



Strategic Plan Framework Pathway 2018-2020

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Rationale

Purpose

The main purpose of the IAPO Strategic Plan 2018-2020 is to:

- Identify priority issues and core advocacy areas for the coming three years;
- Provide a vision as to the role IAPO aims to play in shaping these issues and healthcare processes in general;
- Outline expected outcomes and provide an understanding of the impact IAPO aims to generate

IAPO's Previous Strategy 2015-2017

The previous IAPO Strategy covered the period 2015-2017 and was built around three main objectives:

- 1) Leading the patient voice on global healthcare issues**
- 2) Advancing patient engagement**
- 3) Empowering the global patient movement**

Whilst much work is still needed towards the full fulfilment of these objectives, IAPO has developed and led a wide range of activities during the past three years in accordance with the vision outlined in the plan. By clicking on this [link](#), it is possible to receive a detailed overview of IAPO's achievement during the three-year period 2015-2017.

The process

With the period covered by the previous plan approaching to its end, IAPO started developing a new strategy in September 2017.

A preliminary draft was submitted to the IAPO Governing Board by the end of the month.

After IAPO Board Members' comments had been incorporated in the draft, IAPO held an on-line member consultation throughout October 2017, which provided IAPO members with an opportunity to input in the developing strategic plan and apply to be part of the newly constituted IAPO Strategic Plan 2018-2020 Committee (The Committee) .

Following the Member consultation, The Committee was established with the aim of assisting IAPO in sharpening the focus of its future strategy. The Committee was put in place according to the principles of patient leadership and cross-stakeholder partnership. Its membership includes representatives from:

- IAPO Team (1)
- IAPO Members (3)
- IAPO Board Members (4)



- Former IAPO Board Members (2)
- IAPO Industry Partners (1) - directly nominated by IAPO Industry partners

The Committee's members are:

IAPO Team

Kawaldip Sehmi, Chief Executive Officer, IAPO, UK

IAPO Board Members

Jolanta Bilińska, Chair, IAPO Board, Poland

Penney Cowan, Chair-Elect, IAPO Board, USA

Hussain Jafri, IAPO Board member, Pakistan

Andrew Spiegel, IAPO Board Member, USA

Former IAPO Board Members

Regina Namata Kamoga, Executive Director, Community Health and Information Network (CHAIN), Uganda

Joshua Wamboga, Executive Director, Uganda Network of AIDS Service Organizations (UNASO), Uganda

IAPO Members

Danjuma Adda, Executive Director, Center for Initiative and Development (CFID)/ Chagro-Care Trust (CCT), Nigeria

Orajitt Bumrungrakulswat, Assistant Secretary General, Heart to Heart Foundation, Thailand

Paula Menezes, President of ABRAF - Hipertensão Pulmonar, Vice-President of Sociedade Latina de Hipertension Pulmonar, Brazil

IAPO Industry Partners

Catharine Trzaskawka, Head, Global Advocacy, Bristol-Myers Squibb, USA (nominated by IAPO industry partners as industry representative in the committee).

The document that will be produced by IAPO in collaboration with the Committee will be submitted to the IAPO Board for approval.

The IAPO Strategy 2018-2020 will then be disseminated and discussions with the global community of members on how to translate it into effective and practical advocacy activities will be held at the 8th [Global Patients Congress](#) in Miami, Florida, USA.



About IAPO

Who we are

The International Alliance of Patients' Organizations (IAPO) is a global alliance representing patients of all nationalities and disease areas. IAPO promotes patient-centre healthcare and acts as a focal point and facilitator for local, national, regional and international patients' organizations. The essential principles guiding patient-centred healthcare are that healthcare systems should be designed in such a way so that patients' needs are answered. IAPO works with our 265 member patient organizations representing more than 70 countries and 50 disease areas. IAPO is a non-state actor in official relations with the World Health Organization (WHO) and engages with the wider community of patients and civil society. IAPO builds and promotes constructive dialogue with decision makers, policy makers, industry, researchers and professionals around the world to promote patient-centred healthcare and universal health coverage.

