



# Healthcare Industry Partners' Framework

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.

Penney Cowan  
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 250 members, representing over 50 disease areas and over 60 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.

**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, 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 2015-17: See Full 3 Year Report ([FR 2015-17](#))**

- Set-Up IAPOs Research Unit in 2017
- Took over [www.PatientResearchNetwork.org](http://www.PatientResearchNetwork.org)
- Held an African Members meeting and engaged the African Medicines Agency and NEPAD on African Medicines Regulatory Harmonization Programme
- Delivered one WHO official side event and 5 unofficial side events with our industry partners at the 70<sup>th</sup> World Health Assembly 2017. We were partners and instrumental in two Resolutions: WHA70/19 Global consensus on the blood donation and management and WHA70/7 Improving the prevention, diagnosis and clinical management of sepsis
- Delivered a [Great Global Patients Congress 2016](#) 9-11 April. Programme developed with members and bursaries awarded to facilitate access.



- Continued to develop IAPO's Regional strategy through holding regional meetings in Latin America in [2014- 2016](#)
- Supported IAPO members to attend WHO Regional Meetings in Africa, Europe, Eastern Mediterranean, Western Pacific and Americas , including delivering interventions on key issues, and regional networking
- Patient Solidarity Day held worldwide December 2015 and [2016](#) with participation from over 170 organizations in over 40 countries, with official support from the African Regional Office for WHO, and endorsement by Western Pacific Office for WHO. [Report 2016 PSD](#).

### **Current Cross-Sector Collaborations, Strategic Alliances and Partnerships**

IAPO has a strong belief in the importance and efficacy of collaboration with policy-makers, health professionals, academics, industry representatives and other stakeholders in order to achieve positive change in healthcare worldwide. IAPO prioritizes collaboration during the development and implementation of its own policy activities.

- In official relations with the [World Health Organization \(WHO\)](#)
- Special Consultative Status with [UN Economic and Social Council \(ECOSOC\)](#).
- Official partnership with the [World Medical Association \(WMA\)](#), [International Council of Nurses \(ICN\)](#) and the [International Pharmaceutical Federation \(FIP\)](#)
- Project Partner on [Innovative Medicines Initiative \(IMI\)](#)-led [GETREAL](#) Project incorporating real-life clinical data into drug development
- Member of [Health Policy Forum of the European Commission](#)
- Member of the European Medicines Agency ([EMA](#)) Patients and Consumers Working Party (PCWP) and Pharmacovigilance Risk Assessment Committee (PRAC)
- NGO Committee Rare Disorders (a part of Conference of NGOs with Consultative Status to the United Nations Economic and Social Council (CoNGO))

### **IAPO's strategic objectives for the 2018-20 Strategy are being set and will**

We will strive to empower patient communities globally to advocate effectively for Patient-Centered Universal Health Coverage in all WHO Member States and drive the research processes and the development of evidence base needed for the establishment of PC-UHC and support the shaping of healthcare law, policy and practice needed at global, regional and national levels by:

#### 1) Leading the patient voice on global healthcare issues

IAPO will take the lead on identifying key issues in healthcare on which to advocate at all levels of decision-making. IAPO will undertake research, produce briefings and toolkits for its members, and ensure the patient voice is heard in global, regional and national fora. IAPO will speak out on these key issues with a clear voice and seek to make its voice strongest where it can have most impact.



### 2) Advancing patient engagement

IAPO will develop and disseminate models, drawn from our membership experience, of effective patient engagement at all levels of healthcare decision-making. IAPO will work to show how patient engagement leads to more effective healthcare.

### 3) Empowering the global patient movement

IAPO will build the ability of its members to understand the key healthcare issues identified, and advocate effectively and clearly. This programme will include briefings, resources, webinars, and opportunities for face to face sharing and learning from each other at events. IAPO will also strengthen its regional networks, recognizing that each region will have different ways to develop, and will be led by members in each region to enable appropriate IAPO support. In addition, none of the work of IAPO or the delivery of its goals can happen without the organization itself being strong, sustainable and committed. This objective will include strengthening IAPO itself as a responsible global organization working to achieve its vision and mission.

## **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](http://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](mailto: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](mailto: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	✓	✓	-
<b>Benefits at the Global Patients Congress</b>			
• 1 x delegate observer place	✓	✓	✓
• 1 x extra delegate observer place with discounted registration	<b>50% discount</b>	<b>25% discount</b>	<b>10% discount</b>
• 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)	<b>10 copies</b>	<b>5 copies</b>	<b>2 copies</b>
<b>Acknowledgement on IAPO website:</b>			
• Company name and level of support listed	✓	✓	✓
• Link to Corporate Website	✓	✓	✓
• Partner Profile (summarizing the Partner's mission, work and involvement with IAPO)	<b>✓ 600 words</b>	<b>✓ 300 words</b>	<b>✓ 100 words</b>
Acknowledgement of support in end of year newsletter	✓	✓	✓
<b>Acknowledgement in Industry Partners Booklet:</b>			
• 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  
London, N1 6AH  
United Kingdom

Telephone: +44 20 7250 8280  
Fax: +44 20 7250 8285  
Email: [info@iapo.org.uk](mailto:info@iapo.org.uk)  
Website: [www.iapo.org.uk](http://www.iapo.org.uk)

### Governing Board Members

IAPO's 2018 Board Members are listed below. Please contact the IAPO office for their contact details.

**Ms Penney Cowan, IAPO Chair Board Member** and Executive Director, American Chronic Pain Association

**Ms Jolanta Bilińska, IAPO Immediate Past Chair** and President, Patients Safety Foundation, Poland

**Mr Andrew Spiegel, IAPO Chair-Elect Board** and CEO of Global Colon Cancer Association

**Mr Hussain Jafri, IAPO Board Treasurer** and Secretary General of Alzheimer's Pakistan, Vice Chair of the Advisory Group of WHO's Patients for Patients Safety programme

**Ms Androulla Eleftheriou, IAPO Board Member** and Executive Director, Thalassaemia International Federation

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

**Ratna Devi** 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.

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

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

## 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.