

## IAPO Planned Activities in 2021

### Strategic Plan 2019-2021

#### Empower patient communities globally to advocate effectively for safe, quality, accessible, acceptable affordable patient-centred universal health coverage for all

1. Design, develop and deliver capacity building programme aimed at ensuring patients are equipped with the necessary skills for advocacy:
  - a. Gene and cell therapy for all. Use IAPO's existing tool kit and operationalise it into:
    - i. Moodle Online Advocacy Course for Patient Advocates.
    - ii. Course delivered via a webinar with keynote speakers.
    - iii. Hold a LMIC Virtual Conference on the use of the tool kit in the Sickle Cell Disease Advocacy.
  - b. Biotherapeutics for all. Operationalise and digitise IAPO's original 2018 biotherapeutic course on advocacy on biologic originators and their biosimilars in Asia Pacific, Africa and Latin America:
    - i. Translate into Mandarin and Spanish (French optional).
    - ii. Develop an Advanced Moodle Course on Advocacy in Biotherapeutics.
    - iii. Hold an Africa Congress and give a platform for biotherapeutic advocacy.
  - c. New tool kit: *Collaborative Working in a New Digital Age*. Develop a new tool kit from our successful tools kits: *Working with partners and Stakeholders* and the *Advocacy Fieldbook*.
  - d. Programme for patient co-creation in *WHO Flagship Decade of Patient Safety 2020-30*. The WHO Member State plans to implement WHO Flagship Decade of Patient Safety will be firmed up:
    - i. Hold a session on *WHO Decade of Patient Safety in our congresses: Africa and Latin America*.
    - ii. Hold a session on WHO Decade at the World Health Assembly.
    - iii. Prepare briefing papers and patient education material.
  - e. Develop a tool kit on Health Technology Assessment, Value Based Health Care and Person Centred Health Care.
2. Hold side-events and invite patient advocates to join IAPO at key global and regional health events in collaboration with our MOU partners.
3. Develop collaboration with PAIR - Patient Academy for Innovation and Research and Patients for Patient Safety Observatory

#### To drive research processes and strengthen patient involvement in research

1. Develop the collaboration with Patients for Patient Observatory on patient's engagement in patient safety research.
2. Engage with other Research Opportunities in PROMs, PREMS and COVID19 research initiatives. ISQUA, ISPOR and Solidarity Trials TBC.
3. Facilitate IAPO members' participation in international, multi-stakeholder research on key global issues. Help recruit (TWIN) IAPO Members with current research programmes on COVID-19.

4. Metrodora Awards 2021 to empower and recognize women leaders who are delivering positive changes in the care and management of non-communicable diseases.

### Shape law, policy, and practice in safe, quality, accessible, acceptable affordable patient-centred universal health coverage at global, regional, and national levels.

1. Develop a new tool kit for Policy makers on Patient Engagement with Regulators. Kit to target African Medicines Agency, European Medicines Agency and FDA - U.S. Food and Drug Administration on incorporating patient engagement and co-creation in regulation.
2. Develop a second tool kit targeted at ICI International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use on patient engagement and co-creation in regulatory harmonisation and regulatory reliance.
3. Develop a tool kit and Moodle for engagement with World Health Assemblies and Regional Committees. Strengthen IAPO's official collaboration with the World Health Organization (WHO) and ensure that patients' voices are adequately represented in the global arena by playing a leading role in relevant events, policy consultations, educational programmes, and research activities.

## COVID-19 related activities

### Introduction

IAPO will pursue the 9<sup>th</sup> Global Patients Congress (GPC 2020) theme of *Co-creation in innovative healthcare during Covid-19* and our *Call to Action for 2021*. IAPO will also take into account recommendations of WHO Executive Board: *Special session on the WHA 73.1 COVID-19 response* recommendations.

IAPO will promote, advocate and support activities, projects and programmes that help us in ensuring:

- Every WHO Member State (WHO MS) starts to **build back better** by engaging their whole of patient community within their whole-of-government and whole of society COVID-19 response to control and eliminate the COVID19 Pandemic.
- Every WHO MS **legally institutes Expert Patient** oversight and **co-creation** in the **COVID-19 control and treat ecosystem**. We call on all Member States to create an enabling environment with the appropriate **legally binding frameworks** for expert patient engagement and co-creation.
- Each WHO MS to **fully implement** World Health Assembly Resolution **WHA 73.1** and provide equitable and appropriate protection for their populations, in particular people with pre-existing health conditions, other vulnerable groups, as well as groups at risk, including health professionals, and other frontline workers.
- Each WHO MS fully implements the **WHA 72.6 on Global Patient Safety** ensuring necessary health system capacity to provide access to safe and quality care for everyone, in normal state or in an emergency, respecting patient centricity and equity, leaving no one behind.
- Each Member States **engages expert patients in research, policy formulation** and implementation, so to better respond to their needs. We urgently need patient engagement and co-creation in the **test, treat, trace and isolate** programmes.
- Each WHO MS uses patient engagement in co-creating effective **shielding programmes** for patients with NCDs and multimorbidity.

