

1ST

ASIA-PACIFIC PATIENTS CONGRESS



REPORT |



Executive summary

The first Asia Pacific Patient Congress (APPC) was held on 13th -14th November 2019, in Taipei Taiwan (ROC) at the Sheraton Grand Taipei Hotel.

150 member organizations and stakeholders, representing 25 countries in the Asia Pacific Region, came together to look at how patient engagement can support harmonisation of patient-centred Universal Health Coverage (UHC) in the Region.

Co-hosted with IAPO's regional members, the Psoriasis Association of Taiwan (PAT) and the Taiwan Alliance of Patient Organizations (TAPO-ROC), the APPC created an enabling environment within which delegates could actively contribute to a wide range of interactive sessions, workshops, and networking activities to improve healthcare in the Asia-Pacific Region..

The APPC applied a community of practice and adult learning principle to empower delegates by giving them an opportunity to develop useful skills, knowledge and networking contacts during the meeting that will help to improve their reach, effectiveness and impact in the coming months as they address harmonisation of patient-centred Universal Health Coverage (UHC) in the Region

IAPO has created a new cross-sector approach to collaboration on UHC in the region. The APPC actively encouraged patient advocates, providers, policy-makers, industry representatives, healthcare professionals, academics, researchers and regulators to find solutions together.

The APPC helped build trust by engaging delegates in a safe environment in lively and informative sessions around the current healthcare challenges and issues in the region. This approach will be needed through the next ten years to UHC 2030.

The APPC boosted the motivation and confidence of patients and health policy makers to work together in the co-creation of future interventions, thus ensuring that a patient centric universal health coverage takes root throughout Asia Pacific region by 2030.

The APPC encouraged delegates to look at the full spectrum of the healthcare value chain. The APPC began with a discussion on improving access to innovative healthcare and the role of patient groups can play in advancing Universal Health Care (UHC) through their participation in Health Technology Assessment.

Delegates participated in specific sessions on specialist areas of patient advocacy, public policy, health economics, stakeholder engagement, and regulatory policy including patient-focused drug development, clinical trial participation, patient safety, communications and organizational development such as resource mobilization and volunteering

The first Asia-Pacific Patient Congress finished by adopting the Asia-Pacific Patients Congress Declaration. The Declaration urges United Nations, World Health Organization and Asia Pacific Economic Cooperation Member States in the region to scale-up, prioritize and accelerate delivery of:

A safe, quality and patient-centred universal health coverage by 2030 that promotes protects and fulfils the patients' right to healthcare that is available, accessible, acceptable, affordable and non-discriminatory.

To this end, delegates urge the Member States to keep to their commitments as adopted within the:

- World Health Assembly Resolution 72.6 Global action on patient safety Agenda item 12.5 (WHA72.6 adopted 72nd World Health Assembly May 2019)
- United Nations Political Declaration of the High-Level Meeting on Universal Health Coverage: “Universal health coverage: moving together to build a healthier world” (Adopted at UN General Assembly 23 September 2019)

Lastly, delegates urge Member States to create an enabling environment for effective State and patient organization partnerships to participate, engage and support in the co-planning, co-designing, co-delivery and co-evaluation of UHC 2030 above. The Asia Pacific Region needs to cooperate on delivering the universal health coverage by 2030 with the full spectrum of essential, quality health services, from public health prevention and promotion, and treatment, rehabilitation, and palliative healthcare.



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Protecting the right of patients to participate in the decision-making within their national universal health coverage must be protected and promoted. Patient advocacy organisations must do this.

Orajitt Bumrungkulswat
Heart to Heart FDN Thailand

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Background

The International Alliance of Patients' Organizations is grateful for the support and participation of many stakeholders to bring about the hosting of this successful event.

We want to thank the following formally:

- The APPC Organising Committee for the direction and programme design
 - Patient organizations in the Asia-Pacific region for their participation and contribution to the Congress and in providing excellent speakers
 - The Ministry of Health Taiwan (ROC), Centre for Drug Evaluation and other State agencies who provided excellent speakers
 - Our co-sponsors and organisers Psoriasis Association Taiwan and Taiwan Alliance of Patient Organisations
- Pharmedia Taiwan for their excellent event management services
 - Our industry partners who not only provided resources, but also speakers and supported many patient advocates to attend the event. This event had kind support from:
 - o MSD - Platinum Sponsor
 - o Johnson and Johnson
 - o Roche
 - o Leo Pharma
 - o Amgen
 - o Abbvie
 - o Pfizer UpJohn





Objectives

IAPO's Asia-Pacific Patient Congress (APPC) was envisaged as a great platform to bring together the patient movement in Asia-Pacific region closer together and:

- To bring together all patients' groups and key high-level stakeholders in the region to discuss important issues concerning patients specifically from the Asia-Pacific region
- To highlight IAPO's vision to see patients at the centre of healthcare throughout the world and its mission to help build patient-centred healthcare and UHC worldwide
- To inspire patient groups to establish national patient alliances that will align and become members of IAPO.



Theme and Sessions

The main congress theme was inspired by the UN HLM Political Declaration on UHC focusing on addressing the 'harmonisation of patient-centred universal health coverage' in the Asia-Pacific Region.

The APPC programme was designed to offer both plenary discussions and parallel sessions on specific topics of interest to the audience. Plenary and parallel sessions were designed to look at the value chain of healthcare decision-making and patient engagement in the setting up UHC, including all key components to a patient-centred healthcare, from: integrated health system, health finance, health technology assessment, and regulation, to research, health innovation, artificial intelligence and machine learning.

The APPC also included capacity building of patient organizations including networking and specific sessions on areas of interest such as patient advocacy and influencing policy, patient involvement and engagement, patient safety, organizational development, resource mobilization and volunteering.





