



International Alliance of  
Patients' Organizations

A global voice for patients



## Innovation improving sustainable access: boosting your reach and impact

# 7<sup>th</sup> Global Patients Congress: Programme

### Innovation to achieve universal, patient-centred and sustainable access to health

- 193 UN member states agree, as a component of the Sustainable Development Goals 2030, to establish sustainable universal health coverage (UHC) to ensure healthy lives and well-being for all.
- All IAPO member organizations worldwide, as expressed in the Declaration on Patient-Centred Healthcare and Principles on Universal Health Coverage, support the proposition that the only way to achieve sustainable UHC is for patients to participate as partners in the development and delivery of healthcare.

### Innovation in every aspect of health will be featured at IAPO Congress 2016

- Innovation and collaboration are needed to transform health systems to achieve universal and sustainable health coverage, deliver better outcomes for patients, and to meaningfully engage patients as stewards in their own health and wellbeing.
- Participants will gain insights into innovative restructuring of healthcare delivery and much more. Patients and patients' organizations are innovatively taking charge of everything from virtual patient communities to crowd-funding for drug discovery and clinical trial participation.
- Patient-engagement and advocacy within re-organization of health systems, including financing and service delivery structures, are essential to assuring quality, safety, efficiency, effectiveness and sustainability of healthcare.

### How will participants benefit?

Participants will focus on **innovation** and what works, **peer learning** across countries and disease areas, and **collaboration**. Congress will deliver knowledge, tools, and skills that participants will take back to their own member communities, enabling them to engage as active partners in today's complex global and national environments. Participants will share and learn from the experience of peers and experts. They will take away relevant, practical and inspiring ideas they can apply to their communities to achieve greater impact and better outcomes for patients around the world.

Participants will:

- **Input** into IAPO direction and priorities.
- **Showcase** member initiatives, promoting peer-to-peer learning.
- **Stimulate** thinking around innovation and impact.

<b>Day 1</b>	<b>IAPO members</b>	<b>Saturday 9 April 2016</b>
<b>From 08:00</b>	Registration	
<b>08:30-09:00</b>	1. Orientation Meet and greet with IAPO Governing Board Chair Jolanta Bilińska	
<b>09:15-10:30</b>	2. IAPO Annual General Meeting	
<i>Refreshments</i>		
<b>11:00-11:15</b>	... IAPO Annual General Meeting continued	
<b>11:15-11:25</b>	3. Welcome and introduction Jolanta Bilińska, IAPO Governing Board Chair and Kawaldip Sehmi, IAPO Chief Executive	
<b>11:25-12:00</b>	4. Keynote speaker <b>Nicolas Sireau (Chair, AKU Society UK) on new approaches to community mobilisation and increasing impact</b>	
<b>12:05-12:40</b>	5. Keynote speaker <b>Peter Boyle (FRSE FFPH FRCPS FRCP FMedSci) on responding to the challenge of rising global cancer rates</b>	
<i>Lunch</i>		
<b>14:00-15:30</b>	6. Workshop sessions: Patients' organization-led innovation <b>Patients' organizations innovating together for greater impact</b>	
6a. <b>Innovation in rare or stigmatized diseases and disorders and treatment</b> Facilitator: Anders Olauson, European Patients Forum and Agrenska, Sweden Speakers: Rubby Chawla, Indian Patients Society for Primary Immunodeficiency; Joshua Wamboga, Uganda Network of AIDS Service Organisations (IAPO Board Member)		
6b. <b>Building a regional movement with impact: Latin America</b> Facilitator: Eva Maria Ruiz de Castilla, ESPERANTRA, Peru Speakers: Migdalia Denis, Latin Society of Pulmonary Hypertension, Latin America; Carolina Cohen, Alianza Latina, Latin America; Marco Espíldora H., CancerVida, Chile		
6c. <b>Building effective and innovative networks and campaigns for greater impact</b> Facilitator: Hussain Jafri, Alzheimer's Pakistan Speakers: Katharina Kovacs Burns, Best Medicines Initiative, Canada; Gi-jong An, Korean Alliance of Patients' Organizations; Anne Charlet, Lupus Europe; Flora Raffai, Findacure, UK		
6d. <b>Innovative collaborations to increase impact</b> Facilitator: Mary Lynne van Poelgeest-Pomfret, World Federation for Incontinence Patients Speakers: Bejon K. Misra, Consumers Online Forum, India; Kerstin Morrison, European Lung Foundation, UK & Europe; Ofra Balaban, CHEN (Patient Fertility Association), Israel; Gertrude Buttigieg, Malta Health Network; Joan Jordan, EUPATI patient representative, Europe		
<i>Refreshments</i>		
<b>15:45-16:30</b>	7. Plenary panel <b>Patients' organization-led innovation - what works?</b> Introduction and facilitation of Q&A: Durhane Wong-Reiger, Consumer Advocare Network, Canada (IAPO Board Member) Speakers: Matthias Wienold, European AIDS Treatment Group (IAPO Board Member); Penney Cowan, American Chronic Pain Association (IAPO Board Member)	
<b>16:30-16:45</b>	8. Member Workshop feedback and takeaways Facilitator: Joshua Wamboga, Uganda Network of AIDS Service Organisations (IAPO Board Member)	
<i>Drinks reception</i>		

