

# Advanced breast cancer patients denied opportunities to join clinical trials

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Lesley Stephen. Credit: Lesley Stephen

Clinicians and the wider research community involved in treating advanced breast cancer (ABC) need to do more to help and encourage patients to join clinical trials, according to a patient advocate who is

leading a study that shows only 14 percent of ABC patients in the UK have been recruited to a trial.

Reporting on the study that involved collaboration between patients, clinicians and researchers, Lesley Stephen told the virtual meeting of the Advanced Breast Cancer Sixth International Consensus Conference (ABC 6): "Clinicians and the wider research community, including the pharmaceutical industry, need to work better together to enable patients with metastatic breast cancer to be included in [clinical trials](#)."

It is well known that patients tend to do better if they are included in clinical trials, regardless of what treatment they receive. Yet despite this, Ms. Stephen discovered that many patients with advanced, [metastatic breast cancer](#) (cancer that has spread beyond the site of the primary tumor) had never discussed clinical trials with their doctors. So she decided to carry out the current study.

"I have been on a clinical trial for almost six years, and it has given me six years of life I never expected to have. Since my diagnosis and after talking with other advanced breast cancer patients, I realized that most had never had a conversation with their clinician about a clinical trial. I wanted to understand why this was."

She teamed up with Professor Carlo Palmieri, a consultant in medical oncology at The Clatterbridge Cancer Center, and University of Liverpool, UK, Professor Janet Dunn, head of the Warwick Clinical Trials unit at the University of Warwick, UK, and Dr. Ellen Copson, associate professor of [medical oncology](#) at the University of Southampton, UK, to conduct a UK-wide survey.

The online study was launched in May 2021. By 23 August 627 responses had been received (626 women, 1 man). The survey remains open, but Stephen and her colleagues do not expect the key messages to

change. Analysis continues and further data will be available in early 2022.

Analysis of the responses so far show that 77 percent of patients had never been asked about joining a clinical trial (466 of 627), and 69 percent (433) had not asked their clinician about trials. Only 14 percent (90) had been recruited to a trial; of these 80 percent (72) found it a positive experience. The 31 percent of patients (189) who inquired about trials received a variety of responses, which ranged from positive and supportive to "vague and dismissive."

Patients gave the following comments to the survey:

- "Still waiting for a response. Talking to my oncologist is like shouting into a cave. All I get back is my own voice"
- "I was told that I'd be informed if there was an appropriate trial"
- "oncologist very unsupportive. She said most trials fail and should only ever be a last resort"
- "I wasn't aware I could travel to another hospital to access a trial, I thought I would need to participate locally."

When asked about traveling for studies, 56 percent (350) were willing to travel, 37 percent (211) for up to two hours to another UK center and 43 percent (248) were willing to travel worldwide. When asked about funding travel, the amount patients could afford varied from nothing to over £100, with 25 percent (138) willing to pay over £100 per month to travel. If travel costs were covered, the proportion willing to travel to participate in a trial increased to 61 percent (381).

When asked about the benefits of participation in clinical trials, 93 percent (586) felt it would give early access to potential new treatments and 90 percent (565) felt it would be beneficial to future patients. However, 63 percent (392) were concerned about the possible side

effects of treatment on a trial and 43 percent (268) were unsure of its potential benefits. Thirty-one percent (192) of patients worried that they wouldn't know what the trial was about, and 8 percent (48) had other worries, such as that they would be given a placebo or that a trial was a last resort.

The majority of patients (78 percent) preferred getting information about clinical trials from trusted healthcare professionals, and 90 percent (535) would search a database if it was patient friendly. Of those that searched for information about trials (13), 57 percent (78) could not find the information they were looking for.

"Our survey has several key findings: Patients with advanced breast cancer lack opportunities to participate in clinical trials; clinicians are important in providing information about clinical trials; patient-friendly databases are needed urgently; and many patients are willing to travel to take part in a trial and financial support would help them to do this," said Stephen. "Clinicians act as gatekeepers, and this study shows that they often don't mention or discuss trials, and if they do, they tend to look only for local trials and don't ask their patients if they are willing and able to travel. They hold a lot of the power in the relationship and we need to encourage them to discuss trials as a treatment option with their patients. However, clinicians can't do this alone; we need the pharmaceutical industry, which funds clinical trials, to work with us, as well. We also need to educate patients about trials and empower them to be proactive and ask their oncologist about them. In addition, patients often think that a trial is a 'last resort' or that they will be given a placebo. This demonstrates the need for more education of patients about the importance of trials as a potential 'extra' treatment option."

Chair of the ABC 6 conference, Dr. Fatima Cardoso, director of the Breast Unit of the Champalimaud Clinical Center in Lisbon, Portugal, who was not involved with the research, said: "This study raises some

important questions about access to clinical trials for patients with advanced breast cancer. Clinical trials are the only way to advance knowledge on how to treat [cancer](#) and to prove the value of new therapies. All of us—clinicians, researchers, the [pharmaceutical industry](#), academic groups and funders—need to work together to reverse this situation. This is not just a problem in the UK; it is difficult in most countries for patients with [advanced breast cancer](#) to join clinical [trials](#) and, in some countries, it is impossible. This needs to change urgently in order to find new therapies and provide better care for these [patients](#)."

Provided by Associação Advanced Breast Cancer Global Alliance

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