



**Leading, advancing, empowering:**  
IAPO's Strategic Plan 2015-2017

**2017 WORK PLAN**

# Strategic Plan 2015-2017

## Work Plan 2017



### Introduction

We are now entering into the third and final year of our [2015-17 Strategic Plan](#).

In 2017, we will first consolidate and then build on our successes of the past two years (2015-16), and we then propose to embark upon an innovative strategy to:

- Set-up a research unit
- Develop high-skilled advocates on UHC
- Deliver our patient empowerment capacity building programme-involving our toolkits and workshops
- Roll out our biologics and biosimilar programme with IFPMA in Latin America, Africa and South Asia ( Brazil, South Africa and India- three of the largest biotherapeutics manufacturers)
- Develop our WHO antimicrobial resistance (AMR), migrant and refugee patients' health and selective vaccination programmes' advocacy
- Roll out our regional programmes. Latin America will be in partnership with FIFARMA and the Africa and South Asia regional programmes with others.

This will keep us well-on track to achieve our three Strategic Objectives (SOs) by December 2017:

1. Leading the patient voice on global healthcare issues
2. Advancing patient engagement
3. Empowering the global patient movement

### Building on 2015-16 successes

In *Appendix 1 –Summary of Key Activities 2016* we have highlighted our key achievements and outcomes in 2016.

This proposed 2017 Work Plan details the main events that we have planned and the key projects that we will be developing this year. This Work Plan also includes work streams which underpin our organizational development, enabling us to become more effective and efficient in 2017.

Our Latin American, African and South Asian work plans form a separate stream of regional activities. These projects will be developed in partnership with regional bodies and industry partners.

## **IAPO Research Unit 2017**

A major change from the 2015-16 plans is the setting-up of a patient-led Research Unit at IAPO under our Dr. Antonio Ciaglis in partnership with key academics and industry partners.

The Unit will be set-up to support patient engagement in research. Initially, we will provide patient perceptions to help the research community to triangulate and validate some of their current approaches and research designs; later we hope to support them with better decision-making in their research design and early engagement of patients into their research projects.

On a practical note, the Unit will help researchers, policy-makers and practitioners in improving their recruitment, retention and engagement of patients into research using IAPO to validate their approaches. This Unit will give us invaluable insight over many years to come on how patients can direct and shape research programmes as equal partners.

Separate from the research agenda above, in a completely different project IAPO will engage with the patient community through [www.patientresearchexchange.org](http://www.patientresearchexchange.org), a major patient research communication website previously owned and managed by Novartis, and develop online communications platforms and material to support our objectives.

In yet another separate development, Novo Nordisk and their ASPIRE group of some 20 patient groups and trustees in the USA, have now agreed to investigate further and prepare a business plan for a [Rest-of-the-World EUPATI](#) in partnership with IAPO.

In 2017 we start our research programme with three projects: Get Real, Prefer and PONS (see appendix for details and work-in progress).

## **Developing highly-skilled UHC Advocates with Dechert LLP(SDG 2030 UHC)**

IAPO has formed a partnership with Advocates for International Development ([www.a4id.org](http://www.a4id.org)), an NGO set-up by over 500 law firms in the UK, and Dechert LLP ([www.dechert.com](http://www.dechert.com)) the 7<sup>th</sup> largest global law firm that provides legal advice to global companies, international institutions and organizations.

They will help us develop a cadre of 'elite patient advocates' who can understand global health governance and the international institutional and legal framework. These advocates will work with international legal instruments (UN treaties, regulations, declarations and resolutions) and then

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apply them nationally to bring about universal health coverage (UHC) in their countries. UHC is critical to the economic and social development of a country.