<b>Day 2</b>	<b>Members, partners and others</b>	<b>Sunday 10 April 2016</b>
<b>08:00-08:45</b>	10. Registration for newcomers	
<b>08:45-09:00</b>	11. Welcome and 1 <sup>st</sup> day summary Kawaldip Sehmi, IAPO Chief Executive	
<b>09:00-10:30</b>	12. Keynote addresses <b>Where in the world is Universal Health Coverage?</b> Facilitator: Kawaldip Sehmi, IAPO Chief Executive Panellists to include Nittita Prasopa-Plaizier, Patients for Patient Safety Programme Manager, Service Delivery and Safety Department, World Health Organization	
<b>10:30-11:30</b>	13. Plenary panel <b>Exploring strengths and weaknesses of different approaches to innovation in Universal Health Coverage and Patient-Centred Healthcare</b> Facilitator: Jolanta Bilińska, Polish Patients' Safety Foundation (IAPO Board Chair) Panellists to include Joshua Wamboga, Uganda Network of AIDS Service Organisations (IAPO Board Member); Robert Johnstone, National Voices, UK (IAPO Board Member)	
<i>Refreshments</i>		
<b>12:00-13:30</b>	14. Workshop sessions <b>Effective innovation in practice: demonstrating what works</b>	
14a. <b>Innovation in training for action, and achieving demonstrable results</b> Facilitator: Penney Cowan, American Chronic Pain Association (IAPO Board Member) Speakers: Tamás Bereczky, EUPATI, Europe; Mary Lynne van Poelgeest-Pomfret, World Federation for Incontinence Patients; Christine Janus, Global Skin/International Association of Dermatology Patient Organizations; Krystal Boyea, Barbados		
14b. <b>Patient involvement in research: innovation in the drug development and access pathway</b> Facilitator: Antonio Ciaglia, IAPO Speakers: Alison Lightbourne, IAPO; Jane Meijlink, International Painful Bladder Foundation; Ricardo C Santiago, Health Insight; Tom Ruane, Quintiles		
14c. <b>Innovation to expand access and strengthen health systems</b> Facilitator: Kawaldip Sehmi, IAPO Chief Executive Speakers: Lars Ettarp, International Federation of Psoriasis Associations; Sylvie St-Laurent, Inflammation Area Lead, International Public Affairs, Pfizer; Representative from the Access Team, Novartis		
<b>Please note different timing: 11:45-13:45</b> ( <i>This workshop is limited to 25 participants</i> )		
14d. <b>WHO - Global leadership supporting national action</b> Facilitators: Nittita Prasopa-Plaizier, Patient for Patient Safety Programme Manager, Service Delivery and Safety Department, World Health Organization; Felicity Pocklington, Consultant, Patients for Patient Safety Programme, Service Delivery and Safety Department, World Health Organization; Hussain Jafri, Alzheimer's Pakistan		
<i>Lunch</i>		
<b>14:30-15:15</b>	15. Small group networking and discussion groups	
<b>15:30-16:15</b>	16. Plenary panel <b>Exploring different approaches to innovation in patient involvement and access</b> Facilitator: Penney Cowan, American Chronic Pain Association (IAPO Board Member) Speakers: Victoria Pinkney-Atkinson, Patient Health Alliance of Nongovernmental Organisations, South Africa; further speakers TBC	
<b>16:15-16:30</b>	17. Workshop feedback and takeaways Facilitator: Kawaldip Sehmi, IAPO Chief Executive	
<b>16:30-17:00</b>	18. Group photo opportunity	
<i>Close of formal programme 2<sup>nd</sup> day at 17:00</i>		
<b>19:00</b>	Drinks and Gala Dinner	

Day 3	Members, partners and others	Monday 11 April 2016
08:45-08:55	19. Welcome Jolanta Bilińska, IAPO Governing Board Chair	
09:00-10:40	20. Plenary panel <b>Exploring industry, pan-regional and researcher-led innovation</b> Facilitator: Penney Cowan, American Chronic Pain Association (IAPO Board Member) Panellists to include: Nathalie Bere, European Medicines Agency; Hilde Vanaken, Transclerate eConsent Workstream Lead, Janssen; Katherine Beaverson, Patient Advocacy Lead, Rare Disease Research Unit, Pfizer; Andrew Bushell, Global Program Head, ; Kate Knobil, Chief Medical Officer, GlaxoSmithKline	
<i>Refreshments</i>		
11:00-12:00	21. Closing keynote speakers <b>Exploring innovation by healthcare professionals and global NGOs in conflict areas</b> Facilitator: Tessa Richards, British Medical Journal Speakers: Stijntje Dijk, International Federation of Medical Students Associations; Bruce Eshaya-Chauvin Health Care in Danger Project, International Committee of the Red Cross	
12:00-12:10	Closing comments and next steps Jolanta Bilińska, IAPO Governing Board Chair	
12:10	Lunch and depart	

## Find out more

Read more about Congress at [www.iapo.org.uk/gpc2016](http://www.iapo.org.uk/gpc2016)

