

IAPO 2021 Highlights

IAPO Strategy in 2021

In 2021, the last year of our 2019-2021 Strategic Plan, our vision remained to see patient-centred universal health coverage (PC -UHC) established in all countries

Our main objective was to ensure that there is a sufficient availability of patient-centric, safe and quality promotive, preventive, curative, rehabilitative and palliative healthcare services in each WHO Member State, along with essential and innovative medicines and health devices, which are accessible, acceptable and affordable, and delivered without the patients suffering financial hardship or discrimination.

Our 2021 strategy was to:

- 1. Empower patient communities globally to advocate effectively for patient-centred universal health coverage for all.
- 2. Drive research processes and the development of evidence base for patient-centred universal health coverage.
- 3. Shape law, policy and practice in patient-centred universal health coverage at global, regional and national levels

Empowerment in 2021

IAPO has been collaborating with several organisations in 2021 in developing resources for patient groups on specific areas of:

- Patient Safety
- Antimicrobial Resistance
- Gene and Cell Therapies

In addition, IAPO supported the development of a Beta Moodle Platform to test out a new platform to make our reports, toolkits, resources, and videos more accessible and in a structured manner.

In 2021 IAPO collaborated with the International Federation of Medical Associations to develop new guidelines on <u>Patient Involvement in Medical Education</u>. These guidelines empower patients by giving them a road map of how to engage and co-produce medical education curricula that is patient centred and improves medical practice on the frontline.

In 2021 IAPO used two Regional Congresses as capacity building events to empower our patient groups in Africa and Asia-Pacific.

The full Africa congress programme and videos can be accessed here:

- African Patients Congress 2021 General Information
- African Patients Congress 2021 Full Programme and Speaker Session Details and Recordings

The full 3rd Asia Pacific Patients Congress programme and videos can be found here:

- https://www.iapo.org.uk/events/3rd-asia-pacific-patients-congress
- https://www.youtube.com/user/IAPOPatientVoice



Empowering patients on WHO Global Patient Safety Action Plan

IAPO is fully committed to reducing avoidable patient harm to zero in all our healthcare services from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course. At the 74th World Health Assembly, IAPO endorsed the resolution proposed by the WHO Executive Board to adopt the WHO Global Patient Safety Action Plan 2021-2030. See full copy of plan https://apps.who.int/iris/rest/bitstreams/1360307/retrieve

At our 3rd Asia Pacific Patients Congress, November 2021, IAPO started a training and education programme on the Plan by hosting a workshop to determine what action is needed by patients and families and how their engagement can be enhanced having understood their knowledge and skills needs. The full course will be available on line.

Patient Solidarity Day 2021

Patient Solidarity Day takes place each December. Thousands of people from around the world rally around one key issue facing patients and raise awareness by hosting events and showing support for the Day.

On Friday 3rd December 2021, health stakeholders from all over the world stood together, united in celebration of Patient Solidarity Day (PSD). This was the ninth year running that we have joined hands to mark the Day.

PSD 2021, saw IAPO members, patients, various healthcare organizations, policy-makers, academia, institutions, industry and other stakeholders come together to call for patient cocreation in the implementation of the *Global Patient Safety Action Plan 2021–2030 (GPSAP 21-30)* to ensure zero patient harm globally.

PSD 2021 theme, 'Patients Co-creating Safe Healthcare', allowed us to rally around a key tenet of IAPO's Patient-centred Healthcare Declaration that patients must be able to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives.

PSD 2021 was used as an opportunity to urge the whole of government and whole of society to work with the whole of the patient community in national unity and global solidarity to ensure that patients and families are engaged and empowered to help and support the journey to safer healthcare (Strategic Objective 4 of GPSAP 21-30).

Shape law, policy, and practice in patient centred-universal health coverage at global, regional, and national levels in 2021



74rd World Health Assembly

IAPO values its special status as a non-State Actor in Official Relationship with WHO and uses this privilege to advocate on important global health matters affecting our patient organisations by addressing the Member States at each World Health Assembly.

IAPO participated in the Special session of World Health Assembly 29 November 2021 - 1 December 2021. Due to the ongoing COVID19 restrictions, this special virtual session replaced the in-person World Health Assembly we were all used to.

