

ACTIVITIES PLANNED IN 2022

INNOVATION, ACCESS, GOVERNANCE AND EQUITY

Background to the activities to be undertaken in 2022

The international Alliance of Patients Organizations must adapt its strategy to match the rapid and chaotic post-pandemic healthcare ecosystem changes our members are experiencing currently.

Our [2022-24 Strategic Plan](#) has been 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, ensuring that patient centred healthcare is not undermined in the recovery phases going on globally.

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

In 2022 IAPO is going to advocate strategic whole of government-society and- industry investment in build back better and FAIRER. This means we must:

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

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

IAPO activities in innovation and access

IAPO is 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:

- **Gene and Cell Therapies.** IAPO backed the RDI UN Resolution4Rare. This builds on our 2019 Gene and Cell Therapy Tool Kit launched at WHO WHA 72. We want to raise more awareness and improve advocacy to ensure gene and cell therapies become a standard part of the essential medicines list in all WHO Member State UHC 2030. The Moon Shot that was the COVID19 vaccine race has liberated many technologies that can address new therapeutic areas, and this bodes well for rare diseases



- **Personalised healthcare and precision medicine (genomic medicines).** This gives us an opportunity to leverage the focus on increasing public awareness on the biotechnology and genomic medicine engaged in the Moon Shot to find Covid19 vaccines. We want to build upon advances in immunotherapy. We start from biomarkers, early diagnosis (liquid biopsies), precision oncology, targeted therapies, and monoclonal antibodies within the remit of immunotherapies (CAR-T and BiTE etc).
- **Cancer Vaccines** IAPO is putting these new Vaccines are medicines that help the body fight disease. They can train the immune system to find and destroy harmful germs and cells. There are many vaccines that you receive throughout your life to prevent common illnesses. There are also vaccines for cancer. There are vaccines that prevent cancer and vaccines that treat cancer.
- **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- AI-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 EUNeHTA 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.

ACTIVITIES TO BE UNDERTAKEN IN 2022

1. EMPOWERMENT

- Personalized Cancer Care Alliance- Development and empowerment of WHO Eastern Mediterranean (MENA) patients’ alliance with Al Hazar University
- Creating a Moodle Platform for Patient Education to host:

- New Resource on Digital Health
 - New Health Technology Assessment and Value Based Healthcare Resource (EUNetHTA collaboration)
 - New Personalised Cancer Care/ Precision Oncology Resources and Briefings on Cancer Vaccines
 - New Biosimilars Toolkit
 - New Gene and Cell Therapy Tool Kit
 - Global Patient Safety Action Plan (Duke NUS Singapore Resources)
- Develop WHO Global Patients Safety Action Plan (Duke NUS Singapore) Patient and family engagement briefing resources and capacity building events
- Webinars:
 - 6 Webinars on Personalised Cancer Care
 - 4 Webinars on Biosimilars
 - 2 Webinars on Global Patient Safety Action Plan
- 2. EMPOWERMENT THROUGH IAPO CAPACITY BUILDING EVENTS**
- Latin American Patients Congress Virtual Argentina June 2022
 - Global Patients Congress UAE September 2022
 - 4th Asia Pacific Patients Congress Virtual Thailand Nov 2022
- 3. SHAPING LAW, POLICY, STANDARDS**
- Forming and supporting the African Medicines Agency Treaty Alliance (African AMATA) and securing it a seat at the African Union and African Medicines Agency
 - Health Technology Assessment (Duke NUS Singapore) develop our research findings to policy documents and patient education courses
 - Value Based Healthcare- Collaborate with Texas University and Prof Elizabeth Teisberg and pursue this work already conducted with [Global Centre for Person Centred Value-Based Healthcare](#)
 - Collaborate with The Global Coalition for Circulatory Health on NCD
 - Collaborate with the NCD Alliance
- 4. INSTITUTIONAL ENGAGEMENT ON LAW, POLICY AND STANDARDS**
- WHO:

- Engage on the Global Patient Safety Action Plan and the World Patients Safety Day 2022
- Participate in the World Health Assembly and make the appropriate interventions
- Participate in the Regional WHO Committee meetings in Africa, Eastern Mediterranean, Europe, Pan American (PAHO/WHO) Southeast Asia, and Western Pacific
- Asia Pacific Economic Cooperation- Engage and collaborate with APEC Health on all health and patient initiatives
- World Bank-Continue work with WB on UHC 2030
- EUnetHTA and INAHTA collaborate developing new patient engagement in HTA frameworks

