important because one size doesn't fit all. It's good to learn what treatments are good for different communities.



We encourage our patients to talk to us and ask us questions. Patients are in control. We're not here to tell patients what to do. We're here to navigate them through and let them make the decisions.

# 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. My nurse booked me in for an MRI and CT scan, which revealed 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 don't think I would be here had I not taken that up."***

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

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 there were trials going on at Barts. I made that decision to go ahead with the trial drug.

I was the given hard core facts and reality of the potential risks. But it's a risk that I wanted to take because I was at my tether.

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.



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

# References

1. Breast Cancer UK. Facts and figures [Internet]. 2024. Available from: <https://www.breastcanceruk.org.uk/about-breast-cancer/facts-figures-and-qas/facts-and-figures/> [Last accessed 13/Jun/2025]
2. Breast Cancer Now. Breast cancer in ethnic communities [Internet]. 2019. Available from: <https://breastcancernow.org/support-for-you/breast-cancer-in-ethnic-communities/> [Last accessed 13/Jun/2025]
3. Meredith S. Caribbean and African Women Twice as Likely to Get Late-stage Cancer Diagnosis [Internet]. Medscape. 2023. Available from: <https://www.medscape.co.uk/viewarticle/caribbean-and-african-women-twice-likely-get-late-stage-2023a10001pb> [Last accessed 13/Jun/2025]
4. Breast Cancer UK. Breast cancer risk and ethnicity: Explained [Internet]. 2023. Available from: <https://www.breastcanceruk.org.uk/breast-cancer-risk-and-ethnicity-explained/> [Last accessed 13/Jun/2025]
5. Hussain-Gambles M, Atkin K, Leese B. Why ethnic minority groups are under-represented in clinical trials: a review of the literature. Health and Social Care in the Community. 2004 Sep;12(5):382–8. [Last accessed 13/Jun/2025]
6. CDC. The Untreated Syphilis Study at Tuskegee Timeline [Internet]. The U.S. Public Health Service Untreated Syphilis Study at Tuskegee. 2024. Available from: <https://www.cdc.gov/tuskegee/about/timeline.html> [Last accessed 13/Jun/2025]
7. West R. Bridging the Ethnicity Gap in Clinical Trial Participation: Education and tailored communications needed [Internet]. Ipsos. 2024. Available from: <https://www.ipsos.com/en-uk/bridging-ethnicity-gap-clinical-trial-participation-education-and-tailored-communications-needed> [Last accessed 13/Jun/2025]
8. Scharff D, Mathews K, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: Understanding Mistrust about Research Participation. Journal of Health Care for the Poor and Underserved [Internet]. 2010 Aug;21(3):879–97. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4354806/> [Last accessed 13/Jun/2025]
9. British Medical Association. Reflections on systemic racism in the NHS | BMA blogs [Internet]. The British Medical Association is the trade union and professional body for doctors in the UK. 2023. Available from: <https://www.bma.org.uk/news-and-opinion/reflections-on-systemic-racism-in-the-nhs> [Last accessed 13/Jun/2025]
10. Farrar N, Elliott D, Jepson M, Young B, Donovan JL, Conefrey C, et al. The role of healthcare professionals' communication in trial participation decisions: a qualitative investigation of recruitment. 2024. [Last accessed 13/Jun/2025]