



Healthcare Industry Partners' Framework 2020

Collaboration and Support for Patient-Centred Healthcare

Message from the Chair

Patients and healthcare industry stakeholders (including companies, foundations and associations involved in pharmaceuticals, medical technology, biotechnology, nutraceuticals, homeopathic medicines and health insurance) are vital to one another, yet there can be insufficient dialogue and few partnerships and collaborations between them towards, often, common goals.

We have developed our Healthcare Industry Partners Framework to provide a clear framework which enables our global patients' movement and industry stakeholders to interact and collaborate in a transparent, accountable and highly effective way, whilst ensuring that our independence as a patients' organization is maintained.

An important part of this work is increasing the dialogue between patients and industry stakeholders on issues of importance, ensuring each others' views are heard and acknowledged, and possible solutions to challenges are discussed. Partners have the opportunity to work with IAPO and our member patients' organizations on a variety of issues relevant both to themselves and to patients, and are entitled to many other benefits. Partners commit to providing us with various levels of financial support.

Through the ongoing commitment to interaction between IAPO and our Partners, we want to demonstrate that effective industry-patient relations are possible, in fact vital, if we are to promote positive change in healthcare.

Ratna Devi
IAPO Chair

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Part One - Introducing IAPO

A global voice for patients

IAPO is the only global 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 over 270 members, representing over 50 disease areas and over 70 countries, and has a network that represents an estimated 365 million patients.

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 healthcare policy areas, from overarching patient issues, such as patient safety, to specific issues such as health literacy. Our goal is to engage with all patients' organizations committed to patient-centred healthcare.

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 all 194 United Nations Member States (MS) by 2030.

Our Objective is 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 MS, 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 strategy is to: 1. Empower patient communities globally to advocate effectively for PC-UHC for all. 2. Drive research processes and the development of evidence base for PC-UHC. 3. Shape law, policy and practice in PC-UHC at global, regional and national levels.

IAPO delivers its mission worldwide by:

- Realizing active partnerships with patients' organizations, maximizing their impact through capacity building
- Advocating internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies
- Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives

Key Achievements 2018

IAPO's financial report and evaluation in 2018 is lodged with the publically accessible Charity Commission Register See Link [2018 Accounts and Financial Report](#)

Our vision in 2018 remained to see patient-centred health care established in all countries. This would now mean the establishment of patient-centred universal health coverage (UHC) in all 194 United Nations Member States (MS) by 2030.

Our 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 World Health Organization 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 strategy in 2018 was to empower patients to advocate for patient-centred universal health coverage so that we can drive research processes and the development of evidence base for PC-UHC to shape law, policy and practice in PC-UHC at global, regional and national levels ([Strategy 2018](#)).

IAPO measured its outcomes across the three strategy goals:

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

Outcomes 2018

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

Global Patients Congress Miami May 2018- Globally Empowered Patients. Building the Momentum

In December 2017 IAPO began to plan our flagship Global Patients' Congress for May 2018. This is a premier event is a great policy education opportunity to bring together and share best practice and evidence base with our stakeholders. It gives IAPO the platform to empower members and other patient advocates in advancing patient-centric universal health coverage globally.

The GPC 2018 was an ambitious undertaking as IAPO had elected to hold the GPC in Miami Florida USA for the very first time. The rationale was that Miami's proximity to Latin America and its rich cultural and linguistic diversity and its world class food would attract more of our Latin American members who had difficulties getting to London in 2016.

The programme was carefully crafted by the GPC Advisory Committee. We elected the theme Globally Empowered Patients, Building the Momentum. The 'momentum' referred to was our drive towards having a safe and quality PC-UHC in each WHO Member State by 2030.

The programme committee invited key-note speakers, our members, notable expert-patients, academics, regulators, health finance people and our industry partners to contribute towards informing, advising and educating our members on the full range of issues affecting a PC-UHC during a range of plenary sessions, work-shops and side-events on key issues like:

- Patient Empowerment in Universal Health Coverage
- Patient Empowerment through Consortium and Partnerships
- Patient Empowerment through Policy and Advocacy
- Patient Empowerment in Regulation
- Patient Empowerment for Global Advocacy and Multi-stakeholder Collaboration
- Role of Expert Patients in Patient Engagement and Empowerment
- Patient empowerment in WHO Patients for Patient Safety Programme
- Empowering Caregivers and Self Care in Healthcare
- Patient empowerment in Fight the Fakes campaign
- Patient empowerment on advocacy on Biotherapeutics and Cell and Gene Therapies using IAPO's Advocacy Fieldbook and Biosimilars Toolkit

See full Congress Report for outcomes and the pictures here:

- Congress Report <https://bit.ly/2nnPXH6>
- Congress Photographs : <https://bit.ly/2vO554s>

Patient Solidarity Day 2018: Safe Medication and Healthcare for All

During the lead up to this year's Patient Solidarity Day 7 Dec 2018, IAPO had intensive member engagement in choosing the overall theme and direction this year. IAPO also arranged a number of small grants to support members plan their national events.