In order to build back better, each Member State must prepare itself and ensure we have patient engagement and co-creation, and the appropriate investment, to ensure we have a sufficient quantity of safe, quality, accessible, acceptable and affordable healthcare services across the full spectrum of COVID-19 health care from diagnosis, health promotion, prevention, treatment, rehabilitation, and palliative care.

### Patient engagement in other UN and WHO declarations under International Health Regulations 2005

IAPO to advocate patient engagement in the International Health Regulations (IHR 2005) and other declarations made in pursuance of IHR 2005:

- WHO DG Declaration Public Health Emergency of International Concern on novel coronavirus (2019-nCoV) 30 January 2020.
- Recommendations issued by the Director-General under the International Health Regulations (2005), upon the advice of the Emergency Committee convened in response to 2019-nCoV.
- United Nations General Assembly resolutions 74/270 (2020) on global solidarity to fight the coronavirus disease 2019 (COVID-19) and 74/274 on international cooperation to ensure global access to medicines, vaccines, and medical equipment to face COVID-19.
- WHO Executive Board resolution EB146.R10 (2020) on strengthening preparedness for health emergencies: implementation of the International Health Regulations (2005).

### UN and WHO Humanitarian Response Plans for COVID-19-Sphere Humanitarian Standards

IAPO advocates patient engagement in the humanitarian elements of the WHO's Strategic Preparedness and Response Plan and the United Nations' Global Humanitarian Response Plan for COVID-19.

IAPO advocates the implementation of the United Nations General Assembly resolution 46/182 of 1991 and resolution 74/118 of 16 December 2019. Each Member State must respect international law, including international humanitarian law, and strengthen the coordination of humanitarian emergency assistance.

IAPO urges all parties to further base their activity on the **Sphere Handbook on Humanitarian Standards**, one of the oldest initiative in the field of humanitarian standards, which is a rights-based approach respecting that people have the right to assistance, the right to life with dignity, the right to protection and security, and the right to fully participate in decisions related to their own recovery.

### Patient engagement in primary health care COVID-19

IAPO advocates each WHO MS to make expert patient engagement in primary health care the cornerstone of their health systems. IAPO urges all international development agencies to work with the patient movements in a concerted effort to restore primary health care system integrity and capacity.

### Patient engagement in mental health

IAPO advocates that we have a sufficient quantity of safe, quality, accessible, acceptable and affordable Mental Health healthcare services across the full spectrum of health care from promotion, prevention, treatment, rehabilitation, and even palliative care as COVID-19 patients in hospices have developed severe mental health problems due to their isolation from families. They are facing prospects of dying alone.

## Health professional safety

IAPO firstly acknowledges the great sacrifice made by health professionals and frontline workers, a sacrifice often paid in life and disability.

IAPO urges Member States to prioritise the safety needs and welfare of health professionals, health workers and other relevant frontline workers, especially women, who represent most of the health workforce.

## Vaccine & Solidarity Trials

### Patient Engagement in COVID-19 vaccination deployment

- Each IAPO member and partner to promote **patient participation in the COVID-19 vaccine clinical trials** needed to test and evaluate COVID-19 vaccine efficacy in patient groups with NCDs and multimorbidity.
- Each IAPO member and partner to promote patient engagement and co-creation in COVID-19 vaccination clinical trials in the full spectrum of EUPATI Roles in setting research priorities, research design and planning, research conduct and operations, and most important in dissemination and communication of results to combat infodemic:  
<https://eupati.eu/resources/patient-engagement-roadmap/>
- Once candidate vaccines have received the regulatory approval, IAPO and its members to engage in promoting them and combating vaccine hesitation.

### Patient engagement in solidarity trials

The development of effective vaccines, their manufacture in large quantities and then distribution via mass vaccination programmes is going to take time.

IAPO follows WHO position that in the interim alternative already approved and repurposed existing small molecule, biotherapeutic and cell therapies and other interventions to reduce the mortality within patients infected with COVID -19. The WHO Solidarity Trial is evaluating the effect of drugs on 3 important outcomes in COVID-19 patients: mortality, need for assisted ventilation and duration of hospital stay.

IAPO advocates patient engagement in WHO Solidarity Trials. This international clinical trial aims to find an effective treatment for COVID-19. It is the largest international randomized trials for COVID-19 treatments, enrolling almost 12 000 patients in 500 hospital sites in over 30 countries.