Vision

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

To IAPO, being at the centre of healthcare means:

- Recognising that patients have the right to be fully and adequately involved in decisions concerning their own healthcare;
- Ensuring that patients play a key role in health services and technologies design, delivery, and development;
- Ensuring that patients do not simply participate in research but act as co-shapers and co-drivers of healthcare research processes;
- Ensuring that patients have a meaningful say in healthcare law-, policy-, and decision-making at all levels.

Mission

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

IAPO pursues its mission by:

- Advocating internationally with a strong patient 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;
- Developing and delivering capacity building initiatives aimed at making patient-led advocacy activities as effective as possible.

Patient-centred healthcare

IAPO is aware that the concept of patient-centred healthcare might acquire different meanings and implications according to the region or disease area to which it applies. Consistent with our global approach and scope, IAPO has identified five universally applicable principles of patient-centred healthcare. It is up to each IAPO member to plan and develop feasible strategies in order to ensure these principles can be successfully implemented in the disease areas or countries/regions in which they operate.

As per IAPO's Declaration, the five principles of patient-centred healthcare are:

1. Respect

Patients and carers have a fundamental right to patient-centred healthcare that respects their unique needs, preferences and values, as well as their autonomy and independence.

2. Choice and empowerment

Patients have a right and responsibility to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. This requires a responsive health service which provides suitable choices in treatment and management options that fit in with patients' needs, and encouragement and support for patients and carers that direct and manage care to achieve the best possible quality of life. Patients' organizations must be empowered to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choices.

3. Patient involvement in health policy

Patients and patients' organizations deserve to share the responsibility of healthcare policy-making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to healthcare policy but include, for example, social policy that will ultimately impact on patients' lives. See IAPO's Policy Statement at: www.iapo.org.uk/patient-involvement

4. Access and support

Patients must have access to the healthcare services warranted by their condition. This includes access to safe, quality and appropriate services, treatments, preventive care and health promotion activities. Provision should be made to ensure that all patients can access necessary services, regardless of their condition or socio-economic status. For patients to achieve the best possible quality of life, healthcare must support patients' emotional requirements, and consider non-health factors such as education, employment and family issues which impact on their approach to healthcare choices and management.

5. Information



Accurate, relevant and comprehensive information is essential to enable patients and carers to make informed decisions about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual's condition, language, age, understanding, abilities and culture. See IAPO's Policy Statement at www.iapo.org.uk/patient-information-and-health-literacy

External Challenges: Context and Developments

Policy arenas are competitive environments due to their limited capacity. Not all policy issues make it to the top of governments' agendas. Furthermore, even when that happens and the urgency of an issue is actually perceived and recognised (e.g. universal health coverage), that does not guarantee that that issue will be addressed from the angle for which one organisation is advocating (patient centricity). This shows how important it is to develop a compelling case for our cause by generating solid evidence and ensuring that all key decision makers and health stakeholders look at patient-centred healthcare as an ambitious objective that is likely to generate benefits beyond the patient realm. IAPO has conducted a quick mapping of our environment to understand what will ensure that by 2030 that there is a sufficient availability of quality and safe promotive, preventive, curative, rehabilitative and palliative health services in all of the WHO member countries, along with essential and innovative medicines and health devices, that are accessible, acceptable and affordable, delivered without the patients suffering financial hardship or discrimination.

We have collected these as statements of insights in a STEP- D

- Social developments
- Political developments
- Technological developments
- Economic developments

Social Developments

- There is a strong drive to establish an **integrated people centred health care model** that aims to bring together health and social care into one package. This has access and quality dimensions. It has patient centricity and ownership of health systems
- Drive towards a **rights based approach** in health is gathering momentum. This is coming out patient charters linked with social welfare and access to justice. Patient centricity as a tool of equity, social cohesion and right to health being accepted now.
- **Personalised medicine** (as a social phenomenon- see technological phenomenon) is here. Angelina Jolie's case of Personal Medicine: decision to have double mastectomy and surgical removal of her ovaries and fallopian tubes to reduce the risk of ovarian cancer due to the faulty BRCA1 gene she was born with.
- **Social Media and Access to Internet Resources** improves health literacy as well as creates problems of quality (cyber-chondria and fake cures).
- Social media as an advocacy and **patient support tool** has a great potential.



