

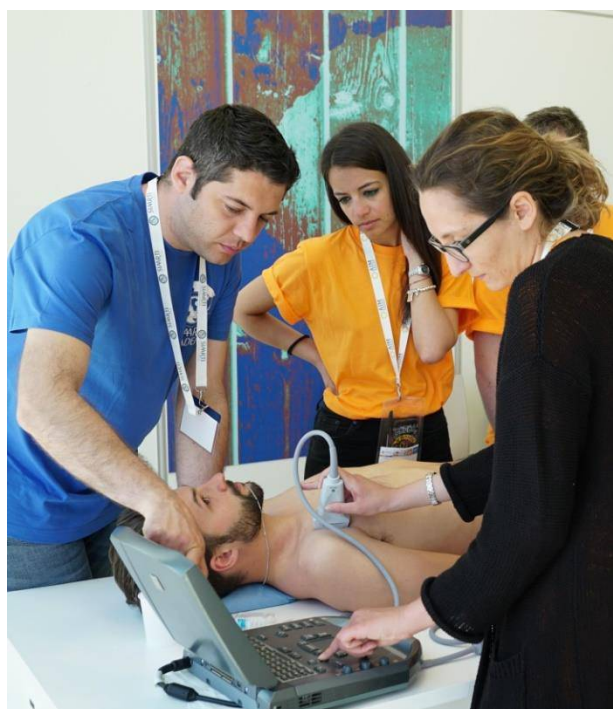
# Why and how to involve patients in scientific congresses



Author:  
**Francesca Manzani** - Head of Florence Office  
AIM Group International

**A broader view of treatments and therapies; identification of unmet needs; rich content; increased media exposure and public awareness are some of the reasons why you should include patients in medical congresses. This White Paper provides some perspectives on why you should consider the integration of patients in your next congress and how to do it with success.**

by **Francesca Manzani**, head of Florence Office AIM Group International



Patient involvement in clinical care and research has gained momentum in recent years, firstly because the **patient community itself is asking for a more active role**. But also, because patient participation in healthcare systems has been proven to improve treatment outcomes.

Also scientific associations are increasingly recognising that **patients can contribute to the success** of congresses and health care meetings. But involving patients in scientific congresses is a sensitive matter which must be carefully managed: decision-making needs to involve all stakeholders and **ethics and compliance rules** need to be **scrupulously followed**.

### **Strict compliance**

*Including patients at congress needs a careful assessment and compliance with **regulations and ethical standards**, specific to the industry, medical field, country, region as well as to the rules of the regulatory authorities and associations. Usually at scientific congresses **you are not allowed to offer sponsored content, dedicated exhibitions or advertisements to patients**. Rules vary per region: if you organise a national congress you must comply with the national legislation; if you organise an international congress you must follow the rules of the host country and also follow applicable **international rules**.*

## How to actively involve patients

For a long time, traditional **medical congresses and training have focused on the Health Care Professionals (HCP)** perspective with less attention to the patient's point of view or with their experience with the healthcare services and treatments. At medical events, virtual patients, simulated patients (by "actors"), patient models (as mannequins) and, in some cases, **real patients have been involved** passively to facilitate HCP learning. In recent years, it has been widely accepted that **providing patients with a more "active" role** can change mind-sets and open new and enriched learning opportunities.



### **Patients Associations are gaining momentum**

*In the last decade, we have experienced a massive growth in **patients associations**. These groups are actively escalating their voice in the healthcare debate, increasing awareness and offering opportunities for mutual support and knowledge sharing.*

*The **International Alliance of Patients Organisations (IAPO)** has organised several congresses where patients from all countries across all disease areas, discuss healthcare issues, how to get patients' voices heard and the relationships with the other healthcare stakeholders.*

The **role the patient can play at congresses can vary** depending on the congress purpose, on the association conducting the meeting and on the medical specialty. When considering including patients in congresses, it is necessary **to assess the various needs and opportunities**, in order to make a shared decision, which satisfies all the stakeholders. For instance, **chronic or epidemic diseases** are more suitable for this purpose because it is more likely that patients have developed a community with an identity, an history, a recognised association, visibility and where institutional relationships with authorities are already in place.

