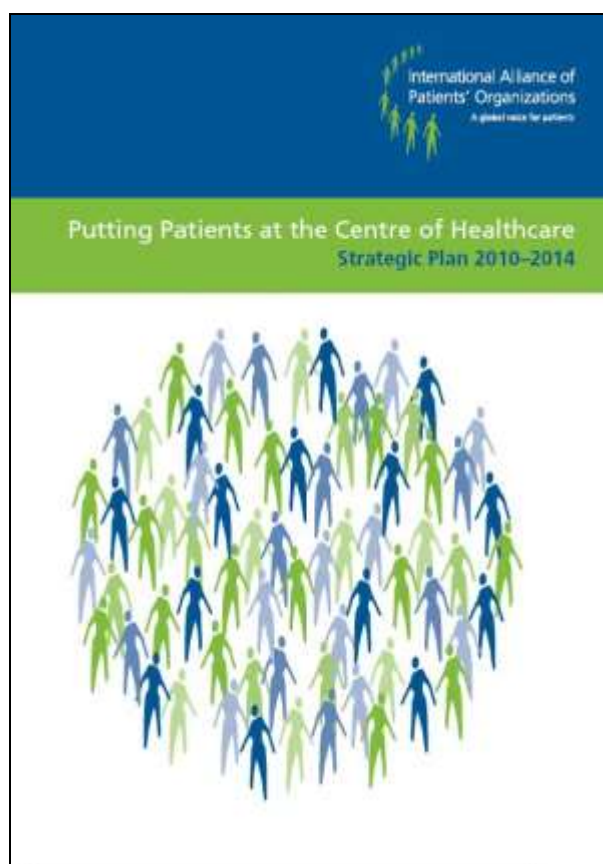


# International Alliance of Patients' Organizations

## Strategic Plan 2010-2014 Progress in 2013

IAPO is undertaking a five-year Strategic Plan from 2010-2014 with the strategic goal: To strengthen the impact of the global patients' voice in decision-making processes globally.



This paper outlines the four strategic objectives identified in the Strategic Plan 2010-2014 (1 – Engagement; 2 – Voice; 3 – Member-led and 4 - Sustainability), the specific activities and progress made towards these objectives in 2013. A copy of our Strategic Plan 2010-2014 and Progress in 2011 and 2012 can be accessed online at [www.patientsorganizations.org/development](http://www.patientsorganizations.org/development).

# Strategic Plan 2010-2014

## Progress in 2013



### 2010-2014 Strategic Objective 1: Engagement

Patients' organizations will be better engaged in influencing decision-making at an international level by:

- a) Strengthening IAPO's collaborations with the World Health Organization (WHO) and United Nations Economic and Social Council (UN ECOSOC).
- b) Facilitating the engagement of patient representatives in WHO activities and decision-making processes.
- c) Proactively working with key international organizations to develop and implement appropriate and realistic frameworks for patient engagement.
- d) Accurately representing and communicating the global patients' voice.

#### 2013 Activities

- IAPO will undertake activities to ensure that Official Relations status with the World Health Organization is maintained and productive through IAPO's collaboration with WHO Patient Safety and active participation on the Steering Group of Patients for Patient Safety. **Official relations renewed in January 2013 (with WHO Patient Safety) for three years (2013-2015).**
- IAPO will continue to develop and maintain informal working relationships with multiple sections/ regional offices of WHO and investigate potential projects to become an implementing partner on. **IAPO has engaged with the department on non-communicable diseases as well as health financing and the cluster for health systems. IAPO has been involved in the update to WHO'S report, '[Priority Medicines for Europe and the World 2013 Update](#)'. . IAPO continues to explore the potential to develop informal working relations with WHO.**
- IAPO will monitor its application for consultative status with the United Nations Economic and Social Council (ECOSOC) which will be reviewed in May/June 2013. Following this IAPO will develop its relationship with UN ECOSOC. **Consultative status with UN ECOSOC status was recommended in January 2014.**
- IAPO will represent the patient voice at the WHO Executive Board (EB) Meeting and World Health Assembly (WHA) through interventions on relevant agenda items and meetings with stakeholders. **Interventions were made at the WHO Executive Board in January 2013 on: WHO Reform, Millennium Development Goals (MDGs), and the prevention and control of non-communicable diseases, and at the WHO World Health Assembly in May 2013 on the following agenda items: universal health coverage, counterfeit medical products, Twelfth General Programme of Work.**
- IAPO will facilitate and support IAPO Member representatives to attend and to engage at the WHO Executive Board, WHA and WHO Regional Committee Meetings. **IAPO facilitates the involvement of one Governing Board and one member at the WHO Regional Committees. In 2013, IAPO supported representatives to attend the WHO Regional**