- New opportunities are opening for patients and patient advocates to **drive progress** in healthcare (patient-led research, patient education and health literacy programmes, stronger role for patients in mainstream research and decision making-processes – see BMJ)

Political Developments

- **SDG 2030** and Commitment to UHC 2030
- **Access** to medicine and IPPR
- **AMA and Regulatory Harmonization.** Harmonization initiatives developing in the Americas as well, while in Europe the Brexit process casts shadows about the future of patient engagement in the EMA.

Technological Developments

- **Biotechnologies and genetic engineering** brings personalised medicine nearer- personalising and tailor making your drugs and treatment
- **Biotherapeutics as monoclonal antibodies** having a great impact and application. The biologics and their biosimilar regulations critical. It is becoming increasingly important to clearly identify “what patients need to know” with regard to biotherapeutics and biosimilars. This will determine the nature of role patients will be able to play.
- **Contract researchers** and patient engagement in research have several dynamics
- **Telehealth and end-to-end computerization** of patient records have new dynamics
- **Pharmacovigilance** signal detection and action via social media and other advances in electronics has a great potential. In particular, new technologies have a role to play in adverse events reporting.

Economic Developments

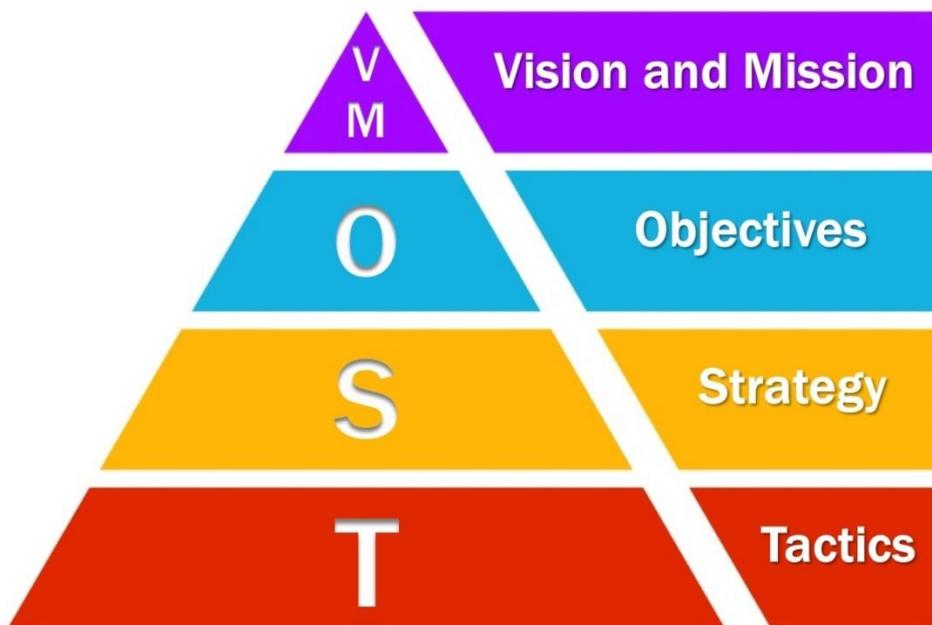
- **Universal health coverage** and health financing strategies everywhere.
- **Health Technology Assessment** gathers pace. Increasing trend at global level on the necessity of developing guidelines on how to carry out HTA properly and how to structure HTA in LMIC, in which the cost-benefit ratio acquires a completely different meaning than it does in the West.
- WTO, World Bank and Regional Development Banks and UHC.
- **Patient centricity** as an economic tool to advance reach, efficacy, efficiency and impact gaining momentum in cost reduction. It also is seen as an investment as part of SDG 2030 17 goals- health in all economic development.

Internal Challenges: Sustainability

IAPO's uniqueness lies in its membership. IAPO is the only organisation representing patients from all disease areas globally. Due to the variety of groups that constitutes its membership, IAPO has established itself as the global voice for patients. The diversity of IAPO's membership, in terms of scope, disease areas, expertise, must be valued to make sure that all views and perspectives are adequately represented. In this respect, the process of patient empowerment necessarily brings about the question as to what role empowered patients can actually play in healthcare. In fact, there

is a lot that patients and patient advocates can do to empower themselves and increase their influence in health policy process. However, for this influence to be exerted, healthcare stakeholders and decision makers must recognise patients as partners. While working to empower patient communities globally, IAPO must also advocate and call on decision makers and stakeholders to value empowered patients and make the most of the unique skills and views that they add.