Introduction To Programme Sessions

In an integrated and patient-centred UHC, the role of the patient voice and perspective is vital in planning, designing and delivering of healthcare services. This improves safety, quality, access, acceptability, equity and even affordability as co-designed, co-created and co-delivered services have a higher uptake and avoid wasteful models of healthcare service delivery.

It is now clearly established that patient engagement must start at the head of the healthcare value chain at the research and development stages of medicines and health devices. Academics and researchers now seek patient experts, besides patients as research subjects, for their knowledge and experience of living with the conditions or the devices they are using.

Patient engagement is not constricted to a narrow area of Research & Design on the value chain. Many health systems want to see patient engagement during the full lifecycle of medicines and devices. Patient authors join research teams to publish results and help in the dissemination of research findings. They then participate during the regulatory and market authorisation stages and finally in the post authorisation where they take part in HTA, pharmacovigilance right up to patent exhaustion when the medicine becomes a generic.

Patient experts, patients who have chronic conditions and have navigated most of the clinical, social and health policy pathways, are increasingly being used by healthcare policy and decision-makers within their health system's institutional, legislative, policy, practice and standards frameworks. This makes for more robust, effective and efficient frameworks that advance equity and social cohesion.

The Patient expert role in the health value chain, a specialist role, is reserved for patient experts who have knowledge, skills and experience of health economics. The last role of patient experts in Health Technology Assessment (HTA) is critical. This will determine whether we have a voice in HTA and early access to innovative health drugs and other health technologies, and at what price.

Patient engagement in HTA is vital in any robust UHC. As public funds (via taxes or national insurance schemes) are used for the financial protection, it is a duty of every patient expert to be engaged in HTA decision making.

The programme sessions were designed to follow the healthcare value-chain and find opportunities and challenges that patients in Asia-Pacific region may face when it comes to harmonising UHC 2030 in the entire region.



Day 1



Opening Ceremony and Ministerial Keynote

Dr. Ratna Devi, Chair of the IAPO Board, and other Board members welcomed Jui Yuan Hsueh, the Deputy Minister of Health & Welfare of Taiwan and 145 patients and delegates from 25 countries.

The Chair introduced the Minister with a warm welcome and moved the congress to get ready for two days of participatory and thought-provoking sessions delivered by some of the best minds on healthcare in the region. She thanked the speakers who had given their valuable time and said that Taiwan has set up a unique universal health coverage model in the region and we are delighted to hold our first APPC congress in Taiwan.

The Deputy Health Minister Jui Yuan Hsueh's keynote address highlighted the importance of having a universal health coverage. He also endorsed patient participation in universal health coverage. A people-centred and participatory UHC has health, social and economic benefits.

The Deputy Minister added that Taiwan had made a bold move in 1995 to establish the National Health Insurance (NIH) by bringing together several employer, private,

state and professional health insurance schemes into one National Health Insurance and single payer model. The Minister highlighted the importance of investment in healthcare staff, patient advocacy and digital systems and Taiwan's commitment to support knowledge transfer and harmonisation in the region through the Asia-Pacific Economic Cooperation (APEC). The Minister concluded by thanking everyone and assured all that Taiwan will keep working with the patients in the region and support IAPO to improve healthcare for all in the Region.

IAPO CEO reiterated the Deputy Minister's sentiments and said that IAPO had held its 1st APPC in Taiwan because the Taiwanese model of patient and community participation in healthcare policy and decision-making was a great patient-centred approach in delivering universal health coverage. It is a good practice model that needs to be replicated and adapted across the region.



Plenaries

Universal health coverage as a driver of equity, inclusive growth and regional prosperity from the lens of healthcare financing.

At the United Nations General Assembly 2019 (74th UNGA) it was highlighted by the Japanese Prime Minister Shinzo Abe that in 1961 Japan viewed health financing of their UHC not as a cost, but as an investment to boost their economic and social development at a time of severe economic stress in a post-war society. This bold decision has delivered more than monetary returns in prosperity; it also improved social cohesion and equity in the Japanese society. Apart from promoting human health and well-being, UHC 2030 will accelerate sustainable economic growth, inclusive social development, and poverty reduction.

This session started the debate on harmonising UHC in the Asia-Pacific region by looking at various patient perspectives.

We do not want UN Member States to think that they can discharge their burden to deliver UHC 2030 by delivering a basic healthcare service. The patient challenge in UHC is about extending the range of essential healthcare to cover innovative healthcare services, medicines and health devices, and extending them to an even larger population of uncovered patients.

The heart of UHC debate is financial protection. Out-of-pocket expenditures to cover additional services or innovative medicines can undermine this.

This session looked at the already established UHCs in the region and how they have, through patient engagement, extended the services to cover more people and bring in innovative services for patients.

The moderator, Karen Villanueva, IAPO Board Member from Asia-Pacific region (Philippines), introduced the three eminent panelists:

- Challenges and Achievement of National Health Insurance Scheme in Taiwan Prof. Ming-Chin Yang, Institute of Health Policy & management, Taiwan
- Patient perspectives on National Health Insurance Scheme in Taiwan Ya Hsin Wang from Psoriasis Association Taiwan, Board Member TAPO and IAPO
- 'The Ayushman Bharat' India's Universal Health Coverage for 1.2 billion people Dr. Ratna Devi, CEO Dakshama Health and Education and Chair IAPO

Prof. Ming-ChinYang highlighted the challenges of selecting the right healthcare finance models for a country and its economic system, elaborating on the single payer, Beveridge and Scandinavian models and hybrid single-payer/private insurance schemes.