Members began with a core assumption that patient solidarity must advocate that each healthcare system must have safe healthcare and medication policy, practice and standards as bedrock of its PC-UHC.

Adverse events and patient injuries cost lives result in suffering and take away essential health professional time, effort and budgets in correcting or alleviating the effects of this damage. Patient injuries may also cost the health system a lot in litigation costs and in the final compensation. This makes health systems unsustainable.

The members approached PSD 2018 from the bioethics perspective too. IAPO members believe that any increased expenditure in enlarging the capacity of a healthcare system should first do no harm- primum nil nocere. There must be a planned and corresponding investment in patient safety measures and in health workforce strengthening before capacity is expanded.

As a non-State actor in official relationship with WHO and a participant in the WHO's Patients for Patient Safety Programme, IAPO has been a champion in advocating investment in overall patient safety monitoring, surveillance and reporting systems. IAPO wants patient safety to be considered as routine within health workforce strengthening and in investment in healthcare facilities, essential medicines and pharmacies.

Patient Solidarity Day 2018 has started this journey to ensure a safe and quality PC-UHC by 2030. A report will follow in February 2019. A summary of the day is available online: <https://www.iaopo.org.uk/news/2018/dec/14/achieving-safer-healthcare-all-world-unites-psd2018>

Membership Engagement

One of the main membership engagement activities this year was to introduce the members to the main healthcare issues that needed to be addressed in IAPO's Strategy 2018-2020. 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 has continued this membership engagement activity in 2018 by providing information, advice and support to our members on various issues during the year. During 2018 there were a number of issues that we engaged our members on.

- **ACCESS**

- o Access in UHC
- o Access to Clinical Trials and Ethics
- o Health Technology Assessment and Health Finance
- o Non-communicable diseases
- o Primary Healthcare
- o Value Based Outcomes (VBO)
- o Carers and Self-Care
- o Multi-Chronic Conditions and Poly-Pharmacy
- o Pain management

- **INNOVATION**

- o Biotherapeutics -Biologic and Biosimilar Medicines
- o Gene and cell therapy
- o Oncology and monoclonal antibodies and chimeras
- o Rare Diseases and Disorders
- o Antimicrobial Resistance

- **SUPPLY CHAIN, SAFETY and REGULATIONS**

- o Substandard & Falsified Medicines (Fight the Fakes)
- o WHO Patients for Patient Safety²⁷⁵
- o Quality and Safety (Medication without errors)
- o Regulation and pharmacovigilance-African Medicines Agency and EMA

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 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

GetReal 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 sized research enterprises. The primary goal of GetReal 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 EU. 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 is an IMI initiative that 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 Economist 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. Not successful.
- African Oncology- Follow up to their report: State of Oncology in Africa. Waiting for funding opportunities.

TransCelerate BioPharma Inc (TCBP). IAPO is having ongoing discussions on the ASPIRE project (a collaboration with Novo Nordisk) to help patients engage with clinical trial teams to co-drive research 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. Several ideas have emerged but waiting for funding opportunities.

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.

Goal 3 Shape law, policy and practice in PC-UHC.

In order to shape law, policy and practice on a safe and quality PC-UHC, in 2018 IAPO planned to:

- Engage a number of global institutions that have an impact upon healthcare law, policy and practice
- Use a range of policy instruments to support IAPO advocacy
- Form partnerships with State and non-State organisations that have competency in healthcare law, policy and practice

Engaging Institutions

Engaging the United Nations UNGA 2018. 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 healthcare law, policy and practice issues. The 2014 Ebola outbreak in West Africa attests to this power. The global impasse and inaction on the issue was broken by President Barack Obama, acting as a UN Permanent Member of the Security Council, when he mobilised the USA Centres for Disease Control and the United States Army to act.

