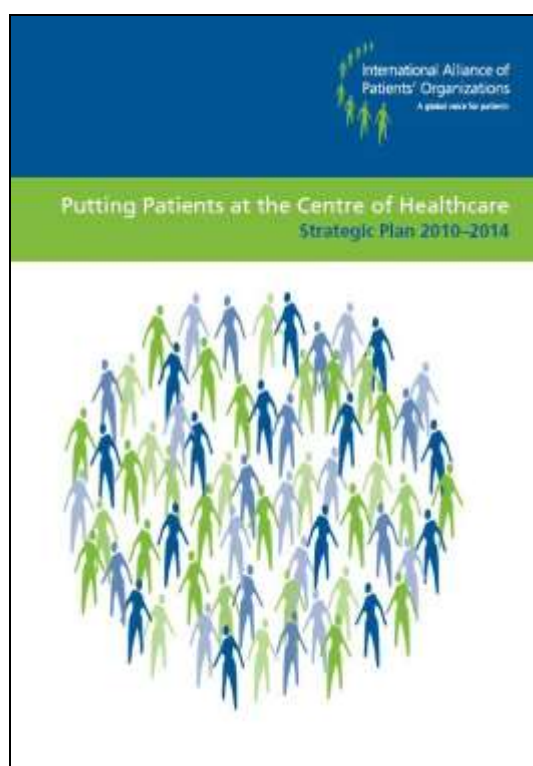


# International Alliance of Patients' Organizations

## Strategic Plan 2010-2014 Progress in 2014

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 2014. A copy of our Strategic Plan 2010-2014 and annual progress reports can be accessed online at [www.iapo.org/uk/strategy](http://www.iapo.org/uk/strategy)

# Strategic Plan 2010-2014

## Progress in 2014



**The overall theme for the year of Universal Health Coverage ran through many of the activities over the year.**

**The three top priorities for 2014 were:**

- 1. Registration as a UK Charity: registration and development of new systems and procedures – Complete** – Since January 2014, The International Alliance of Patients' Organizations (IAPO) has been a charitable company registered in the UK with the Charity Commission of England and Wales (company no: 8495711, registered charity no. 1155577). The operation of IAPO is regulated through the Memorandum and Articles of Association (or Statutes)
- 2. Policy and Advocacy: Development of and advocacy for patient-centred principles for universal health coverage (including development at the Global Patients Congress) – Complete** – IAPO's Principles on Universal Health Coverage have been developed and used for advocacy at WHO Regional Committees and as the focus of Patient Solidarity Day (<http://iapo.org.uk/universal-health-coverage>)
- 3. Strategic Plan: impact assessment of the 2010-2014 Strategic Plan and development of the 2015-2017 Strategic Plan – Complete** – An external consultant undertook an impact assessment and IAPO's Strategic Plan 2015-2017 has been developed and approved by the IAPO Governing Board (<http://iapo.org.uk/strategy>)

### **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

#### **2014 Activities**

- 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 – **We were active in highlighting IAPO's position on universal health coverage, WHO reform and non-communicable diseases through interventions and meetings with key stakeholders (<http://iapo.org.uk/policy-and-advocacy>)**