# Strategic Plan 2010-2014

## Progress in 2013



**Committees in Africa (for the first time), Western Pacific, Eastern Mediterranean, Europe and the Pan-America region. IAPO supported more members to attend than ever before (4 Governing Board Members and 5 Member Representatives). Another first was a member-developed Declaration which was taken to the Pan American Regional Committee. In addition, the WHO presented during IAPO's Latin American Regional Meeting in September.**

- IAPO will aim to organize a meeting as a side event to the WHA to raise the profile of the patient voice with an audience of WHO member country delegates, health professional representatives, patient group representatives, journalists and others. **A side meeting to the WHA was held. It was entitled: [Patient Engagement in Medication Safety](#), and was hosted by the Government of Australia and IAPO in collaboration with the [WHO Patient Safety Programme](#) (PSP). This is the first time IAPO has held a side meeting with the support of a government; attendance at the side meeting was estimated at over 200 people.**
- IAPO will promote its policy positions through presentations at external meetings and conferences. **IAPO presented at 43 external meetings. IAPO responded to a number of consultations in 2013: [Declaration of Helsinki](#) (World Medical Association), IAPO responded to two sets of WHO consultations on non-communicable diseases (NCDS), the [Global Action Plan](#) and [the Global Coordination Mechanism](#) (GCM) for Non-Communicable Diseases (WHO) and a further two on WHO's engagement with non-State Actors in [March](#) and in [October](#). Additionally, IAPO responded to a [European Medicines Agency consultation on clinical trial data transparency](#). IAPO developed a supporting statement for the [Alltrials campaign](#) (Alltrials).**
- IAPO will develop a Briefing Paper on Biosimilar Medicines to provide information to patients' organizations on the status of Biosimilars Medicines globally. IAPO will convene a workshop on Biosimilar Medicines. **19 patient representatives and other stakeholders including European Generic Medicines Association (EGA), International Hospital Federation (IHF) and project sponsors were present at a workshop held in May 2013. Speakers from WHO, Finish Medicines Agency (Fimea) and Alliance for Safe Biological Medicines participated in the workshop. The workshop provided educational presentations, time for discussion and debate around issues identified as important by participants such as access, action planning exercises and feedback on the draft paper. The toolkit (including a briefing paper) was published in November and two webinars were held in December. See: [www.patientsorganizations.org/biosimilars](http://www.patientsorganizations.org/biosimilars)**
- IAPO will publish a review of the literature supporting patient-centred healthcare. **Deferred to 2014.**

# Strategic Plan 2010-2014

## Progress in 2013



- IAPO will develop an educational paper on the patient perspective and needs with regards to innovation. IAPO provided a grant for an academic to develop an academic educational paper for use by patients' organizations. **This has been completed and will be published in 2014.**

IAPO is involved with numerous coalitions and initiatives that enable it to be involved in policy and advocacy work on numerous aspects of patient-centred healthcare in our priority areas of:

- 1) Meaningful patient engagement in healthcare policy decision-making.
- 2) Access to health, treatment and care.
- 3) Access to good quality health information which is communicated effectively.
- 4) Access to safe and quality healthcare services.

These will include working on: biosimilar medicines; chronic disease prevention and management; clinical trials; counterfeit medicines; health literacy; health technology assessment, patient-health professional communications and pharmacovigilance. A number of these initiatives are listed in the table below and further information can be accessed through the hyperlinks.

Type of collaboration	Organization	Details
Official relationship	World Health Organization (WHO)	Official Relations Status through <a href="#">WHO Patients for Patient Safety</a> . Engagement with WHO Regional Offices
Official relationship	United Nations Economic and Social Council (UN ECOSOC)	Special consultative status recommended January 2014 <a href="http://www.un.org/News/Press/docs//2014/ecosoc6592.doc.htm">http://www.un.org/News/Press/docs//2014/ecosoc6592.doc.htm</a>
Official relationship	<a href="#">International Hospital Federation</a> (IHF)	Memorandum of Understanding
Official relationship	<a href="#">European Patients Forum</a> (EPF)	Memorandum of Understanding
Official relationship	<a href="#">World Medical Association</a> (WMA)	Official Partner
Official relationship	<a href="#">International Council of Nurses</a> (ICN)	Official Partner