Dr. Devi then explored India's approach of slowly increasing the coverage across the population by first using health finance to cover the low income and vulnerable groups (includes rural communities) first and later the middle-classes. This session lastly looked at the tensions between public healthcare providers and privately owned healthcare providers.

Ms. Wang looked at the positive experiences and challenges of patient participation within the National Health Insurance Scheme in Taiwan and how patient organizations prepared for and engaged with the various stakeholders.

Patient involvement in Health Technology Assessment and Universal Health Coverage.



A robust patient and citizen Involvement in Health Technology Assessment is important for Asian-Pacific health systems. The State should realise that a patient submission to the HTA is not a petition. The patient advocates in reciprocity must remember that the HTA is not a forum to air grievances. We all work together.

Prof. Ann Single
Chair Patient and Citizen Involvement Interest Group

Health is a political choice and the choice to finance new health technology (new medicines, health devices, procedures and services) would compete with other national priorities like investment innovation in industry, agriculture, education and so forth.

In order to make the decision to invest in a new health technology, the Treasuries and the Health Ministries need more than the clinical effectiveness evidence - they need robust cost-benefit, cost-effective analysis, life-cycle costs, economic utility and other data.

- Patient involvement in Health Technology Assessment- Prof. Ann Single -Chair Patient and Citizen Involvement interest group of HTAi
- My reflection patient engagement experience in Taiwan HTA, Prof. Jasmine Pwu, co-chair of HTAi and director of National Hepatitis C program office, Ministry of Health and Welfare

Prof. Single stressed that patient and citizen engagement in Health Technology Assessment is important for your health systems. The process of assessing clinical and economic data, called a Health Technology Assessment (HTA), has been adopted by many legislatures in a form of independent or arms-length HTA bodies to undertake this assessment and inform that political choice. The UK National Institute of Health and Care Excellence (NICE), Taiwan Center for Drug Evaluation (CDE) are just few examples.

In the Asia-Pacific region, many countries are now adopting the HTA approach in decision-making. Like the Thai 30 Baht UHC that evolved into Universal Coverage Scheme (UCS).

At a political level, and at policy implementation stages, the fact the HTA process had patient expert engagement can give legitimacy to the choices. It reassures the community that the HTA bodies and academia have conducted a sound assessment to support the policy decision-making - this can either be to accept or reject new medicines, health devices, procedures and services.

Professor. Pwu looked at patient engagement with CDE Taiwan and how this has improved the healthcare decision-making in Taiwan. In the Asia-Pacific context, where many cultures value family over individual choices and collective community choice over individual family choices, HTA is ripe for a whole of society engagement and decision-making. This means that patient experts can be at the heart of this multidisciplinary process to evaluate the social, economic, organisational and ethical issues of any new health intervention or health technology for the 'good of all'.

This session laid out the current HTA landscape and offered delegates space for debate and discussion.

Patient advocacy in Asia: Where is it now, where is it going and what to focus on?

The Asia-Pacific is a region of complex cultures and societies. Regional UHC patient advocates need knowledge and skills to understand the social and cultural milieu in order to put forward contextualized approaches and solutions. In such a setting, where health is a sovereign matter, one-size-fits-all approaches will fail.

At the same time, there is an acute need to harmonise the role-out of UHC 2030 regionally to ensure meeting the targets set. If no one is to be left behind, UHC 2030 approach must especially be targeting the patients in the low- and middle- income countries in the Asia-Pacific region.

This session provided an opportunity to understand this complexity of decision-making frameworks and work with them.

Dr Neda Milevska Kostova, IAPO Board Member moderated the session inviting following speakers to share their views and perspectives:

- Raising the patient voice in Asia, Karen Alparce-Villanueva, IAPO Board Member IAPO from the Philippines Alliance of Patients Organizations (PAPO)
- Japan and NANBYO (Difficult-Diseases) Framework, Yukiko Nishimura, President of NPO Advocacy Service for Rare and intractable diseases (ASRID), Japan
- Korean National Health Insurance Service and Advocacy, Won-Young Jang, Korea Blood disease Cancer Association

The session highlighted the great diversity in patient advocacy approaches in the region as dictated by different cultural and social norms when it comes to speaking up for patients' rights. At the same time, the audience had an opportunity to hear that a passionate, technically and culturally competent patient advocate is resourceful and can work around any obstacles.

Ms. Alparce-Villanueva highlighted the importance of why patients need to raise their voice in the Philippines. Like many other economies in the region, patients in the Philippines are struggling to get a priority as other pressing economic, social, education and housing issues are putting the economic and political system under pressure. Patients need to get their voice over this 'noise' to get better healthcare policy and better

treatment options, funding, and research. Patient advocacy in Asia is alive and growing and we must focus on skilling-up of the Asia-pacific network of patient groups to consolidate the UHC momentum and easily link the region to global development.

Ms. Nishimura shared the Japanese perspective and what issues and challenges are faced by patients in their advocacy efforts to get the services and medicines needed. They had been successful in getting legislative changes in order rare diseases were recognized by the healthcare policy-makers. Patient advocacy within the development and adoption of NAN-BYO Laws (rare diseases laws) in Japan was led by ASRID an intermediary organization. ASRID took leadership and supported collaboration among all stakeholders to improve healthcare for all patients with rare diseases. NAN-BYO laws could not have been achieved without contribution from the whole of the patient community and carers. By integrating all the patient and carer voices into one group, ASRID amplified that voice.

Mr. Yang, a lymphoma survivor, shared his experience of patient advocacy at Korea Blood Disease Cancer Association. He highlighted why patients need to get personally involved in advocacy. In Korea, such personal advocacy plays a pivotal role in getting you the best treatment without financial burden and overcoming the shortcomings of an insurance policy. Health literacy is important as is capacity building programmes to develop patient advocates.

