

Bringing Patient Voices to Medical Meetings



Scientific meetings have always helped drive medical advancements. The 2019 American Society of Clinical Oncology (ASCO) meeting was no exception, bringing together over 40,000 healthcare professionals to discuss premier research in oncology. And the meeting's theme—Caring for Every Patient, Learning from Every Patient—was a reminder that patient voices are essential to every part of medical research and care.



Medical meetings are well-known opportunities for healthcare professionals to network, share groundbreaking research and learn about the latest industry innovations. But where are the people these innovations are intended for? Patients are often still absent from discussions around the critical trial research that is impossible without them.

Listening to patient voices by making patients true participants in the conversation can greatly increase the flow of information and help uncover valuable insights. In fact, incorporating patient voices as the base of the medical research pyramid has helped provide stronger treatments and better care for some of the world's largest patient groups.

With patients in mind, we turned to some of the world's leading health communications experts—read on for perspectives from GLOBALHealthPR partners on elevating patient voices at the largest scientific and medical meetings.

PARTNER SPOTLIGHT:

UNITED KINGDOM



NEIL CRUMP

Chief Innovation Officer and Owner, Aurora Healthcare Communications

How have you seen patient voices integrated into a medical meeting? When has it been most impactful?

NEIL: I've supported more than 200 major medical meetings in my career. The first time I attended a medical meeting that prominently encouraged patient voices was about 20 years ago—the 12th World AIDS Conference in Geneva, Switzerland in June 1998. This conference was attended by a patient community in crisis and the medical world was unfamiliar with their level of engagement.

Patient advocacy is inseparable from the story of HIV/AIDS drug development. People were dying, gay men in particular, and 1998 was the early period of treatment and diagnostics. It was challenging times to say the least. At the World AIDS Conference, the patient community was advocating strongly, in some cases taking direct action. One company had activists come to their stand and throw red paint—signifying blood—over the whole thing. There was a strong community presence, but this wasn't limited to a patient only track at a meeting, which you can sometimes experience these days. Patients were present as delegates, taking part in the full programme, scientific sessions, company symposia—they were asking challenging questions and ensuring that they were heard.

I was there running a series of events for Roche Diagnostics, including a patient event called ‘Everything You Wanted to Know About Your Viral Load, But Have Never Asked’. At the time, the scientific breakthrough in HIV/AIDS diagnostics was using polymerase chain reaction (PCR) to measure viral load below ‘levels of detection’—in other words, 50 copies of the virus per mL of blood. This viral load is now called ‘undetectable’ and today we know HIV cannot be transmitted at this level.

My experience at the World AIDS Conference opened my eyes to the necessary role of patient voices to ensure the industry is making the best possible decisions for them. And together, patients, science, healthcare providers and the pharmaceutical industry really did change this disease. It was hard fought, and often antagonistic, but something that people should be proud of.

Are there ways to include, or better utilize, patient voices at medical meetings?

NEIL: I think that for a short period the medical community and conference secretariat forgot the benefits that incorporating patients can bring. But it's important to always have patients at these meetings. I have seen the power of this over and over again.

Patients keep everyone at a medical conference grounded in reality—that's vitally important if we are going to turn scientific breakthrough into medicines that actually work for patients. That means shifting mindsets to look beyond just efficacy and safety into tolerability, convenience and practicality as well. Will this shiny new innovation fit into people's lives in a way that will work, in a way they can actually access?

Including patients in the storytelling and research process is a vital component to enhancing lives and advancing medicine. Patient involvement and engagement is a powerful and beneficial activity. I'd encourage every decision maker at a medical team to harness the benefits.

ADDITIONAL PARTNER PERSPECTIVES:

UNITED STATES



Having strong, compelling scientific and clinical data that could potentially change the treatment landscape of a disease is great—but nothing can compete with the emotional patient story that reveals the true impact that a treatment can potentially have on changing lives.

MICHELLE GROSS
President, Spectrum

ARGENTINA



Engaging patient voices in medical meetings is key to promoting an integrated model in healthcare, with the final aim being a more sustainable health system—one where patients are involved in their own treatment so that results can be improved.

EUGENIA DE LA FUENTE
Director & Partner, Paradigma

For additional insights or communications support around medical meetings, please contact GHPRHQ@GLOBALHealthPR.com