

## IAPO HIGHLIGHTS 2022

### INNOVATION, ACCESS, GOVERNANCE AND EQUITY

#### Background to the activities undertaken in 2022.

The international Alliance of Patients Organizations adapted its 2023 strategy to match the rapid and chaotic post-pandemic healthcare ecosystem changes that our members were experiencing.

Our 2022-24 Strategic Plan had to be modified to not only meet the demands of these rapidly changing current external healthcare ecosystem, but also to ensure that we build back a better universal health coverage 2030 by ensuring that patient centred healthcare is not undermined in the recovery phases going on globally.

We aimed to keep our health systems safe, accessible, acceptable, affordable, and non-discriminatory, delivering quality healthcare throughout the build back better phases.

In 2022 IAPO advocated that the whole of government-society and- industry increase investment in building back better and FAIRER. Health systems This required that we must:

- Empower patients.
- Drive patient led research into patient preferences and global health systems.
- Shape law, regulation, policy, practice, and standards.

We requested our membership, alliances, and industry partners to support us in 2022 in the following areas:

#### IAPO activities in innovation and access

IAPO established new alliances and networks and held webinars empowering patients, driving research, and shaping law, policy, practice, and standards framework to improve patient centred healthcare and open access in the following innovative health technologies:

- Personalised healthcare and precision medicine (genomic medicines). IAPO set-up the Personalised Cancer Care Alliance in 2022 to leverage the increasing public awareness on the biotechnology and genomic medicine to find Covid19 vaccines to promote advances in immunotherapy. We held 6 webinars to mark the advances and benefits of biomarkers, early diagnosis (liquid biopsies), precision oncology, targeted therapies, and monoclonal antibodies within the remit of immunotherapies (CAR-T and BiTE etc).
- Digital health- Digital health is an all-encompassing approach that has a transformational impact in not only high-income countries, but also in low- and middle-income countries. For a start, digital health is needed to ensure we deliver universal health coverage in time globally. DH can improve access to health care services for all, especially for hard-to-reach communities. DH is important in delivering patient safety and quality in healthcare services and medicines. DH has a bigger reach and impact for LMICs in health literacy as it can improve knowledge and access of health workers and communities to health information. For health economics, DH promises cost savings and efficiencies in health services delivery. Lastly, when all the government and economy is digitalised, DH can integrate with e-economy and e-social welfare and change the social, economic, and environmental determinants of health.
- Virtual clinics and telehealth care- This is digital health's specific application. The pandemic has ensured public acceptance of remote healthcare support and advice. Virtual clinics with e- prescription and online pharmacies has made healthcare accessible for hard-to-reach groups. This development also brings its own safety, ethical and governance issues.
- Self-care- Digital healthcare and virtual clinics means that a lot of healthcare has moved out from the healthcare facilities and into the patients' homes. This has important consideration for health literacy, safety,

ethics, and support. With QR Code and GS1 Standards, medicines and health devices can now have better and enabling patient information, support, and after purchase services.

- **AI and Machine Learning:** IAPO is supporting artificial Intelligence, machine learning and robotics in healthcare to free up the healthcare teams from routine and operational tasks to devote more time to deal with the human element of medicine practice and patient care. AI with digital health will improve early diagnostics and pick out patterns from big data that can improve personalisation of healthcare and its effectiveness, patient safety, and experience.
- **Patient Engagement in Research and Development.** IAPO is supporting the development of national EUPATI type of structures and Patient Academies. IAPO is engaging the European Union and EMA on their improved pathways for patient engagement in medicines development, end to end. Early and through value chain patient engagement.
- **Humanising Healthcare- Al-Jazeera TV Patient Quote:** The pandemic has robbed many health systems of their humanity. Post pandemic, many health systems are moving from patient centred to person centred and then humanisation of healthcare. We want to build back better and fairer health systems that have equity and compassionate healthcare at their heart. For a pandemic prepared health system, the corner stone is the patient centred healthcare with its focus on the patient and his/her personal needs and preferences regarding the disease and its treatment. We then have the personalised health care (stratified healthcare) that looks at the whole patient and their social determinants of health from health literacy, promotion, prevention, treatment, rehabilitation, palliative care, and end of life (a person-centred life course approach). We then have the WHO Framework on Integrated and People Centred healthcare. This together with WHO's compassionate healthcare that looks at humanisation of care by focussing on ALL stakeholders involved in care. It humanises health system processes and structures.

