



2019 ACHIEVEMENTS

Introduction

The International Alliance of Patients' Organizations' vision is to see patient-centred healthcare established globally.

IAPO's Strategic Plan was developed in 2017 and approved at the Global Patients' Congress in Miami 2018. IAPO members wanted to advocate the pursuit of the establishment patient-centred universal health coverage within all WHO Member States.

In 2019, IAPO's main programme engaged with UHC2030 Global Partnership on advocacy targeted at the *United Nations High Level Meeting on Universal Health Coverage* and participate in the process to formalise an acceptable *Political Declaration on Universal Health Coverage*.

Our 2019 programme and activities focussed on getting across the message that the attainment of the *United Nations Sustainable Development Goals Target 3.8 Universal Health Coverage* requires a Member State to adopt patient-centred healthcare in the heart of its healthcare policy and decision-making. It was important that all State and non-State advocate patient engagement and an acceleration of the momentum to establish patient-centric universal health coverage (PC-UHC) for all by 2030.

In 2019, IAPO Strategy built upon the achievements of 2018 and pursued a multi-agency and cross-stakeholder global effort to support our 3 strategic goals:

- Empower patient communities globally to advocate effectively for PC-UHC for all.
- Drive research processes and the development of evidence base for PC-UHC.
- Participate in the shaping of law, policy and practice towards PC-UHC at global, regional and national levels.

IAPO believes that a comprehensive PC-UHC will ensure the availability of a sufficient quantity of patient -centric, safe and quality promotive, preventive, curative, rehabilitative and palliative healthcare services in each country. These healthcare services, along with the essential and innovative medicines and health devices that compliment them, must be accessible, acceptable and affordable, and delivered without the patients suffering financial hardship or discrimination.

YEAR 2 OF STRATEGIC PLAN 2019

Goal 1 Empower patient communities globally to advocate effectively for PC-UHC for all.

Asia-Pacific Patient's Congress 13-14 Nov 2019 Taipei Taiwan

IAPO's Asia-Pacific Patient Congress was envisaged as a great two-day platform to bring together the regional patient movement in Asia-Pacific closer together and:

- To bring together all patients groups and key high level stakeholders in the region to discuss important issues concerning patients specifically from the Asia region
- To highlight IAPO's vision to see patients at the centre of healthcare throughout the world and its mission is to help build patient-centred healthcare and UHC worldwide
- To inspire patient groups to establish national patient alliances that will align and become members of IAPO

The APPC targeted:

- Patient advocates
- Government and policy makers
- Industry representatives
- Healthcare professionals
- Academics and researchers
- Regulators

The Congress was organized and co-delivered by IAPO's regional members Psoriasis Association of Taiwan (PAT) and the Taiwan Alliance of Patient Organizations (TAPO).

- [APPC Report](#)
- [APPC Photographs](#)

7th Patient Solidarity Day 2019: 'Accelerating Progress for Safe Patient-Centred Universal Health Coverage.

On Friday 6th December 2019, health stakeholders from all over the world came together, united in a celebration of Patient Solidarity Day (PSD). This was seventh year running that we have joined hands to mark the Day. On PSD 2019, IAPO members, patients, various healthcare organizations, policy-makers, academia, industry and other stakeholders came together to call for '*Accelerating Progress for Safe Patient-Centred Universal Health Coverage*' to guarantee safe healthcare for all.

2019 has been a great year for global health advocacy. There was a global commitment to achieve safe and quality Universal Health Coverage (UHC). Heads of State and Health Ministers made two ambitious and comprehensive commitments:

On 24th May 2019 the World Health Organization Member States unanimously adopted Resolution 72.6 Global Action on Patient Safety in Geneva to address global patient safety in concerted manner.

On 23rd September 2019 The United Nations General Assembly adopted the Political Declaration of the high-level meeting on universal health coverage in New York, strongly recommitting to achieving UHC by 2030 scaling up the global effort to build a healthier world for all.