An active **patient association** is crucial to establish a good relationship with patients and to involve them as a key stakeholder. Patient associations usually develop **vast and specialised knowledge** in the illness, treatments and health services provided as well as a deep understanding of the relevant national/regional legislation. Patient associations usually establish **strong relationships** with the media, public authorities and other stakeholders and can often be considered as go-to place to reach relevant patient populations. So if you want to involve patients, involving the patient association is considered best practice.

Once a decision has been made to strategically involve patients in the congress, they can be entrusted to play different roles, such as:

➔ **Logistics counsellor.**

It is important to take care of the physical and medical needs of patients at the congress venue. Patients can be invited to provide advice on the various aspects of the meeting, accommodation options, venue, location and also cost implications to ensure that they reflect the needs of individual patients. They can also be consulted on the kind of additional **facilities that could be needed**: an infirmary, a rest space, elevators for wheelchairs, an emergency room, etc.



➔ **An additional point of view.**

Patients can be engaged as **active audience participants** and/or as patient experts for **interactive panels**, workshops or even education programs for health care team members (focusing on soft skills development). Also, patients can intervene as **speakers**, adding a new voice to the discussion.

➔ **Event co-designers.**

Patients can contribute to **developing the scientific programme**: they can help identify core conference themes, propose speakers and advise on the kind of activities or workshops which they feel are more relevant to their needs.





***Inclusion Innovative Policies***


**Stanford University, one of the most advanced research centers** in medicine has created a highly patient-centred approach. They have developed a **specific protocol, called Everyone Included**<sup>™</sup>, which involves a series of design and leadership principles intended to drive collaborative health care change and principles of mutual respect and inclusivity. Among the principles they recommend co-design (promotion of co-design with patients and health care stakeholders), the importance of giving value to each person's knowledge, experience and skills, and to provide a stage from which the hardest, most important **stories may be told and shared**.


## The positive, win-win effect


Various research studies and several international initiatives have demonstrated the **positive effect of patient involvement** which strongly surpasses any eventual risks and associated costs. **The win-win collaboration** between healthcare professionals and patients at congresses can provide major benefits, including:

 Patients can **contribute their personal experiences**, express issues that matter most to them and ask essential questions that lead to engaging conversations. Patient feedback and insights are crucial to understand how effective medical treatments and solutions are and how they can be improved. Integrating patients in conferences can contribute to a change in the culture and lead to a more **patient-centric approach**.

 By attending congresses, patients can be **updated on the most recent research** in clinical treatments which have a **direct benefit on their health**. Being involved in the discussion can also contribute to their psychological wellbeing, helping them feel less alone, more respected and listened to.

 Participating in the congress helps patients establish better **collaborative relationships** with physicians and healthcare professionals (HCPs), and to understand their perspectives, difficulties and challenges. Patient involvement can facilitate healthcare professionals to understand **how to communicate effectively with patients** and how to motivate them to take responsibility for their own care (medicine adherence). All stakeholders involved **will be more cohesive, will have mutual trust** and this will have long-term benefits.

 **Patients and their families are social hubs**, simply through word of mouth they contribute to raise awareness of illnesses and **catch the attention of the media**, due to the human nature of their stories. These cases are more impactful and attractive than the press releases disseminated during scientific conferences. The increased visibility will benefit the overall organisation of the congress and will ultimately have a positive impact for the scientific association.

 As **social media ambassadors**, patients active on social media are able to function as influential hubs to disseminate information to a broad community, beyond the conference attendees. According to some studies, conferences with patients have statistically a significant more number of social media posts, which contribute to **raise the quality and quantity of discussions** on social media.

### **Out of the congress**

The organiser can also consider **realising side bar events**, conferences, forums for patients and for the general public, which are run **out of the congress center, in more convenient city venues**. They provide an opportunity to meet a larger number of patients, offer updates on treatments and research as well as promote open discussions.

## How we did it:

### A Case Study from the World Systemic Sclerosis Congress

At AIM Group, we have developed **strong and long-lasting collaborations with the scientific and medical community and have been strong advocates for the involvement of patients** in events. This broad stakeholder approach and collaboration has resulted in the creation of new events like the **World Systemic Sclerosis Congress**.

Scleroderma is a rare and serious disease and for a long time has only been on the agenda of the Rheumatology Congresses. Since there was no unique treatment to solve all the complex symptoms of the disease, there was a **special need to share experiences** and knowledge among physicians, nurses and also patients. **Patient feedback can be crucial** to understand how effective the treatments are.



