



Healthcare Industry Partners' Framework 2021

Collaboration and Support to Build Back Better Pandemic Prepared and Patient Centred Healthcare

Background

Patient engagement in the global health governance ecosystem is particularly important today. Health can no longer be treated as a simple sovereign matter. The COVID-19 root-cause findings will show us that our health systems are now fully integrated into a global domino chain. A failure of one health system can trigger a catastrophic failure of all.

The COVID-19 pandemic has revealed great fault lines in our healthcare ecosystems that now need to be repaired through innovative patient engagement and cocreation strategies in healthcare systems. For a start, we need to invest in new robust partnerships with the whole of government, pharmaceutical industry, regulators and the whole of the patient movement to build back better pandemic prepared and patient centred One Health for all.

Our patient centred and One Health partnerships must refocus our attentions on to the Universal Health Coverage 2030 road map. UHC 2030 should now be the main driver of all other Sustainable Development Goals 2030. There is no social and economic development without UHC 2030 and pandemic preparedness.

IAPO and the Pandemic

The high COVID-19 morbidity and mortality amongst patients with chronic underlying conditions was a wakeup call for all international, regional, and national patient organisations that we must work in national unity and global solidarity as we are all vulnerable. The aftermath of the pandemic has left us an uphill struggle now to ensure that our health systems resume normal healthcare services and ensure our patients have their access restored to high quality and safe healthcare quickly. Delayed diagnosis and foregone treatment appointments, surgery and other support has severe consequences for our patient members.

At our Global Patients Congress 2020 IFPMA and its five big biotech industry members highlighted the critical need for industry and patient collaboration in innovative vaccines and medicines research. The WHO Solidarity Trial research into repurposed drugs for COVID-19 also reaffirmed a critical need for expert patient engagement and cocreation in clinical research. Most important of all, the regulators like US Food and Drug Administration and the European Medicines Agency stressed the acute need for patient engagement regulatory and market authorisation activity and in supporting patient education to counteract the infodemic.

To build back better now, we must empower patient communities globally to drive research and development of the evidence base needed to shape law, policy, practice, and standards that ensure that patients get timely access to quality, and safe innovative and essential healthcare, medicines and healthcare devices that are delivered without discrimination and in an accessible manner which is respectful, compassionate, and patient centred across the whole healthcare system from health promotion to prevention, treatment, rehabilitation, and palliative care.

Lastly, IAPO's 2021 Healthcare Industry Partners Framework reframes healthcare expenditure as an investment and not a revenue expenditure. Before the COVID-19 pandemic, the World Bank had suggested that countries needed to INVEST just US \$ 1.69 per person per year to reach an acceptable level of the SARS-CoV-1 epidemic preparedness. This sum now seems trivial considering the trillion of USD \$ expenditure made on economic stimulus packages and social welfare programmes today. Investment in global health protects us all. No one is safe until everyone is safe.

2021 Healthcare Industry Partners Framework

IAPO's 2021 Healthcare Industry Partners Framework (HIPF 2021) harnesses the new high-level global momentum in building multistakeholder and cross sector collaborative partnerships in global healthcare.

Our HIPF 2021 envisages a new partnership arrangement in patient advocacy that engages the whole of government, whole of pharmaceutical industry, whole of regulatory authorities and the whole of the patient movement to build back better a pandemic prepared patient centred One Health for all.

This HIPF 2021 is now increasing the dialogue between patients, industry stakeholders and society on the emergence of new issues of importance, and ensures each other's views are heard and acknowledged. We want to work at cocreating effective solutions with our partners to meet these challenges. The HIPF 2021 enables us to discuss these issues in a timely, appropriate, and effective manner.

Our partners will now have new opportunities to work with IAPO and our member patients' organizations at a global, regional, and even national levels on a variety of issues relevant both to themselves and to patients. We now have several Memorandum of Understanding with key academic institutions and have set up the [IAPO Patients for Patient Safety Observatory \(IAPO P4PS Observatory\)](#) in Geneva to carry forward our activity in addressing the WHO Global Patient Safety Action Plan 2030 and in addressing the antimicrobial resistance challenge through our [AMR Patients Alliance](#).

Further, IAPO has a partnership with *Patient Academy for Innovation and Research (PAIR)* to take forward our capacity building activity in low- and middle-income countries, starting with the Asia Pacific Region. IAPO has also set up the *African Medicines Agency Treaty Alliance (AMATA)* to address the issues of patient engagement and cocreation in African medicines regulatory affairs.