However, IAPO will only be able to adequately represent patients' voice if its sustainability can be guaranteed over time and its organizational capacity can be properly developed. This means having in place precise rules and procedures aimed at strengthening key strategic features such as human resources, organizational management, and administration. In this respect, the figure below provides a glimpse on how IAPO believes internal and external factors interact and influence each other.





Strategic Objective

Our proposed broad objectives in 2018-20 (and beyond to 2030) are to ensure that there is a:

Sufficient availability of patient centric, quality and safe, promotive, preventive, curative, rehabilitative and palliative health 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

The case for patient-centric universal health coverage (PC-UHC)

In 25 September 2015, the General Assembly of the United Nations adopted Resolution [A/RES/70/1](#). By officially endorsing this document, the leaders of the 193 United Nations (UN) Member Countries agreed on a comprehensive set of goals and targets and committed themselves to work tirelessly to implement this Agenda fully by 2030. The 17 [Sustainable Development Goals \(SDGs\)](#) and 169 targets of Agenda 2030 identify the global priorities that will guide, inspire, and stimulate UN Member Countries' political action for the next 15 years.

[Strategic Goal 3](#) is centred on good health and well-being Strategic Goal 3 is underpinned by a set of specific targets. Although these targets are global in scope and ambition, each government can establish how to best incorporate them in their national policies, processes, and plans of action by taking into account national circumstances. While multiple roads can be paved towards the fulfilment of the SDGs and related targets, the content of each target and the ambition behind them apply to all countries globally. Amongst the nine targets that underpin Strategic Goal 3, stands Target 3.8, which reads:

To achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

Patient groups have an important role to play in this long-term journey. First, patients are well placed to ensure that governments develop and properly follow-up on feasible policies in the three dimensions of UHC. Depending on local and national context, the degree of urgency with which these dimensions are perceived will vary considerably across countries. Patients are called on to identify which are the most sensible and urgent priorities, around which political and policy action is needed in order to progress towards UHC for all.



Goals

IAPO is aware that achieving truly patient-centred universal health coverage is a long-term challenge which requires a cross-stakeholder effort. Over the next three years, IAPO will devote their efforts to promoting and advocating for PC-UHC, looking at it as a global priority issue. Based on input received from the global community of IAPO members, PC-UHC will be addressed from a variety of angles, such as patient empowerment, research and evidence generation, influence over health policy and practice. These streams of work will flow into a strong, unified call for PC-UHC for all by 2030 as stated in the Sustainable Development Goals 2030.

The goals for 2018-2020 will be:

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

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

Shape law, policy and practice in PC-UHC at global, regional and national levels.

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

Patients and patient organizations will only be able to make a difference in their quest for PC-UHC if they are aware of their rights, duties are and the practical steps they can take to encourage progress towards PC-UHC. Patients are today called on to equip themselves with the tools and know-how that is needed to make a contribution and make a difference. However, the availability and quality of these opportunities of empowerment vary considerably across the world. Some areas exhibit strong barriers to patient empowerment such as poor-quality information and lack of access to basic health services, including patient information. If patients are not put in the conditions that are needed to become more aware and knowledgeable about their health, the principle of patient empowerment will be undermined at its core.

At the same time, it is paramount that health stakeholders and decision-makers recognise in parallel the role that empowered patients can play in healthcare to achieve higher-quality health outcomes. IAPO will continue to engage its community of members and other patient organizations in capacity building, networking, and research and policy development activities. The main objective is to ensure that patient communities deepen their awareness and knowledge of the most urgent health issues and strengthen their set of skills in order to more effectively advocate for universal health coverage for all by 2030.

In the same way as patient-centred healthcare, patient empowerment is a principle that can acquire various connotations depending on the context and/or disease area one refers to. IAPO will advocate at global level to ensure patients are put in the ideal conditions to influence healthcare processes. At the same time, IAPO urges its members to identify the patient empowerment avenues that are more likely to generate impact in their own community and in relation to their disease area of interest.