At the United Nations General Assembly 2019 (74th UNGA) it was highlighted by the Japanese Prime Minister Shinzo Abe that in 1961 Japan



Patient advocacy in rare diseases is now gaining momentum in Japan and in the region. When we look at a single rare disease the number of patients is low, but when cumulated globally, patients with rare diseases exceed more than the population of USA. Having a legal definition NAN-BYO (difficult-illness) helped ASRID create a framework of legal, policy and practice on rare diseases in Japanese universal health coverage. Together we can motivate research and development of new genetic therapy cures and therapies in the region.

Yukiko Nishimura President and Founder ASRID

Disruptive technologies in Asia- Pacific UHC- Artificial Intelligence (AI) & machine learning. Can the Asia-Pacific Region transform global UHC models through innovative disruptive technologies?

Hong Kong based Proviti and ESI Thought Lab Survey 2019 affirmed that the Asia-Pacific region is now leading on artificial Intelligence, machine learning, digitisation and other innovative services relying on high-speed communication networks like 5G.

These disruptive technologies will find their way into healthcare and have a paradigm shifting impact on UHC.

Asia-Pacific region's leadership in disruptive technologies can make our UHC safe, quality, accessible, acceptable, affordable and non-discriminatory - in short, a patient-centric UHC 2030.

Asia-Pacific's patient expert led innovation is now transforming many healthcare settings, devices and services. This can transform UHC 2030 delivery models and reduce costs, improve effectiveness and bring in economy-of-scale efficiencies as disruptive technologies have done in other industries.

This session started the discussion on patient engagement in digitalisation, artificial intelligence and machine learning within healthcare in Asia-Pacific region. Patient engagement within digitisation of healthcare is critical as healthcare decision-making is being taken over by Artificial Intelligence (AI) and Machine Learning. Algorithms need to co-designed and co-created with patient centrality in mind. There is a need to reflect upon patient engagement frameworks in medicines and therapies design now.

The session was moderated by Dr. Sabine Nick, Director Strategic Partnership's at IAPO who invited two speakers to share their experience and views:

- Patient Co-Creation and Ethics of disruptive technologies use in the Asia-Pacific Universal Health Coverage (UHC), Kawaldip Sehmi, CEO, IAPO
- Patient-focused medicines development (PFMD), Chi Pakarinen, Programme manager, The Synergist

This session was particularly important for all patients living in this technologically rich region with a young digitally savvy population. The disruptive potential of digitization to change patient advocacy and healthcare is enormous.

Mr. Sehmi introduced the idea that digitisation, particularly AI and machine learning, can transform the healthcare landscape and promises the ultimate patient centeredness by supporting precision and personalised medicine. He

asked the patients to imagine that their medicines and therapies made from their very own cells and immune systems resulting in faster targeted treatment with less toxicity and side effects. Their entire clinical healthcare can revolve around them and not the hospital system's needs. Near patient homebased health devices, portable scanners, remote cameras and web-based communication can help support the patient in their own home and community. This is good for the mental health and wellbeing of the individual patient and reducing the financial pressure and cost of your UHC.

Ms. Pakarinen introduced the idea of building a global patient engagement framework. PFMD is working towards building conditions for effective and meaningful patient engagement designs. This approach can reduce variation of quality of engagement and result in better co-design of medicines and therapies.

The full potential of Disruptive Technologies is still unexplored. This session provided examples of how patients need to be prepared not only use technology, but to act more upstream by engaging with software developers and medical teams to put patient perspective into the algorithms they design. AI and machine learning can deliver safe and ethical personalised healthcare and add patient centricity to UHC.

Patient Engagement in Research, Regulation and UHC Economics in the region

Patient engagement is vital in research, regulation and UHC economics. European Patients' Academy on Therapeutic Innovation (EUPATI) has established a programme to develop capacity in European patients to engage in the medicines research and development activity.

Large regulators Food and Drug Administration (FDA) and European Medicines Agency (EMA) have set-up structures and bodies like the Patient Engagement Collaborative (PEC) and the Patients' and Consumers' Working Party (PCWP), respectively, to bring patient experts into the heart of medicines regulation.

Asia-Pacific Economic Cooperation's Health Working Group (HWG) has started engaging patient experts in their health and economic development agenda. This session added detail and depth to the previous discussions on patient engagement in the healthcare value chain.

This was an important session as patient engagement within a technical area of clinical research, economics and regulation is a new concept for all in the region, unlike Europe where EUPATI and the EU/EMA programme have institutionalised patient engagement in research and regulation.

The session had four speakers:

- Patient engagement in good manufacturing and regulatory practice to improve patient safety and pharmacovigilance, Dr. Shou Mei Wu, Director General, Taiwan Food & Drug Administration
- Patient engagement in research to improve medication safety, pharmacovigilance and pharmacy, Prof. Hsiang-Wen Lin, Vice Dean, China Medical University School of Pharmacy
- Putting patients first, Dr. Michelle Vinchin, Executive Director, Global Lead for Patient Advocacy & Strategic Alliances, MSD
- A Stroke Champion's Journey to life after Stroke. Patient and family engagement in developing innovative stroke rehabilitation services and support, Tracy Chan and Ivan Tan, National Stroke Association Malaysia (NASAM)

Dr. Mei Wu spoke about the importance of patient engagement in patient safety and pharmacovigilance within the Good Manufacturing Practice & Regulation. Because of patient engagement and advocacy within regulatory affairs, recently the Taiwan FDA used patient-led pharmacovigilance & patient safety initiatives to recall 38 stomach medications as a precaution due to them containing a chemical that could cause cancer. She highlighted the mission of FDA to engage patients to jointly monitor and protect patients from drug damage. The FDA uses specialised systems in Taiwan like the 'Drug injury relief database' & 'National ADR Reporting system'. Patients are encouraged to actively participate in both.