Lastly, 2020 has reset our relationships in public health and we are now all working to a common goal of ensuring that we attain global herd immunity quickly through the global vaccination programmes. We then want to ensure that all healthcare services suspended over the lockdowns are built back better.

Projects IAPO is pursuing in 2021.

In 2021 IAPO will be advancing: WHO 74th World Health Assembly Agenda and Resolution: *Item 13.3 Expanding access to effective treatments for cancer and rare and orphan diseases, including medicines, vaccines, medical devices, diagnostics, assistive products, cell- and gene-based therapies and other health technologies; and improving the transparency of markets for medicines, vaccines, and other health products.*

- 1) Comprehensive vaccination. From COVI-19 herd Immunity through to life-course vaccinations-
#VaccinesWork #Vaccines4life
- 2) Digital Healthcare – Artificial Intelligence and Machine Learning Enhanced Healthcare
- 3) Precision Medicines and Personalised Health Care- IAPO's EB148 Statement
- 4) Cell and gene and therapies-Beyond the toolkit WHO 72rd WHA
- 5) Biotherapeutics (biologics and their biosimilars). WHO 70th WHA
- 6) Self-Care and Homebased Care-telehealth
- 7) WHO Global Patient Safety Plan 2021-2030
- 8) Antimicrobial Resistance AMR Patients Alliance
- 9) Patients and Health Economics and Health Technology Assessment
- 10) EUPATI in Low and Middle Income Countries

Part One - Introducing IAPO

A global voice for patients

IAPO has come of age and is the only 21-year-old global patients alliance representing patients across all disease areas and promoting patient-centred healthcare around the world. Our Full Members are patients' organizations working at the international, regional, national, and local levels to represent and support patients, their families, and carers. Our Associate Members are other health-related, non-profit organizations working towards patient-centred healthcare.

IAPO has also introduced a new membership category in 2021: Affiliated Member. This gives patient groups who are members of our member alliance an opportunity to engage in our activity and programmes.

IAPO has over 280 members, representing over 50 disease areas and over 70 countries, and has a network that represents an estimated over 1 million patients directly through its member alliances.

The impact of IAPO's voice is created by the diversity and breadth of members which incorporates the views of international and umbrella disease associations with those of community-based, self-help groups. IAPO advocates on a wide range of global health policy areas. With COVID-19 and its aftermath, we are now increasing engagement in public health policy and mental health policy. We are strengthening our engagement in healthcare financing, Health Technology Assessment and UHC 2030. Our core policy engagement remains in ensuring the delivery of safe and quality healthcare, which is accessible and with health equity.

We continue to pursue our engagement in health system strengthening and policies aimed at creating an enabling environment so that patients' organisations committed to patient-centred healthcare can engage in cocreation across the entire health system.

Our vision is to see patient-centred health care established in all countries. This means the establishment of patient-centred universal health coverage (UHC) in which patients do not suffering financial hardship in all 194 United Nations Member States (MS) by 2030.

Our Objectives In order to establish patient centred universal health coverage across the whole spectrum of healthcare from promotive, preventive, curative, rehabilitative and palliative healthcare services we want the establishment of:

- Safe Healthcare
- Quality Healthcare
- Accessible Healthcare. Access is across four areas.
 - Non-Discriminatory Healthcare
 - Physically Accessible Healthcare
 - Information Accessibility
 - Affordable Healthcare

- Acceptable Healthcare: Culturally Competent and Patient Centred (Broader Definition)

Our strategy is to:

- **EMPOWER** -Empower members with cutting edge knowledge and advocacy skills to enhance the reach, efficacy, and impact of our membership and the global patient movement in bringing about healthcare that is PC, PP and a UHC
- **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.
- **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.

IAPO delivers its mission and strategy globally through:

- Engaging with relevant and representative patient organisations and forming active partnerships and impact through capacity building
- Developing effective and enduring partnerships with global health institutional stakeholders and medicines regulatory authorities
- Developing innovative, timely and relevant policy and practice guidelines for patients and health policy makers
- Amplifying our message through relevant patrons (policy elite and high-level global health personalities) and publics (teachers, nurses, doctors, and medical students)
- Developing effective promotional mix that matches message, messenger and medium like websites, social media, conferences, WHO side-events, and resources.
- Advocating with one strong patient voice on relevant aspects of healthcare policy, with the aim to influence global, regional and national health agendas.

