



International Alliance of
Patients' Organizations

A global voice for patients



6th Global Patients Congress 2014

Meeting Report





International Alliance of Patients' Organizations

A global voice for patients

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Introduction



I am delighted to share with you this report from the International Alliance of Patients' Organizations' (IAPO) 6th Global Patients Congress, held in Ascot in the UK from 29–31 March 2014. If you were one of the 155 delegates who attended the event, then I am sure that, like me, you found it an intellectually stimulating and collegiate experience, providing an opportunity to share your activities, find out more about the work of your colleagues around the world, make new friends and collectively work towards strengthening the patient voice.

This report shares the highlights of the Congress and we hope it will be an aide memoire and a useful resource for you in continuing to engage with the issues discussed. It includes a summary of the theme of **'Better access, better health: A patient-centred approach to universal health coverage'**, and outlines some of the issues and threads discussed during the event.

In two case studies, participants share their experiences and the steps they will take as a result of attending the event. These truly inspirational stories show the impact that our working together can have for patients around the globe. The report also includes some links to resources and information on how digital engagement extended the reach of the discussions to engage a global audience beyond those that attended in person.

As ever, the Congress is only possible because of the energy and commitment of our members who helped to shape every aspect of the event. The Advisory Committee dedicated their time and expertise to planning a substantive and engaging agenda which provided opportunities to share resources and information, and a forum for constructive debate and development of views and common principles on universal health coverage.

We would like to thank the European Union for awarding a conference grant, and to acknowledge our event sponsors for their generous financial support, without whom, the Congress would not be possible. In particular we would like to thank our Premium Sponsors: Janssen, Lilly and Pharmaceutical Research and Manufacturers of America (PhRMA).

We would like to thank all our partners and speakers that supported the event. In particular, the International Council of Nurses, International Hospital Federation, International Pharmaceutical Federation, World Confederation for Physical Therapy, World Dental Federation, World Health Organization and the World Medical Association. All made valuable contributions to the Congress, including donating their time and expertise to present or run sessions.

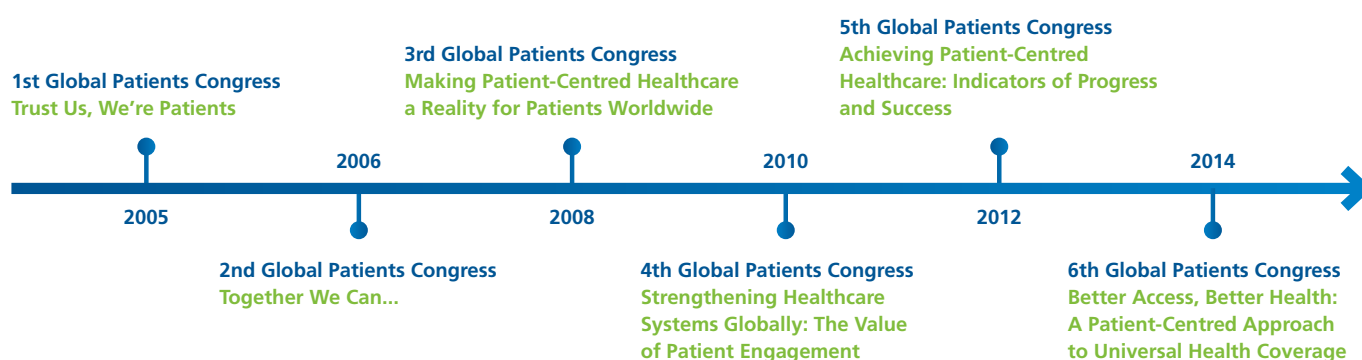
Finally, I would like to thank everybody who participated in the Congress and contributed to taking the event to the next level. Through the Congress we were able to develop a set of draft principles on universal health coverage from a patient perspective. These will be key in our advocacy efforts, as IAPO at the international level, and as patient groups at the regional and national level this year and into the future.