The United Nations General Assembly (UNGA) is a powerful global general assembly 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 GPW 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).

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 (Medication without Harm). Medication errors have 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.

Patient Safety Assessment Tool. 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.

WHO Regional Committees. IAPO continues to engage with the WHO Regional Committees and attended six WHO Regional Committee meetings in:

- WHO AFR (Dakar Sep 2018) Jolanta Bilinska
- WHO EMR (Khartoum-Oct 2018) Hussain Jafri
- WHO EUR (Rome Sep 2018) Neda Milevska-Kostova
- WHO PAH (Washington-Sep 2018) Penney Cowan and Hussain Jafri
- WHO SEAR (Delhi Sep 2018) Ratna Devi
- WHO WPR (Manila-Oct 2018) Ya-Hsin Wang

IAPO engaged the Member States and regional 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.

WHO International Advisory Group on Primary Health Care for UHC. IAPO has a seat on this group and 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 in the Astana Declaration and primary health care to achieve universal health coverage and the Sustainable Development Goals.

The Astana PHC for UHC Conference was held at the Palace of Independence and was co-hosted by the Government of Kazakhstan, WHO and UNICEF. Over 500 high-level health policy delegates and legislators participated in the conference to discuss a road-map to PHC in UHC 2030. IAPO was the invited organization and advocated on dismantling of silos in healthcare and encouraged Member States to utilise expert-patients as one of the great underutilised resource in primary healthcare planning and decision



making. Other organizations also commented that expert-patients could also be employed within the healthcare frontline as phlebotomists and community health workers where patient experience and insight would be a great asset in improving practice.

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.

Participation in developing PC UHC policy change instruments.

Currently a number of global, regional and national State and non-State actors are developing UHC 2030 policy instruments that will change the healthcare law, policy, practice and standards by 2030.

In 2017 IAPO mapped a range of policy instruments that our members have been engaged in over the years on healthcare law, policy and practice change. This is shown as a stepped-ladder matrix. Lower rungs occupied by national patient registers and disease specific protocols. Upper rungs of this tier are occupied by national consultations, white papers and All-Party parliamentary groups. See Appendix.

IAPO is participating in developing briefings, consultations and guideline at the moment. IAPO is also engaged in advocating for UN and WHO resolutions and declarations by staging interventions at UNGA and the WHO World Health Assembly and Regional Committees.

This activity has been slow to start globally. The UN Declaration on Universal Health Coverage scheduled for UN General Assembly September 2019 will prompt most Member States to change their healthcare law, policy, practice and standards to meet their obligations to set up UHC by 2030.

Forming partnerships.

IAPO has an ongoing relationship with the Advocates for International Development (A4ID) with whom we shared our offices for one year. They offer legal opinion on global healthcare law and institutional arrangement.

IAPO is also relying on its partners with whom we have a memorandum of understanding to work towards advocating PC-UHC. The International Hospital Federation, World Medical Alliance, International Council of Nurses, European Patients Forum and the International Prevention Research Institute

Conclusion

We have had a good start to our 2019-20 Strategy and thank all our members, partners and the global health organizations for supporting us to deliver our mission.

We now need to build on this in 2020 and ensure all our members in our programmes and activities. The 2020 plans have been finalised now and are online.

Part Two - Introducing the Healthcare Industry Partners



A framework for collaboration

IAPO's Industry Partners are companies, foundations and associations who commit to providing us with various levels of financial support in exchange for numerous benefits and entitlements. The Partners' Framework provides a clear method which allows IAPO and industry stakeholders to interact and collaborate in a transparent, accountable and highly effective way.

The importance of core support through partnership

IAPO is a small organization with seven permanent staff members. At this stage in IAPO's development, core funding is vital. It enables us to participate in important international policy activities such as our work with the WHO and World Health Professionals Alliance and the development of policy statements which it would not be appropriate for external supporters to fund directly. Resource constraints sometimes impose challenges on the ability of IAPO to address emerging issues as thoroughly and quickly as required in today's global political environment. Through a Partners' Framework 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. Examples of eligible organizations include pharmaceutical, nutraceutical, homeopathic and medical devices manufacturers; biotechnology and health insurance companies; and industry associations such as those representing the pharmaceutical, biotechnology or medical devices industries.

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 Partners Framework, 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 are able to 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

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 Congress and Briefing Papers. Partners receive priority notice of these exciting opportunities.