For an effective health policy to be implemented, patient advocates must generate and exploit four critical enabling conditions:

- High level political engagement
- Widely distributed quality evidence produced by influential bodies and academics backing the policy
- Wide spread media and public awareness and support for the policy
- A 'window of opportunity' to bring the above three elements together

We want all the patients to receive the health services they need by 2030- without patients and their families suffering the financial hardship when using the services. UHCs should cover the full spectrum of essential, quality health services including health promotion, prevention and treatment, rehabilitation and palliative care. The enabling conditions for UHC have been now been established globally. Patient advocates need to replicate and establish these nationally:

- In September 2015, 193 Heads UN General Assembly Member Countries have given their high level political commitment to work progressively towards establishing sustainable universal health coverages in their countries by 2030 under UN General Assembly resolution 70/1 SDG 2030-sustainable development goal 3.8
- This policy is backed by evidence from the United Nations, World Bank, WHO and the other powerful health and economic development institutions. UHC is the main pillar of sustainable development. SDG 2030 addresses health and the socioeconomic determinates of health in one global strategy.
- SDG 2030 and UHC has received wide spread publicity and backing from the media and the public. The governments cannot ignore this. Our patient groups are the vanguards to this promotion.
- We have a clear window of opportunity that has opened with UN Resolution 70/1. Every UN Member State has 15 years to working progressively towards establishing sustainable universal health. This is a long window of opportunity that advocates can exploit to get UHCs by 2030, or sooner!

IAPO now wants to develop a cadre of 'elite patient advocates' who can not only address the establishment of UHCs in their countries, but also address the

immediate and current issues of quality, accessibility and patient safety within their health systems.

These advocates will address issues of the availability of fully functioning health care facilities and essential medicines and ensure that their health systems are (AAAQ-SET standard):

- Accessible
- Affordable (co-payments reduced)
- Acceptable (culturally competent and respectful of medical ethics)
- Of high quality -scientifically and medically evidence based and delivered to international guidelines, standards and protocols
- Safe- pharmacovigilance and other patient safety mechanisms are in place
- Delivered with equity and equality in mind
- Transparent, accountable and participatory (patient centered) eliminating corruption

Our advocacy is not only about setting-up a health financing system and the 'AAAQSET' standards above; it is also about advocating a 'complete national package' involving changes and investment in:

- Health service delivery systems- WHO Framework on people-centred and integrated health systems
- Health workforce strengthening
- Health facilities upgrading and modernizing
- Health communications networks and health informatics
- Health technology investment
- Quality assurance systems and mechanisms
- Good governance and health legislation.

## **IAPO Member Engagement and Empowerment Plan**

IAPO's research unit, policy team and membership officer have developed a [Member Engagement and Empowerment Plan](#). The members will be empowered and given opportunities to advocate around key healthcare issues and strengthen their networks. The four themes we will support are:

- Patient-centred healthcare (February – April)
- Access (May-July)
- Transparency and accountability (August-October)

- Patient Solidarity Day - theme to be decided by members (October – December)

### **Biologics and biosimilars programme**

IAPO's global survey on bio-therapeutic use, policy, practice and regulation, in partnership with the *International Federation of Pharmaceutical Manufacturers Associations* will be out in May 2017.

We intend to use these perspectives of patients, physicians, pharmacists, regulators and other stakeholders develop further our biologic and biosimilar strategy and programme for 2017 and overhaul our existing toolkit in May 2017

We will then hold some workshops in South Africa, India and Brazil to develop patient advocates who can support access, safety and quality issues affecting bio-therapeutic use.

### **WHO AMR, migrant and refugee patients' health and selective vaccination programmes for patients**

In 2016, during the World health Assembly, WHO Regional Meetings and at the UN High Level Panel on Migrant and Refugees, we met with the WHO, UN High Commission for Refugees (UNHCR) and the International Committee of Red Cross (ICRC) medical teams to work on three programmes in 2017:

- *Antimicrobial resistance (AMR)* affects chronically ill patients disproportionately. These patients happen to have compromised immune systems and are most likely to pick-up 'nosocomial' infections in hospital environments. IAPO will work with a wide cross section of stakeholders to bring about patient centric approaches to WHO global AMR strategy.
- *Migrant and refugee patients' health is critical.* They are now the most vulnerable patients; the continuity of their health-care is disrupted by health system collapses and large scale emergencies and conflict. Their right to health is breached by many belligerent actors, despite the international conventions and safe guards. IAPO will work with UNHCR, ICRC and WHO to bring about patient-centric approaches to migrant and refugee patients' healthcare.
- *Selective vaccination programmes for chronically ill patients:* Patients, especially chronically ill children, must be routinely vaccinated (including periodic booster shots). There should be selective vaccination programmes for all patients as their immune systems are compromised.