KP Tsang
Chair, International Alliance of Patients' Organizations



Overview of the Congress Journey

The focus of the 6th IAPO Global Patients Congress was ‘**Better access, better health: A patient-centred approach to universal health coverage**’. The 2014 Congress was the latest step in a significant progression over the five previous Congresses, from the basic rights of patients to be empowered and involved, to using the wealth of experience and expertise held within the membership to start a journey that will define universal health coverage from the patient perspective.



In 2006, at the 2nd Global Patients Congress in Spain, IAPO defined the principles of patient-centred healthcare from a patient perspective and launched the Declaration on Patient-Centred Healthcare. Since then, IAPO and our members and partners have been raising awareness of patient-centred healthcare.

Our Congresses held since 2006 have refined the message. At the 3rd Congress in Hungary, IAPO called on all stakeholders in healthcare worldwide to include patients in a meaningful way at all levels of their work and at all points of decision-making. The 4th Congress, held in Turkey, provided an opportunity for patient advocates, across diseases and across borders, to come together and examine how patient engagement can be strengthened to improve healthcare systems. The 5th Congress, held in the UK, was a time to take stock of progress in patient-centred healthcare, consolidate the evidence of what has been achieved, and drive forward the process of defining indicators for patient-centred healthcare so it can be realised in practice.

“
All partners need to work together to make positive changes and lead to better health. Yes we can.”

Yoram Cohen, Global Alliance of Mental Illness Advocacy Networks Europe

Throughout 2014, IAPO is exploring access to healthcare from a patient perspective, and defining patient-centred principles for universal health coverage (UHC). The 6th Global Patients Congress was a vital part of this process and the Congress programme was designed to stimulate discussion and debate and demonstrate the value of patient-centred healthcare and its role in improving access to healthcare. Much of this engagement took place in three streams of breakout sessions, each of which focused on one of the three pillars of universal health coverage: equity, quality and financing.



Member Expectations

Held on the first morning, the Breakfast Briefing provided a great opportunity for IAPO to discuss the relevance of Congress with members, and how best they could maximise their participation in this key event. The briefing opened with a thematic overview from IAPO Chair-Elect, Jolanta Bilińska, outlining the value of the event and member participation.

Long-standing IAPO member representative Roger Kendall (Epilepsy HERE) shared his experiences from several previous Congresses, and the benefits of participating in the event. Over 50 members, the majority of whom were attending Congress for the first time, then discussed their expectations and what they hoped to contribute. This was insightful for IAPO and provided members with the opportunity to network, discuss hopes for the Congress, and how they aimed to make the event as productive and inspiring as possible.

Members shared their key expectations and opportunities at the Congress which included:

- Networking and partnership building opportunities, which were considered most important, and meeting so many diverse stakeholders
- Learning about universal health coverage
- Sharing experiences and information, and gaining knowledge about regional issues
- Learning what barriers to accessing healthcare have been overcome in different countries

The Breakfast Briefing set an exciting tone for the rest of Members' Day and the Congress.

“The networking opportunity provided by the Congress was one of the most valuable parts of the event. Where else does one have access to such a rich variety of experience?”

Andrew Spiegel, Global Colon Cancer Association, IAPO member

100%
of Congress evaluation
respondents stated that
their experience of the
Congress was excellent
or very good





Access to Healthcare and Universal Health Coverage

Pre-Congress Work

To enable IAPO's members to make the most of the Congress and support their understanding of universal health coverage, a series of activities were undertaken in the run-up to the Congress, which included:

1. **A member consultation** – to help IAPO to understand the issues affecting patients in relation to access to healthcare and inform the development of the Congress programme and materials. The results of the consultation led to the development of information papers.
2. **Two information papers on universal health coverage** – to build the knowledge and capacity of IAPO's membership on universal health coverage. One paper provided an overview of universal health coverage, whilst the second paper outlined examples of countries from around the world who have implemented policies to improve access to healthcare.
3. **A Congress webinar** – to provide a briefing to members on the Congress which included what they could expect to get out of the Congress, an overview of the programme and an introduction to the theme.



Overview of the Congress Programme

The focus of this year's IAPO Congress, 'Better access, better health: A patient-centred approach to universal health coverage', marked the beginning of a journey where IAPO explored what universal health coverage means from a patient perspective. The Congress programme was a lively mix of streamed breakout sessions and plenary and panel discussion and debates.