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

Gold Industry Partner: \$50,000 / [£ spot rate]

Silver Industry Partner: \$25,000 / [£ spot rate]

Bronze Industry Partner: \$10,000 / [£ spot rate]

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 can be explored 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 Industry Partners can be found at www.iapo.org.uk/healthcare-industry-partners

Part Three - Partner Benefits and Entitlements

This section sets out the benefits and entitlements that Partners receive within the framework of the Industry Partners Framework:

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. For example, IAPO's publication, *What is Patient-Centred Healthcare? A Review of Definitions and Principles* benefited from review from a wide stakeholder group including health professionals, policy-makers and IAPO's Industry Partners.



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 Global Patients Congress

All Partners have the opportunity to give advice during the development of the bi-annual Congress Programme to the Programme Facilitator and the Organizing Committee. They are able to send delegates with exclusive "observer status", attend VIP sessions and their Partnership and support is acknowledged.

Free copies of IAPO's publications

The Partner is entitled to receive free copies of IAPO's 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, or funding the capacity building of our members, please email us at info@iapo.org.uk.

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 face-to-face 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 Global Patients Congress			
• 1 x delegate observer place	✓	✓	✓
• 1 x extra delegate observer place with discounted registration	50% discount	25% discount	10% discount
• 1 x extra delegate observer place at regular price	✓	-	-
• Acknowledgement and level of support in Congress Programme	✓	✓	✓
• Attendance at VIP sessions/receptions	✓	✓	✓
Free copies of IAPO publications (on request to info@iapo.org.uk)	10 copies	5 copies	2 copies
Acknowledgement on IAPO website:			
• Company name and level of support listed	✓	✓	✓
• Link to Corporate Website	✓	✓	✓
• Partner Profile (summarizing the Partner's mission, work and involvement with IAPO)	✓ 600 words	✓ 300 words	✓ 100 words
Acknowledgement of support in end of year newsletter	✓	✓	✓
Acknowledgement in Industry Partners Booklet:			
• Company name and level of support listed	✓	✓	✓
• Corporate Logo	✓	✓	-



Part Four - Becoming an Industry Partner

Application

For further information, please contact our office 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
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United Kingdom

Telephone: +44 20 7250 8280
Fax: +44 20 7250 8285
Email: info@iapo.org.uk
Website: www.iapo.org.uk

Governing Board Members

IAPO's 2019 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 Hon. Secretary Executive director of Centre for Regional Policy Research and Cooperation "Studiorum", think-tank working on health and wellbeing policies in South Eastern Europe

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

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

Ya Hsin Wang Board Member Secretary-General of Psoriasis Association Taiwan and the Executive Director of Taiwan Alliance of Patients' Organizations

Carol Ossai Board Member is the Founder and Chair of Sickle Cell and Young Stroke Survivors United Kingdom

Appendix 1 – IAPO's Values

IAPO believes that it is crucial to have a set of core values to inform our work. These values ensure that the organization strives to serve our membership in the best way possible and that we have a clear and open relationship with partners and other organizations. We will use our values to evaluate our work, learning on an ongoing basis how we can more effectively meet the commitments we have set out.

Our values are expressed in single words. Alongside these values is a sentence explaining how we are working or striving to work towards them. As with any organization IAPO can only work with the resources available, and therefore cannot always achieve everything we hope to. However our values help us in our endeavour to fulfil our mission as effectively, appropriately and clearly as possible.

Accessibility: IAPO is committed to ensuring that the work it does is accessible to its members and partners. We recognise the challenges that accessibility brings and the resources required to ensure accessibility and strive to ensure that our events, publications and website are accessible.

Accountability: IAPO is accountable to its membership through our Annual General Meeting (AGM) and our Governing Board, elected by the members. The Board is the accountable body for IAPO and staff report directly to them. We are committed to having clear decision-making processes. We believe strongly in the importance of being a patient-led organization. All IAPO full members are patient-led organizations and are committed to ensuring that the patient's voice is at the centre of their decision-making processes.

Commitment to Diversity: We recognise and celebrate the diversity within IAPO's membership. We realise the challenges that this commitment brings given language barriers, cultural difference, the differing resource levels of organizations and the global disparity in access to healthcare. Yet, we are committed to working in a way in which all patient-led organizations can be actively involved with IAPO, contributing their own unique perspectives.

