

1.0 Leading Patient Voice

Research, Policy and Strategy Development

The Policy Manager's report, submitted to the Board, has summarised our research, policy and strategy development activity from May 2015 to Dec 2015.

We are putting research and policy into practice, and practice into research and policy.

We are taking lead from *WHO People-centred and integrated health services: an overview of the evidence WHO (WHO/HIS/SDS/2015.7)* and adopting their five evidence based strategies in our strategy, programme and projects to deliver patient centred health care. (See BPB)

The policy department has been re-structured so that we now have a part-time membership engagement officer, a Latin American regional coordinator and a Ph.D researcher involved in establishing latest evidence base and the membership engagement team seeking views and input from members to shape IAPO's research, policy and strategy agenda.

Policy activity from May through to October 2015 has focused extensively on WHO including relationship building, reporting and planning, projects and meeting interventions and briefings; ongoing committed projects; and external meetings and engagement. This bridged the transition period of embedding a largely new staff team, and with the successful staff recruitment in October the Policy Manager will be able to focus on core policy development, review and advocacy.

Policy activity from Q3-4 2014 to May 2015 initially focused primarily on finalising the patient-centred principles on universal health coverage and completing an evaluation report on the 2014 Global Patients Congress, followed by handover with Jo Groves and activity to maintain key policy relationships and projects, and on WHO Executive Board and World Health Assembly.

Coincidentally, one our weak areas, lack of experience in using strategic litigation and health legislation as policy change instruments, has been resolved as Advocates for International Development have moved into CAN Mezzanine are our direct neighbours!

Policy communications awareness raising, information and education campaigns

Communications Officer's (Ian Ford) report summarises our activity from May 2015 to Dec 2015.

2015 has been a productive year for IAPO communications. IAPO's digital presence (website, newsletter and social media) is stronger than ever and reaches several thousand people each month. IAPO's voice and brand is more accessible and consistent, members continue to use new and existing IAPO resources and engage in IAPO activities, and 2015 has seen more external opportunities – and a higher external profile – than previous years.

We want to strengthen this area by bringing in interns with social media expertise to lead on Twitter, Facebook and Youtube.

WHO Collaboration Patients for Patient Safety-WHO Status 2016

The Operations Director, Policy Manager and Communications Officer prepared a report jointly with Board member Hussain and presented it to NP of WHO patients for patient safety programme. Report in BPB.

Global Health Bodies

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WHO WHA

KP, Stephen and KS attended the 2015 WHA. We made two interventions:

- 1) WHO Framework on collaboration with non-state actors
- 2) Post 2015-Sustainable Development Goals and patient safety and other patient indicators to be developed.

We managed to speak to CEO's of a broad cross section of NGOs, including the International Federation of Hospitals, International Federation of Medical Students Associations and NCD Alliances.

We also spoke to our industry partners, securing a pledge to fund a parliamentary advocacy toolkit from Merck Serano. This project is now aligned with Novartis Tool Kit and we are looking for two more partners.

World Bank/IMF

This area is currently being scoped out and developed. We will have input from our industry partner Sarbani Chakraborty of Merck Serano (a former World Bank Policy Director), and we will also approach Maria Martinez, a World Bank advisor, who presented at our Latin American Congress. The health policy area we would like to engage with the World Bank is in health system reforms, universal health coverage and Sustainable Development Goals.

The long-term advocacy goal is to encourage the World Bank to undertake an economic study to evaluate the impact of patient involvement in health systems. Research may evaluate patient involvement in reducing costs and improving effectiveness of health systems in low to middle income countries as a part of UHC initiative to validate economic efficiencies of patient-centric health systems.

UN

World Heart Federation, the NCD Alliance and the Global Partnership for Maternal, New-born and Child Health marked the launch of the *Sustainable Development Goals* in September in New York at the UN 70th anniversary summit. We had no budget to cover this event but managed to get a mention at the event through the Global Partnership for Maternal, New-born and Child Health.

WHO AFRO

This region has an acute need for patient mobilisation, and patient organization and institutional development. It is also a region that does not attract industry partner interest and funding. Our strategy is to segment African countries into regional economic units, like the East African Community (EAC) and Southern African Development Community (SADC), and target funders willing to support activities in 'emerging markets'. A proposal was prepared for an EAC funding application that is still looking for an appropriate funder. Proposal in BPB.

The AFRO regional committee meeting was cancelled.