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IAPO will work with the GAVI Alliance members to bring about patient-centric selective vaccination programmes as a part of national UHCs

### Key Events Planned: 2017:

Period	Event	Detail	S.O.(s)
January	IAPO Research Unit Launch PRE Website Relaunch	Unveiling IAPO patient-led research programme Relaunch PRE with Novartis.	1, 2 & 3
April	Biosimilar Tool Kit	Draft IFPMA report Ready for testing	1, 2 & 3
May	World Health Assembly	Board/staff attendance, networking (TIF/IAPO) Side meetings, presentation of Interventions	1
June/July	African Regional Workshops	June 2017 Delivery	1, 2 & 3
August	South Asia Workshop	Biosimilars Toolkit Testing	1, 2 & 3
Sep-Oct	Latin American Country Cluster 2 and 3 and Alianza Latina	2 and 3 Cluster Sep-Oct 2017 Evaluation & follow-up Nov 2017	3
Sept-Oct	WHO Regional Committees	Member attendance, capacity-building Regional engagement Presentation of Interventions	1, 3
December	Patient Solidarity Day	Planning (resources produced, event promoted) – Jun-Dec 2017 Event held Dec 2017 [Evaluation Jan 2018]	1

### Key projects planned 2017:

Duration	Project	Detail	S.O.(s)
May-Dec	Bio-therapeutics Project- Biosimilars Toolkit	IAPO IFPMA Survey Completed May 2017 Update toolkit finished May 2017 Testing and developing toolkits June-December in Workshops	1, 2, 3
Jan-Dec	Continued- Advocacy Empowerment Toolkit from 2016	May 2017 Finishing Compellation June-Dec 2017 Delivery of training in workshops	3
Jan-Dec	ASPIRE Project	IAPO and Novo Nordisk Business Plan	1, 2
Jan-Dec	SDG 2030 Advocacy	UHC as a SDG 2030 Goal	1, 2
Jan-Oct	Prefer (see below)	Delivery of work plan	1, 2
Jan-Dec	POMS (see below)	Delivery of work plan	1, 2

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### Organizational development and other work streams:

<b>Trustee Board, Governance &amp; Finance</b>
<ul style="list-style-type: none"> <li>• Board meetings (2) and sub-Committee meetings (audit, membership, etc.)</li> <li>• Gold Health Industry Partner meetings (2)</li> <li>• Annual external audit; Companies House &amp; Charity Commission compliance</li> <li>• Bye-Laws redraft to be compliant with Mem and Arts and Charity Law</li> <li>• 2018-20 Strategy Formulation</li> </ul>
<b>AGM</b>
<ul style="list-style-type: none"> <li>• Plan 2017 AGM in USA</li> <li>• Nominations and Election Plan</li> <li>• Elections</li> </ul>
<b>Membership development &amp; capacity-building</b>
<ul style="list-style-type: none"> <li>• Information Commissioner Database improvement. Upgrade Salesforce</li> <li>• African and LatAm regional workshops</li> <li>• Empowerment and Biosimilar Advocacy Toolkits rolled out</li> <li>• Patient-centred content, training and support developed for members</li> <li>• Informative resources completed/circulated to members and other interested organizations</li> </ul>
<b>Communications</b>
<ul style="list-style-type: none"> <li>• Publicize patient-centred healthcare (and key policy messages) with decision-makers and health professionals</li> <li>• External authors/ experts in IAPO communications</li> <li>• IAPO attendance and profile at targeted events</li> </ul>
<b>Collaboration &amp; project development</b>
<ul style="list-style-type: none"> <li>• Develop plan with targets and objectives for engagement, assessing collaboration opportunities which fit with IAPO key objectives</li> <li>• Develop potential projects in line with key objectives; discuss with stakeholders and possible partners</li> </ul>
<b>GPC 2016</b>
<ul style="list-style-type: none"> <li>• Set-up steering group (SG)</li> <li>• Select venue with members and SG</li> <li>• Appoint Events Manager</li> <li>• Prepare Sponsorship Handbook</li> <li>• Select theme</li> <li>• Select speakers</li> <li>• Arrange bursaries</li> </ul>



## **APPENDIX 1 SUMMARY OF KEY ACTIVITIES 2016**

**1) World Health Organization-Executive Board Geneva-Jan 25-30, 2016.** Jolanta Bilińska (Chair) and Hussein Jafri attended the event.