## Governance

Good governance in healthcare enables patient engagement and co-production, and enhances patient safety, quality, and access. IAPO is engaging in:

- **WHO Global Patient Safety Action Plan 2021-2030:** IAPO has supported this flagship programme of the WHO from its earliest inception. 194 WHO Member States adopted this plan. The plan has is an authoritative policy instrument that now places on obligation on the State to undertake certain measures to reduce avoidable patient harm to zero. There is a 7x5 Matrix that requires all stakeholders, including patients and families, to address patient harm effectively: <https://apps.who.int/iris/rest/bitstreams/1360307/retrieve>
- **Regulatory and HTA ecosystems** IAPO is keen on shaping the governance in the Regulatory and HTA ecosystems to ensure that patients can co-produce, through co-creation, a seamless and enabling regulatory and HTA ecosystem that ensures we get timely access to safe, quality, acceptable, accessible, and affordable innovative medicines, and health devices/products. IAPO wants to shape the regulatory and HTA pathways so that they allow patient engagement in all decision-making. As part of IMI Prefer, IAPO are looking at how EMA and EUNetHTA are working seamlessly. IAPO is also looking at NICE UK and its guidance on how patients can work with HTA and MHRA UK. IAPO wants the role of patients be strengthened in all health technology assessment bodies and to ensure that patient preference and real-world data is used all financial modelling and decision-making.
- **Data Governance:** As health informatics, and especially bioinformatics, is central to innovation and development of precision medicine, personalised healthcare, and digital health. IAPO is focussed on ensuring that we have proportionate and a collective response to the Big Data response in current health data governance frameworks. We don't want to lose the opportunity offered by Big Data to advance innovation, personalised healthcare, precision medicine and access in our health systems by having inappropriate data protection, privacy, and other information safeguards. We can make sure our healthcare is safe, quality, acceptable, accessible and affordable, while instituting a framework respecting patient rights, privacy and human dignity, we want to see proportionate responses by the State, the regulators and the patient community.
- **Transparency International:** IAPO supports the work of Transparency International's Health Sector

programmes to improve information, accountability, and patient and citizen participation in good governance.

## Equity

- UHC 2030, Healthcare Financing and Patient/Public/Private Partnerships Universal Health Coverage means improving ACCESS. This means that all individuals and communities receive the health services they need without suffering financial hardship. IAPO is supporting the initiative by WHO and the UN Declaration on UHC 2030 to ensure that all out of pocket expenditure is first reduced. IAPO wants the dual roles of the State as a regulator and a provider of healthcare services, as in many countries, to be strengthened through patient engagement and oversight in all decision-making affecting health financing and the safety, quality, accessibility, acceptability, affordability, and non-discriminatory aspects of health care delivery. IAPO will work with the World Bank, Regional Development Banks and the economic cooperation authorities in each region to advocate provision of UHC 2030.
- Rare Diseases: The UN Resolution on Persons Living with a Rare Disease December 2021 is the first-ever UN Resolution on “Addressing the Challenges of Persons Living with a Rare Disease and their Families.” IAPO is mindful that the Moon Shot that was the race to find a vaccine has unleashed many genomic health technologies. Its important our patients have access these very early on.
- Paediatrics UN Convention on the Rights of the Child and other frameworks require that the health of children must be addressed through child patient centred approaches throughout the healthcare value chain. This starts with clinical research and medicines development that engages children and is not an afterthought, or worse still recommending off label use of adult medicines. Paediatrics forms a vertical and we can look at childhood diabetes, cancer, mental health and lung diseases with a special focus.
- Women’s Health: With IAPO’s Metrodora Awards in place now, it is important that we advance engagement of women patients in healthcare decision making and medicines and service development.
- Mental Health: As mental health is part of 5x5 NCD initiative, IAPO want to pursue this area of patient engagement as a special programme. With the prediction that mental health will become a critical issue post-pandemic, we will integrate mental health in all our programmes.

## IAPO ACTIVITY AND HIGHLIGHTS 2022

In 2022, the first year of our 2022-2024 Strategic Plan, our vision was to attain a Patient Centred (PC) and Pandemic Prepared (PP) Universal Health Coverage (UHC 2030) 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 2022 strategy was to:

1. Empower patient communities globally to advocate effectively for patient-centred and pandemic prepared universal health coverage for all.
2. Drive research processes and the co-creation of evidence base in support of patient-centred and pandemic prepared universal health coverage and strengthen patient involvement in clinical research and global health institutes.
3. Shape law, policy and practice by applying the empowered patient community and evidence base created to shape the institutional, law, policy, practice, and standards framework to bring about patient-centred and

pandemic prepared universal health coverage at global, regional and national levels.

