

Using online patient communities and new trial approaches to optimize clinical research

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As oncologists already know and newly diagnosed lung cancer patients learn, the kind of treatment given to patients is increasingly becoming dependent on the specific gene mutation present in the cancer. But, as lung cancer moves from being one common disease to multiple different diseases at the molecular level, learning about and getting access to the right treatment within clinical trials can be challenging for these subpopulations of patients that may be widely dispersed around the globe.

Dr. Howard (Jack) West, medical director of the Thoracic Oncology Program at the Swedish Cancer Institute in Seattle, and Dr. Ross Camidge, director of the Thoracic Oncology Clinical Program at the University of Colorado School of Medicine are looking for ways to help patients tackle these geographic barriers using both online patient communities and innovative trial approaches.

Their article "Have Mutation, Will Travel" is published in the March issue of the [Journal of Thoracic Oncology](#) (JTO), the journal of the International Association for the Study of Lung Cancer's (IASLC). It explains that the first step is to get the appropriate message out to patients wherever they are located. West leads a free social media community for patients called the Global Resource for Advancing Cancer Education (GRACE). At GRACE, www.cancergrace.org, West hosts interactive question and answer forums and produces short written summaries and audio/video podcasts relating to multiple different cancers. During one such podcast in February 2010, Camidge explained

the promising early results of a clinical trial involving the drug crizotinib that was being given to patients proven to have a specific molecular change in their cancers called an ALK gene rearrangement. The podcast was subsequently viewed more than 1,300 times, and patients travelled to the University of Colorado (CU) for participation in the trial from 15 different U.S. states and one from South Africa.

"CU has traditionally done very little advertising, nationally or internationally, to attract patients," Camidge says. "When we're talking about relatively rare subtypes of cancer, this approach allowed us to expand our potential patient pool dramatically."

"Online patient communities can now be leveraged to partner with clinical researchers to ensure that patients are appropriately informed. Working more directly with highly motivated patients and caregivers can accelerate the rate of clinical research, especially as the patient populations become smaller and harder to find in a single geographic area," West says.

In addition to the importance of informing patients about a trial, the move towards personalized medicine in thoracic oncology has introduced new practical challenges in conducting these trials. Potentially eligible patients are now far more geographically dispersed than in trials conducted in patients without molecular preselection. As a result, clinicians are looking for new ways to structure clinical research. West and Camidge suggest that a lot more could be done to make trials participation much easier for patients who live a long way from their nearest trial center. Their proposals range from reimbursing patients for aspects of travel and accommodation, through to having the sponsor cover the costs of the trials teams for consenting [patients](#) remotely and for using local resources for trial procedures whenever possible. In addition, which trials sites are chosen may also have to be reconsidered in the future.

"Realistically, it may be most economically feasible to pursue a model that involves opening molecularly specific trials at a few geographically dispersed centers, like an airline places its hubs at key points over any major landmass, rather than clustering them all in one or two areas," Camidge says.

"We've entered a new era with molecular oncology, which has created its own new challenges for our increasingly outdated approach to clinical trials," West says. "We need this kind of forward thinking approach to optimally address it in the future."

Provided by International Association for the Study of Lung Cancer

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