# Strategic Plan 2010-2014

## Progress in 2014



- IAPO will continue to develop and maintain informal working relationships with multiple areas of the WHO, beginning with gaining clarity within IAPO on which areas to be prioritised for approach - **IAPO has engaged with the department on non-communicable diseases as well as health financing and the work on non-state actors. IAPO worked with WHO to collect patient testimonials to support the WHO People-centred Integrated Health Systems Strategy and also contributed to an expert consultation on this and on WHO's new strategy on Patient and Family Engagement.**
- IAPO will facilitate and support IAPO Member representatives to attend and to engage at the WHO Executive Board, WHA and WHO Regional Committee Meetings. This will include webinars on the issues to be raised at these meetings. It will also review the process for selecting members to attend meetings - **IAPO facilitated the engagement of Governing Board Members and Members to participate in the WHO Executive Board, World Health Assembly and the following Regional Committee Meetings (Eastern Mediterranean, Europe, the Pan American Region and the Western Pacific). Highlights included delivering a member-developed Declaration at the Pan American Regional Committee and four organizations supporting IAPO's intervention on non-state actors at the European Regional Committee Meeting.**
- IAPO expects a final decision on its consultative status with the United Nations Economic and Social Council (ECOSOC) in May. A plan for understanding the relationship and for engagement will be drawn up. **In May 2014, IAPO was awarded Special Consultative Status with UN ECOSOC. A plan for engagement will be drawn up in 2015.**
- IAPO will work on managing and implementing the three year work plan (2013-2015) with the WHO Patient Safety Programme - **Collaboration and activities in 2014 included patient testimonials, promoting clean care, input in expert WHO consultations and WHO high level engagement and input in IAPO Global Patients Congress.**
- IAPO will promote its policy positions through presentations at external meetings and conferences - **IAPO presented 37 external meetings. IAPO responded to a number of consultations in 2014 including the WHO consultation on its statement regarding the registration and publication of trials and their results, and supported two external statements. The first was on people and patient-centred integrated healthcare for all, led by the International College of Person-Centred Medicine (ICPCM). Secondly, we confirmed our support for the European Medicines Agency (EMA) led statement on tackling medicine supply shortages. IAPO also contributed to the UK All Party Parliamentary Group on Global Health report, 'Patient empowerment: for better quality, more sustainable health services everywhere'.**
- IAPO will provide the patients' perspective in the GETREAL and PROTECT projects - **IAPO has been active in both of these projects. For GETREAL IAPO has facilitated member**

# Strategic Plan 2010-2014

## Progress in 2014



**engagement with background research into the patient perspective on clinical trials and provided input in the preliminary stages of the project. For PROTECT which is in its final stages, IAPO has worked with the consortium to develop lay-audience appropriate reports and materials to disseminate the project findings.**

- IAPO will disseminate its toolkit on biosimilar medicines, including developing an online platform as an interactive educational resource for patient organizations, in English and Spanish – **The toolkit has been disseminated to IAPO’s network of patients’ organizations. Feedback indicates that it is a comprehensive and useful resource. IAPO has used the toolkit for training in a number of conferences and workshops in 2014 in Europe and Latin America.**
- IAPO will commission a review of the literature supporting patient-centred healthcare (funding to be sought, or through volunteer help). **This will be reconsidered in the context of the new Strategic Plan in 2015.**
- IAPO is involved with and will continue to participate in 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: 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. Attendance and interventions at Executive Board, World Health Assembly and Regional Meetings
Official relationship	United Nations Economic and Social Council (UN ECOSOC)	Special consultative status awarded May 2014.

# Strategic Plan 2010-2014

## Progress in 2014



Official relationship	<u>International Hospital Federation (IHF)</u>	Memorandum of Understanding
Official relationship	<u>European Patients Forum (EPF)</u>	Memorandum of Understanding
Official relationship	<u>World Medical Association (WMA)</u>	Official Partner
Official relationship	<u>International Council of Nurses (ICN)</u>	Official Partner
Official relationship	<u>International Pharmaceutical Federation (FIP)</u>	Official Partner
Membership	European Commission	Directorate General for Health and Consumers (DG SANCO) - Member of the <u>EU Health Policy Forum</u>
Membership	Council of Europe	Involvement in the <u>European Directorate for the Quality of Medicines and Healthcare (EDQM)</u>
Membership	<u>Health First Europe (HFE)</u>	Membership
Membership	European Medicines Agency (EMA)	<ul style="list-style-type: none"> <li>• <u>Patients and Consumers Working Party (PCWP)</u></li> <li>• <u>Pharmacovigilance Risk Assessment Committee (PRAC)</u></li> </ul>
Project	Innovative Medicines Initiative (IMI)	Project Partner - <u>Pharmacoepidemiological Research on Outcomes of Therapeutics by a European Consortium (PROTECT)</u>
Project	Innovative Medicines Initiative (IMI)	Project Partner - <u>GetReal</u>
Membership	<u>European Network on Patient Empowerment</u>	Membership
Membership	<u>Medical Technology Group (MTG)</u>	Membership
Membership	<u>NCD Alliance</u>	Member of the Common Interest Group
Membership	<u>International College of Person-Centred Medicine (ICPCM)</u>	Membership
Project	International Diabetes Federation, Novo Nordisk and Steno Center	<u>Diabetes Attitudes Wishes and Needs (DAWN) 2</u>
Project	International Council of Nurses,	<u>Consensus Framework on Ethical</u>