*Reach:* 194 ministers of health and 160 NGOs. World Media live broadcast of NGO interventions.

*Activity:* Networking and made a statement on the Framework of engagement with non-State actors

*Outcome:* EB resolution to continue IAPO's status as an NGO in official relationship with WHO



**2) World Health Assembly 69th Geneva May 23-29 2016.** Chair Jolanta Bilinska, Board Member Matthias Wienold and Hussein Jafri attended the event. Supported by Kawaldip Sehmi

*Reach:* 194 ministers of health and 160 NGOs. World Media live broadcast.

*Activity:* Held three side-events and made three interventions: i) health of migrant and refugee patients, ii) health in sustainable development 2030 –patient focus on UHC, iii) health of patients during large scale emergencies and health system collapse (natural disasters and Ebola)



*Outcome:* WHA acknowledges the principle that patient engagement is essential in decision-making on migration, large-scale emergencies and humanitarian health planning and relief. Patients are core to SGG 3.8 and UHC. Social media recognition that IAPO is the first patients'-group championing patients' engagement in humanitarian and relief planning.

**3) UN General Assembly Summit Pre-meeting Refugees/ Migrants health and welfare July 18 2016** (Physically Hussein Jafri) and **9<sup>th</sup> September 2016** remotely via Webex Link Kawaldip Sehmi

*Reach:* UN Agencies and NGOs involved with refugees and migrants.

*Activity:* Informal interactive multi-stakeholder meeting on health of migrant, refugee and internally displaced patients at the United Nations, New York.

*Outcome:* IAPO placed patient-centred approaches and seamless health care on the agenda of all humanitarian bodies dealing with refugee and migrant issues. Patients' right to health must be respected by all belligerent parties.



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### 4) WHO Afro 66<sup>th</sup> Regional Committee Addis Ababa Ethiopia 19 to 23 August 2016 Chair-elect Joshua Wamboga

*Reach:* 44 ministers of health and 40 NGOs. African Media live broadcast.

*Activity:* Two interventions: i) health of migrant and refugee patients, ii) health in sustainable development 2030 –patient focus on UHC

*Outcome:* WHO Afro acknowledges the principle that patient engagement is essential in decision-making on migration, large-scale emergencies and humanitarian health planning and relief. Patients are core to SGG 3.8 and UHC. Social media recognition that IAPO is the first patients-group championing African patients' engagement in humanitarian and relief planning.



### 5) WHO SEARO 66<sup>th</sup> Regional Committee 5-9 September 2016, Colombo, Sri Lanka Chair-Jolanta Blinska and Board Member Bejon Misra

*Reach:* 12 ministers of health and 40 NGOs. South Asian Media live broadcast.

*Activity:* Two interventions: i) health of migrant and refugee patients, ii) Access to patient-centred health and fitness programmes

*Outcome:* WHO SEARO acknowledges the principle that patient engagement is essential in decision-making on migration, large-scale emergencies and humanitarian health planning and relief. Patients are core to SGG 3.8 and UHC. Health and wellbeing programmes should be accessible to all. Social media recognition that IAPO is the first patients-group championing South Asian patients' engagement in humanitarian and relief planning.



### 6) PAHO and WHO Americas 68th Regional Committee 26-30 September 2016, Washington, USA Board Member Migdalia Denis

*Reach:* 35 ministers of health and 80 NGOs. US and LatAm Media live broadcast.

*Activity:* Two interventions: i) Resilient Health Systems ii) WHO Framework Engagement non-State Actors (Fensa)

*Outcome:* WHO PAHO and Americas acknowledges patient-centric health systems are resilient health systems and that UHC needs health system strengthening. SDG 2030 Goal 3.8 attainment needs health system strengthening. WHO engagement of non-state actors from the NGO sector needs a light- touch engagement to encourage participation.



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**7) WHO Western Pacific 67th Regional Committee 10-14 October 2016, Manila, Philippines** Karen Villanueva (Manila PAPO) and 2 other Philippines member organizations from Manila were attending event.