A number of high-profile and exciting keynote speakers gave presentations at the Congress, including: Dame Sally Davies, Chief Medical Officer for the UK Government; Marie-Paule Kieny, Assistant Director General of Health Systems and Innovation at the World Health Organization (WHO); and Sir Michael Hirst, President of the International Diabetes Federation, as well as a high-level panel discussion which included representatives from IAPO membership, WHO, industry and healthcare professionals.

In her keynote address, Dame Sally Davies outlined the various mechanisms in the UK to involve patients more in health research. The National Institute for Health Research (NIHR) has patients at the centre of its work, and is increasing the volume of research on issues that matter to patients and the wider public.

In a panel session, Dr Otmar Kloiber of the World Medical Association, Stephen Murby-Wright from Consumers Health Forum of Australia, Dr Robert Sebbag from Sanofi, and Dr Hernan Montenegro, Health Advisor for WHO, discussed barriers to access to universal health coverage. These included a lack of prioritisation of health budget by governments, stigma and a lack of collaboration between healthcare stakeholders. Solutions included using 'value' rather than 'cost' when talking about healthcare funding, the importance of solidarity, and the importance of all stakeholders working in partnership.

In the closing plenary, Marie-Paule Kieny, Assistant Director General of Health Systems and Innovation at WHO, stated that universal health coverage is a way of improving health for all. She shared that WHO has actively engaged patients to ensure better services, and provides evidence that engaging families, carers and patients strengthens health systems. Sir Michael Hirst outlined his work in diabetes advocacy. He spoke about his own journey, from his daughter's diagnosis of diabetes, through long-term international advocacy for improvements to care. Sir Michael also highlighted challenges for the future for all patients' organizations, including ensuring that health is included in the post-2015 development agenda.



IAPO Member Case Study:

Karima Roumila, Director of Support and Education,
Hydrocephalus Association, USA

This was my first time attending and I felt it was a very humbling experience to be part of IAPO's 6th Global Patients Congress. There was general warmth and a feeling of welcome, and the passion of the participants from all parts of the world was inspiring and motivating. It is also refreshing to hear the common goals for so many organizations is better access to health services for all the communities

we represent. Highlights for me were the regional sessions, where we explored how different countries within regions were implementing universal healthcare and the different challenges and successes we were all facing.

The most valuable and beneficial thing for me was the sense of community and collaboration that came out of the Congress. The ultimate feeling of working together for better health access, better health education and the overall empowerment of patients and their families from all over the world.

I learnt about how other organizations are providing patient support and education, so my hope is to continue to learn from them on how to implement these new ideas in my own work, and how we can provide better services to our constituents. The Hydrocephalus Association is a member of several North American associations, such as fellow IAPO member the National Health Council, and the Congress reinforced the importance of collaboration and working together. I feel the most beneficial outcomes of attending this year's event was making new connections and finding new partnerships. One direct outcome was that I met potential speakers for our upcoming Conference on Hydrocephalus, which was a great benefit.

In future, we hope to further our understanding of global health and learn best practices in providing health education programmes at a global level from IAPO and its members. We hope to lend our voice and be united for patients and their carers to access services and get the support they need. This is why we joined IAPO and why we aim to continue working together in the future.

The Hydrocephalus Association aims to stimulate innovative research and provide support and education for all dealing with the condition thus eliminating challenges. They have been IAPO members since 2012. For more information visit: www.hydroassoc.org

Karima's attendance was partially supported by the IAPO Member Bursary Fund, an important element of IAPO's member support. In 2014, more members were supported through the bursary fund than ever before; a total of 13 members from all over the world, reflecting the truly global nature of the IAPO membership.

93% of Congress evaluation respondents agreed that the Congress has improved their knowledge of universal health coverage

Members' Day

The 6th Global Patients Congress was an opportunity for members to let IAPO know what the key issues in patient-centred healthcare were from their perspectives. Members' Day brought together 85 member organizations to explore insights on healthcare and access issues at national, regional and global levels.

