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Advanced breast cancer patients denied opportunities to join clinical trials Patient advocate calls for collaboration to improve access to trials

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% 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) [1]: “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.” [2]

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 tumour) 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 realised 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 Centre, 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 Ms Stephen and her colleagues do not expect the key messages to change. [3] Analysis continues and further data will be available in early 2022.

Analysis of the responses so far show that 77% of patients had never been asked about joining a clinical trial (466 of 627), and 69% (433) had not asked their clinician about trials. Only 14% (90) had been recruited to a trial; of these 80% (72) found it a positive experience. The 31% 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 travelling for studies, 56% (350) were willing to travel, 37% (211) for up to two hours to another UK centre and 43% (248) were willing to travel worldwide. When asked about funding travel, the amount patients could afford varied from nothing to over £100, with 25% (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% (381).

When asked about the benefits of participation in clinical trials, 93% (586) felt it would give early access to potential new treatments and 90% (565) felt it would be beneficial to future patients. However, 63% (392) were concerned about the possible side effects of treatment on a trial and 43% (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% (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%) preferred getting information about clinical trials from trusted healthcare professionals, and 90% (535) would search a database if it was patient friendly. Of those that searched for information about trials (13), 57% (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 Ms Stephen.

She continued: “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 Centre 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.”

(ends)

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<https://cattendee.abstractsonline.com/meeting/10525/presentation/364>.

The research was funded by Make 2nds Count and the UK National Institute for Health Research (NIHR). The project was co-designed and co-led with clinicians and researchers at The Clatterbridge Cancer Centre and the Universities of Liverpool, Warwick and Southampton.

[1] Around 1,000 participants from countries all over the world are attending the Advanced Breast Cancer Sixth International Consensus Conference (ABC 6). The meeting has moved online from its normal venue in Lisbon, Portugal, due to the COVID-19 pandemic.

[2] Lesley Stephen was diagnosed with advanced breast cancer in 2014. She joined a clinical trial at the Beatson West of Scotland Cancer Centre, Glasgow, in 2015 and remains on the same treatment.

[3] https://warwick.co1.qualtrics.com/jfe/form/SV_4SBdAaEL1nEjRFX

Advanced breast cancer is defined as cancer that has spread beyond the site of the first (primary) tumour to other sites either within the same breast such as the skin, chest wall and some lymph nodes (locally advanced) or other parts of the body (metastatic cancer). There are no reliable figures for the numbers of women (and men) living with advanced breast cancer. However, there are over two million new cases of breast cancer a year in the world and 0.6 million deaths. In developed countries, about 5-10% of cases are either locally advanced or have spread to other parts of the body (metastasised) at diagnosis, and these figures reach almost 80% in developing countries. About a third of all early breast cancer cases will become metastatic even with the best care, and the average overall survival for these patients is around three years.