Hsiang- Wen Lin shared insights on patient engagement in research to improve medication safety, pharmacovigilance and pharmacy. In Taiwan, pharmacists have full access to their patients' health records and prescription history, enabling them to know diagnoses, adverse events, hospitalizations, and basic vital signs (blood pressure, cholesterol etc.) for each patient. All patient data is recorded on their personal Pharma Card, an important tool for research into improving medication safety.

Dr. Michelle Vinchin shared a personal story of a friend recently diagnosed with breast cancer, whom she referred

to a local advocacy group as a proven way for getting support and learning about cancer care management from peer patient experts and survivors. MSD prides itself in engaging patients at all levels. The CEO has championed patient engagement. MSD in supporting patients to organise themselves and engage in research and development. She highlighted the value of patient experience in developing good healthcare and the important role of empowered patients & advocates who help policy-makers, providers, manufacturers and regulators to understand the patient needs better and to deliver better services and products that improve health outcomes through good solutions in medicines, services and regulation. Patient perspectives are critical in innovative medicines development.

Ms. Tracy Chan and Mr. Ivan Tan then looked at implementation of the research and regulation into practice through patient engagement in a specific setting in Malaysia: Stroke management. Research led this group to develop an easy to understand mnemonic for a protocol for families: F.A.S.T. Following F.A.S.T rehabilitation is essential, and patient engagement in the process - critical. Rehabilitation is an important component of good healthcare and UHC but is often ignored and underinvested by many health systems. NASAM offered to the delegates their experience with 'holistic care' model of using stroke survivors as champions to reintegrate other survivors into the society, focusing also on addressing patient confidence and social stigma of life after stroke. The 'NASAM Ambassador Programme' for self-motivation & 'NASAM Stroke Games' became nationally recognised and have social acceptance of celebrating life after stroke.

HTA & Health Economics

This session built upon the keynote from Prof. Ann Single. It brought back the focus onto the 'real-world' experience. A Taiwanese patient organisation and the Taiwan Centre for Drug Evaluation discussed how they engaged in HTA process together.

The session was moderated by Ann Single, Chair of HTAi, who invited two speakers to share their expertise and views:

- Patient Values and Engagement in HTA-Experience of Taiwan, Dr. Li-Yin Huang, Director, Division of HTA, Taiwan Centre for Drug Evaluation

- Patient perspectives of engagement in CDA HTA in Taiwan, Mr. Harry Yi-Mou Ko, Chairman, Psoriasis Association Taiwan (PAT).

Dr. Huang shared the Taiwan Centre for Drug Evaluation (CDE) experience and practices of patient involvement in HTA in Taiwan. By law, the Pharmaceutical Benefits and Reimbursement Schedule joint committee (PBRS) should invite patient organisations to voice their opinions. This led to birth of Taiwan Alliance of Patient Organisation (TAPO) in March 2016. Over the years, 2016-2019, CDE together with other related agencies and patient groups have prepared HTA reports that brought a greater level of understanding on HTA and its efforts to ensure effective transparent government policy.

Mr. Yi Mou Ko shared patients' perspective on HTA from his experiences as a patient living with psoriasis for a long period and working with PAT & International Federation of Psoriasis Associations (IFPA) to advocate patients' rights in Taiwan. He voiced that together with patients' awareness and motivation to engage in HTA, it is critical that the responsible agency ensures proper patients' mentoring, which the CDE undertook in excellent enabling and capacity building programmes for patients. Further, trust between the patients, regulators and authorities is key and must be developed and nurtured, which over time ripens the fruit of meaningful engagement, instead of a tokenistic invitee at the HTA meetings.

HTA and other health economic approaches like cost-benefit, cost-effective analysis, life-cycle costs, economic utility, may be blind-siding health policy makers by giving them the cost and not the value of the health technology to the patient. In other words, focused on clinical benefits and costs, HTA often overrides the patient voice. We need an informed patient voice in the HTA process.

Patient-reported outcome measures (PROMs) and Patient-reported experience measures (PREMs), if incorporated early in drug development and service delivery, can give depth to HTA, and evidence of the real value of technology in patients' lives.

Multi-criteria decision analysis (MCDA) can enhance HTA and its weighted-sum and quality adjusted life-years numerical approach.

Lastly, rare diseases and their need for health technologies like gene therapies, biotherapeutics and cell therapies present difficulties for HTA which is geared at larger population of patients and bigger research evidence and data.

Patients need to understand their role in shaping public policy on UHC in depth. What are your strengths,



weaknesses and boundaries, and how you can surmount them?

This session provided space for exchange of experiences in patient engagement in Health Technology Assessment (HTA) from different countries in the region, looking further into how Patient Reported Outcome Measures (PROMs) and Patient Reported Experience (PREMs) are accounted for within the health economic considerations in the region.

Public policy: role of patients in extending uhc and reducing out-of-pocket expenditures

This end-of-the-day session brought two speakers' experiences of working within well-established UHCs in the region:

- Maintaining momentum on 30 Baht reforms- covering more people with innovative health services, Orajitt Bumrungrskulswat , Assistant secretary General, Heart to Heart Foundation, Thailand
- Extending the basic coverage to cancer education, advocacy, family services and building a resource center, Margaret Chang, Consultant HOPE Foundation, Taiwan.

Ms Bumrungrskulswat shared with the delegates the experience from the 30 Thai Baht 30 programme and its growth. Once the Thai UHC has been established

in 2001, Thai patients had to engage with it continually and help to develop it to extend across more of Thai population. They also had to advocate to have better health service packages (including innovative treatments) and reduce the risk of catastrophic out-of-pocket medical expenditures. Today, '30 Thai Baht' is further evolving and patients need to stay engaged in this process.