*Reach:* 29 ministers of health and 30 NGOs. Asian and Australian Media live broadcast.

*Activity:* Two interventions: i) SDG 2030 and UHC ii) WPRO Emerging Diseases Strategy



*Outcome:* WHO WPRO acknowledges that patient centric approaches need to the SDG 2030 Goal 3.8 attainment. WPRO needs to place patient best interest and engagement in emerging diseases strategy.

**8) Prince Mahidol Award Conference & NICE Intl-priority setting Thailand Jan 2016:** Ryan Lee (NICE IAPO Designate) & Kawaldip Sehmi .

*Reach:* Health Ministers from 26 SE Asian Countries and 1200 delegates from global public health and patient advocacy.

*Activity:* Joint presentation with NICE Int on patient group engagement and embedding in HTA process, having permanent patient presence on NICE International and national HTA boards. Participation in WHO workshop and session with DTA on Quality and Compassion in UHC. Sharing a panel with Sir Marmot on health inequality and patient engagement.

*Outcome:* Our expertise on patient involvement in HTA recognised and our presence in the region acknowledged.



**9) Universal Health Coverage Annual Financing Forum April 14-15 2016** Tele-conference Kawaldip Sehmi.

*Reach:* World Bank UHC Forum (120 key health finance stakeholders)

*Activity:* Advocated in panel discussions that Patients Centred UHC critical for all. IAPO UHC principles promoted. Advocated that a patient-centred UHC is core to achieving sustainable development goals 2030. Financing alone is not enough.

*Impact:* Acknowledgement that patient-centred UHC central to SDG 2030



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### 10) Global Forum on Incontinence Berlin Germany April 29 2016 Panel Kawaldip Sehmi CEO

*Reach:* 250 State and non-State Global Stakeholders involved in Continence Care

*Activity:* Presentation and panel on patient centred continence care. Devices, care products and care should be acceptable and patient-centred.

*Outcome:* IAPO interest in patient-centred continence care acknowledged by all. Patient-centred continence care touches many disease groups and ages, not only elderly. Products must be acceptable and fit for young active patients too.



### 11) European Conference on Rare Diseases and Orphan Products May 27 2016 Edinburgh Panel Durhane Wong-Reigar and Kawaldip Sehmi CEO

*Reach:* 800 participants and 86 patient organizations involved in rare diseases.

*Activity:* Panel-chair on advocating for a public health response on rare diseases at the international level

*Outcome:* IAPO leadership in rare diseases and orphan drugs in low and middle income countries acknowledged.



### 12) State of Oncology in Africa Report Launch and iPRI National Cancer Institute's Directors Meeting July 11-13 2016 Jolanta Bilińska and Joshua Wamboga

*Reach:* 50 directors of National Cancer Institutes from low and middle income countries. 20 Oncology organizations and national Ministry of Health Agencies.

*Activity:* Jolanta advocated Patient Centred Oncology a priority. Joshua expanded on oncology in Africa. Uganda's only radiotherapy machine is not working.

*Outcome:* IAPO leadership in patient-centred oncology low and middle income countries acknowledged. Professor Boyle may collaborate with us on an African project



### 13) FIFARMA meeting Panama City July 26-27 2016 Latin American Pharmaceutical Manufacturers-Kawaldip Sehmi

*Reach:* 80 Pharmaceutical heads in Latin America

*Activity:* Presented our plan as to how we can collaborate with FIFARMA to benefit patients' in LATAM.

*Outcome:* Latin American funding strategy and country cluster workshop idea developed. November launch opportunities



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### 14) The BIO International Convention (BIO) FIFARMA meeting 6-9 June 2016

*Reach:* Attracts over 15,000 biotechnology and pharma leaders

*Activity:* Held a booth in Patient Forum Arena and intensive networking to discover new opportunities and promising partnerships with a wide spectrum of Biotech firms.

*Outcome:* Opened dialogue with a number of organizations on biotherapeutics. Biosimilars tool kit update funding secured.



### 15) UN NGO Committee for Rare Diseases inauguration in New York. 11 November 2016

Migdalia Denis and Durhane Wong-Reiger joined Anders Olauson, Agrenska Foundation, to bring visibility and understanding of rare diseases to the United Nations.