IAPO made 4 interventions, addressing the WHO Member States on:

- Agenda Item 13.1 Global action on patient safety
- Agenda item 13.2 Political declaration on NCDs and Agenda item 13.3 Expanding access to effective treatments for cancer and rare and orphan diseases
- Agenda Item 13.7 Standardization of medical devices nomenclature
- Constituency Statement on Agenda item 17 and Agenda item 18

IAPO felt that while COVID19 raged, it distracted health systems from address our needs as many health services were suspended or curtailed. Patient safety become a serious issue as hospital acquired infections (COVID19) increased and patient harm due to medication and treatment errors increased in stressed health systems.

IAPO also saw the 'Moon Shot' that was the race to find an answer to our immunity to the virus unveil new health technologies and platforms (mRNA and AdeneoVirus platforms) that could help us increase access innovative cancer and rare diseases treatment. IAPO wanted personalised healthcare, precision oncology and gene and cell therapies to become institutionalised in healthcare and UHC.

SEE FULL STATEMENTS: https://www.iapo.org.uk/news/2021/jun/2/iapo-statements-74th-world-health-assembly-may-2021

WHO Regional Committees

IAPO repeated the same messages that we advocated on at the World Health Assembly at the Regional Health Assemblies:

We participated virtually in the WHO Regional Committees:

- Regional Committee for the Western Pacific
- Regional Committee for Europe
- Regional Committee for Africa
- Regional Committee for South-East Asia
- Regional Committee for the Americas
- Regional Committee for the Eastern Mediterranean Region

WHO World Patient Safety Day 2021

IAPO has now established the marking of the WHO World Patients Safety Day on 17 September as an annual event with our members. IAPO and its Members marked the day by promoting the theme Safe maternal and new-born care.

IAPO had a special webinar conference on safe and respectful maternal and new-born healthcare in prisons and refugee camps. IAPO's campaign attracted over 900 delegates to hear from Hon. Penilla Gunther MP, Member of Swedish Parliament, who has led maternal and new-born care reform in prisons and other social settings.

The delegates also heard from Lars Klingsbo, founder EEZER AB, the motor bike ambulance services in Africa, on how maternal and new-born mortality has been reduced through early and safe travel to antenatal clinics using motor bike ambulance. https://eezer.org/?lang=en



The delegates then heard from a number of organisations on child birth within refugee communities and the unacceptable conditions endured by the mother and new-borns resulting in high mortality and morbidity.

https://www.iapo.org.uk/news/2021/aug/23/announcing-world-patient-safety-day-2021

African Medicines Agency Treaty Alliance AMATA

The African Medicines Agency Treaty Alliance (AMATA) is a multi-stakeholder alliance set up to advocate for the ratification and implementation of the African Medicines Agency (AMA) Treaty and for meaningful engagement with patients and other relevant parties, in all aspects of the Agency framework.

The idea of the alliance was born in view of the urgency unveiled by COVID-19 where IAPO saw the need to support African patient organisations access to safe and quality vaccines, medicines, personal protection equipment, health devices and diagnostic kits to face present and future pandemics.

Together with a group of 46 organisations (now 55), IAPO issued in February 2021 a Multi-stakeholder Call for AU Heads of State to Ratify the AMA Treaty. The Call highlighted the importance of including in the governance of the future Agency, a mechanism to engage with a range of stakeholders who would benefit from regulatory harmonisation and could bring their expertise to the discussion.

The Multi-stakeholder Call was inspired by the Entebbe Statement, an earlier declaration made by patient organisations at IAPO's Patient Regional Congress in Uganda in 2017, calling for early drafting, adoption and ratification of the AMA Treaty and advocating for patient engagement in all aspects of the Agency framework.

AMR Patient Alliance building awareness and capacity

IAPO has gone strength to strength with our partner patient organizations from different regions and countries in advancing our Global Patient Consensus Statement and a Call to Action. The newly formed AMR Patient Alliance has convened civil society groups representing patients, carers and advocates in a global alliance to address the AMR pandemic. The AMR Patient Alliance is a place where patients can exchange views, be educated, and acquire knowledge andresources that we need to raise awareness about the importance of sustaining the efficacy of antibiotics - foras long as possible, for as many patients as possible. Learn more about the Alliance here: https://bit.ly/3nE4GLF