However, the most important role for patient experts in the context of a UHC setting within an Asian Society is that they must encourage compassion and humanise healthcare. Patient-centred healthcare policies and strategies can bring compassion. This is particularly important with high cost and rare diseases. Ms Orajitt shared the experience of the Thai National Patient Support Network, which helps extend the Thai UHC to cover high cost disease patients to get relief and reduce healthcare contributions.

Ms. Chang echoed OB's sentiments, pointing that patient participation in Taiwan UHC is an ever-evolving engagement process. Patients continually need to have their capacity developed in policy planning and analysis. The State needs to keep on engaging with the civil society and in community development. However, the most important area that patient advocates need to concentrate on is that of developing good relations and communication with bodies responsible for regulating and paying for new medicines and services like the HTA (CDE Taiwan) and the NHI Policy Teams. This comes with trust and has a positive dividend in improved joint healthcare public relations, crisis management, media relations, government affairs, professional and advocacy affairs, market access, reimbursement price strategy and policy shaping.



Day 2

Plenaries

IAPO Strategy and plans for the Asia-Pacific Region

The presenters were:

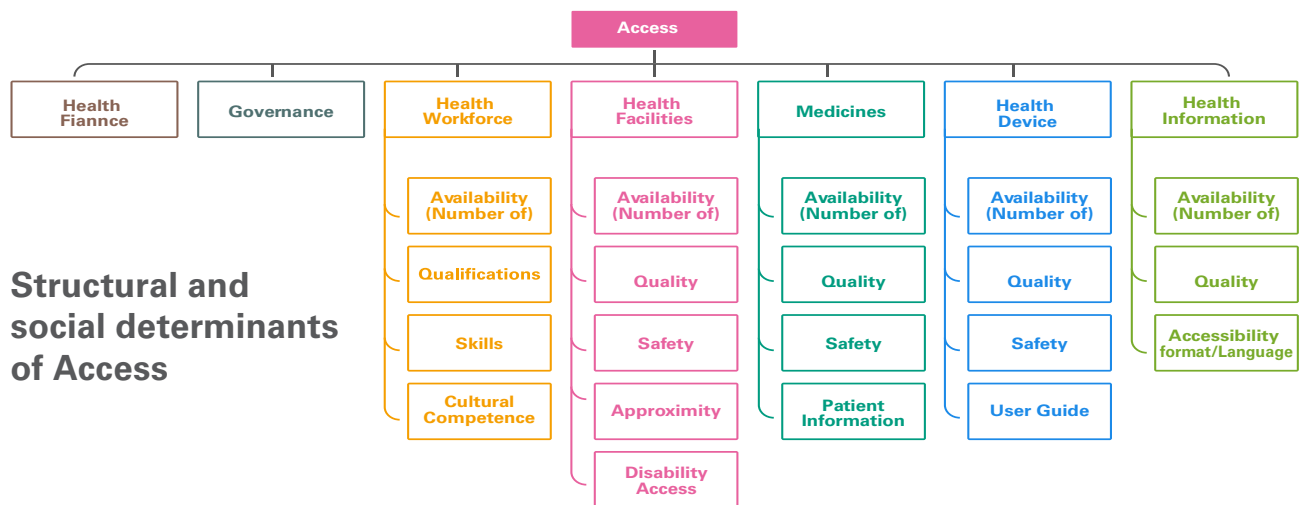
- Dr Ratna Devi, Chair of the IAPO Board
- Dr Neda Milevska-Kostova, IAPO Board Member
- Ellos Lodzeni, IAPO Board Member and Treasurer

The access to healthcare survey, recently undertaken among IAPO members and other patients' organisations in Asia-Pacific region, was used to set the scene for this session. It formed the basis to discuss IAPO Strategy and Plan for the Asia-Pacific region.

According to the survey, the variability of structural and social determinants of healthcare in the region has a great influence on access to healthcare nationally. Access was not a matter of price only.

Before any future strategies to establish patient-centric UHC in the region, patient advocates have to understand that meaningful patient advocacy is affected by:

- External factors and global health agenda
- Specific burden of disease triggering under-investment of some diseases e.g. rare diseases, oncology or endocrinology
- Health system infrastructure and financing arrangement
- Global and national shortages of human capital in health care, contributing to belated diagnosis, treatment, rehabilitation and palliative care, and thus huge sufferings for the patients and costs/losses for the society.
- Shortages of specific health devices or pharmaceutical products, such as lack of MRI equipment, insulin pumps or monoclonal antibodies affects access.
- Discrimination of specific groups (age, gender, ethnicity, nationality, multi-morbidity, LGBT and AIDS) in some countries affects their access.



IAPO, through its Board members, encouraged participation of the current and new members from the Asia-Pacific Region in the three-pillar strategy to empower patient communities, drive research and shape law & policy at regional and national levels.

IAPO is now looking at consolidating advocacy in the region by creating a regional hub for APPC, increase representation, and disseminate best practices by keeping the momentum up with an annual regional congress.

A consensus developed that in Asia-Pacific patients need to use modern advocacy approaches to address new and developing issues. Capacity building will be a prime tool to improve the quality of patient engagement and shape patient centric healthcare. There is a huge potential to hear youth patient voices at the national and WHO regional level. IAPO proposed using youth led campaigns and the setting up a scientific advisory council to have a regional representative voice to guide the Board. The Scientific Board could support collaborative proposal writing & policymaking strategies. The session also opened its doors to strategic partnerships with various organisations like ISPOR, IFPMA, WMA, ISQua and HTAi to develop new toolkits to serve the needs of the region.