Patient empowerment marks a line of continuity between the previous and the current strategic plan. From a global perspective, [patient empowerment](#) entails three different dimensions:

- **Empowerment as a process** by which patients become more knowledgeable and aware of their conditions and take control over their healthcare journey. In this context, information and education become enabling factors of patient empowerment.
- **Empowerment as a state** whereby patients develop “an ability to make autonomous, informed decisions”.
- **Empowered behaviours** which involve adopting a proactive mind-set whereby patients can be in control of their health and healthcare decisions.

The journey towards PC-UHC can only be successfully completed if patients pursue all of these forms of empowerment. Below is a brief overview of the actions that IAPO will develop towards the achievement of this goal.



Lines of Action towards Goal 1.

To empower the global community of patients to advocate in favour of PC-UHC for all, in 2018-2020 IAPO will:

- Identify and segment regions, countries, partners and patient organizations affected by health legislation, policy and practice supporting PC-UHC;
- Identify, describe, and tackle the most striking obstacles to patient empowerment worldwide and define feasible strategy to overcome them.
- Design, develop, and deliver capacity building programmes that are aimed at ensuring patients are equipped with the necessary skills to advocate for PC-UHC;
- Pursue effective communication and knowledge brokering. Targeting key audiences by matching message, medium and messenger like doctors, nurses, health professionals and teachers, who can enhance your policy education and advocacy. These audiences have a strong collective voice in health policy making across their associations and industry representative bodies;
- Support initiatives aimed at promoting patient centrality in the processes of generation, development and dissemination of information in healthcare (medicines, technologies, research).

Goal 1: KPIs

The degree of success in fulfilling this goal will be evaluated against IAPO's ability to:

- Create opportunities for IAPO members to input in UHC policy and legislation at all decision-making levels.
- Develop a solid understanding of the factors currently preventing patient empowerment, with an emphasis on low and middle income countries and concentrate efforts in those areas.
- Involve its members in the development, run, and management of its capacity building programmes focused on PC-UHC.
- Increase key stakeholders' awareness of the urgency of having PC-UHC implemented worldwide.
- Become a pivotal actor in the field of patient information and health literacy, which represent two key pre-conditions for PC-UHC.

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

The issue of appropriately engaging with patients in healthcare research is acquiring greater importance at a global level. Research is indeed one of the most important realms in healthcare within which empowered patients can come across multiple of ways of making a difference. Being empowered in research not only means being involved in research as a participant, but becoming a co-partner in the research process. For example, patient input can shape the way in which research is reported after the study, like communicating how patient input was used and what it helped to achieve. In this way, [patient empowerment in research](#) creates a more patient-centred process and outcome.

Because patients are meant to be the primary beneficiaries of research, they must be enabled to have a say on the way in which research is designed, carried out, and eventually communicated and disseminated. In this regards, healthcare stakeholders are realising that involving patients as co-drivers of the research process is not simply “the right thing to do”, but can also generate positive effects on the overall quality of the research processes.

Patient empowerment in research means being informed of what research they can take part in, being involved in decision-making regarding the research process, and knowing their rights and responsibilities when taking part in research. In the coming three year, IAPO will work towards creating appropriate conditions for patients to become better informed about, involved in, and aware of research. This strategic goal will be pursued by ensuring that the community of IAPO members can bring their perspectives and expertise into our research programmes, stably contribute to research projects that are led by partners and stakeholders, and set a solid agenda of research priorities in support of PC-UHC.

Lines of Action towards Goal 2.

To drive research processes and strengthen patient involvement in research, in 2018-2020 IAPO will:

- Work with members to set priorities through the IAPO Research Unit. IAPO and its members will be able to design, undertake and develop patient-led research projects;
- Facilitate IAPO members' participation in international, multi-stakeholder research, including pharmaceutical R&D, and in WHO-led research programmes on key global issues;
- Undertake policy research, policy implementation evaluations and modelling to identify the alternative policies that might facilitate achievement of PC-UHC;
- Improve the quality of research dissemination by engaging IAPO members in the development of dissemination tools and involving them as reviewers, assessors, and patient-centricity experts.
- Support educational, research dissemination, and capacity building activities by building on the success of similar initiatives (EUPATI, EPAP) and by relying on the findings/outputs generated by IAPO-led research.