On PSD2019, we called on all leaders to act on the promises they have made in 2019 to guarantee safe patient-centred universal health coverage for all.

On PSD2019 patient advocates raised their voices to share the stories of the millions of people still waiting for health, to call on leaders to make bigger and smarter investments in health, and to remind the world that a safe Health for All is imperative to create the world we want.

Link: www.iapo.org.uk/patient-solidarity-day

Membership Engagement

One of the main membership engagement activities this year was to reinforce our commitments on the main healthcare issues that needed to be addressed within IAPO's Strategy 2018-2020. and specify the goals and activities for the next three years. IAPO engaged its members and the wider stakeholder community to see how we can:

- Empower patient communities globally to advocate effectively for PC-UHC for all
- To drive research processes and strengthen patient involvement in research
- Shape law, policy and practice in PC-UHC at global, regional and national levels.

IAPO's 2019 membership engagement activity involved providing information, advice and support to our members on various issues during the year. During 2019 there were a number of issues that we engaged our members on.

- Patient Safety
 - WHA Resolution 76. 2 and 1st World Patient Safety Day
- Innovation
 - Biotherapeutics -Biologic and Biosimilar Medicines
 - Gene and cell therapy
 - Oncology and monoclonal antibodies and chimeras

- Rare Diseases and Disorders
- Antimicrobial Resistance
- Supply Chain, Safety And Regulations
 - Substandard & Falsified Medicines (Fight the Fakes)
 - WHO Patients for Patient Safety
 - Quality and Safety (Medication without errors)
 - Regulation and pharmacovigilance-African Medicines Agency and EMA
- Access
 - Access Survey- Structural and Social Determinants of Health
 - Access to Clinical Trials and Ethics
 - Health Technology Assessment and Health Finance
 - Non-communicable diseases
 - Primary Healthcare
 - Value Based Outcomes (VBO)
 - Carers and Self-Care
 - Multi-Chronic Conditions and Poly-Pharmacy

Goal 2 Drive research processes and the development of evidence base for PC-UHC.

IAPO believes that early patient participation in research activity allows IAPO to incorporate patient perspectives within it. Any evidence base and good practice emerging from this participatory approach will help us develop patient-centric healthcare and medicines, and ultimately realise our vision for a PC-UHC by 2030.

In 2019 we conducted our 1st Access Survey to determine the role that structural and social determinants played in shaping access for our members.

In 2018 IAPO has been involved in strengthening patient involvement in research to get to our primary objective of PC-UHC through three interventions:

- GetReal Initiative IMI
- PREFER IMI
- IAPO in-house research initiative

Since June 2018, IAPO has been involved in the GetReal Initiative. This is a two-year project of the Innovative Medicines Initiative (IMI). The IMI is a public-private consortium comprising researchers from the pharmaceutical companies, academia, HTA agencies, medicines regulators, patient organisations and other small to medium research enterprises.

GetReal Initiative's primary goal is to research upon and drive the adoption of evidence based tools, methodologies and best practices to increase the quality of real-world evidence (RWE) generation in medicines development and

regulatory/HTA processes across Europe. This helps IAPO as it will influence universal health coverage providers in planning their health finance, essential medicines lists and priorities far better.

PREFER initiative aims to establish recommendations 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. This is very important in ensuring a safe and quality PC-UHC.

Over the next five years, PREFER will run patient preference studies in both academic and industry settings. This patient voice and experience will provide industry, Regulatory Authorities and HTA bodies a better understanding of what is the recommended best-practice approach in patient-preference studies. It will also show how patient preference studies can give valuable information to support decision making for regulators and HTA bodies.