## **Empowerment in 2022**

IAPO has been collaborating with several organisations in 2022 in developing resources for patient groups on specific areas of:

- Health Literacy
- Patient Safety
- Antimicrobial Resistance
- Personalised Medicine

### **Empowering patients through Congresses**

In 2022 IAPO used two Regional Congresses as capacity building events to empower our patient groups in Latin America and Asia-Pacific. The Congresses are our flagship event where we bring together our membership with a variety of high-level health care stakeholders to discuss important issues for patients worldwide.

The 1st Virtual Latin American Patients Congress programme and videos can be accessed here:

- [1st Virtual Latin American Patients Congress General Information](#)
- [1st Virtual Latin American Patients Congress Full Programme and Speaker Session Details and Recordings](#)

The 4<sup>th</sup> Asia Pacific Patients Congress programme and videos can be found here:

- [4th Asia-Pacific Patients Congress General Information](#)
- [4th Asia-Pacific Patients Congress videos](#)

### **Empowering patients through health literacy**

IAPO in collaboration with Viatris created the Patient Academy whose vision is to create communities of empowered patients that take ownership in the management of their medical condition through customized health information. The site currently features different modules based on specific medical conditions. It provides patients access to disease awareness videos, posters, patient stories, frequently asked questions, additional resources and contact details for support centres. Some of the topics are: Atopic Dermatitis, Mental Health, Cardiovascular Disease, Hepatitis, Oncology, Pain and Digital Health.

### **Empowering patients on quality primary healthcare in the UHC 2030 equation**

IAPO believes that primary healthcare (PHC) is primary for a reason - it is closest to patients and caregivers and can provide the most comprehensive, holistic and continued care. In line with this, we collaborated with IAPO Patients for Patient Safety (P4PS) Observatory and the Primary Health Care Performance Initiative (PHCPI) to drive greater action, investment, accountability, and improvement for strong primary health care globally. As part of this project, we conducted a survey to understand what can be improved in PHC for acute conditions and continuity of care for patients with chronic and multimorbidity status. See the results here:

To mark UHC Day, on 12 December 2022, we organised a webinar titled: "How important is safe and



quality primary healthcare in the UHC 2030 equation?” to discuss the importance of a safe and quality primary healthcare (PHC) as part of UHC. See the recording here: <https://youtu.be/al596Ac8UeI>

Lastly, we stood with 150+ organizations to urge action on PHC through launching of the Allies Improving PHC’s Open Letter during UNGA 77, urging leaders to prioritize primary health care as a 3-for-1 investment in universal health coverage, health security and better health and well-being.

## **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 4<sup>th</sup> Asia Pacific Patients Congress, IAPO held a session titled ‘Translating the WHO Global Patient Safety Action Plan - Patient and Family Engagement Section into National Patient Safety Networks and Alliances in Asia-Pacific’ which raised awareness and developed common strategies to advance WHO’s Global Patient Safety Action Plan’s fourth strategy to Engage and empower patients and families to help and support the journey to safer health care.

## **Patient Solidarity Day 2022**

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

On Friday 9th December 2022, health stakeholders from all over the world stood together, united in celebration of Patient Solidarity Day (PSD). This was the tenth year running that we joined hands to mark the Day. PSD 2022, saw IAPO members, patients, various healthcare organizations, policymakers, academia, institutions, industry and other stakeholders come together to call for medication safety in recognition of the prevalence of medication-related harm. PSD 2022 theme, ‘Patients for Medication Safety’, 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 2022 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 2022**

### **IAPO collaboration with the World Health Organization in shaping global health policy in 2022**

#### *WHO Executive Board 150th session, January 2022*

The 150th session of the World Health Organization’s Executive Board (EB) took place virtually on 24th - 29th January 2022. Thanks to IAPO’s official relations status with the World Health Organization, we leveraged this meeting by delivering three statements in line with our call for global patient-centred healthcare.

