

8th Global Patients Congress

The Report



Introduction

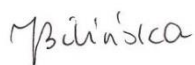
The 8th Global Patients Congress was a great success. This year was special in that it was the first time IAPO held a congress in North America, where we were able to ensure better access for North American and Latin American delegates. This provided an excellent platform on which to expand our reach and continue to strive to establish quality patient-centred universal health coverage by 2030. The congress theme was: Globally Empowered Patients, Building the Momentum.

The programme drew attention to the healthcare value chain – researchers, regulators, providers and patients – and how empowered patients have been engaging and collaborating with these. This year, we had a broad range of stakeholders represented sharing inspiring stories and the innovative projects taking place all over the world.

Attendees from a myriad of backgrounds mapped and discussed best practice examples, their own experiences, and challenges related to engaging the patient community in healthcare systems. Delegates gained a greater understanding of patient empowerment efforts within the healthcare value chain and the challenges faced by others (some similar and some different to their own). Above all, many went away with fresh ideas to apply in their field, a resolve to support each other through an increasingly strong network to address key issues in the future, and a strong feeling of being united in raising the patient voice to make a real difference in the health sphere and beyond.

This report outlines the events of the Congress: who attended, a brief summary of the programme, and key messages on building momentum for patient empowerment that were highlighted during the event.

I would like to take this opportunity to again thank delegates, board members, IAPO staff, hotel staff, and industry partners who supported us generously to achieve such an important event.

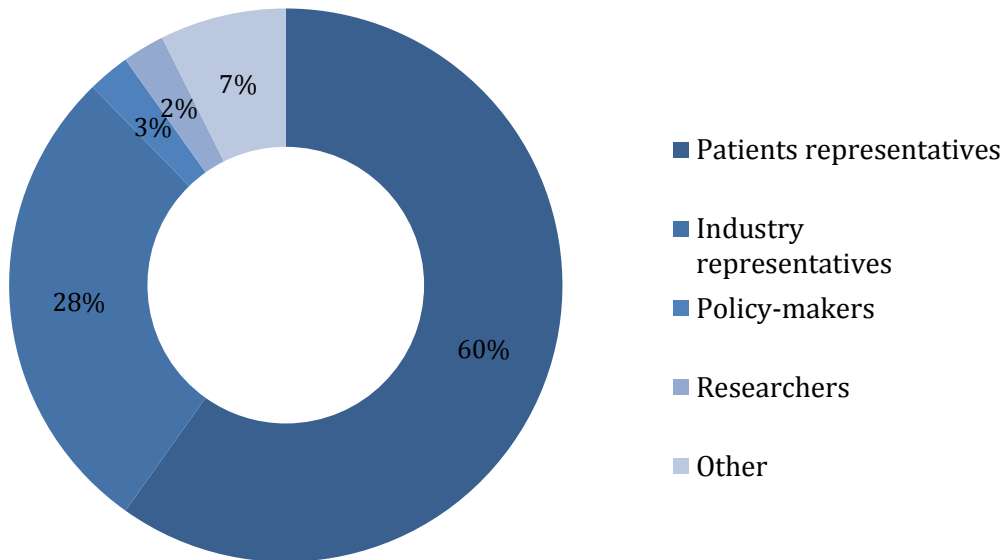


Jolanta Bilińska, IAPO Chair.

Who attended?