Highlights of IAPO Activity in 2020

IAPO's full list of activities in 2020 have been listed in the link below.

https://www.iapo.org.uk/sites/default/files/files/IAPO_2020%20Highlights.pdf

Additionally, all our activities can be followed on our Facebook

<https://www.facebook.com/IAPOvoice/> and on our Twitter account @IAPOvoice.

Our 2020 activity was framed around:

- Empower patient communities globally to advocate effectively.
- Drive research processes and the development of evidence base
- Shape law, policy and practice global, regional and national levels

Empower patient communities globally to advocate effectively for patient centred-universal health coverage for all.

- Held our 9th Global Patients Congress 2020 over 1500 delegate
- Held our 2nd Asia Pacific Patients Congress 2020 over 3000 delegates
- Marking IAPO's anniversary – 21 years of shaping our healthcare ecosystem

- COVID-19 activities IAPO COVID-19 statement
- IAPO's COVID-19 resources hub
- IAPO Members' response to COVID-19
- Voices of Safety - World Patient Safety Day 2020 storytelling campaign
- IAPO established a Memorandum of Understanding with Patient Academy for Innovation and Research (PAIR) to provide quality patient capacity building courses and training.

Drive research processes and development of evidence base for patient centred-universal health coverage.

- IAPO set up its Scientific Advisory Board
- IAPO set up the IAPO Patients for Patients Safety Observatory
- IAPO set up the Metrodora Award – recognising outstanding women achievers in science and health.
- IAPO further participated as advisory capacity on the research and development of various evidence-based guidelines being produced by:
 - Union for International Cancer Control (UICC)
 - Global Self-Care Federation
 - Global Coalition for Circulatory Health (GCCH)
 - Antimicrobial Resistance Patient Advocacy Group
 - Global Alliance of Sickle Cell Disease Organisations (GASCDO)

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

- IAPO participated at the World Health Organization 73rd World Health Assembly and presented a strong statement on the need for effective patient support and access to services, and the need for vaccines and re-purposed medicines. Statement
- IAPO repeated this statement at the WHO Regional Committees
- IAPO has set up the AMR Patient Alliance <http://amr.iapo-p4psobservatory.org/>
- IAPO is now a member of the Fight the Fakes Alliance Board
- IAPO participated at the 10th Asia Regulatory Conference. We promote Regulatory Reliance.
- IAPO has re-started the Campaign to ratify the African Medicines Agency Treaty

Part Two - Introducing the 2021 Healthcare Industry Partners Framework

A framework for collaboration to build back better.

IAPO's Industry Partners comprise companies, foundations and associations who commit to providing us with various levels of financial and in-kind support in exchange for relevant and appropriate benefits and entitlements. The HIPF 2021 provides a clear framework which allows IAPO and our industry stakeholders to interact and collaborate in cocreation a transparent, accountable, and highly effective way.

The importance of core support through partnership

IAPO has remained a streamlined and efficient small organization with four permanent staff members and two consultants. With COVID-19 build back better, core funding has become extremely important for IAPO.

Core funding will enable us to participate in important international policy activities in the global health governance arena such as our work with the WHO and collaboration with other global alliances with whom we have a Memorandum of Understanding in the development of policy statements. This activity would not be appropriate for external supporters to fund directly.

Resource constraints have imposed challenges on the ability of IAPO to address COVID-19 and other emerging issues as thoroughly and quickly as required in today's global political and digital environment.

Through HIPF 2021 that is well supported on a multi-year basis, IAPO can greatly enhance its ability to rapidly address complex policy issues and to undertake our core work towards patient-centred healthcare.

Defining Industry Partners

Industry Partners are companies who produce healthcare-related products or services, company-owned foundations, or the foundations and associations who represent such companies. We welcome biopharmaceutical, health devices, health informatics, health APPs and AI, digital imaging, nutraceutical, and other relevant manufacturers.

Operation

The interaction between IAPO and our Industry Partners is based on regular transparent communication. Each Partner is entitled to nominate one individual to be their Representative. This person receives a dedicated monthly update from IAPO to ensure they are kept informed about our activities and receive priority notifications as appropriate.

Partner Representatives of Gold Partners are also invited to join representatives of the other Partners in a meeting with the Governing Board once or twice per year. The benefits of these meetings include exchange of information, updates on IAPO's development and activities, in-depth discussion of current and emerging issues of relevance for Partners and patients' organizations.