#### **Fundraising activities**

When organising an event which involves patients, it is good practice to **create fundraising activities** that can **leave a legacy** for local patients associations, research centers, hospital foundations, etc. This kind of initiative – such as silent auctions, fundraising lotteries or charity dinners – leaves a positive impact on the **patient community** through common and shared initiatives which can ultimately reinforce the collaboration and contribute to the overall goals of the organisation / meeting.

In 2010, a small group of specialised professors decided to dedicate an entire congress to the medical research and practices related to this complex disease and to **the improvement of the lives of those affected**. It has been challenging because **rare diseases attract less attention and funds** and it has meant **building the entire congress from scratch**. In response, the specialised doctors, together with the [World Scleroderma Foundation](#) and with **AIM Group International** as preferred partner, created a collaborative working group involving the European League Against Rheumatism ([EULAR](#)), the European Rheumatology Association, the European research centres ([EUSTAR](#)), and the [Federation of European Scleroderma patients associations](#) (FESCA).

One of the main features of the 3-days congress is that it **gathers not only physicians, health care professionals and researchers but also patients** affected by this impactful disease. The connection between physicians and patients makes this congress really original and particularly rich in building human empathy. The presence of patients over the years has contributed to maintaining a greater attention to their needs and **helping make improvements to their daily lives**.

Furthermore, thanks to the bi-annual congress, year-on-year patient participation has increased, the **patient community has grown** and has established strong relationships and advocacy at international level. Finally, one of the core aims of the World Scleroderma Foundation to raise the public awareness of the illness, has been met through the strengthened patient voice which has helped **increase the flow and dissemination of information about the disease**.



Prof. Marco Matucci Cerinic, World Scleroderma Foundation and Congress's Chairman explained: "The **Congress contributed significantly to the fortunes of the World Scleroderma Foundation (WSF)** in different ways: image, awareness, organisation, fund raising, etc. The Congress and its positive outcome are the result of a shared effort by the scientific world and the Professional Conference Organiser (AIM Group). The WSF will be able to continue its mission thanks to these results and our hope is that our studies and research will produce a cure for scleroderma".




This **experience demonstrates that involving patients is a winning solution**, it means adding a voice and a point of view to the congresses, providing a way to highlight awareness amongst the public, whilst finding new and beneficial treatments and results for patients and the community.

**The role patients can play  
at the medical congresses**

 <b>Event co-designers</b>	 <b>Active audience and speakers</b>
 <b>Social media ambassadors</b>	 <b>Logistics counsellors</b>

**Win-win benefits from  
patients involvement**

 <b>Specific approach</b>	 <b>Crucial feedback</b>
 <b>Direct health benefits</b>	 <b>Improved relationships</b>
 <b>Media visibility</b>	 <b>More engagement on Social Media</b>





**Author: Francesca Manzani**  
Head of Florence Office  
AIM Group International

**Francesca Manzani** has been working at AIM Group International as **Business Manager, Head of Florence Office – Congress Division since 2011**. She has a background in Marketing and Communication and a degree as Parliamentary Interpreter and Translator (from English and German). She has been **working in the meetings industry since 1995**, first at a multinational biomedical company; then developing B2B and B2E platforms for EU projects; then as Marketing & Sales Manager for a Florentine PCO for 7 year. She has developed a huge experience with international congress management and with international relations. She has been **Board Member of ICCA** (International Congress & Convention Association) in 2010-2016, after she has founded the Italian chapter of this international association in 2006 and managed to host the ICCA Congress 2009 in Florence (Italy) as **Co-Chair of the Local Host Committee**. She is also an **active speaker at international events** and workshops.

## AIM GROUP INTERNATIONAL

**Barcelona, Berlin, Brussels, Budapest, Dubai, Florence, Hamburg, Lisbon, Madrid, Milan, Munich, New York, Paris, Philadelphia, Prague, Rome, Vienna.** At AIM Group International we have worked in the meeting and event management industry for almost 60 years committed to help clients reach their goals, to personalise their event experiences, to provide an innovative environment, and to make a difference. We organize over **three thousand events and meetings every year**. Despite our size, AIM Group still has a “tailor-made” approach to **client partnership**.

### Services & Solutions:

Professional Congress Organizer (PCO) - Association Management Services (AMC) - Communication Agency - DMC Services - Meeting and Event Management - Continuing Medical Education - Healthcare and Pharma Meetings.