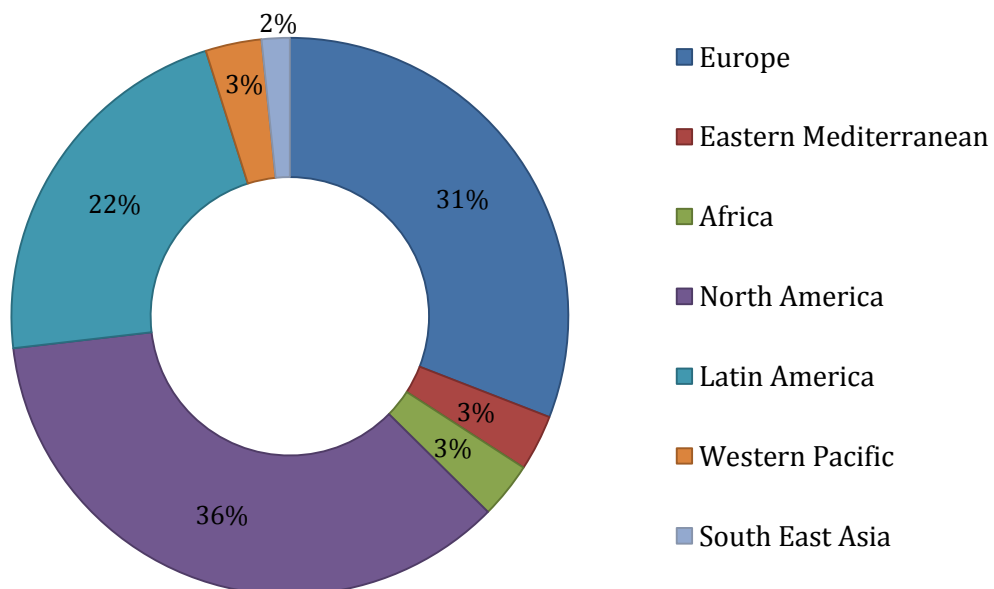
Delegates by field

122 delegates from different backgrounds and groups attended the Congress; the pie chart below shows the representation of delegates' areas of work.



Delegates by geographical region

Delegates from all over the world came to the Congress in Miami; the chart below indicates the proportion of people from different regions. For a full list of attendees, please see the Congress Handbook (<https://www.iapo.org.uk/sites/default/files/files/Handbook%20Final.pdf>).



The programme

In 2018, IAPO's Congress aimed to promote best practices and evidence of how empowered patients have been engaging and collaborating with health financiers, service providers, pharmaceutical industry, regulators and researchers from across the world to ensure sufficient availability of healthcare services and medicines provided through international guidelines and standards.

The Congress programme intended to walk the delegates through concepts of patient empowerment, patient engagement, and multi-stakeholder collaboration. It also allowed patient organizations to have a deeper understanding of the way the value-based healthcare chain incorporates the patient perspective, priorities, values, and needs. Through a variety of presentations, panels, side events, networking opportunities and posters exhibitions, participants were able to hear, learn and discuss the role of the patient in the healthcare system and the efforts being made to empower patients.

Day 1 was marked by two keynote speeches that helped set the scene and enabled delegates to gain an initial understanding of different avenues of patient empowerment.

The first session addressed how patients can be empowered through building Consortium and Partnerships. Dr Linda Porter, Director of the Office of Pain Policy, shared details about the US experience of the National Institutes of Health's (NIH) Pain Consortium, which was established to enhance pain research and promote collaboration among researchers across NIH Institutes and Centers that have developed initiatives addressing pain.

Penney Cowan – IAPO Chair Elect and Founder of the American Chronic Pain Association – was the discussant to the keynote address, highlighting the importance of evidence-based pain management policy, infrastructure and healthcare services in patient-centric healthcare systems.



The second keynote speaker set a different tone. Professor Yasmin Rashid spoke of her 'Road to Damascus Epiphany' and the revelation that conventional patient advocacy (even when led by a prominent and well-connected ex-President of the Pakistani Medical Association) was not enough to improve the availability, access, quality, safety and affordability of healthcare in a lower middle income country. Professor Rashid highlighted that patients need to step up their efforts and join the legislature, just as she joined a political party and stood for elections in the constituency of the ousted Prime Minister.

Prof Rashid's discussant was Amber Huett-Garcia from the Obesity Action Coalition and Teach for America. Amber is a candidate running for Tennessee's House of Representatives, District 86. This was a story similar to the former in Pakistan in the sense that Mrs Huett-Garcia, tired of having her voice ignored by the legislature, upped her advocacy tactics by going for a seat at the House of Representatives and becoming a legislator herself. Both speeches emphasised how recognising patients as partners within the health environment creates real opportunities for empowering patients.