WHO EMRO

This is a region that has greatest potential as it is a region with great need (especially the disaster and emergency humanitarian health care response) and also has some of the most financially active oil and gas economies. The overarching Saudi Arabian leadership in the region is being matched by some of the most generous engagements in health by the United Arab Emirates (Sharjah will host the Global NCD Alliances meeting in November).

We planned three interventions at WHO EMRO: *UHC, MDG to SDGs, and Emergency Response*. Lack of VISA for ex-board member from the region hindered us in delivering the full programme.

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We aim to develop more links with non-State Actors in the high income Emirates, and with physician and patient led initiatives in the low-income regions to develop capacity.

WHO PAHO

Eva Maria and the regional coordinator are well connected with the WHO PAHO committee. There are regular contacts with them. At the WHO PAHO regional meeting EM and Maria Serrano (Chile) intervened on three topics: *HTA and health systems, strategy on health law interventions supplied.*

WHO PAHO and biosimilars regulations are a big item within the regional health related legislation. It is region that also attracts industry partner interest. The regional coordinator and the WHO PAHO secretariat will be encouraged to maintain their close relationship.

Our Latin American Regional Membership owns and drives this strategy. We may have to diversify and look at regional and in-country based funding opportunities from partners to sustain the growth in the region (EM to be consulted on feasibility of this approach).

WHO EURO

WHO EMRO was a well-attended event with many civil society organisations. The overwhelming presence of CSOs put the WHO EURO regional committee under pressure as everyone wanted to read a statement out. An impasse developed that was very generously resolved by Dr Zsuzsanna Jakab. She asked the staff to photo copy every statement and put it in the delegate packs, and also convened an early morning meeting with CSOs where it was decided that programmes with official treaty status with WHO (WHO FCTC Alliance and the UN Declaration on NCDS Alliance) will read out their statements, the rest should submit a joint statement that was to be read by a young doctor from the International Federation of Medical Students Association.

We had three interventions *Health systems strengthening and PCH (includes UHC and SDGs links) interventions published and distributed in delegate packs, and third developing patient-centric health workforce read as a joint statement.*

WHO WPRO

KP Tsang and Karen Villanueva attended the regional meeting, we had two interventions: 1) *Regulatory systems strengthening; 2) UHC.* The region has great need (smaller island States) and big economies in the South (Australia and New Zealand) and in the north pacific (Japan, Korea and China).

There is great potential to develop links with Taiwan and Korea, using good offices of Board Members who have very close link with the patient groups (especially Durhane).

Publications

We produced a range of material for the Latin American Congress involving translating into Spanish:

- Presentation Slides
- Accompanying Notes
- Work-shop papers
- Fact sheets
- Speeches etc

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Research Dissemination

Google Analytics and e-mail requests show that research on biosimilars is being accessed regularly by patients groups, academics and health professionals/policy makers. The Ministry of Health of Bosnia and Herzegovina used our working with patient groups fact sheets and research and translated the tool kit for local use.

Tool Kits

The biosimilars tool kit has now been distributed very widely in Latin America, Australia and Northern Europe in hard copy. Google Analytics and e-mail requests show that the online toolkit is accessed even wider and we have patients groups, academics and health professionals/policy makers accessing the toolkit from WHO PAHO, EMRO, SEARO, WPRO and Euro Regions (outside EC).

There have been discussions to update the biosimilars toolkit with our partners. (BMB)

Newsletter

These have been duly published each month and distributed electronically. Google Analytics and e-mail requests show that individual articles and news items being accessed by an even wider audience.

Reports

We haven't issued any new research reports yet. Our GetReal and Protect reports were minor submissions. The WHO PFPS report was duly submitted.

Booklets, presentations and collateral support material

We have produced a number of resources for the Latin American Congress which were translated and distributed in Panama and placed online. See Latin American Congress section below.

2.0 Advancing Patient Engagement

Advocacy

Our website, newsletter and attendance at events continue to advocate that patient engagement should be institutionalised systematically and systemically within the health care policy, legislation and practice.

Policy Manager's Report (in BPB) covers this area extensively.

Represent Patient Voice on diverse forums

We continue to take the opportunity to attend 'paid for/reimbursed' meetings. The Board Members have undertaken key-note and general speaker's tasks at a number of events to highlight patient needs and rights, and advocated that patient centric approaches be institutionalised in all aspects of health systems.

We have RJ's presence on EU Forums, with EM taking on Latin American forums, DW representing us on rare diseases, HTA and North American Forums, JW undertaking considerable work on East African Forums. KP and Hussain (still active and supporting us) are representing us in EMRO, SEARO and WPRO regions.