IAPO in-house research: From time to time, IAPO has collaborated with a number of research partners and written up joint speculative research proposals in partnership with these important research institutions. The collaboration in 2018 was with:

- **The Economic Intelligence Unit** (part of the magazine The Economist) - developed a collaborative research proposal patient electronic patient consent. The proposal has been finalised and we are waiting for a suitable research funding opportunity.
- **Institute for Prevention Research (IPRI)**- collaborated on two research proposal with them:
 - Bridging scientific Evidence, applications for Learning, policy Initiatives and public engagement for improving Vaccination among the Elderly
 - African Oncology- Follow up to their report: State of Oncology in Africa
- **TransCelerate BioPharma Inc (TCBP)**. IAPO is having ongoing discussions on the ASPIRE project (a collaboration with Novo Nordisk) to help patients engage with clinical trials and are building IAPO's relationship with TCBP
- **International Society for Quality in Health Care (ISQua)**. ISQua is a member-based, not-for-profit community and organisation dedicated to promoting quality improvement in health care. IAPO is working with them to improve the quality and safety of health care worldwide. IAPO endorses and supports ISQUA's education, knowledge sharing, external evaluation, supporting health systems worldwide and connecting like-minded people through our health care networks.

IAPO has also been working on developing some in-house membership surveys to support us to empower patient communities globally to advocate effectively for PC UHC for all. IAPO has ongoing work on:

- Systemic and Structural Factors affecting member organization's access to health
- Planning the policy research for 2019 in relation to the PC-UHC at global, regional and national levels.

Shape law, policy and practice in PC-UHC.

In order to shape law, policy and practice on a safe and quality PC-UHC, IAPO needed to engage a number of global and national institutions and use a range of policy instruments to support advocacy.

Engaging Institutions

Engaging the United Nations

Health is a political choice (WHO Euro). The United Nations Security Council and its five permanent members (China, France, Russia, the United Kingdom, and the United States) have considerable power and resources to influence global health issues. The 2014 Ebola outbreak in West Africa signified this power when the global impasse and inaction was broken by President Barack Obama, acting as a UN Permanent Member of the Security Council, when he mobilised the Centres for Disease Control and the United States Army.

UNGA 2018. The United Nations General Assembly is the next most powerful global entity that can impact global health. In September 2018, IAPO attended the 73rd United Nations General assembly and participated in the third High-Level Meeting called to review the implementation of the 2011 Political Declaration of the High-Level Meeting of the UN General Assembly on the Prevention and Control of Non-communicable Diseases.

IAPO advocated that patient participation and engagement within the comprehensive review of the global and national progress achieved in putting measures in place that protect patients from dying too young from heart and lung diseases, cancers and diabetes was extremely important.

IAPO reiterated that while most of the NCD control strategy has been driven by public health bodies in changing laws and regulations on sugar, fats, tobacco and sedentary lifestyles, secondary prevention measures like statins and diabetic management clinics have been under appreciated. Patients living with these conditions, especially expert patients, can make a great impact if they are engaged and supported appropriately in primary and secondary healthcare decision-making.

UN CoNGO Rare Diseases. The Conference of NGOs in Consultative Relationship with the United Nations (CoNGO) is an umbrella body of all non-State actors engaged with the UN. The NGO Committee for Rare Diseases (NGO CRD) of the EURODIS Rare Diseases International is a member. IAPO has a seat on NGO CRD and has collaborated in 2018 in setting the agenda, theme and programme of the UN Congo high level meeting in Feb 2019.

UN Political Declaration Universal Health Coverage 2019. IAPO will support UNGA and the Member States in their high level meeting to endorse

their political commitment and declaration in supporting Universal Health Coverage to be made at the UNGA 2019.

Engaging WHO

WHO was created by the United Nations Member States as the directing and coordinating authority on international health, enabling the nations of the world to act together for the health of all people. IAPO is aware that health still remains a sovereign matter and that the role of WHO is confined to providing scientific evidence and support to Member States to engage in evidence based decision-making in healthcare. IAPO members still have to engage with their own national parliaments and healthcare agencies to ensure that they have access to safe and quality PC-UHC in their own countries.