The day continued with a session on IAPO's Strategy 2018-2020, where delegates were able to familiarise themselves with IAPO's plans for the coming years to build the momentum towards a patient-centred universal health coverage (UHC) by 2030.

Kawaldip Sehmi (IAPO) outlined the IAPO Strategy and was followed by presentations on two case studies that illustrate members' work in line with our strategy.

Ratna Devi (IAPO board member & Dakshama Health & Indian Alliance of Patient Groups) showcased the NCD Alliance's projects, and Danjuma Adda (Center for Initiative and Development Taraba) presented the Hepatitis B national advocacy campaign that his organisation led in Nigeria.



The first day was concluded by a workshop in which Durhane Wong-Rieger (Canadian Organization for Rare Disorders) provided an overview of biosimilars, while Dr. May Orfali (Pfizer) introduced cell and gene therapies. The workshop facilitators also discussed a patient-centred vision for advocacy in these areas.

Day 2 began with a range of presenters and panels that showcased how patients are empowered in different areas of the healthcare value chain.

The first panel was on Patient Empowerment in universal health coverage (UHC), and the presenters were: Peter Boyle, International Prevention Research Institute (iPRI), who gave a video presentation; Regina Namata Kamoga, Community Health and Information Network (CHAIN) Uganda; and Ratna Devi, IAPO board member & Dakshama Health & Indian Alliance of Patient Groups (IAPG). They discussed the importance of creating an enabling environment for patients to play a central role in progressing towards UHC, with the panellists exploring current challenges and opportunities in healthcare delivery in India and Rwanda.

The second panel on Patient Empowerment in Regulation saw three of the most influential regional medicines regulators and an Australian patient advocate share their views. Margareth Ndomondo-

Sigonda, African Union's New Partnership for Africa's Development (NEPAD) Agency, who presented virtually; Nathalie Bere, European Medicines Agency (EMA); Andrea Furia-Helms, Food and Drug Administration (FDA); and Russell McGowan, Health Care Consumers Association of the ACT presented real cases of how patients have been engaged in regulatory processes in Europe, United States and Africa, as well as the positive outcomes of this and the importance of patients' contributions in the work of regulatory agencies.

The third panel addressed the issue of Patient Empowerment in Research. Discussing ways to ensure research is patient-centred were: Katharina Kovacs Burns, Best Medicines Coalition of Canada & University of Alberta & Alberta Health Services; Christine Janus, International Alliance of Dermatology Patient Organizations (IADPO); Amy Price, The BMJ; Annekatrin Krause, Novartis; Marta Nowotarska, Novo Nordisk; Kawaldip Sehmi, IAPO; and Lisa Stewart, Patient-Centered Outcomes Research Institute (PCORI). Their presentations highlighted how the engagement and empowerment of patients in clinical research helps to ensure that research efforts address patient needs and patient-centred clinical questions.

The final panel of the day was on Patient Empowerment for Global Advocacy and Multi-stakeholder Collaboration. It showcased best practice of patient engagement within the pharmaceutical and healthcare industry. The speakers represented a wide range of organisations and included: Janis Bernat, International Federation of Pharmaceutical Manufacturers & Associations (IFPMA); Maria Pia Ruffilli and Jay Purdy, Pfizer; Ruth Wilson, Teva Pharmaceuticals; Lasse Funch Jacobsen, Novo



Nordisk; Camilla Krogh Lauritzen, LEO Pharma; Myrna Burgos, Policy Wisdom LLC; Kate Beale, Pharmaceutical Research and Manufacturers of America (PhRMA); and Erik Kreyberg Normann, International Hospital Federation (IHF) & Norwegian Hospital and Health Service Association. We heard how industry and other stakeholders include the patient voice in their work, recognising them as key partners, and promoting equitable access to the tools and care patients need to manage their own conditions.