The day took members on a journey of discovery and exploration, with each session acting as a step towards greater understanding of the issues around universal health coverage and how to work towards this goal. Focusing on the Congress theme of 'Better access, better health', the day investigated what access to healthcare issues were around the world, and then assessed how universal health coverage would need to be shaped to address these concerns. In sessions throughout the day, members were able to share their experiences on issues facing patients globally, regionally and nationally.

The opening plenary introduced the theme of access and universal health coverage through a panel discussion with three member representatives from Peru, Thailand and Germany to explore diverse country contexts. Matthias Wienold, from the European Aids Treatment Group, highlighted the stark reality that discrimination was a major killer creating large barriers to accessing healthcare. Orajitt Bumrungskulswat, from the Heart to Heart Foundation, Thailand, shared the people's rights approach her country was implementing to universal health coverage for all citizens. Eva Maria Ruiz de Castilla, IAPO Governing Board Member and from Esperanta, Peru, shared innovative financing mechanisms that Peru had undertaken to improve better access to healthcare in rural communities. The panel explored the diversity of issues and challenges to access that their countries face, as well as highlighting the commonalities at a global level and how all patient organizations can work towards ensuring access for marginalised groups and equal access to quality healthcare.



Following the plenary, members broke out into six world regions: Africa, Asia Pacific, Eastern Mediterranean, Europe, North America and Latin America. The regional meetings helped members explore national and regional challenges in accessing healthcare and what universal health coverage would need to include to address regional contexts. These breakout groups were a useful space to explore commonalities and differences within regions and between countries. Many groups felt that basic access and equity were leading problems in their regions, with a lack of adequate health resources and infrastructure proving to be problematic and creating barriers to accessing healthcare, made worse by increasing non-communicable disease burdens. All felt that health systems around the world needed to undergo significant reorientation to ensure a patient-centred focus.

“

[It was...] wonderful to bring a common interest together and reignite the commitment and passion for serving patients.”

April Abernethy, National Psoriasis Foundation

In the last session of the day, participants combined their knowledge and experiences to draft a set of principles they felt universal health coverage would need to include. These principles were further developed throughout the Congress and will guide IAPO's upcoming work. Participants were able to develop several broad themes of what essential principles patients would want from universal healthcare coverage. These included the key areas as listed on page 8.

- **Patient-centred:** all stakeholders need to work together to ensure that health systems prioritise and meet the needs of patients, their families and carers
- **Accessibility:** universal health coverage must ensure that all patients can access the health services they require
- **Equity:** all people, regardless of age, gender, race, disease or condition, and economic circumstances must have equitable access to healthcare
- **Quality:** care must be of high quality at all levels and stages of healthcare
- **Empowerment:** patients must be actively involved in all levels of healthcare decision-making
- **Collaboration:** all stakeholders, including patients, must work together to ensure improved access to healthcare for all
- **Value of healthcare:** it is essential to place priority on the value, not the cost of providing access to high-quality, equitable and affordable healthcare for all
- **Accountability:** health systems must be accountable to the patients they serve, as accountability and transparency are vital to ensuring safe, effective healthcare

The day highlighted that no system is truly universal if it is not providing equitable, high-quality access to healthcare. Throughout the day, participation and the sharing of information and experiences were of key importance. This Members' Day was the most interactive yet, with active engagement from all, providing a space where members could share concerns and challenges and devise innovative, patient-centred solutions together.

Equity, Quality and Financing

Following Members' Day, the Congress opened to a multi-stakeholder audience and held breakout sessions themed under the three pillars of universal healthcare: equity, quality and financing.

Equity: To achieve better access, it is essential that patients have equitable access to the treatments they need. This stream explored what the barriers are to accessing equitable access to healthcare, which included geographical location and socio-economic status. The second session in this stream shared case studies of the work of patients' organizations to enhance patient-centred healthcare and improve access to healthcare in their countries. It included a case study from Argentina, where an IAPO member has been working to ensure more people are able to access fertility treatments, and examples of work from IAPO members in Africa to celebrate Patient Solidarity Day. The final session explored the role of the patient in the future and how an empowered patient can not only manage their own healthcare, but play an essential role in healthcare decision-making too.