Goal 2: KPIs

The degree of success in fulfilling this goal will be evaluated against IAPO's ability to:

- Establish a member-led, sustainable, and fully operational Research Unit.
- Involve members in IMI, WHO research programmes of which IAPO is part or facilitate links between research institutes and members.
- Initiate research programmes that have a clear and neat link with PC-UHC.
- Increase the variety of roles with which IAPO members contribute to research (authors, reviewers, advisors)
- Adequately promote dissemination tools to members.

Goal 3 - Shape law, policy and practice in PC-UHC at global, regional and national levels.

PC-UHC builds on patient empowerment and on strong evidence base. Equally, fulfilling this objective requires a high level of commitment to meaningfully engaging with key decision makers (regulators, institutional organizations, governments) and healthcare actors (industry, professionals, experts). IAPO will continue to play a central role in cross-stakeholder alliances based on the belief that this is the most effective way to generate tangible impact in policy-, law-, and decision-making. Furthermore, by representing and engaging patients in global policy making arenas, IAPO will pursue its vision of making healthcare systems truly centred on patients. This objective will be fulfilled by representing and inputting patients' voices in on-going regulatory harmonisation processes and in health law, policy and practice at all levels.

Lines of Action towards Goal 3.

To shape law and policy at all levels of healthcare decision-making, in 2018-2020 IAPO will:

- Map the regional and global legislative, policy and institutional frameworks underpinning the drive towards a PC-UHC and health care systems globally;
- Actively promote and engage in cross-stakeholder alliances in which IAPO members can contribute to health services design and delivery;
- Fuel and strengthen our official collaboration with the WHO and ensure that patients' voices are adequately represented in the main global policy arenas by playing a leading role in relevant events, policy consultations, educational programmes, and research activities;
- Promote and lead outcome-oriented collaborations with state and non-state actors and strategic international partners (European Patients' Forum, NCD Alliance, Alianza Latina) to advocate for PC-UHC;
- Advocate for increased financing and strengthening of systems of health to reduce health disparities across the world and become more strongly involved in new regulations focused on Quality of Life/psycho-social burden of disease/treatment;
- Build a strong evidence base to promote PC-UHC resolution at UN/WHO.

Goal 3: KPIs

The degree of success in fulfilling this goal will be evaluated against IAPO's ability to:

- Generate a systematic understanding of each Region's journey towards UHC;
- Increase its involvement in multi-stakeholder for a;
- Increase the number of joint projects and initiatives carried out in collaboration with the WHO;
- Increase collaboration with strategic international partners;
- Promote fairer health financing policies across world regions;
- Have a resolution approved at UN/WHO level.



Implementation

This Strategic Plan will inform the planning and development of yearly plans of activities aimed at making progress towards the three strategic goals. A specific session will be held at the 8th Global Patients Congress in Miami to discuss the newly developed IAPO Strategy. Per each strategic goal, a member-led ad-hoc committee will be established. The three committees will be in place for the entire period covered by this strategic plan and will be invested with the following duties:

- Monitor progress made by IAPO against each strategic goal;
- Regularly liaise with IAPO and suggest strategic adjustments;
- Input in development of IAPO's yearly plans of activities.



Acknowledgements

IAPO Strategic Plan 2018-2020 Committee

Danjuma Adda (Member)
Jolanta Bilińska (Board)
Orajitt Bumrungrakulswat (Member)
Penney Cowan (Board)
Hussain Jafri (Board)
Paula Menezes (Member)
Regina Namata Kamoga (Former Board Member)
Kawaldip Sehmi (CEO)
Andrew Spiegel (Board)
Catharine Trzaskawka (Industry Partner)
Joshua Wamboga (Former Board Member)

IAPO Governing Board

Jolanta Bilińska (Chair)
Penney Cowan
Ratna Devi
Androulla Eleftherieou
Hussain Jafri
Neda Milevska
Andrew Spiegel

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