# Strategic Plan 2010-2014

## Progress in 2013



Official relationship	<a href="#">International Pharmaceutical Federation</a> (FIP)	Official Partner
Membership	European Commission	Directorate General for Health and Consumers (DG SANCO) - Member of the <a href="#">EU Health Policy Forum</a>
Membership	Council of Europe	Involvement in the <a href="#">European Directorate for the Quality of Medicines and Healthcare</a> (EDQM)
Membership	<a href="#">Health First Europe</a> (HFE)	Membership
Membership	European Medicines Agency (EMA)	<ul style="list-style-type: none"> <li>• <a href="#">Patients and Consumers Working Party</a> (PCWP)</li> <li>• <a href="#">Pharmacovigilance Risk Assessment Committee</a> (PRAC)</li> </ul>
Project	Innovative Medicines Initiative (IMI)	Project Partner - <a href="#">Pharmacoepidemiological Research on Outcomes of Therapeutics by a European Consortium</a> (PROTECT)
Informal collaboration	<a href="#">European Network on Patient Empowerment</a>	
Membership	<a href="#">Medical Technology Group</a> (MTG)	Membership
Membership	<a href="#">NCD Alliance</a>	Member of the Common Interest Group
Membership	<a href="#">International College of Person-Centred Medicine</a> (ICPCM)	Membership
Project	International Diabetes Federation, Novo Nordisk and Steno Center	<a href="#">Diabetes Attitudes Wishes and Needs (DAWN) 2</a>
Project	International Council of Nurses, International Federation of Pharmaceutical Manufacturers and Associations, World Medical Association	<a href="#">Consensus Framework on Ethical Collaboration</a>
Informal collaboration	UK Government	Informal engagement with <a href="#">All Party Parliamentary Group on Global Health</a> Attendance at Department of Health Global Health Team External Partners Meeting
Informal collaboration	Australian Government	Collaboration on side meeting at WHO <a href="#">World Health Assembly</a> 2013

# Strategic Plan 2010-2014

## Progress in 2013



In addition, IAPO became involved in one new collaborative project in 2013:

- The [GetReal](#) project started in October 2013 and is funded by the European Innovative Medicines Initiative (IMI). The project aims to increase the efficiency of the medicine development process by better incorporating real-life clinical data into drug development and to enrich decision making by regulatory authorities and Health Technology Assessment (HTA) bodies

# Strategic Plan 2010-2014

## Progress in 2013



### 2010-2014 Strategic Objective 2: Voice

The global patients' voice will be strengthened; ensuring it accurately reflects the diverse needs and experiences of patients globally and is well communicated by:

- a) Developing the capacity of patients' organizations globally.
- b) Supporting the development of active and empowered networks of patients' organizations (within world regions and globally).
- c) Enabling patients globally to develop and communicate a strong unified voice on shared agendas.

### 2013 Activities

- IAPO will review and develop the Patients' Exchange and other online services to ensure these remain up to date, relevant and promote exchange of information between IAPO members. **Development and updating of the Patients' Exchange so that the information is up-to-date and relevant was carried out in 2013. Further review and development of services will be undertaken in 2014.**
- IAPO will scope a Networks Project, supporting the development of networks of partner organizations initially linked to the Regional Strategy and exploring the need for further non geographical networks. **IAPO has been supporting the development of patient group networks on a global and regional basis throughout 2013. A review of this work and decisions on next steps will be undertaken in 2014, and will feature as part of the further development of the regional strategy (see below).**
- IAPO will undertake planning for the 6<sup>th</sup> Global Patient Congress to be held in March 2014 in London. **Planning well underway, with venue, speakers and workshops booked, and 100 delegates registered, well ahead of the same point in the 2012 Congress planning. Information on the programme and speakers can be found at: [www.globalpatientscongress.org](http://www.globalpatientscongress.org)**

IAPO will continue to roll out its regional strategy, supporting action plans in Africa, Latin America and Asia-Pacific and developing strategies for engaging with members in North America, the Eastern Mediterranean and Europe. IAPO will also hold regional meetings (subject to funding). **In September 2013, IAPO held its third regional meeting in Latin America which brought together 21 patients' organizations from 10 different Latin American countries, 15 local Mexican patient's organizations, and over 70 multi-stakeholders, to develop the action plan, enable training and set out concrete activities for the remainder of 2013 and 2014. At the meeting, IAPO worked with the Regional Network in order to develop a position paper to present to delegates at the WHO Regional Committee for the Americas, held just after the meeting. See [www.patientsorganizations.org/latinamerica](http://www.patientsorganizations.org/latinamerica)** In December, the first ever South-East Asian regional meeting was held in India with 16 patient representatives from three countries. An action plan for 2014 was