Quality: Expanding the provision of healthcare whilst maintaining a high quality of service is a challenge that all health systems must overcome if they are to achieve universal health coverage. In the first session in this stream, participants from Mexico, Nigeria and Australia all shared the work they had done to improve healthcare in their countries. For example, in Nigeria, patients' organizations have been protesting against substandard medical treatment for patients with HIV and AIDS. The second session, run by the World Health Organization's Patients for Patient Safety Programme, explored the role of this programme in supporting initiatives to improve patient safety worldwide. Patient Safety Champions from around the world shared their case studies. The final session called for patient-defined quality indicators to measure success in healthcare and explored what these indicators may look like.

Financing: Achieving universal health coverage requires sustainable financing mechanisms. The first session in this stream explored the current healthcare context, including an increasing number of actors involved in healthcare as well as the financial constraints that governments are under. The second session explored who decides which medicines and technologies are funded by health systems. It explored the role of health technology assessment (HTA) in delivering cost-effective healthcare choices, and the potential to ensure that the patient voice is part of this decision-making process. The final session shared case studies from Thailand, Venezuela and the USA who have all been undergoing healthcare reforms, with participants sharing the patient perspective on the success of these reforms in terms of improving access to healthcare. This session also explored what the principles are for universal health coverage from an industry perspective.

Overall, the diversity of the speakers and the variety of case studies ensured an enriching and stimulating programme which enhanced participants' knowledge and understanding of universal health coverage.



IAPO Member Case Study:

Estela Maria Chardon De Zlotogwiazda, Coordinator,
CONCEBIR, Argentina

I work for CONCEBIR, a patients' organization in Argentina who work with infertile couples, same sex couples and single mothers. We have three main objectives: share our experiences and help other people; increase knowledge about infertility and Assisted Reproduction Treatments (ART) both in clients and society in general; and work for a non-restrictive ART law to be passed in the National Congress.

We have many activities including working with patients, families, and single mothers; participating in conferences related to infertility issues; holding an annual CONCEBIR Congress with the participation of doctors and other healthcare stakeholders; working with legislators to promote an ART law and using different media to share the details of what is important to infertile people.

CONCEBIR has been a member of IAPO since 2008 and the value in being part of this network includes: improving our knowledge as an NGO; developing skills (communication, finances, dealing with volunteers, media, etc.); sharing experiences and learning from other organizations; helping our organization to be known in other countries; and learning new concepts about health.

This is the third IAPO Congress I have attended and, as in the previous events, it was a very important experience to learn, to meet people and to share ideas and experiences. For me, the theme of the Congress, universal health coverage, reflects the need to identify the problem and the solution at different levels and in different countries and cultures. Within the key principles of this, it was very important for me that patients have 'rights and duties' and do not only focus on their 'needs'.

Attending the Congress allowed me to come back and share some important concepts with other members of CONCEBIR and other patients' organizations, and to send current information to the media. We have two different levels of follow up; the first is with other Latin American associations, promoting the value of working together. We have a Latin American group of infertility associations and we know how hard it is to keep working for something in common. We also have the challenge to share the concept of universal health coverage in our country, as we did with the IAPO Declaration on Patient-Centred Healthcare. In Argentina, we have public hospitals where people can receive free health services, but as happens in many other countries, there can sometimes be a lack of budget which affects supplies. At the Congress, we realized that in Argentinian cities, health services are much better than in other parts of Latin America and we could work together more to address this.

I really enjoyed my time at IAPO's Congress and I will recommend other organizations take part and make their best efforts to participate!

CONCEBIR is a non-profit organization, created in 1996 to provide emotional support to patients facing fertility issues, and to work towards national legislation which regulates Assisted Reproduction Techniques in Argentina. The organization facilitates patient meetings to provide patients with the latest information about progress in treatment for infertility.

Estela's attendance was partially supported by the IAPO Member Bursary Fund, an important element of member support for IAPO. In 2014, more members were supported through the bursary fund than ever before; a total of 13 members from all over the world, helping to reflect the truly global nature of the IAPO membership.