*Reach:* UN and WHO policy makers and over 2000 patient groups

*Activity:* Live Stream debate to the world.

*Outcome:* IAPO recognised as a part of the global strategy on rare diseases at UN level.



### 16) Health of 1.2 billion people 11th National Quality Conclave, Quality Council of India and Indian Alliance of Patient Groups (IAPG) Roundtable 18-20<sup>th</sup> August 2016, New Delhi, India

Bejon Misra and Matthias Wienold

*Reach:* Over 200 allopathic medicine and traditional ayurvedic treatment quality regulators and health policy makers in India

*Activity:* Led seminars and workshops on Quality of Care in UHC

*Outcome:* IAPO recognised as a patient leader in UHC quality issues



### 17) Association for Medical Education in Europe (AMEE) International Congress, Workshop Co-Chair and speaker 29-30<sup>th</sup> August 2016 Barcelona, Spain

Matthias Wienold and Stijntje Dijk  
IFMSA Liaison Officer for Medical Education

*Reach:* Over 3200 delegates from academia, industry and other NGO sectors engaged in medical education

*Activity:* Led seminars and workshops on Patient involvement in teaching and the medical curriculum

*Outcome:* Patient centric medical education curriculum recognised as a policy issue and IAPO as a leader in developing it.



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### 18) 1<sup>st</sup> World Sepsis Congress Online Workshop

Matthais Wienold led inaugural online Seminar marking WSD 2016

*Reach:* Over 8000 patients, health care professionals and other stakeholders online

*Activity:* Led seminar on sepsis and challenges of patients and families

*Outcome:* IAPO recognised as the patient group with a sepsis care interest.



**M. Wienold**  
Germany



**GSA**  
GLOBAL SEPSIS ALLIANCE

1<sup>st</sup> World Sepsis Congress  
September 8<sup>th</sup> to 9<sup>th</sup>, 2016

**#WSC16**

### 19) World Health Summit, Berlin Germany 10th Oct 2016 Panel

**The Contribution of Biologic Medicines to Public Health** Matthias Weinold Co Chiar and Speaker: and Durhane Wong-Reiger

*Reach:* Over 15000 participants includes ministers of health, health policy makers and patient organizations

*Activity:* Matthias Wienold co-chaired the panel on biotherapeutic medicines

*Outcome:* IAPO recognised as opinion leader and patient voice on biotherapeutics

**20) Patient Solidarity Day 3<sup>rd</sup> December 2016.** A very successful patient solidarity day on 3<sup>rd</sup> December 2016 that linked in with UHC Day 12<sup>th</sup> December 2016. Theme, logos and supporting material already prepared.

<https://www.iapo.org.uk/patient-solidarity-day>



*Reach:* Report being prepared over 130 groups participated world over

*Activity:* Walks, social media, health screenings and meetings.

*Outcome:* Patient Solidarity Day being established in mainstream health policy advocacy (Report in 2017)

### 20) Think Health Romania's Health Conference 13<sup>th</sup> October 2016

Board Member Androulla Eleftheriou attended this event in Romania.

*Reach:* Nearly 100 Central and Eastern European Health Policy Makers

*Activity:* Participated in CE Europe Health Strategy. Live stream of debates and workshops

*Outcome:* Improved IAPO standing in Central and Eastern Europe



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**21) WHO African Region WHO Global Dialogue Meeting NCDs and SDG 2030 Balaclava, Mauritius, 19– 21 October 2016** Dalilah Kalla from Lupus Alert Mauritius attended two meetings on our behalf

*Reach:* 54 African Countries represented through 40 civil society organizations.

*Activity:* Participated in two workshops.

*Outcome:* IAPO now part of the African non-State actors' network and the regional Framework for the prevention and control of Non-communicable Diseases (NCDs)



**22) Pre-ICDRA at International Conference of Drug Regulatory Authorities Cape Town 27<sup>th</sup> Nov-29<sup>th</sup> Nov 16**

*Reach:* 100 National Medicines Regulatory Authorities Present, including the 54 African NMRA and over 50 NGOs in official relationship with WHO and other non-State Actors organizations.