Objectives

Through the HIPF 2021, IAPO believes that clear and mutually beneficial relations between the patients' movement and industry stakeholders can be demonstrated. Whilst supporting IAPO's core work through annual contributions, Partners can develop meaningful and effective working relationships with both IAPO and our member patients' organizations. This facilitates dialogue and effective patient-industry relations at the local, national, regional, and international levels, so that issues of common concern to patients and the industry can be addressed, such as the issues of patient information, advertising, transparency, and adherence to therapy.

Financial Support

Core Funding

Partners commit to providing IAPO with regular financial support, which is unrestricted in nature. This support contributes to our core capacity building and policy programme costs, and increases the sustainability and diversity of our funding, allowing us to plan our activities more effectively. We strongly believe in the importance of not being dependent on one particular source of income; others include membership fees, publication sales, donations, in-kind support and project funding for work such as the Congresses and Briefing Papers. Partners receive priority notice of these exciting opportunities.

The three levels of core support the Partners can provide to IAPO are:

- Gold Industry Partner: \$50,000
- Silver Industry Partner: \$30,000
- Bronze Industry Partner: \$20,000

Partners are encouraged to commit to a minimum of three years in the Partners Framework, again to ensure effective financial planning and to ensure that the full benefits of partnership are realised, Partners can explore this further with IAPO.

Partners' benefits and entitlements differ depending on the level of support provided. These benefits are described in Part Three of this booklet.

A complete list of IAPO's past Industry Partners can be found at www.iapo.org.uk/healthcare-industry-partners

Project Funding

While core support allows us to address systemic and general global healthcare issues, project funding helps us address specific areas of healthcare. Some of these areas are address patient awareness and education on some innovative healthcare development (gene and cell therapies) or some projects address traditional issues of access and patient safety under new circumstance like the uptake of digital and telehealth to improve access and the WHO Resolution on Global Patient Safety Action Plan.

Some projects may be specific to some of our industry partners like immunotherapy and oncology. Here we work collaborative with two or three other partners to improve our reach and impact. Other partners may have a project with a regional focus.

Project funding is carefully planned with the industry partners and to specific budget thresholds.

Congresses and Events

IAPO holds an annual regional congress and a biennial Global Patients Congress. The theme and agenda for these vary year to year. In addition, IAPO holds side events at the World Health assembly and other global health forums of interest and significance for patient advocacy.

Event budgets are drawn up after discussion with the funders and suppliers.

Part Three - Partner Benefits and Entitlements

This section sets out the benefits and entitlements that Partners receive within the Core Funding arrangements of Health Industry Partners Framework 2021. Project and Congress benefits follow this but may be more specific and additional to these.

Transparent & Accountable Framework

Becoming a Partner provides an opportunity to work with the patients' movement at the international level in a transparent and accountable framework, with open dialogue and clear financial arrangements to ensure that the Partners' support is demonstrated, whilst IAPO's independence as a patients' organization is maintained.

Representation

Each Partner nominates one individual to represent them in their communications with IAPO to ensure there is a clear focal point for effective communications.

Involvement

Partnership ensures regular involvement and consultation on key healthcare issues. The Partner Representative from Gold Partners are entitled to attend one/two face-to-face meetings with other Partner Representatives and IAPO's Governing Board per year to plan collaborative activities, exchange views on current issues, discuss industry-patient relations, and work on developing the Partners Framework further.

Regular communication

The Partner's chosen representative (and any other contact from the company) receives a dedicated monthly email update to keep them informed of IAPO's development and policy activities and quarterly telephone or face-to-face updates, as requested. These updates also keep Partners up to date with the various discounted services offered to them, including website links, publications and Congress registration. Our dynamic website can also provide a useful source of reference.

Policy Framework

IAPO's policy development is directed by our Policy Framework. Policy positions are based on consultation with members and reflect only their views. But it is vital to include other stakeholders in this process; to promote multi-stakeholder debate and understanding and to consider the views, knowledge, and information that they can contribute.

Priority notice and consideration

Notice and priority consideration for upcoming partnership and sponsorship opportunities, e.g. for events, publications, grants and awards.

Involvement, attendance & acknowledgement at the Virtual Global Patients Congress

Pre-COVID-19, all Partners had the opportunity to give advice during the development of the virtual or face to face bi-annual Congress Programme to the Programme Facilitator and the Organizing Committee. They could send delegates with exclusive "observer status", attend VIP sessions and their Partnership and support is acknowledged.

In the new virtual format, IAPO is replicating this with the virtual platforms like GPC2021 V-Fairs congress and other planning sessions.