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Capacity Building Advocacy

Latin American Patients' Organizations' Congress

In August 2015, we held our fifth IAPO Latin American regional meeting, moderated the third Latin American Summit of Patients' Organizations sponsored by Novartis and participated in the seventh Latinapso meeting (network of Psoriasis organizations).

On 24 and 25 August, we held our fifth regional meeting in Latin America, which included a multi-stakeholder seminar and capacity-building workshops. Regional meetings are one of the cornerstones of IAPO regional programmes, in line with the IAPO Strategic Plan 2015-2017.

Multi-stakeholder seminar was hosted by: Dr Caroline Chang Campos, ORAS-CONHU under the theme "Equal access to essential medications is held as a universal human right" -

We hosted a half-day multi-stakeholder seminar on Innovation, Regulation and Patient-Centred Healthcare, divided into two panels. We explored how the legislator can contribute to improve healthcare policies, the challenges in financing them, how open innovation systems strengthen the public provision of healthcare, regulation of Biologic and Biosimilar Medicine and personalized medicine. The seminar was attended by more than 70 healthcare stakeholders including patient groups, industry, academia and policy-makers.

Capacity-building workshops were facilitated by Carlos Castro Sanchez, Asociación ALE under the theme: *"There are many things we can do. Don't be afraid of doing them. We have to be persistent, and never feel defeated"*

44 patients' organizations from 14 countries in Latin America actively participated in our capacity-building workshops. We invited experts to work with our members on how to generate evidence to strengthen advocacy, evidence-based data management and health technology assessment (HTA), and how patients' groups can build their national strategy to advocate for involvement in decision-making for regulation in pharmaco-vigilance on Biologic and Biosimilar Medicines.

Our last workshop offered an open-space for members to share about their programmes and strategies highlighting networking, public awareness, communication, advocacy and knowledge management. Finally, we shared information about IAPO strategy, upcoming events and consultations – Patient Solidarity Day, IAPO Global Patients Congress, HTA, social determinants of health, and IAPO representation at PAHO/WHO Directing Council.

IAPO also moderated the third Latin American Summit of Patients' Organizations and participated in the seventh Latinapso Meeting

During the seventh Latinapso meeting held on 21 August, Eva Maria Ruiz de Castilla talked about the importance of strengthening the patient group network and synergy of teamwork in social organizations.

The congress and meetings provided a space for patient groups to share experiences, acquire tools and share information for enhancing work with patients and eventually improve the welfare of patients in general. They key messages developed were:

"The core of any healthcare system is the patient. We believe that your contribution is essential. You are the voice of the patient. You can ensure that patient's views are taken into account"

"Patient-centred healthcare benefits all in society. It makes clinical, economic and social sense to create patient-centred health systems in the Latin American Region"

We thank our sponsors – ABBVIE, Amgen, Janssen, Pfizer and Novartis – for their support and participation during the event. We thank our speakers for promoting our core value: patient-centred healthcare. It will have an invaluable impact on the development of our activities at local, regional and global levels.

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Build Partnerships

We have continued our partnership building with the regulators and medicines control entities in Europe. IMI2 and we are now in discussions with five other organisations in an initial consortium formation for future research partnerships in Get Real. We have maintained our links with EMA and helped them in their survey on communication about EMA patient involvement activities.

Our support for European Generics Association Biosimilars Group continues with us participating in their discussions and events. We are linking in with the International Federation of Integrated Health Care by participating in their events.

Our collaboration with professional associations continues with WMA & national medical associations at their conferences. Our new collaboration, unofficial, was at the WHO Regional meetings with the International Federation of Medical Students Associations.

RJ's membership of the European Health Property Network (EuHPN) and our MOU with the International Hospitals Federation give us a good standing on patient-centric health facilities and health estate.

Human rights approaches development

This area is still under development. Advocates for International Development have moved offices and now sit beside us in the CAN Building. Our first collaboration was on the PAHO statement on health related legislation. We are exploring further areas of cooperation within the Sustainable Development Health Related Goals and on our Patient Solidarity Day- healthcare is a human right. The World Bank is now fully engaged in using economics and human rights as an instrument of change in health systems. Maria Martinez will support us on this initiative.