5. DRIVE RESEARCH AND CO-CREATE EVIDENCE BASE

- Duke NUS Singapore and IAPO will continue its collaboration putting research into practice and practice back into research on HTA
- Duke NUS Singapore in Asia Pacific: Global Patients Safety Action Plan 2021-30
- Al Hazar University Cairo Egypt and IAPO will continue collaboration on African Medicines Agency engagement of expert patient researchers
- Continue research collaboration with IMI Prefer on engaging HTA and Regulatory Bodies on incorporating patient preferences into value-based health care consideration and in HTA and Medicines Licencing
- Continue research collaboration with Get Real Institution on engaging HTA and Regulatory Bodies on incorporating real world data into value-based health care consideration and in HTA and Medicines Licencing

APPENDIX TO ACTIVITIES 2022

ACTIVITY OUTPUTS YEAR 1 2022			
	<p>EMPOWER Empower members with cutting edge knowledge and advocacy skills to enhance the reach, efficacy, and impact of our membership in bringing about healthcare that is PC, PP and a UHC</p>	<p>DRIVE RESEARCH Co-create evidence based in support of healthcare that is PC, PP and a UHC and strengthen patient involvement in clinical research and global health institutes.</p>	<p>SHAPE LAW, POLICY, STANDARDS Apply the empowered patient community and evidence base created to shape the institutional, law, policy, practice, and standards framework for about healthcare that is PC, PP and a UHC at global, regional, and national levels.</p>



Form Respective Committees	<ul style="list-style-type: none"> Global Patient Safety Action Plan Group Personalised medicine, healthcare and cancer care Continue with African AMATA 	<ul style="list-style-type: none"> Maintain our Scientific Advisory Group Continue with the Duke NUS Committee 	<ul style="list-style-type: none"> Form a Committee with Advocates 4 International Development on Patient Charters
Assemble Respective Task groups	<ul style="list-style-type: none"> Congress Committees (LatAm, APC & EMR MEA) World Patients Safety Day Patient Academy Biosimilars 	<ul style="list-style-type: none"> HTA continue with Duke NUS. Form new group in Africa HTA 	<ul style="list-style-type: none"> Pandemic Preparedness Treaty participation
New Alliances	<ul style="list-style-type: none"> Continue work with Fight the Fake Personalised Cancer Care Alliances Joint work with Africa Rare Diseases Work with the Pandemic Preparedness Alliance 	<ul style="list-style-type: none"> Formalise the IMI Prefer (Patient Preferences) Alliance post finishing of project Continue work with the Get Real Institute 	<ul style="list-style-type: none"> Continue collaboration with Africa, Asia NCD Alliances Establish new links with NCD Latam Alliance
Conduct Appropriate Surveys	<ul style="list-style-type: none"> Expand the HTA Survey in WHO EMR Use IMI Prefer Patient Preference Recommendations with members 	<ul style="list-style-type: none"> Further Surveys on personalised medicine and cancer care Conduct studies on humanising health care 	Global patient safety Action Plan- Patient and family engagement surveys in other regions post APPC Duke NUS
Conduct Appropriate Consultations	WHO NCD WHO Patient Safety WHO Equity Survey Biosimilars Tool Kit		
Produce Appropriate Factsheets (FS)	Personalised medicine (cancer care etc)	Research on Personalised Medicine (cancer care etc) health literacy	WHO Policy on Genomic Medicine
Produce Appropriate Briefing Papers (BP)	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70
Produce Appropriate White Papers	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70
Conduct Appropriate Research Projects	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70
Publish Appropriate Research Reports	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70
Publish Appropriate Research Papers	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70
Produce Appropriate Practice Guidelines	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70	TBC in May 2022 after WHA 70
Produce Appropriate Toolkits	PCCA, Biosimilar and HTA	PCCA, Biosimilar and HTA	PCCA, Biosimilar and HTA
Conduct Light Courses	PCCA, Biosimilar and HTA	PCCA, Biosimilar and HTA	PCCA, Biosimilar and HTA
Conduct Full Accredited Courses	PCCA, Biosimilar and HTA	PCCA, Biosimilar and HTA	PCCA, Biosimilar and HTA
Produce Appropriate Newsletters	12 News Letters a year and 4 special issues on PCC and HTA	IAPOVoice	IAPOVoice
Promote IAPO On Social Media (Twitter FB)	IAPOVoice	IAPOVoice	IAPOVoice



Inform, Educate and Train using Webinars	5 webinars	5 webinars	5 webinars
Inform, Educate and Train using Conferences	IAPO GPC, APPC LatAM Conferences	IAPO GPC, APPC LatAM Conferences	IAPO GPC, APPC LatAM Conferences
Advocacy at the WHO WHA EB RC	WHA 70, WHO RC Afro, Euro, LatAm, Searo, WPRO	IAPO GPC, APPC LatAM Conferences	IAPO GPC, APPC LatAM Conferences
Advocacy Regulators ICDRA/AMA/EMA/FDA	EUPATI IAPO	HTA IMI Prefer	AMATA Africa
Advocacy UNGA			