Free Digital copies of IAPO's publications

The Partner is entitled to receive free copies of IAPO's digital publications, such as our Briefing Papers (upon request to info@iapo.org.uk).

Acknowledgement online

All Industry Partners' names and levels of support are fully acknowledged on our website, with further benefits such as logos and corporate profiles depending on the Partner's level of support. The Industry Partners will also have a dedicated area of our website which explains the nature of the collaboration between IAPO and our Partners.

Acknowledgement in Healthcare Industry Partners documents

Full acknowledgement of Company name and level of support in IAPO Partner documents and publicity materials, where appropriate. All Partners will be listed with the level of support in this Industry Partners booklet.

Note that the benefits and entitlements Partners receive are dependent on the level of support they provide. Please see the Benefits Matrix on the following page to see the differences.

About other sponsorship opportunities

If you are interested in sponsoring IAPO in other ways, such as sponsoring the Global Patients Congress, Asian Pacific Patients Congress, African Patients Congress in 2021 or funding the capacity building of our members, please email the CEO at kawaldip@iapo.org.uk

CORE FUNDING BENEFITS MATRIX

Benefits to Industry Partner	Level of Support		
	Gold	Silver	Bronze
Working with the patients' movement in a transparent and accountable framework	✓	✓	✓
Representation of the Partners industry sector in IAPO's work for positive change	✓	✓	✓
Dedicated monthly email newsletter	✓	✓	✓
Attendance by the Partner Representative at 1-2 virtual meetings per year	✓	-	-
Quarterly teleconference with IAPO's Chief Executive Officer or Policy Manager for an update or on a topic of your choice (on request)	✓	✓	-
Priority consideration for partnership and sponsorship opportunities	✓	✓	-
Benefits at the virtual Events <ul style="list-style-type: none"> • 1 x delegate patient relations officer place • 1 x extra delegate observer place • Acknowledgement and level of support in Congress Programme • Special workshops and planning sessions 	✓	✓	✓
Free digital copies of IAPO publications (on request to info@iapo.org.uk)	✓	✓	✓
Acknowledgement on IAPO website: <ul style="list-style-type: none"> • Company name and level of support listed • Link to Corporate Website • Partner Profile (summarizing the Partner's mission, work and involvement with IAPO) 	✓	✓	✓
	✓	✓	✓
Acknowledgement of support in end of year newsletter	✓	✓	✓
Acknowledgement in Industry Partners Booklet: <ul style="list-style-type: none"> • Company name and level of support listed • Corporate Logo 	✓	✓	-
	✓	✓	-

Part Four - Becoming an Industry Partner

Application

For further information, please contact our CEO +447443101055 and we will arrange a meeting in a convenient location to discuss potential Partnership further.

Letter of Agreement

IAPO enters into partnerships with organizations upon signature of a Letter of Agreement outlining the terms of partnership by representatives of both IAPO and the partner organization.

Contact Details – IAPO Office

International Alliance of Patients' Organizations
49-51 East Road
London, N1 6AH
United Kingdom

Telephone: +44 20 7250 8280

COVID-19 Office: +447443101055

Fax: +44 20 7250 8285

Email: info@iapo.org.uk

Website: www.iapo.org.uk

Governing Board Members

IAPO's 2021 Board Members are listed below. Please contact the IAPO office for their contact details.

Dr. Ratna Devi IAPO Chair CEO and Co-founder of Dakshama Health and Education, India. Board Chair of Indian Alliance of Patient Groups and is a Partner at Prism Consulting Group.

Dr. Neda Milevska-Kostova IAPO Vice Chair Executive director of Centre for Regional Policy Research and Cooperation "Studiorum", think-tank working on health and wellbeing policies in South Eastern Europe

Karen Alparce-Villanueva Secretary is currently the Vice-President of the Philippine Alliance of Patient Organizations (PAPO)

Ellos Ellard Lodzeni IAPO Hon. Treasurer Patron and founder trustee of Patient and Community Welfare Foundation of Malawi

Orajitt Bumrungkulswat Board Member is the Assistant Secretary General Heart to Heart Foundation in Thailand

Bisi Bright is a Consultant Clinical Pharmacist, Lecturer and Public Health Manager. She is 1st Vice Chairman and CEO of LiveWell Initiative LWI

Liliana Tieri is the Founder and Executive Director Association for the Care of Diabetes in Argentina CUI.D.AR.