IAPO made 3 interventions, addressing the WHO Member States on:

- Agenda Item 7: Political declaration of the third high-level meeting of the General Assembly on the prevention and control of non-communicable diseases
- Agenda item 7b: Draft recommendations to strengthen and monitor diabetes responses within national non-communicable disease programmes, including potential targets
- Agenda Item 14: Standardization of medical devices nomenclature

SEE FULL STATEMENTS: <https://www.iapo.org.uk/news/2022/feb/22/iapo-statements-who-executive-board-150th-session-january-2022>

### *75<sup>th</sup> 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 75th session of the World Health Assembly on 22 May 2022 - 28 May 2022.

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

### *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

### *Side event at WHO Regional Committee for Africa:*

On 24 August 2022, IAPO held a virtual side event to the World Health Organisation (WHO) Regional Committee for Africa on how African Patient Organizations can influence change in Africa by becoming non-State actors in official relations or an accredited organisation in WHO Africa. With the WHO's Regional Committee for Africa adopting, for the first time, a procedure for accreditation for regional non-State actors not in official relations with the WHO to participate in the sessions of the WHO Regional Committee for Africa, our event was an opportunity to come together to review the requirements for the accreditation process and how we can work together to ensure more patient organizations in Africa achieve this status.

### *Side events WHO Regional committee Southeast Asia in Bhutan*

[Side-Event 1- How are you going to mark world patient safety day in WHO SEA on 17 September 2022?](#)

What do you need to prepare to promote Medication Without Harm this WPSD : Know, Check, Ask ?

IAPO convened a meeting in Paro at the Tashi Namgay Conference Hall that was easily accessible to the main Regional Committee Le Meridian Conference Centre to discuss ideas with WHO Member States on making the



World Patient Safety Day a great event. We shared our ideas and directed people to the Official Campaign site. We wanted to make sure that on 17th September 2022, the whole of government, whole of society and the whole of patient movement marks World Patient Safety Day. 20 NSAs and 7 High Level Member States and Bhutan Minister of Health dropped in to wish us good luck. 150 People attend the event.

### Side-Event 2 A compassionate and humanised health system will always deliver safe healthcare to all everywhere.

Our local partner, Bhutan Visit, provided free guides and transport to help our 60 delegate participants to get to TaktSang Conference Centre at the base of the TaktSang Monastery (AKA Tiger's Nest).

We had a small walk with 60 participants along an exciting trek historic and gathered at a local Monastery on the foothill. Due to the inclement weather, this walk could not be carried out to the top and the Tiger's Nest and we ended up holding a small assembly (Sangha) at the TaktSang Conference Centre and followed by a local cultural programme and country cooking meal. We had a high Lama come and discuss with us the nature of compassionate and humanised healthcare Southeast Asian culture.

This event was a follow-on side-event from our initial side-event at the 75th World Health Assembly in Geneva in May 2022. The Bhutan Ministry of health sent the Director of Public Health to speak on behalf of Health Minister of Bhutan Her Excellency Dasho Dechen Wangmo, we also shared this session with WHO Patient Safety and Quality Units, International Council of Nurses (ICN), World Medical Association (WMA), International Experience Exchange with Patient Organizations (IEEPO) and IAPO about compassion in healthcare and Bhutan's Service with Care and Compassion Initiative (SCCI).

IAPO highlighted WHO's commitment to compassion in healthcare as promoted in their:

- Policy recommendation: Policy Levers to Enhance Health Workforce Performance for Compassionate and Respectful Care (2021) <https://bit.ly/3RIUPIE>
- Learning Briefs: The role of compassion in maintaining EHS during the COVID-19 pandemic (2022) <https://bit.ly/3pZcASr>

IAPO also highlighted IEEPO Position Paper Humanising healthcare: a call for transformational change. <https://bit.ly/3COwpDM>

### Side event 3- Bhutan Traditional Sports with Patients Organizations

We held archery and Kuru darts Disability Olympics in Paro on Sunday with Bhutan Cancer Society and patients from the local children's care home and hospice, including a local dialysis treatment centre. A cultural programme followed with prize giving to best archers and dart throwers, and dancers.

### WHO World Patient Safety Day 2022

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 Medication Safety and calling for Medication Without Harm.