*Activity:* Participated in one side-meeting and two workshops on patient engagement in strengthening and harmonising medicines regulation, especial access to biotherapeutics

*Outcome:* NMRAs recognise IAPO as a representative patient body that they can engage with in strengthening and harmonizing medicines and health device regulation. African NMRAs, Regional Economic Bodies and non-State actors aware of IAPO's patient-centric approaches.



**23) WHO WRPO Technical Advisory Group 1<sup>st</sup> meeting for the Universal Health Coverage Manila Philippines 12 Dec 2016** IAPO member Josef De Guzman President Psoriasis Philippines attended on or behalf

*Reach:* 28 WHO WPRO Member States and their National Health Authorities and over 20 NGOs in official relationship with WHO and other non-State Actors organizations.

*Activity:* Participated in workshops and discussions on UHC to learn from each other and work together, along with distinguished experts and other advisers, to identify priorities for the way forward.

*Outcome:* IAPO now an official member of the WHO UHC Technical Group



## ONGOING PROJECTS 2017



**Joint Survey Biologic and Biosimilar- additional work:** After our 2017 IFPMA report, we will continue developing capacity amongst Patients Organizations, Regulators, Physicians, Prescribers and Pharmacists to bring about patient-centricity approaches to the bio-therapeutics (biologics and biosimilars) regulation, clinical practice and prescription practice. IFPMA and IAPO are planning a series of workshops and other events to develop and test a new robust toolkit.



**Three Year Collaboration:** Working with our Designated Technical Officer in the Patients for Patient Safety Section on a series of collaborative projects mutually supporting our work in developing patient safety, workforce, systems, policies and resources. Participation in each-others events: World Health Assembly, Regional Committees and Consultations.



**GetReal:** IAPO is currently leading the patient research stream within GetReal, a multi-stakeholder research project in which IAPO investigated patient acceptability and perceived usefulness of research methods and the use of Real World Evidence in the drug development process. We are particularly developed a wide range of research activities with the aim of exploring patient acceptability of pragmatic trials and will be sharing this in 2017 with our membership via peer reviewed papers and capacity building workshops at regional meetings to develop their awareness, capacity and efficacy in effectively engage in clinical research.  
<https://www.iapo.org.uk/getreal>



**PREFER:** Will start in Jan 2017. It is a five-year IMI funded research project. We will be investigating with our membership and other patient groups how patient preferences can be used in the medicinal product life cycle and at what stage it can be particularly appropriate to look at and attend to patient preferences within drug development.



Advocates for International Development  
Lawyers Eradicating Poverty

**SDG 2030, UHC and right to health:** We are working with consortia of international lawyers to develop a joint-brief and a programme for patient advocates on how to use the right to health and the Sustainable Development Goals 2030 to get access to treatment and universal health coverage. Right-to-health was developed by the Committee on Economic, Social and Cultural Rights in its General Comment 14 in 2000. SDG 2030 were brought in in 2015 and they have opened a new avenue in advocacy and renewed interest in human rights based approaches to health.



**IAPO Research Unit:** A model for an IAPO Research Unit/Process has been designed with the aim of making IAPO's involvement in research activities more active. The overarching aim is to establish ourselves as initiators of research processes, which will also enable us to be part of the conversation from the beginning and identify relevant research questions and objectives.



## **Other projects**

IAPO's involvement in multi-stakeholders research programmes continues with our involvement in a number of initiatives that will help our membership. Thanks to these projects, we can continue promoting evidence-based patient centredness, and at the same time our members have increasing opportunities to make their voice stronger:

**WHO HTA and rival MCDM** – Health Technology Assessment and Multiple Criteria Decision Making are two prioritization methods fighting it out in health care planning today. The issue is especially critical with high-cost medicines. IAPO was a part of the Value for Money Event in Geneva, and is now part of a WHO working group that will be producing guidelines as to how to best conduct health technology assessment. IAPO to provide input regarding patient involvement.

**Collaborations:** Collaborations have been going on lately with a wide range of diverse stakeholders, including:

- Novo Nordisk (ASPIRE project) on patient engagement in research
- Academy of Social Sciences
- Economist Intelligence Unit
- EUPATI