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The Importance of Including Patients in Medical Meetings

The white paper explores advantages of involving patients as attendees and collaborators at medical conferences.

by Francesca Manzani

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Patient involvement in medical care and research has gained momentum in recent years -- partly because the community has been requesting a more active role, but also because patient participation has proven to positively affect treatment outcomes. The following information on patient involvement in the planning and execution of medical meetings is excerpted from the [AIM Group International](#) white paper [Why and How to Involve Patients in Scientific Congress](#) by Francesca Manzani.

Many medical meetings and trainings traditionally have focused solely on the Health-Care Professional (HCP) perspective, with little attention placed on the patient point of view or input. At medical events, virtual patients, simulated patients, mannequins and, in some cases, real patients, have only been involved in (passively) facilitating HCP learning. But the dynamic

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is changing. It has become more accepted that providing these patients with a more active role in the meeting can change mindsets and open the door for enriched learning opportunities.

The role a patient might play in conference planning can vary greatly depending on the meeting's purpose, the association conducting the meeting and on the medical specialty at the core of the conference. When considering including patients outside of the health-care professional realm in the planning process and agenda-setting, it is necessary to assess the various stakeholders needs and desired objectives to better make a collaborative decision.

Note that including patients must be done so thoughtfully and in compliance with regulations and ethical standards, all specific to the industry, medical field, country, region and relevant regulatory authorities and associations. Be especially careful with respect to sponsored content and advertising to patients in any way, as this is typically not permitted. National conferences must comply with domestic regulations, and international gatherings must follow both the rules of the host country and international regulations.

The Patient Role in a Medical Congress



Patients and attendees can play various role in the creation and carrying-out of a medical meeting. *Photo Credit: AIM Group International*

Once a decision has been made to strategically involve patients in a medical conference, it is up to the planner to decide how to get them involved. Following, we look at a few potential roles and advantages of doing so.

- **Event design:** Patients can contribute a new perspective when developing scientific content within event programs. They can help identify core conference themes, purposeful speakers and can advise on the types of activities or workshops they feel are most relevant to their needs.

- **Additional perspective:** Patients can be engaged as active audience participants and/or as patient-experts for interactive panels, workshops or even educational programs for health-care team members. Patients might also contribute as speakers, adding a new voice to an otherwise industry- and HCP-driven discussion.

- **Logistics:** It's important to take care of the physical and medical needs of patients at the event venue. Patients can be invited to provide advice on the various aspects of the meeting, accommodation options, venues, locations and also cost implications to ensure that they reflect the needs of attendees. They might also be consulted on additional facilities that might be necessary, such as an infirmary, rest space, elevators for wheelchairs, an emergency room and so forth.

The Win-Win Effect of Patient Participation



Win-win benefits from patients involvement



Planners and professionals can benefit greatly from involving patients in a medical conference. *Photo Credit: AIM Group International*

[Various studies](#) have demonstrated the positive effect on patient involvement, showing that the benefits strongly surpass any risks and associated costs for accommodating such a group of attendees. The win-win collaboration between health-care professionals and patients at a medical congresses can provide major benefits, including the following.

Personal Experience Perspective

Patients can contribute their personal experience with respect to dealing, working and collaborating with professionals in the field. They might express the issues that matter to them and ask essential questions that lead to engaging conversations.

This type of feedback and insight is crucial to understanding how effective medical treatments and solutions are and how they can be improved. Integrating patients into conferences can contribute to a change in the culture and lead to a more patient-centric approach in research and development.

Knowledge-Sharing

By attending professional medical conferences, patients can be updated on the most recent research in clinical treatments, which could have a direct benefit on their health. Being involved in the discussion can also contribute to their psychological well-being, helping them to feel less alone, more respected and listened to. The new perspective might lead to conversations and industry-wide advancements that would otherwise be overlooked.

Collaborative Relationships

Participating in conferences can help patients establish better collaborative relationships with physicians and health-care professionals, and better understand their perspectives, difficulties and challenges. Patient involvement can help health-care professionals in understanding how to communicate effectively with patients and how to motivate them to take responsibility for their own care. Bringing together all stakeholders will develop mutual trust, leading to long-term benefits for all involved.

Media Attention

Patients and their families are social hubs. Simply through word-of-mouth, they contribute to a rise in awareness and a captivation of media attention due to the human-nature aspect of their stories and experiences. These cases are more impactful and attractive than the press releases disseminated during scientific conferences. The increased visibility will benefit the overall organization and will ultimately have a positive impact on the scientific association.

Patients active on social media are also able to function as hubs of information that can disseminate important findings to the broader community, beyond medical professionals. In fact, several studies show a significantly higher number of social media posts when patients are in attendance, which contributes to higher quality and quantity of discussion on social media.

Note, too, that patient associations are growing. Tapping such associations for representatives is key, not only in attracting media attention but in maximizing word of mouth and significantly expanding the reach of the event.

Access the entirety of this white paper and other resources on the [AIM Group International website](#).



[Francesca Manzani](#), business manager and head of the Florence office, congress division, for [AIM Group International](#), has been working in the meetings industry since 1995. She founded the Italian chapter of the [International Congress and Convention Association](#) in 2006 and served as an ICCA board member from 2010 to 2016. In 2009, Manzani hosted the ICCA Congress in Florence, Italy, as co-chair of the local host committee. She is also an active speaker at international events and workshops.

[Francesca Manzani](#), business manager, head of Florence office, congress division, AIM Group International

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