Additional Resources

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

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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.

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A patient's guide to participating in breast cancer clinical trials

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Context

Health inequities in breast cancer

Breast cancer is the most common cancer in the UK.[1] 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.[2] 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.[3]
- South Asian people, including Indians, Bangladeshis, and Pakistanis, are at higher risk of being diagnosed with late-stage breast cancers.[4]
- 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.[4]

Under-representation in clinical trials

It's important that people from diverse ethnic backgrounds join health research. Everyone's health needs are unique. Different groups may experience health problems in different ways. Their bodies may respond to treatments in different ways. Including a wide range of ethnicities in research can help us better understand these differences. We can then create treatments that work for everyone.

We must also acknowledge that clinical trials have historically under-represented African, Caribbean and South Asian people.[5] They still do so in the UK today. In the past, there have been serious injustices and these actions have caused harm and broken trust in the medical system.[6] It's important to remember these past mistakes as they help ensure today's health research is ethical, respectful, and transparent. Everyone should benefit fairly.

More African, Caribbean, and South Asian people need to take part in clinical trials.[7] This will help us understand more about the advanced and harder-to-treat cancers that affect our communities. It will also help in developing life-saving treatments. This booklet aims to provide better information and support to empower African, Caribbean, and South Asian people to choose to join clinical trials.

What can I do as a person living with breast cancer?

You can participate in clinical trials. By doing so, you might have the opportunity to try new medications or treatments that are not yet available as standard in the NHS. Taking part in a breast cancer trial can mean taking an active role in your own healthcare journey. This can empower you to be more involved in your treatment decisions and overall health management.

How does the health system/clinical trial benefit from my involvement?

By taking part in clinical trials you can:

- Help researchers understand advanced and harder-to-treat breast cancers that affect our communities more. This will advance science and healthcare, improving future breast cancer survival rates.
- Represent the African, Caribbean, and South Asian communities. This is crucial for developing treatments that are safe and effective for our community.

What should I ask my GP, nurse, or doctor?

These are some questions you might ask if you are thinking about participating in a clinical trial. Read through and use them as a guide while speaking to your Clinical Nurse Specialist so you can make an informed decision.

Understanding the Trial

- ☐ Can you tell me why this trial is being done?
- ☐ What are the different treatment groups in the trial? Do I have a choice on which treatment group I would be allocated to?
- ☐ Is the trial 'single arm' (where every patient gets the same treatment)? Or is it randomised (where patients get different treatments that are compared)?
- ☐ What are you trying to achieve with the trial? What impact will it have?

Treatment and Follow-up

- ☐ How long will I have the treatment for? How long will the trial last?
- ☐ For how long, and how often will I have follow-up appointments for after I finish treatment?
- ☐ What treatment will I get if I decide not to enter the trial? Will participating or not participating negatively affect me or my treatment?

Your Involvement

- ☐ What will I have to do day-to-day if I take part?
- ☐ Will I have to do extra tests or scans? Will I have to spend more time in hospital?
- ☐ Will I have to make any specific changes to my diet, movement, lifestyle etc.?
- ☐ Is there anything I am not allowed to do while I am in the trial? Is there anything additional that I will have to do while I am in the trial?

Safety and Confidentiality

- ☐ What are the likely side effects? What will happen if I get side effects?
- ☐ Who will be allowed to see my medical records? What information about me will be stored on the system?
- ☐ Who makes sure the trial is safe and properly run?

Logistics

- ☐ Where will the tests and treatment take place?
- ☐ Will there be any additional costs for me to take part in the trial?
- ☐ At what point in the process will I be asked to take part or when will my participation in the trial be confirmed?

Support and Communication

- ☐ Who can I contact in an emergency?
- ☐ Will my GP be involved in the trial process?
- ☐ How will I find out about the results if I take part?

Flexibility and Withdrawal

- ☐ Can I leave the trial if I want to?
- ☐ At what point(s) can I leave the trial?

FAQs

Participating in a clinical trial can provide access to new treatments and contribute to inclusive research. But, it also has some risks. This section answers common questions about joining clinical trials. It covers side effects, risk management, your rights, and potential costs. Understanding these aspects can help you make an informed decision about joining a trial.

What are some identified 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 evaluated

How are the risks managed during the trial?

All clinical trials must have things in place in case something goes wrong. This includes reporting events to relevant bodies. This makes sure that those things don't happen again. Risks are carefully managed through:

- Close monitoring by your healthcare team to quickly address any side effects or health changes
- Always asking for your consent before anything happens

Will participating in a trial affect my overall treatment options?

Participation in a clinical trial should not impact your overall treatment options. Before joining, discuss with your healthcare team how the trial fits into your broader treatment plan. Whether you decide to participate or not in a trial, you will get the best treatment available to you.

Patients do not have to participate in a study. If you decide not to participate, you will still receive the best treatment available to you on the NHS.

How will my treatment be monitored?

Trials are carefully planned and monitored throughout to ensure your safety. A data monitoring committee oversees safety, trial design, and progress. An ethics committee reviews the trial's progress and any unexpected side effects.

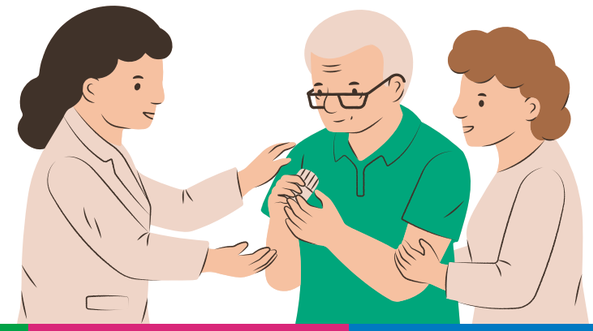
In a cancer treatment trial, the research team works with your regular care team and keeps your GP informed. You will have regular health checks like tests like blood tests and CT scans to manage your health.

Will I incur any additional financial costs?

Many trials cover expenses like travel and sometimes accommodation, so it is essential to confirm what is included. If you have financial issues or need to take time off work, your Clinical Nurse Specialist can advise on benefits and support options.

What decisions can I make in my treatment journey? Can I leave the trial if I experience negative effects?

You have full control over your treatment journey in the trial. You can decide to continue or leave the trial at any time, especially if you have concerns or experience negative effects. Your participation is voluntary. Your health and well-being are a priority throughout the process.



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.

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.”

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