Who Attended the Congress?

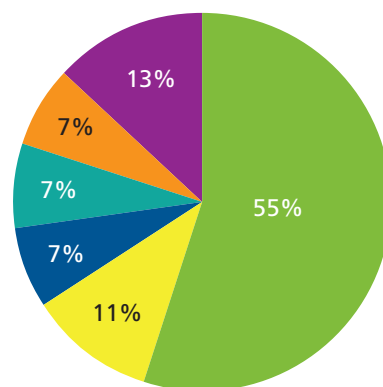
Breakdown of Delegates

A total of 155 delegates attended the 6th Global Patients Congress, of which 63% were patient representatives. A total of 80 patients' organizations were represented at this event.



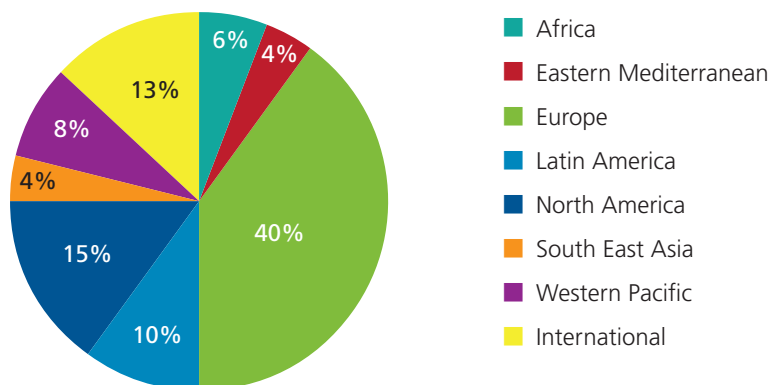
Breakdown of Speakers

- Patient representatives (IAPO members and non-IAPO members)
- Healthcare policy-makers
- Industry representatives
- Academics / researchers
- NGOs and other not-for-profit organizations
- Other



Breakdown of Patients' Organizations Attending by Region

IAPO is pleased to report that since the last Global Patients Congress in 2012, Latin American attendance has increased, from 1 to 10%. IAPO strives to ensure that patient representatives from all world regions have the opportunity to attend the Congress.



86%
of Congress evaluation respondents stated that their
capacity to advocate on patient-centred healthcare had improved



The Way Forward

Since the Congress, IAPO has been working with its members to further develop the principles of universal health coverage. IAPO has since revised the principles based on responses from a consultation with its members, and will be undertaking a second round of consultation with members and external stakeholders to support continued refinement of these principles. Once finalised, IAPO will promote the principles on universal health coverage at the World Health Organization Regional Committees and at the next World Health Assembly in 2015. IAPO will also be exploring what members' needs are in order to advocate on universal health coverage, and will consider the development of further tools and resources to build IAPO's members' capacity and to support their advocacy on this issue.

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It's time to stand up and be counted.”

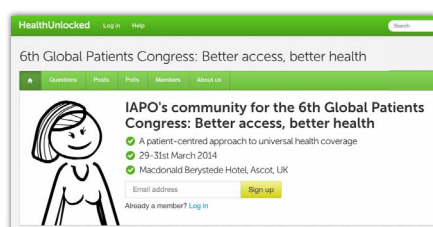
Stephen Murby, Board Director, Consumers Health Forum of Australia (CHF)





Digital Engagement

IAPO used a variety of methods to engage with healthcare stakeholders globally around the theme of the Congress. As well as using traditional methods such as the newsletter and website, IAPO used social media and digital technology to gain interactive input and feedback. Platforms used included:

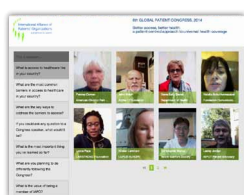


HealthUnlocked

In the run-up to the Congress, IAPO engaged with delegates and members through a new online platform: HealthUnlocked. This is a social network designed specifically for people who care about their health and the health of others, and wish to share important information regarding healthcare. IAPO used this platform to:

- Extend the reach of the Congress and ensure organizations and individuals who were unable to physically attend could join the discussions and participate in sharing information
- Stimulate discussion and debate around the Congress theme of universal health coverage and examine issues such as access and patient-centred healthcare
- Allow networking for delegates and IAPO members prior to the Congress and facilitate information exchanges and partnerships

Join the community at: www.healthunlocked.com/iapo



miituu

IAPO used miituu to gather information through questionnaires in video format before, during and after the Congress. miituu is an innovative and fast way of collecting video feedback from many audiences. It allows people to respond to surveys and questionnaires by recording video responses using their own devices, including smartphones and computers. IAPO used miituu to:

- Gather information from members in video format about specific topics relating to the theme of the Congress. This was a great opportunity for members to get their voices heard and input into the Congress, regardless of whether they are able to attend or not
- Gather information about the experiences of delegates during and after the Congress

You can view the IAPO Congress video wall at: <http://iapo2014.miituu.tv>

Social media

For the first time, the keynote presentations were filmed at the Congress to make them available to a wider audience.



View the Congress photographs at: www.facebook.com/internationalallianceofpatientsorganizations



Follow debates and discussion at: www.twitter.com/IAPOtweets



Watch the plenary sessions at: www.youtube.com/IAPOpatientvoice



Resources

Delegates used a variety of resources during their journey before, during and after the Congress, a number of which were developed by IAPO especially for the Congress. You can find these resources on the Congress website at: www.globalpatientscongress.org

We would specifically like to draw your attention to the following resources:

The 6th Global Patients Congress Handbook where you will find the full agenda and session details, more information on what happened at the Congress as well as speaker biographies.

Videos of keynote presentations: for the first time, the keynote presentations were filmed at the Congress to make them available to a wider audience.

Press release: 'It is time to stand up and be counted', which was distributed through our networks globally, sharing the key outcomes of the Congress.

IAPO Information Paper: Universal health coverage, which was developed to give background information on the Congress theme and to allow all delegates to engage in discussions on similar levels.

Country examples of progress towards universal health coverage, which shared real life case studies of achievements in universal health coverage in different settings.

IAPO Declaration on Patient-Centred Healthcare, which underpins all of the work IAPO does.

Further important resources can be found at: www.patientsorganizations.org/publicationsandtools

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Universal health coverage is a vision that can unify all the different actors.”

Hernan Montenegro, Health Systems Adviser, World Health Organization

IAPO Member Participants

IAPO Full Members

International

Alzheimer's Disease International
www.alz.co.uk

The Cochrane Collaboration
www.cochrane.org

Global Colon Cancer Association
www.globalcca.org

International Diabetes Federation
www.idf.org

International Federation of Psoriasis
Associations (IFPA)
www.ifpa-pso.org

Multiple Sclerosis International Federation
www.msif.org

LIVESTRONG Foundation
www.livestrong.org

World Federation for Incontinent Patients
(WFIP)
www.wfip.org

Regional

Europe

Lupus Europe
www.lupus-europe.org

Global Alliance of Mental Illness Advocacy
Networks Europe (GAMIAN-Europe)
www.gamian.eu

European AIDS Treatment Group
www.eatg.org

National

Argentina

CONCEBIR
www.concebir.org.ar

Argentine Cystic Fibrosis Association
www.fipan.org.ar

Australia

Consumers Health Forum of Australia
www.chf.org.au

Health Consumers Alliance of South
Australia
www.hcasa.asn.au

Health Care Consumers' Association
www.hcca.org.au

Canada

Best Medicines Coalition
www.bestmedicines.ca

The Canadian Continence Foundation
www.canadiancontinence.ca

Consumer Advocare Network
www.consumeradvocare.org

Chile

Communicology Foundation / Fundacion
de la Comunicologia
www.fundacioncomunicologia.org