# Strategic Plan 2010-2014

## Progress in 2014



	International Federation of Pharmacists, International Federation of Pharmaceutical Manufacturers and Associations, World Medical Association	<u>Collaboration</u>
Informal collaboration	UK Government	Informal engagement with <u>All Party Parliamentary Group on Global Health</u>

### 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

#### 2014 Activities

- IAPO will hold its 6<sup>th</sup> Global Patients Congress, in the UK, from 29-31 March 2014, with the overarching theme, *Better access, better health: A patient-centred approach to universal health coverage* – **The 6<sup>th</sup> Congress was held in the UK in March 2014. Key facts: 155 delegates; 80 patients' organizations represented from over 30 countries; 14 member bursaries were provided; supported by the World Health Professions Alliance and the International Hospital Federation.**
- IAPO will develop policy messages on universal health coverage, based on the work done at the Congress – **IAPO's principles on universal health coverage have been developed and finalised.**
- IAPO will continue to roll out its regional strategy, aiming for a base level of regional support in each region: consultation, engagement, steering committees. IAPO will also hold regional meetings (subject to funding) – **IAPO held a successful Regional Meeting in Latin America in August 2014. It brought together 36 patients' organizations from 11 different Latin American countries and over 100 multi-stakeholders to develop the action plan, enable training and set out concrete activities for 2015. At the meeting, IAPO worked with the network to develop a position paper to present to delegates at the WHO Regional Committee for the Americas.**
- IAPO will provide a range of membership services including a Twinning Programme, capacity building workshops and policy briefing webinars (4-6 in 2014) – **One twinning project which**

# Strategic Plan 2010-2014

## Progress in 2014



was started in 2013 was completed in 2014, along with an evaluation report with the two members. A member induction webinar was held in January 2014. A number of resources (especially on UHC) were developed pre-Congress, and a webinar held to introduce topics. Members Day at Congress was an important capacity building opportunity, particularly with a workshop to develop UHC principles with members. The Latin American regional meeting, along with Patient Solidarity Day, both served as capacity building opportunities with members, providing resources for members' work. IAPO has participated and presented in several external capacity building workshops and events in the year.

- IAPO will investigate the possible of fundraising for a fund to strengthen the capacity building programme and the Patient Advocates Academy – **To be reconsidered with the new Strategic Plan.**
- IAPO will review its communications strategy with a particular focus on how it uses social media – **To be reconsidered with the new Strategic Plan.**
- IAPO will continue to 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 - **IAPO's membership has increased/diversified Following the regional meeting in South East Asia in December 2014, IAPO's membership in the region has grown with 2% this year and additional growth is expected in 2015. There has not been any change in targeting increased membership in EMRO in 2014, however, initial research followed up by targeted emails to potential members in the region was undertaken during the year. This resulted in some interest, but so far no membership applications have been received. There has been a great increase in the number of members in Latin America as a result of the regional meeting in 2014, now becoming the second biggest region represented.**
- IAPO will evaluate Patient Solidarity Day from 2013, and refine and implement plans to hold a Patient Solidarity Day in Africa and widen activities to include Latin America and potentially other regions – **The evaluation of PSD 2013 was completed. Highlights included 17 members from 10 countries across Africa supporting the Day, and 4 members had government representatives at their events, including one who signed the IAPO Declaration on Patient-Centred Healthcare. There was increased social media engagement, and a diverse range of events were held to highlight the Day. Following consultation with the board, IAPO launched a global PSD in 2014, encouraging all members and partners to support. UHC was the theme. Numerous resources and tools were developed (including a comprehensive toolkit, example press releases and key messages- all translated into Spanish) for members to use. Over 50 organizations have pledged their support for the**

# Strategic Plan 2010-2014

## Progress in 2014



**campaign, there has been strong social media engagement, and the Latin American members have been very active.**

- IAPO will develop policy messages on patient access, safety, involvement and information – **IAPO has developed some policy messages but this will also be reviewed in the context of the new Strategic Plan.**
- IAPO will start the process of consulting on, refining, and reviewing its Declaration on Patient Centred Healthcare – **This has been deferred for consideration with the new Strategic Plan.**
- IAPO will review its strategy for supporting members to attend conferences and represent IAPO - **A new internal policy on representation has been developed. In 2014, IAPO placed priority on having IAPO member representatives at the WHO regional committee meetings. We increased communication and distribution of invitations to IAPO members through social media, the new website and the IAPO newsletter.**

