

## T.J. Sharpe on why clinical trials matter <sup>[1]</sup>

Patient Perspectives <sup>[2]</sup>

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T.J. Sharpe, melanoma survivor, Blogger & Cancer Advocate

For this installment of my blog series, I wanted to address a topic that many shy away from or don't know much about, but that has been extremely important in my healthcare journey. From personal encounters asking others about cancer treatments, their responses likely draw on the experience of a friend or relative who is undergoing chemotherapy, or on something they've heard in the news. A few may know a bit about new or novel treatments. However, when it comes to the topic of clinical trials, my questions are often met with a blank look or negative reaction.

Clinical trials are a crucial part of the drug development process and play an essential role in bringing the newest and most innovative treatments to patients. Before any drug, treatment or medical device is approved by a regulatory agency (e.g., the US Food and Drug Administration, the European Medicines Agency, etc.), it must undergo clinical trial testing to determine its efficacy and safety. Needless to say, drug development is a long and complex process that prioritizes patient safety.<sup>1</sup> Anyone can rattle off a medication they have taken, but few people truly understand how medications are approved and, more importantly, when they can be made available for their specific healthcare treatment.

Participating in a clinical trial can be an option for some cancer patients, and I therefore recommend discussing this with your doctor if you are ever diagnosed. Thousands of clinical trials are recruiting patients, and it's possible that one or more treatments for your specific cancer are being studied. Trial participants could gain access to advanced treatments that are

not yet on the market, and for those who may have exhausted standard treatment options, a trial could be a game changer and even a lifesaver.

Unfortunately, awareness of clinical trials is low among cancer patients. A survey revealed that 85% were unaware that participation in clinical trials was even an option, and 75% reported that they would have at least considered it if offered.<sup>2</sup> Perhaps not surprisingly, data suggest that just 3% of adult cancer patients actually do participate in clinical trials.<sup>3</sup>

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Patients, like me, certainly want to make the most informed decision they can about their course of action but often rely on their treatment team to help guide their decision making. There are many reasons why a clinical trial may not be presented as an option: the location of a particular trial site, whether or not the trial is active, the maximum number of participants, and patient eligibility criteria. But beyond these factors, doctors are not always aware of all current available trials. I would encourage every patient to do their due diligence by visiting a trial registry like [ClinicalTrials.gov](https://clinicaltrials.gov) <sup>[3]</sup> to find trials that are actively recruiting, and proactively discuss these findings with your doctor.

The Center for Information & Study on Clinical Research Participation, based in the US, reports that healthcare providers are often the first ones to educate patients about clinical trials. In a 2017 survey of patients from around the world, nearly 40% said they first learned about a clinical trial from their primary care physician or specialist, or from a research center doctor or staff.<sup>4</sup> With nearly 1 million doctors and 3 million registered nurses in the US alone, there is an ample workforce that can speak to patients about clinical trials.<sup>5,6</sup> But this conversation needs to happen more frequently and more consistently.

As a patient, a caregiver, or just someone who might know a person embarking on a cancer journey, spreading awareness of clinical trials is one way we can all help those facing a cancer diagnosis. You can make a positive difference by encouraging patients and caregivers to ask the simple question, “What clinical trial options exist for this condition?” Increased awareness could, at the end of the day, improve the lives of many cancer patients around the world.

Be sure to follow along on [Twitter](#) <sup>[4]</sup>, [Facebook](#) <sup>[5]</sup> and [LinkedIn](#) <sup>[6]</sup> as we continue the clinical trials discussion.

**Disclaimer:**

*Disclaimer: When participating in clinical trials, there's a possibility that patients may receive placebo or that the investigative treatment may not be effective. Patients should always consult their doctors when considering treatment options to ensure they have all information necessary in order to make an informed decision.*

*This is the fourth installment in a series of blog posts authored by patient and advocate T.J. Sharpe for [Novartis.com](https://www.novartis.com). Be sure to check back regularly for new installments in this series by T.J. Sharpe. Learn more about T.J.'s story [here](#) <sup>[7]</sup>.*

T.J. Sharpe is not a medical professional, but a patient currently undergoing care for

advanced melanoma. He is being compensated by Novartis for sharing his story. All opinions are his own. Any and all information, tips, advice, etc. included throughout his series of blogs stem from his own personal experience as a patient. Patients should always consult their doctors when seeking medical advice.

#### References:

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