WHO General Programme of Work (GPW) 2019-2023. WHO GWP is a planning and coordinating mechanism to fulfil WHO's global mission. IAPO has participated in planning the WHO thirteenth general programme of work 2019–2021 Promote health, keep the world safe, and serve the vulnerable. http://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_4-en.pdf?ua=1

IAPO worked upon and submitted its own collaboration plan to support the 13th GPW 2019-2021. IAPO GPW 13 collaboration plan works supports IAPO 2018-2020 strategy and promotes safe and quality PC-UHC by 2030. The WHO will announce the renewal of IAPO non-State actor's status and the acceptance of IAPO plan at the Executive Board in January 2019.

As Patients for Patient Safety members, IAPO commitments to the earlier WHO GPW 12 2016-2018 to lead, participate and contribute towards the patient safety programme and decision-making in the WHO. IAPO is a member of the WHO Expert Consultation: Patient Safety Assessments within the context of UHC. IAPO responds to its consultations and attends its meeting (face-to-face and remotely via web-ex).

IAPO is supporting the WHO Global Ministerial Summits on Patient Safety. IAPO engaged with the Third Global Ministerial Summit on Patient Safety (2018) Tokyo, Japan and joined some 500 participants representing high-level government delegations from Ministries of Health of 44 countries across the world and key international organizations to press home how important patient safety is with national health policy. <https://www.who.int/patientsafety/policies/ministerial-summits/en/>

IAPO endorsed the Tokyo Declaration on Patient Safety <https://www.mhlw.go.jp/file/06-Seisakujouhou-10800000-Iseikyoku/0000204005.pdf>

Medication safety has become a big global issue. In a lead up to IAPO's Patient Solidarity Day 2018, In November 2018 IAPO participated and engaged with WHO Consultative Meeting on '*Implementing WHO's Global Patient Safety Challenge: Medication Without Harm Country Guidance*'. We presented our ideas and approaches to medication safety and briefed the Member States about our Patient Solidarity Day 2018.

IAPO is also providing input and comment to the WHO on its new initiative to develop a national patient safety assessment tool that will allow each Member State to assess its own patient safety institutions, legislation, policy, practice, standards and national patient safety surveillance and ombudsmen systems to a recognised standard and report on it. This will help ensure safe and quality universal health coverage.

IAPO continues to engage with the WHO Regional Committees and attended six WHO Regional Committee meetings in WHO AFR (Dakar Sep 2018), WHO EMR (Khartoum-Oct 2018), WHO EUR (Rome Sep 2018), WHO PAH (Washington-Sep 2018), WHO SEAR (Delhi Sep 2018), WHO WPR (Manila-Oct 2018).

IAPO engaged the health legislators and policy makers on the inclusion of expert patients in the non-communicable diseases agenda and to engage patients on a law, policy and practice in universal health coverage, patient safety and patient-centric healthcare systems.

IAPO has a seat on the International Advisory Group on Primary Health Care for universal health coverage and it collaborated with the WHO on the WHO Global Conference on Primary Health Care and Astana Declaration (Alma Ata 40) in Kazakhstan.

IAPO joined over 100 Member States present to renew our commitment to primary health care to achieve universal health coverage and the Sustainable Development Goals. The Conference was held at the Palace of Independence and was co-hosted by the Government of Kazakhstan, WHO and UNICEF with over 500 high-level health policy delegates and legislators meeting to discuss a road-map to UHC 2030. IAPO was the invited organization and advocated on dismantling of silos in healthcare and encouraged Member States to utilise expert-patients as the great underutilised resource in primary healthcare planning and decision making. Expert-patients could also be employed within the frontline as phlebotomists, community health workers and within other roles where their insight would be a great asset.

WHO/UNESCO Council for International Organizations of Medical Sciences (CIOMS)

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 its newly launched working group with the purpose of involving patients as key stakeholders in the development and safe use of medicines. CIOMS has given a seat to one of our African Members on its working group.