IAPO in collaboration with the International Council of Nurses (ICN), International Federation of Pharmaceutical Manufacturers & Associations (IFPMA), International Pharmaceutical Federation (FIP) and World Medical Association (WMA) had a special webinar conference to demonstrate commitment to the WHO Global Patient Safety Action Plan 2021 and advocate for all governments, key stakeholders, and partners to deploy patient safety as a priority in all health sector policies and programs. The event achieved the following:

- Triggered a collective discussion amongst relevant health stakeholders and sealed their commitment towards patient safety in their respective areas of action.
- Showed that all the actors of the health system are aligned and working in partnership.
- Demonstrated our efforts to provide the highest quality health care and products to patients.
- Reminded colleagues of the importance of investing in reliable and resilient health systems and health workforces.

- Showcased practical ways in which each health actor can further patient safety.

### Personalised Cancer Care Alliance

In 2022, IAPO set up the [Personalised Cancer Care Alliance \(PCCA\)](#), an alliance of cancer patients, carers and representatives of patient organizations from within the WHO Eastern Mediterranean and selected countries from WHO Africa and Europe to advance health literacy in cancer, advocacy skills and education on personalised cancer care.

In 2023, the Alliance launched [a position paper on personalised cancer care \(PCC\) in the Eastern Mediterranean](#), the first of its kind in the region to put PCC in the spotlight of high level policy makers while providing a comprehensive road map for patients' organizations and civil society to advocate and lobby for PCC. The paper sets the baseline for further discussion and development of personalised cancer care within our health systems and regions to ensure we have a predictive, preventative, participatory, personalised and pre-emptive (5 Ps) cancer care.

### 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.

On Wednesday, 14 December 2022 the African Medicines Agency Treaty Alliance (AMATA) held an **official side event at the Conference on Public Health in Africa (CPHIA 2022)** on the African Medicines Agency. General consensus was that it was a successful session and that CPHIA was a great opportunity to advocate for AMA and the need for regulatory strengthening in Africa and make the link with pandemic preparedness.

There is a “before Kigali and after Kigali” for AMATA, as having most AMATA founders united, advocating on the ground and meeting in person, made the Alliance stronger. The side-event concluded with Kigali Declaration: **The Time is Now: AMATA Calls for the rapid operationalisation of the African Medicines Agency and for regulatory system strengthening to be recognized as a key element of preparedness for future pandemics and post-pandemic recovery.**

On Wednesday, 27 April 2022, we **launched the AMATA webinar series – AMATA in conversation with key opinion leaders on the shaping of the African Medicines Agency (AMA)**. The webinars were fashioned as a unique opportunity to hear from leading figures from the continent's health policy landscape on the future of AMA and how non-state actors can get involved from the get-go. Bring your questions. Our first guest speaker was Dr. Margaret Agama-Antyetei, who shared the next steps in the operationalization of AMA, who are the actors involved and how patients, industry and civil society can contribute to the development of the Agency.

On Wednesday, 28 September 2022 we held **the second webinar of the AMATA webinar series – AMATA in conversation with guest speaker Hon. Michel Sidibé**, Africa Union Special Envoy for the African Medicines Agency (AMA). He shared the next steps in the development of AMA, both at political and operational level, how we can ensure AMA includes a framework of meaningful engagement with patients, industry, academia and civil society, how we can further align to make meaningful contribution, as a coalition of non-state actors, to the implementation of AMA, as well as how AMATA can help complete the ratification process and shape the future of the Agency and so much more.

### 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 and resources that we need to raise awareness about the importance of sustaining the efficacy of antibiotics - for as 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 2022**

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 as a grassroots 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 centred-universal health coverage in 2022**

### **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 Viatrix held the second edition of the international Metrodora Awards, following the success of the inaugural event in 2020. The international Metrodora Awards 2022 continued the legacy of recognising women leaders and innovators who have made significant contributions across all disciplines of scientific research, clinical practice, health education, health policy, and mental health as well as patient advocacy around the world, especially in key emerging regions of Emerging Asia, Latin America, Africa, Russia/CIS and the Middle East.

The 2022 Metrodora Awards showcased the outstanding achievements and dedication of eminent women in science and medicine around the world. We believe female innovators will continue to play a leading role in encouraging more women and girls to pursue their dream of making more positive contributions in driving scientific and medical breakthroughs.