Member Activities

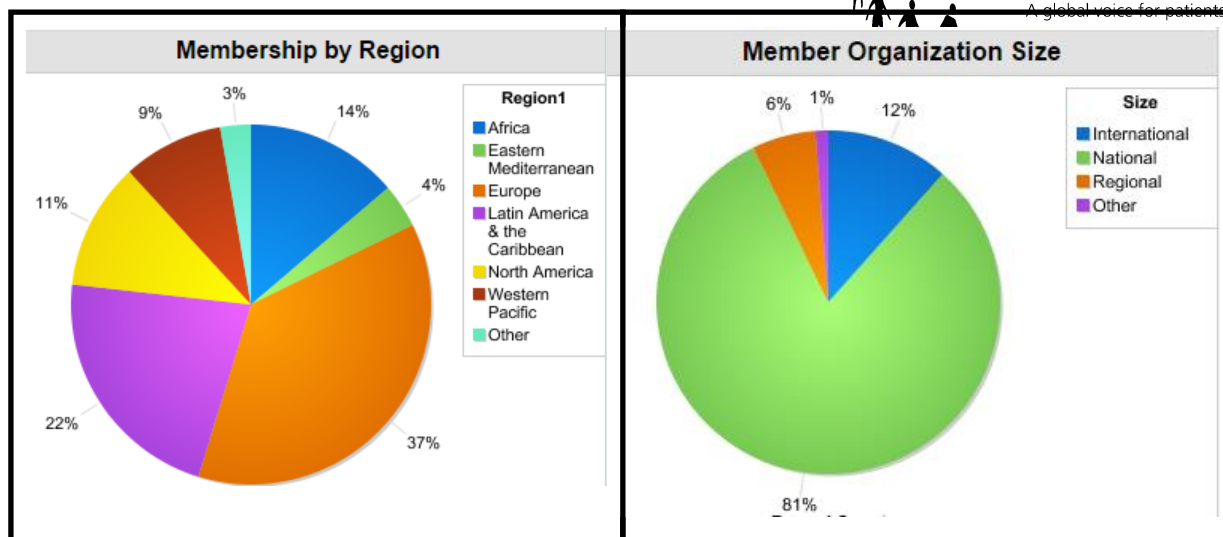
Global Membership Development

IAPO has 254 confirmed Members as of October 2015. Europe, Latin America and the Caribbean, and Africa host 73% of our members; and 81% of all members work at National Level.

There are 15 organizations whose membership is pending: two of these are presented for consideration in the following report; six have yet to provide missing information; and the remaining seven have been approved for Membership by the Committee, but have yet to pay their fees.

Following June's Membership Committee Report, on agreement of the Membership Committee, 12 organizations were sent formal notification of IAPO's intention to vote to terminate their membership at the next meeting of the Governing Board. This date has been postponed from the original date of the 17 August, to allow more time to pay, and will now take place on either 13 or 14 November. There are four further organizations, detailed below, who have allowed their membership fee to expire, and have not responded to requests to make payment.

The recommendation is to send notice of intention to formally terminate membership; and that after at least 18 days has passed, to vote on formal termination of membership of each organization by the entire Governing Board. This is in compliance with IAPO's Statutes and By Laws (Annex 1), but should be considered as a formality, as their membership has already expired.



Congress 2016 Planning

We are undertaking a very challenging planning and funding application exercise at the moment. Carol Stevenson (the consultant) had already started some of the programme planning with BJ and JB. The advisory committee had already agreed certain aspects and speakers list when our new staff joined.

The initial budget is £150,000 using last Congress estimates. We need to reduce this as we may not have EU grants this time.

The Congress approaches, to bring cutting edge insight (key-note speakers) and practical expertise (specialists) to the existing assets and expertise within our membership, is evidence based on Asset Based Social Capital Development activity. We will use the existing capacity and extend it by enhancing knowledge, skills, attitudes and confidence/ empowerment. Details included in BMB.

Patient Solidarity Day 2015

In line with the annual plan for 2015, PSD 2015 went out for consultation with membership four themes:

- Access to healthcare: it's not about the price-tag (focusing on affordable healthcare and universal health coverage)
- I am a patient. I am a person (focusing on promoting patient-centred healthcare and breaking down the stigma around 'patients')
- Health without hazard: safe healthcare for all (focusing on patient safety and universal health coverage)
- Healthcare is a human right (focusing on healthcare as a fundamental human right and universal health coverage)

The membership chose Healthcare is a human right. The theme reflects the *right to health* in the WHO Constitution and resonates with the current patient movements and developments in UHC

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across all low and middle income countries. It has overwhelming endorsement within the Latin American Region.