IAPO in the Fight the Fakes Alliance in 2021

IAPO as a founding member of the new Fight the Fakes (FTF) Alliance, a new multi-stakeholder non-profit association registered in Geneva (Switzerland), continues to fight against fake falsified medicines. IAPO has been a partner in this alliance for over seven years since it was first set up &a grassroot advocacy campaign. IAPO is on the governance structure and the FTF Alliance is taking the fight against substandard and falsified medicines to the next level. We now have over 20 large alliances as members. We have joined health care professionals, manufacturers, wholesalers, researchers and patients. The Alliance is uniquely positioned to scale up action to prevent falsified medicines from endangering people's health and well-being. More information on this: See our Activity https://fightthefakes.org/events/



Driving research processes and development of evidence base for patient centreduniversalhealth coverage in 2021

IAPO Scientific Advisory Board

IAPO Scientific Advisory Board continues to support the organization in its scientific programme in ensuring that patients have access to quality safe and evidence based healthcare. The inaugural Scientific Board and its membership can be found here: https://bit.ly/38scZ6L

Metrodora Award – recognising outstanding women achievers in science and health

IAPO in partnership with Viatris introduced the first international Metrodora Awards, named was a Greek physician who lived between 200 to 400 CE and wrote the first known medical text tobe authored by a woman, to empower and recognize women leaders who are delivering positive changes in healthcare and research.

The 2021 Metrodora awards have been postponed to March 2022 because of COVID19 restrictions. https://metrodoraawards.org/

ISPOR - The Professional Society for Health Economics and Outcomes Research

IAPO continues to collaborate with and contribute towards ISPOR conferences and research programmes.

ISQua - The International Society for Quality in Health Care

IAPO continues to work with ISQUA to improve research and development of good practice globally to improvae access to quality universal health coverage 2030.

Patients for Patient Safety Observatory

IAPO has established a partnership with Patient for Patient Safety Observatory (P4PS Observatory) Geneva too have a single-point global establishment platform for gathering and analysing patients' expertise and experience that would feed into the national, regional and global policies aimed at improving safety and quality of care for patients and by the patients.

The reason why P4PS Observatory was formed was because patient harm has become a great public health problem, and it now requires expert patient oversight and co-creation. To do this, the P4PS Observatory has put patient led research into practice, and patient experience back into research. Patient harm not only causes great suffering, injury and death, it also erodes public trust in healthcare systems andcosts billions of USD to address compensation and fines. The WHO Director General in his report and Resolution WHA 72.6 May 2019 Global Action on Patient Safety has asked every WHO Member State to produce plans to implement this resolution in the global consultation WHO Flagship "A Decade of Patient Safety 2020-2030": https://bit.ly/2KFN1Vg

Duke NUS Singapore and IAPO HTA Research in Asia Pacific and LMIC

IAPO has initiated research in Health technology Assessment and patient engagement in Asia Pacific and Low- and Middle-Income Countries with Duke NUS Singapore. Results will be published in June 2022



Published research papers

Person Centred Value based Healthcare (Sprink, IAPO et al) https://sprink.co.uk/files/2021 09 01 PCVBHC Report.pdf

Self-Care Readiness Indicator (World Self Care Federation https://bit.ly/3BrAafJ)

The impact of COVID-19 on the care of patients with noncommunicable diseases in low-and middle-income countries: an online survey of patient perspectives (R devi et al https://bit.ly/36kXBvN)

A Methodology for Mapping the Patient Journey for Noncommunicable Diseases in Low- and Middle-Income Countries (R. Devi et al https://bit.ly/3Bn8hW8)

IAPO Members survey

IAPO conducted a survey to help identify ways of strengthening collaboration among IAPO members' network and ensure we prioritise our resources and continue to respond to our member organizations' priorities and needs throughout and beyond the pandemic. Results to be launched in 2021.

Communications

Newsletter: Our monthly newsletter reaches out to over 5900 subscribers and has covered our congresses, member activities, the COVID-19 pandemic news and information. In 2022 we are encouraging more patient organizations to submit articles for publication.

Twitter: @IAPOvoice and @PatientSolidarityDay

Facebook: We operate IAPOvoice, International Alliance of Patients' Organizations, African page and Patient Solidarity Day

Website: Continues to be the main focal point for IAPO's dissemination and communications activities. We have seen an increase in number of page views: with over 100,000 page views in 2021 compared to 92,154 in 2020. www.iapo.org.uk