IAPO strongly believes that most countries will have UHC by 2030 and it is up to IAPO & our stakeholders to ensure we have patient centric UHC. To continue the vision, Dr Ratna Devi concluded the session and invited the delegates at APPC 2019 to continue this discussion at the 9th Global patient congress to be held during 16-18th April 2020 in Edinburgh, Scotland.

Areas that need addressed in the region are:

- **Malaysia:** Mental health services need to be established to international standards. Neurological conditions were under invested in and shortages of psychiatrists and neurologists hindered access
- **India:** Demand was high due to a huge population. The health system was stressed everywhere. The variability of access to quality healthcare is vast within inter and intra public and private healthcare systems. Quality and safety are key issues.
- **South Korea** has modern and efficient UHC. It has good outcomes OECD. However, it needs to be patient centric and cover the rare and high cost diseases better. Patient participation is poor, and patients need a better complaints and information redressing system. State must invest in patient led solutions like "Shouting, Healing and Solution".

- **Philippines** as a low- and middle-income country that 'exports' doctors and nurses needs capacity building programmes to make its advocates stronger.
- **Japan** has a good UHC but it has lots to do in rare diseases and implement the NAN-BYO Law. It also needs to mobilise and engage patients in healthcare decision-making
- **Thailand** has a UHC but it is under resourced for rural communities and needs more rural community patient advocates.
- **Taiwan** needs to develop patient advocates who can engage in HTA and on NCDs

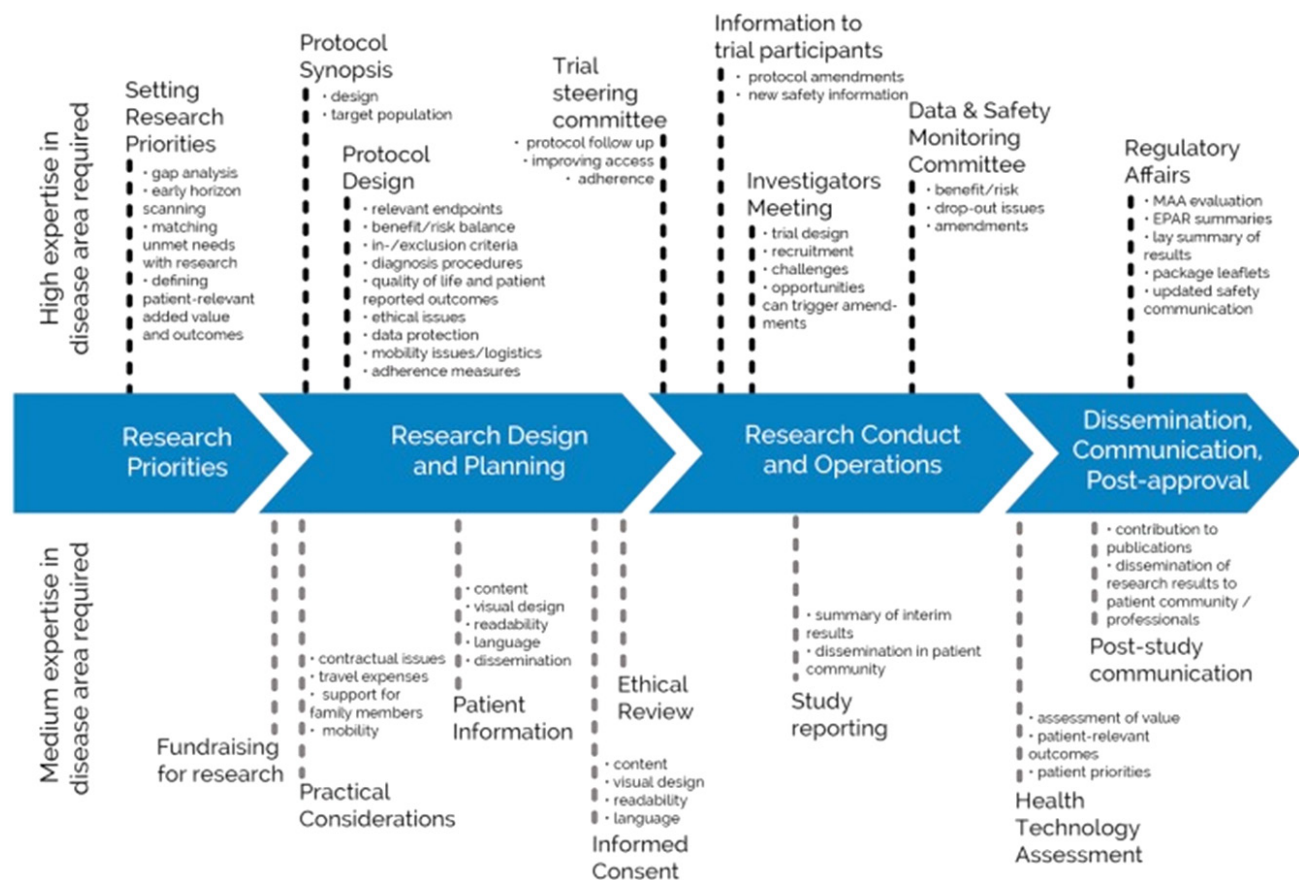
In our Global Patients Congress Miami 2018, IAPO had begun the practice of inviting the Industry Partners to share their innovation and best practice in patient engagement.