The World Bank and EU have also adopted similar approaches to strengthen patient movements to demand participatory and engagement rights (patient centric approaches), and also call for accountability and transparency within health systems.

Patient Solidarity Day was a big success and demonstrated significant growth from the previous year. 108 organizations across 32 countries took part in the Day (up from 80 in 2014), there was official support from WHO AFRO and WHO WPRO (for the first time) and more than 100,000 people were reached by the campaign on social media.

Webinars

This activity was held back until we took control of the organisation and its capacity building programme. Our membership officer (RM) was not skilled enough or knowledgeable enough to pursue this. We have made allowances and recruited PO, our Latin American Officer, and a new part-time member who comes with extensive experience in working with groups at an international level.

We are ready to go out to consult and inform, educate and engage the membership on:

- Patient Solidarity Day 2016
- Novartis tool kit
- Biosimilars toolkit update
- Human Rights and Health (Advocates for International Development will support this)
- Congress 2016

3.0 Governance

Dissolution

We encountered great difficulties in getting IAPO Netherlands entities struck-out of the Netherlands NGO Registers. The difficulties concerned company and charity law on one part and procedural requirements on the other. Without a single Board Member being a resident of Netherlands, with previous chairs being non-EU citizens, IAPO had to produce bona fides of all trustees and directors.

During the bona fide checks, it transpired that somewhere in history (6 years ago), the registers for the foundation and charity were not updated simultaneously. Old founders and board members subsisted in the Foundation register and new board members in the current charity. This resulted in delay; for the resolution to dissolve the charity to be effective, all the registers needed to be up-to-date.

Easier said than done! The updating process required us to remove all old trustees (having their current passports and address proofs notarised) and then reappoint current trustees into the vacated positions. In the end our current IAPO UK trustees were also trustees of IAPO Netherlands

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and also members of the Foundation. With the current chair being an EU citizen, the last task was performed with her identity and signature.

We now have the dissolution certificates.

Update Company Records

We have now updated all records during the dissolution process. Board members are requested to please keep us updated of change in circumstance and address as this has an impact on our compliance. I will speak to each Board member to fill in what details we require as they differ from country to country.

Trading Company

As with the Dutch Entity, we had great difficulties in updating the trading company registers and getting access to the bank accounts. It took us 3 months to get access to the accounts. We had to remove JG from the directors, retain RJ and MB (now needs to resign at next AGM of Trading Company) and appoint KS (CEO as UK citizen balances governance).

SAGE and accounts

The Accountant (GE) will summarise the challenges we encountered in bringing the SAGE system up-to-date. We need to employ a part-time bookkeeper who can work one day a month to update all ledgers and handle the invoicing and budget reports.

Salesforce database

We had undertaken an extensive clean-up of redundant data and records. It seems that IAPO was not using controlled vocabularies and standards to categorise data. Duplication and meaningless strings resulted that confusing report generation.

The problem is particular with membership registers. They have been updated but we need further information about the entities. We have to discuss this at the Board Meeting.

Board Development

The Charity Commission expects all UK registers charities to have Board members who are familiar with the good governance code. www.governancecode.org. This code makes sure that the 'information barriers' are erected between operational and governance decisions to ensure that conflicts of interest do not override or influence decision making. I will expand on this further as we have to establish each member's interests and then have a strategy in place.

Internal Policy systems

We have overhauled our internal policies and need to review and approve them. The policies are in the BMB.

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Marketing and Fundraising

A full detailed report placed in BMB.

4.0 Conclusion

IAPO has come through the transition period with a more stable staffing structure and a good set of skills in place. The 'Mary Celste' moment has passed. We now have managed to retain staff in vital positions to ensure continuity and recruit 2 more part-time staff to strengthen the policy and membership team.

The greatest challenge during this transition period has been that without proper and thorough hand-overs, we lost 'organisation knowledge' and some relationships. This had an impact in all areas of operations: internal and external.

The dissolution and striking-out of IAPO Netherlands has occupied over 4 months of hard work. This was unnecessary workload. If the UK entities had been set-up correctly and the NL entities dissolved in chain, IAPO Netherlands Foundation would not have been left intact.

The incompleteness of the dissolution process placed hurdles for us to get access to the bank accounts, charity/companies house and vital corporate information. It took four months to get all our compliance documentation into shape, update the policies and upload Board member details in 4 separate registers: UK Company House, UK Charity Commission registers, Netherlands Foundations and Netherlands Charity Register.

We are now in a better shape to address fund raising and 2016/17 work plan.