The second day ended with four side-events in the evening.

The first side-event was the WHO Patients for Patient Safety (PFPS) session, which introduced the PFPS Programme, and PFPS Champions shared their country-specific advocating experience, achievements and challenges.

The event on the Role of Expert Patients in Patient Engagement and Empowerment, held by Teva, presented and discussed the Life Effects platform and the research and patients' stories that informed it.

The Role of Caregivers and Self Care in Healthcare session shed light on the innovative approach taken in mapping and addressing the needs of caregivers through Embracing Carers™ (EMD Serono and the International Alliance of Carers Organizations), in addition to the importance of health literacy and self-care to achieve UHC and Bayer's initiatives to promote these.

Fight the Fakes! (IFPMA and partners), a campaign created to raise awareness about the dangers of fake medicines, was discussed in another side event. The campaign seeks to build a global movement of organizations and individuals who will shed light on the negative impact that fake medicines have on people worldwide and to reduce their detrimental effects.

Takeaway messages

We held the GPC 2018 with the view that we must continue building the momentum for patient-centred universal health coverage (UHC), and that patients must be the drivers, not passengers, in this change. Through deeper awareness and knowledge of the most urgent health issues and meaningfully engaging with key health decision-makers, patients are ever more empowered throughout the healthcare value chain.

The main messages delegates took away from the Congress were:

1. Politically empowered patients can advocate more effectively

Several presentations highlighted that health is a political choice, and some of the biggest opportunities and challenges will involve dealing with the power constellations constructed in different countries for and against UHC. We heard from two advocates who gave presentations on their shift towards politics, aiming to become legislators in Pakistan and the USA. They indicated that patient advocates often need to step up their advocacy and go the extra mile to make the patient voice heard. Patients in parliament and politically-engaged patients are empowered patients, representing and further empowering others in the patient community.

2. Patient-centricity is key for the sustainability of UHC financing

Another important and interrelated topic was that of health finance. Experience from around the globe shared at the congress demonstrated that the way forward will be crafting patient-led models to fund healthcare; such financial models must be based on a sustainable balance of taxation, private and social health insurance to ensure maximum reach. Patient empowerment is crucial to make systems patient-centric, effective and sustainable; such systems must meet the needs of everyone, be free at point of delivery and based on clinical need, not ability to pay – the principles of the UK's National Health Service.

3. Empower patients with education

A key concern for many patients at the GPC 2018 was the quality and safety of healthcare and medication in their countries. It was made clear by several presenters that education and awareness are a vital foundation to ensure patient safety. Education empowers patients; whether it is through learning how to practise self-care, managing pain, or identifying falsified drugs, a health-literate patient is an active and empowered patient. The discussions highlighted that patients should get engaged in patient safety in their national healthcare systems to ensure that universal health coverage delivers high quality care and medication.



4. Patient empowerment throughout the health value chain is beneficial for all

GPC 2018 also made clear that we live in an intrinsically connected world and that what happens in one part of the healthcare value chain can quickly impact another. Presenters at the congress demonstrated how the patient voice is being integrated throughout – including in research and medicines’ regulatory lifecycles – via consultation of patient advisory groups, support from committees, collaboration with patients as co-investigators, or reviewing academic publications. Patients are increasingly empowered in all areas of the value chain, as organisations come to realise the need to clearly hear the patient voice in order to meet patient needs. To remain competent, pharmaceutical companies and healthcare providers will now not only need to put research into practice, but also put frontline practice back into research to keep up with patient expectations.

Conclusion

It is clear that patient empowerment plays an increasingly important role in the future of healthcare systems and stakeholders. We must continue to build the momentum globally, getting involved in decision making in the political sphere, forming a community of health-literate and empowered patients and raising awareness amongst stakeholders, and encouraging patients to feed back into the healthcare value chain to ensure that their priorities and needs are met.

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