Croatia

Croatian Coalition of Associations in
Health Care
www.kuz.hr

Croatian Association for Patients' Rights
www.pravapacijenata.hr

Czech Republic

Adam Czech Republic
www.adamcr.cz

Germany

German Pain League (Deutsche
Schmerzliga)
www.schmerzliga.de

Hong Kong

Hong Kong Alliance of Patients'
Organizations
www.hkapo.org.hk

Hungary

Hungarian Osteoporosis Patient
Association
www.obme.hu

India

Dakshayani and Amaravati Health and
Education
www.dakshamahealth.in

Israel

CHEN - Patient Fertility Association
www.amotatchen.org

Italy

Italian Endometriosis Association
www.endoassoc.it

Lithuania

Council of Representatives of Patients'
Organizations of Lithuania
www.pacientutaryba.lt

Mexico

Health, Rights and Justice
www.dvimss.org.mx

Morocco

Moroccan Federation Supporting people
with CKD /Organ transplantation
www.fmairto.org

Netherlands

Ieder(in) (Network for people with
disabilities or chronic illness)
www.iederin.nl

Nigeria

PLAN Health Advocacy and Development
Foundation (PLAN Foundation)

Pakistan

Alzheimer's Pakistan
www.alz.org.pk

Peru

ESPERANTRA
www.esperantra.org

Poland

Patient Safety Foundation
www.patientsafety.org.pl

Polish Diabetes Association
www.diabetyk.org.pl

Portugal

Plataforma Saúde em Diálogo
www.plataforma.org.pt

Romania

Association PAVEL
www.asociatiapavel.ro

Asociatia Sano-Hep Romania
www.sanohep.ro

Slovak Republic

Association for the Protection of Patients'
Rights Slovak Republic
www.informovanypacient.sk

South Africa

Dementia South Africa (Dementia SA)
www.dementiasa.org

Multiple Sclerosis South Africa
www.multiplesclerosis.co.za

Spain

Accion Psoriasis
www.accionpsoriasis.org

Federacion Espanola de fibrosis quistica
www.fibrosis.org

Esclerosis Multiple Espana
www.esclerosismultiple.com

South Korea

Korean Alliance of Patients Organizations
www.koreapatient.com

Uganda

Uganda National Health Users/Consumers Organisation
www.unhco.or.ug

The Aids Support Organization (TASO)
www.tasouganda.org

Ukraine

All-Ukrainian Public Organization Stop Hepatitis
www.hvstop.org

UK

Pelvic Pain Support Network
www.pelvicpain.org.uk

Backcare
www.backcare.org.uk

The Pumping Marvellous Foundation
www.pumpingmarvellous.org

National Voices
www.nationalvoices.org.uk

INPUT Patient Advocacy
www.inputdiabetes.org.uk

Epilepsy HERE
www.epilepsyhere.org.uk

USA

National Psoriasis Foundation
www.psoriasis.org

National Health Council
www.nationalhealthcouncil.org

National Multiple Sclerosis Society
www.nmss.org

American Chronic Pain Association
www.theacpa.org

Multiple Sclerosis Association of America
www.mymsaa.org

Alpha-1 Foundation
www.alpha-1foundation.org

American Autoimmune Related Diseases Association
www.aarda.org

Hydrocephalus Association
www.hydroassoc.org

Venezuela

Venezuelan Federation of Associations of People with Learning Disabilities and their families (FEVEDI)
www.fevedi.org

IAPO Associate Members

International

International Painful Bladder Foundation
www.painful-bladder.org

International Genetic Alliance (IGA)
www.iga.org

Regional

Europe

European Lung Foundation
www.europeanlung.org

National

Afghanistan

Life Saving Organization for Afghanistan

El Salvador

Salvadoran Association for Cancer Prevention
www.cancerelsalvador.org

India

Association of Community Pharmacists of India
www.acpi.in

Consumer Online Foundation
www.safemedicinesindia.in

Macedonia

Centre for Regional Policy Research and Cooperation 'Studiorum'
www.studiorum.org.mk

Mexico

Asociacion ALE, IAP
www.asociacionale.org

Pakistan

Hamza Foundation Welfare Hospital and Blood Transfusion Services
www.hamzafoundationhosp.org

Thailand

Heart to Heart Foundation

UK

Arrhythmia Alliance
www.heartrhythmcharity.org

Safer Medicines Trust

www.safermedicines.org

USA

National Alliance for Caregiving
www.caregiving.org

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