# Strategic Plan 2010-2014

## Progress in 2013



developed. See [www.patientsorganizations.org/south-eastasia](http://www.patientsorganizations.org/south-eastasia) In Africa, Patient Solidarity Day on 30 October 2013 was promoted as a regional activity, part of the Regional Strategy to bring together IAPO members across the continent and grow the regional presence and network. See below for more information on this. IAPO developed two editions of the Asia Pacific newsletter. This was in response to a call from members in the region at the regional meeting in the Western Pacific in October 2011.

- IAPO will provide a range of membership services including a Twinning Programme, WHO Mentor Programme Report and Guidelines for patients' organizations, capacity building workshops and policy briefing webinars. **One twinning project was selected in 2013 and is currently running between the Heart to Heart Foundation in Thailand and the Hong Kong Alliance of Patients' Organizations. This will be concluded in early 2014.** The WHO Mentor Programme Report and Guidelines was published in February 2013 (<http://www.patientsorganizations.org/showarticle.pl?id=1608>). Capacity building workshops were held at the regional meetings and during the biosimilars workshop and policy briefing webinars were held on policy issues.
- IAPO will set up a Policy Working Group to provide opportunities for IAPO members to work together on policy issues. **Deferred to 2014.**
- IAPO will define its process for consultation with patients and patients' organizations, to inform policy positions and act as a guide for other patients' organizations to consult with their constituents. **Deferred to 2014.**
- IAPO will seek to diversify its membership, reaching out to more patient groups in particular in under-represented regions such as South-East Asia and the Eastern Mediterranean. **The South-East Asia Regional Meeting in December provided an opportunity to reach new groups.**
- IAPO will hold Patient Solidarity Day in Africa and investigate the potential of holding an annual global day to raise awareness of patient-centred healthcare. **Patient Solidarity Day held on 30 October 2013 is an initiative started by members and supported by IAPO to gain recognition and support for the vital role of patient representatives in the design and delivery of healthcare. In 10 countries across Africa, Patient Solidarity Day was supported through multiple events in Cameroon, Ghana, Kenya, Liberia, Malawi, Nigeria, South Africa, Uganda, Zambia and Zimbabwe, led by our members. An official Patient Solidarity Day film was launched by IAPO and the event was well covered and supported on social media and through our partners. See [www.patientsolidarityday.org](http://www.patientsolidarityday.org)**



# Strategic Plan 2010-2014

## Progress in 2013



### 2010-2014 Strategic Objective 3: Member-led

Increased participation of IAPO member patient representatives in all aspects of IAPO's work, ensuring that the voice of patients globally will be integral to IAPO's work by:

- a) Providing increased opportunities for IAPO's Members to participate actively in and shape IAPO's work.
- b) Building the capacity of IAPO's Members to participate actively in and shape IAPO's work.

### 2013 Activities

- IAPO will continue to implement its Membership Strategy 2010-2014 taking forward recommendations from members. **IAPO's membership in the African and Latin American regions has grown this year. There are currently 216 members across all world regions; which are made-up of 32 Associate and 184 Full Members. IAPO focuses on ensuring that members can be and are fully engaged in the work; broadening and deepening our membership base, to better represent all patient groups and their needs.**
- IAPO will continue to collect information about members' activities and priorities to contribute to the accurate representation of members' views and needs. **A consultation to establish member needs in the Eastern Mediterranean and Europe regions was sent to members in May. IAPO continues to be active in EU institutions and pan-European activities to represent members across the region. IAPO has formed an Asia Pacific Steering Committee to coordinate activities in this region. IAPO sent out two issues of the new Asia Pacific Newsletter, sent to IAPO's patient group contacts (member and non-members) in the Western Pacific and South-East Asian regions. The members' pages on the website are constantly updated with new information. Members also continue to submit their newsletters and events, which IAPO promotes via the website and social media to keep the alliance informed. Relevant information is also included in the IAPO newsletter sent out monthly to both members and non-members.**
- IAPO will publish a framework, including training and support, of opportunities for all members to participate in shaping and delivering IAPO's work. **Deferred to 2014.**
- IAPO will provide regular communications of opportunities for all IAPO members, primarily through email, the IAPO website, social media and the member newsletter. **12 issues of the newsletter were produced in 2013. IAPO continued to put out press releases and to use social media for keeping members up to date on, for example, advocacy positions, to enable members to follow through at national level.**
- IAPO will develop an induction process and pack for new Members to guide them through their role in the governance of IAPO and their involvement in IAPO's work. **Member induction webinars are available for all members several times a year. The induction outlines the**