Inclusiveness: IAPO strives to be inclusive in all its work. We work with our members and our Board to ensure that IAPO's services, events and membership structure are as inclusive as possible. While ensuring that we are a patient-led organization, we work with other stakeholders through partnerships and collaborations in order to forward discussions in the area of patient centred healthcare.

Independence: IAPO is a patient-led organization independent of government, industry and other professional organizations. IAPO's strategic direction is set by our members through our Governing



Board. We are committed to ensuring that IAPO and our members remain independent, believing that this is the most effective way to represent the needs and views of patients.

Representation: IAPO strives to be fully representative of patients' needs and views. Given the diversity of IAPO's membership, we recognise the challenges this entails. We ensure that consultation with members is an integral part of our work including undertaking an annual survey of members' needs and using all this information to guide future projects and accurately represent our members at an international level.

Transparency: IAPO strives to have clear processes for its work including its decision-making processes, utilising its website and other appropriate communication tools. IAPO has an open, transparent framework to guide its funding agreements. IAPO works in partnership with a number of organizations; all formal partnerships are governed by clear and transparent guidelines.

Appendix 2 - Principles for Industry Support

IAPO is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world.

IAPO's vision is that patients throughout the world are at the centre of healthcare.

IAPO's mission is to help build patient-centred healthcare worldwide by:

- Realizing active partnerships with patients' organizations, maximising their impact through capacity building
- Advocating internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies
- Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy-makers, academics, researchers and industry representatives

IAPO seeks support from corporate entities for its core capacity building and advocacy activities and to help to initiate new and expand existing activities. IAPO also seeks project funding such as Congress and Briefing Paper sponsorship.

IAPO accepts funds from industry stakeholders to support its approved work plans. Examples of eligible organizations include pharmaceutical, nutraceutical, homeopathic and medical devices manufacturers; biotechnology and health insurance companies; and industry associations such as those representing the pharmaceutical, biotechnology or medical devices industries.

IAPO has developed a Healthcare Industry Partners Framework to provide a transparent and accountable methodology which allows Partners to provide financial support to the global patients' movement and to interact and collaborate in an effective way, whilst ensuring that our independence as a patients' organization is maintained. IAPO believes it is ethically sound to accept these funds because partnership occurs within such a framework, and because IAPO's policy development activities are also defined by a clear methodology, IAPO's Policy Framework, to ensure that IAPO's policy positions reflect only the views of IAPO's members.

It is necessary to guard against actual or perceived conflicts of interest in accepting such funds or in working collaboratively with health-related companies. The frameworks developed and the principles outlined below are necessary for all corporate relationships that support IAPO's activities and IAPO believes that this is necessary to maintain and protect the public image and credibility of both parties.

The following principles have been developed to ensure that all funds received from corporate interests and all collaborative efforts with companies are ethical and reflect positively on IAPO and the companies and associations involved:

1. All sponsorship and collaborative efforts between IAPO and corporate entities must advance IAPO's mission, as assessed by the Governing Board.
2. IAPO will not accept restricted or designated funds for activities that are inconsistent with the vision and mission of IAPO and its strategic and other plans.
3. IAPO will at all times maintain an independent position on all issues affecting patients. The potential effects of such positions on the commercial interests of funding sources or collaboration partners shall not be a relevant factor in IAPO's decision-making process. When defining its positions, IAPO will obtain the necessary relevant information from the most objective, credible sources available and undergo consultation with members to ensure that its positions are well-informed and reflect the views of IAPO's members in line with its Policy Framework.
4. IAPO will accept sponsorship for projects involving educational and informational services only when it has full editorial control.
5. IAPO holds final approval of all uses of its name, logo and other identifying symbols. These symbols can be used by commercial entities only if their use furthers IAPO's mission and only with the written consent of the Governing Board.
6. IAPO will accept support for meetings and symposia only when the programme content is determined by a group of patients' organizations or other stakeholders representing IAPO. Funding sources will not exercise control over the programme content for such meetings or symposia.
7. IAPO will not permit presentations which support a commercial product at its meetings or symposia (except when scientific data is presented in an independent and organized fashion).
8. IAPO will provide appropriate recognition of company sponsorship but such recognition should not be interpreted as endorsement of particular policies or products.
9. IAPO will strive to have multiple companies supporting its activities to avoid the appearance of an alliance with any one company, its products, legislative agenda or regulatory concerns.
10. IAPO will ensure that company sponsors and collaborators are familiar with the ethical principles listed above.