### **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

### **2014 Activities**

- IAPO will continue to implement its Membership Strategy 2010-2014 taking forward recommendations from members – **The membership strategy has been implemented throughout the year, deepening engagement with members on a range of topics and issues, as well as bringing in new members into the alliance. IAPO continues to be driven by its members and help shape our work. For example, universal health coverage emerged as a key issue of importance for members, and therefore IAPO has prioritised the topic throughout the year.**
- IAPO will continue to collect information about members' activities and priorities to contribute to the accurate representation of members' views and needs. This will include input into the development of the 2015-2017 IAPO strategic plan – **Members were consulted in the development of IAPO's 2015-2017 Strategic Plan. Members were consulted pre-Congress to assess key issues and priorities for them. Patient Solidarity Day was an opportunity to engage with members, and collect information about activities and get support for the initiative. A survey was sent to members on request to renew**



# Strategic Plan 2010-2014

## Progress in 2014



**their membership to gather information about what issues are of priority for them in 2015 and to gather accurate information about their needs.**

- 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 2014. Member engagement with the newsletter rose continuously from June (9%) to December (18%), measured by number of newsletter clicks. The newsletter has been renovated in terms of design and content, including a new '60 seconds with...' member interview section. IAPO continued to put out press releases, website articles and social media to keep members up to date on advocacy positions and general news. Social media engagement (especially with members) has increased: from May to November, Facebook likes increased by 17.6% and Twitter followers by 33.7%.**
- IAPO will hold at least two induction webinars for new members: **A member induction was held in the beginning of the year for all new members. Due to the increase in Spanish speaking members before the Latin American regional meeting, another member induction was held for new Latin American members was held in July.**
- 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 March 2014 in line with the constitution and two Governing Board Members were elected (one new and one re-election).**
- IAPO will hold two Governing Board Meetings in 2014. In addition, numerous Committees will guide, drive and support IAPO's work during the year – **Two Board Meetings were held. The IAPO standing committees met regularly (via email and teleconference) throughout the year 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 Regional Meeting was supported by a committee of members to guide the events development and members were also involved as speakers and facilitators at the events.**

# Strategic Plan 2010-2014

## Progress in 2014



### 2010-2014 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

#### 2014 Activities

- IAPO will complete the process of registering as a UK charity. As a registered UK charity, new funding avenues will be opened to IAPO. The fundraising strategy will be reviewed and developed as a result. **IAPO has registered as a charity and the fundraising strategy is being reviewed and developed.**
- IAPO will develop, in consultation with members and others stakeholders, a strategic plan for 2015-2017. IAPO will ensure that realistic monitoring and evaluation processes are built into the new strategic plan, and that the staff team are trained in monitoring and evaluation. **The Strategic Plan 2015-2017 has been approved by the Governing Board. A report of the outcomes of the consultation which informed the plan will be disseminated via the website. Staff training on monitoring and evaluation will take place in early 2015.**
- IAPO will develop governance procedures, and institute a programme of governance development for the board and staff. A Governance Manual has been developed, and the Board undertook the a session on governance led by an external advisor at their September meeting.
- IAPO will implement a new database, which will ensure that all relevant data is kept in an accessible way. IAPO has successfully implemented a new database, which has improved how membership, projects and HIP are tracked and managed.
- IAPO will undertake an audit of its policies and procedures. **The policy needs of IAPO was assessed, new policies have been developed (such as a reserves policy and investment policy) and others have been amended.**
- IAPO will review the impact of its last strategic plan. **An external consultant from the National Council of Voluntary Organisations undertook a review for the Board. This review informed the development of the strategic plan.**
- 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). **IAPO has launched a new website which is much easier to navigate and is a rich resource for a variety of healthcare stakeholders. It is updated frequently with new content, is strongly linked with social media and the newsletter, and has**

# Strategic Plan 2010-2014

## Progress in 2014



**helped to drive engagement with others since its launch in September. Members are engaging more by sharing website content via social media frequently.**