# Strategic Plan 2010-2014

## Progress in 2013



### **role of members in IAPO's governance and the opportunities for members to be involved in IAPO's work.**

- IAPO will hold an Annual General Meeting, providing opportunities for Members to guide IAPO's work including through the election of Governing Board Members. **The AGM was held in May 2013 in line with the constitution and three Governing Board Members were re-elected.**
- IAPO will hold two Governing Board Meetings in 2013. In addition, numerous Committees will guide, drive and support IAPO's work during the year. **Two Board meetings were held which all Governing Board Members attended. The fundraising, Congress advisory, membership, audit as well as other committees connected to the projects (all composed of member organisation representatives) met regularly throughout the year mostly through teleconference, and provided key oversight and input into IAPO's work.**
- IAPO members will continue to have opportunities for involvement in the development of IAPO's regional strategies. **The organisation of the Latin American and South-East Asia Regional Meetings was supported by a committee of members from the relevant areas, and members were speakers and facilitators at the events. A steering committee consisting of African members was established for Patient Solidarity Day activities and helped shape the core messages and outreach for the event.**

# Strategic Plan 2010-2014

## Progress in 2013



### Strategic Objective 4: Sustainability

IAPO's capacity and sustainability as an organization will be developed in the most appropriate ways to ensure that IAPO can achieve its vision by:

- a) Sustaining and diversifying the funding base of the organization.
- b) Ensuring an approach to human resources, organizational management and administration that promotes good governance and positive organizational development.

#### 2013 Activities

- IAPO will strive to diversify its funding base through implementation of its Fundraising Strategy. **A fundraising strategy for 2013-2014 has been developed. Industry partnerships for 2013 and early ones for 2014 have been confirmed, including for sponsorship of the two 2013 Regional Meetings and support of the biosimilars project and innovation paper. Conversations were initiated with a number of non-industry funders, such as charitable foundations to support various projects. Outreach and engagement will continue in 2014.**
- IAPO will continue to develop and update its management and governance policies and conduct a review and audit of policies and procedures. **Policies agreed or updated in 2013: Financial Authorisations Policy, Former Board Members representing IAPO Policy, Committees Policy, Contracts Policy, Health and Safety Policy, Paper and Record Retention Policy, Travel Policy for Board Members, and a Volunteer Policy.**
- IAPO will continue to implement a framework for orientation and ongoing training of Governing Board Members. **Building on the Board development done at the end of 2012, there will be further training and induction in 2014 after the UK charitable registration is completed.**
- IAPO will continue the process of registering IAPO in the United Kingdom for the purposes of developing its governance and funding opportunities. **Completed in January 2014.**
- IAPO will continue to systematically plan, monitor and review its work during the 2010-2014 strategic period, including through impact analysis and evaluation. **Evaluation of events and webinars takes place which informs future planning for events.**
- IAPO will implement its Communications Strategy. **Key parts of the Strategy are being implemented.**
- IAPO will develop a new website that will increase participation of members in IAPO's work, will be easier to navigate, be an improved resource for healthcare stakeholders interested in understanding and acting on patients' needs and provide greater opportunities for interaction (subject to funding). **A plan has been developed, and funding sought with no success so**

# Strategic Plan 2010-2014

## Progress in 2013



**far. A new plan to redevelop the website on a modular basis will be developed in the first quarter of 2014.**

- IAPO will continue to develop its Volunteer Programme and recruit volunteers in a number of areas, including translation and membership and capacity building support. **A comprehensive Volunteer Policy and an accompanying Procedure was developed which enabled IAPO to step up its Volunteer Programme. Over the year, IAPO welcomed five volunteers to provide help in areas such as membership development, translation into Spanish, and database administration.**
- IAPO will implement a new database, which will be easier to navigate and more suited to IAPO's needs. **The new database is being implemented over December 2013-January 2014 and will be launched in early 2014.**
- IAPO will implement a new finance system as well as new finance procedures. **A new finance system was implemented and finance procedures were drawn up.**