Watch the event highlight video to get a recap of the Awards and the inspiring speeches from key speakers and winners: <https://www.iapo.org.uk/news/2022/aug/10/2022-metrodora-awards-winners>

### **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 improve 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 research development 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 and costs 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>

### Research Collaboration

#### CIOMS

The Council for International Organizations of Medical Sciences (CIOMS) is an international, non-governmental, non-profit organization established jointly by WHO and UNESCO in 1949. CIOMS represents a substantial proportion of the biomedical scientific community through its member organizations, which include many of the biomedical disciplines, national academies of sciences and medical research councils. CIOMS mission is to advance public health through guidance on health research including ethics, **medical product** development and safety.

IAPO has been collaborating with CIOMS in 2022 and this collaboration led to the co-production of the influential CIOMS Patient involvement in the development, regulation and safe use of medicines Working Group X Report. <https://cioms.ch/publications/product/patient-involvement/>

#### Getreal Institute

IAPO continues its collaboration with the Get Real Institute. We are building on our collaboration success of two IMI projects: GetReal and The GetReal Initiative (learn more), and have brought together a wide variety of stakeholders to drive the sustainable development and adoption of tools, methods and best practices in the generation and use of RWE (real world evidence) for better health care decision-making.

The GetReal Institute is:

- A Platform to reach common understanding and prioritisation of critical opportunities and challenges in the generation and use of RWE
- An Incubator and "design lab" for strategies and tools to clarify scientific and operational uncertainties in RWE approaches and methods
- A Source of trusted, high quality RWE education and training resources
- A Hub for connecting RWE-related initiatives within Europe and beyond

#### IMI Prefer-Patient Preferences

PREFER was set up to research and develop instruments, policies and guidelines to elicit patient preferred outcomes. The recommendations were to support development of guidelines for industry, Regulatory Authorities and HTA bodies on how and when to include patient perspectives on benefits and risks of medicinal products.

Over the last five years, collaborated on running patient preference studies in both academic and industry settings. The Prefer Partners and their experience provided a better understanding of what effective, efficient and equitable recommended best-practice approach to patient-preference studies. IAPO with Prefer demonstrated how patient preference studies can give valuable information to support decision making for regulators and HTA bodies. See Recommendations: <https://zenodo.org/record/6470918#.YmgoMO1ByUK>

## Membership

### IAPO's Annual General Meeting

IAPO held its Annual General Meeting on Saturday 26 February 2022 at 12.00pm GMT. At the AGM, we announced the results of the Governing Board Elections which saw the following Board Members elected to IAPO's Governing Board:

- Lara Bloom, The Ehlers-Danlos Society (UK Resident)
- Tony Holland, International Prader-Willi Syndrome Organisation - IPWSO (UK Resident)
- Ellos Lodzeni, Patient and Community Welfare Foundation of Malawi - PAWEM (African Region)
- Paul Albert S. Mendoza, Psoriasis Philippines (Western Pacific Region)

### Launched the Network Membership Category

We launched a new opportunity to join our global alliance of patient organizations and help us promote patient-centred healthcare across the world. In addition to the existing Full, Associate, and Affiliated membership categories, we now offer the Network Membership: a free membership category available to those organizations who want to be part of our network but have no means to pay for fees. The Network Membership is available to those patient organizations or healthcare-related organizations, networks or alliances committed to improving healthcare and to the principle of patient-centred healthcare.

### Pandemic Rebate and Hardship Discounts

The pandemic saw many patients' organisations fold. Those that remain are all working to very thin budgets and have boards, staff and volunteers who are exhausted. IAPO agreed to give a rebate on the membership fee and wrote off their fee debt. Going into 2023 and 2024 we have to review how we can include more patient organisations from low- and middle-income countries to join us and participate with us without paying fees as Membership Fee forms a small part of our overall income.

## Communications

*Newsletter:* We doubled our newsletter subscription number from 5900 to 12070 subscribers who receive our monthly newsletter which covers our congresses, member activities, Patient centred advocacy news and information. In 2023 we are encouraging more patient organizations to submit articles for publication.

*Twitter:* [@IAPOvoice](#) , [@PatientSolidarityDay](#), [@AfricanAmata](#), [@PCCAlliance](#)

*Facebook:* We operate [IAPOvoice](#), [International Alliance of Patients' Organizations](#), [African page](#), [Patient Solidarity Day](#), [Personalised Cancer Care Alliance](#)

*LinkedIn:* [International Alliance of Patients' Organizations](#), [Metrodora Awards](#), [Personalised Cancer Care Alliance](#).

*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 105,000 page views in 2022 compared to 82,100 in 2021. [www.iapo.org.uk](http://www.iapo.org.uk)