The APPC invited four speakers to continue this practice:

- Patient education and involvement in R&D Lasse Jacobsen, Senior Lead of patient research & Alliances, LEO Pharma.
- Building capacities for patient engagement, Michael Alzona, Regional Director for Patient Engagement MSD Asia Pacific
- Alliance building for patient engagement in UHC innovation, Kylie Park, Amgen.
- Physician and service provider training, Dr Kannan Subramaniam, Senior Medical director, NCD R&D Upjohn, Pfizer

Lasse Jacobsen began the session with Leo's commitment "nothing about you without you" brings patients into the heart of innovation. Leo has supported a multitude of efforts at patient education & involvement in R&D. LEO is working in a high need area with patients having rare and common skin diseases that need innovative medicines and healthcare solutions. They have created patient expert groups who help their clinicians co-create and match protocols to the patients' lives. Lasse Jacobsen also highlighted how the role of patient engagement in research and development grew in Europe. The EU's industry led Innovative Medicines Initiative (IMI) and the European Patients' Academy on Therapeutic Innovation (EUPATI) set-up a new framework of engagement on research. EUPATI developed different roles for patient engagement that LEO utilises in developing its patient engagement in setting priorities, planning and designing the research, conduct and dissemination. EUPATI Patient Involvement in Medicines R&D.

EUPATI PATIENT INVOLVEMENT IN MEDICINES R&D



Michael Alzona began by saying that MSD has developed a life-cycle approach to building advocacy capacity in patient groups. This engagement mirrors the growth of their competencies, first needing information and support and then moving on to engagement in R&D. The mature groups will become patient experts and engage in HTA and higher levels of R&D. It is important that patients continually give feedback and support that 'real world' evidence to improve patient lives. Getting regulatory approval is just the start of the engagement process. MSD keeps listening to the patient voices well past the post approval stages and throughout the medicines' lifecycle. MSD encourages cross-sector and cross-industry partnerships as this ensure better capacity building efforts.

Kylie Park highlighted that Amgen is manufacturing high-end innovative biologic medicines in partnership with patient advocates and society. Amgen is known for manufacturing innovative originator biologics and immunotherapies like BITE. Amgen believes in providing quality information and coordinated efforts to leverage evidence generation, value-based partnerships and

advocacy to support innovative medicines development to change and improve patient care. Having digital technologies means that there are many ways to collaborate within the healthcare system today. Asia Pacific Fragility Fracture Alliance (APFFA) is an initiative by Amgen. Amgen has been involved to support several patient groups and came up with APFFA to address the genuine need to overcome the debilitating social and physical impact on patients.

Kannan Subramaniam had vast experience in working with healthcare improvement through continuous professional development programmes in various settings. He said that when improving healthcare, it is Upjohn good practice to consider both the patient and the physician education simultaneous. The physician education is adapted for lay patients so that both share the same information. It results in better understanding, support and care. UpJohn recently developed person centric videos to make living with NCDs and chronic diseases a little easier. Both patient and physician involvement improved prevention & increased awareness on reducing the burden of NCD's nationally. KS shared videos.



Why is MSD engaging patients throughout its medicines' life cycle? Because your patient journey, experience and outcomes are our journeys, experience and outcomes.

Michael Alzona
MSD



Breakout Sessions

Room 1

Patient Advocacy & the UHC

This session provided three vital dimensions of patient advocacy for UHC:

- Patient engagement in healthcare law, Maria Fatima Garcia-Lorenzo, President Philippines Alliance of Patient Organisations (PAPO)
- Patient Shouting cafes, GiJong An, President, Korea Alliance of Patients' Organizations (KAPO)
- Patient perspective on self-care living with Type 1 diabetes and road to UHC, Dr Apoorva Gomber, co-founder of Diabetes India Youth in Action (DIYA).

Ms. Garcia-Lorenzo began the session by highlighting that patient engagement in UHC legislation must be proactive and early on. While taking into an account that legislative procedures vary by country, Ms. Garcia-Lorenzo pointed that patient engagement should preferably begin at the conception stage, such as the Green Paper stage in the Philippines, when the UHC law is first intimated by the State. It is important that patient organisations have formal talks with their legislators when the White Paper is issued. She discussed how

PAPO was engaged in the PhilHealth Green Paper discussions when it set out proposals on UHC which were still at a formative stage. PAPO was working hard at the White Paper stage as UHC statements of policy got firmed up and the State started setting timetables and ideas for legislative changes. Both the Green and White papers had an opportunity to engage and discuss with All Party Parliamentary Groups. PAPO was busy in advocacy when the Bill was introduced. PAPO worked at the outset and in March 2019 and saw the President enact the Universal Health Care (UHC) Bill into law (Republic Act No. 11223). You need specialised knowledge, skills and attitudes to undertake legislative advocacy tasks. PAPO undertook capacity-building exercises to get lawyers talk to patient advocates.

GJ An said that Korean Alliance of Patients Organizations came up with the innovative idea of 'Patient Shouting Cafes' to raise awareness of the media and policy makers. Both are invited to the Shouting Cafe. Aggrieved patients are given a platform to let out their frustration at health system its failures and any adverse events in their healthcare. These can be quickly picked up by the journalist or policy makers to investigate and change. Patient safety legislation or quality improvement follows these shouting cafes, besides the cathartic experience of shouting that calms down aggrieved patients.

Dr. Gomber spoke of spreading capacity amongst the Indian youth patients in a peer-to-peer Type 1 Diabetes programme that took best practice from the doorstep of the clinics and physicians into the patients' homes. This was a bottom-up approach in changing clinical practice standards. The patients were also very good social media activists and were actively engaged in advocacy to change healthcare law and policy. Universal Health Coverage and diabetes care was an important area to work on nationally. This requires access to affordable and quality biotherapeutics (recombinant DNA Insulin) and health devices (continuous glucose monitor (CGM) and insulin pens).

Room 2

Fundraising and investment

Patient organizations must strike a balance between investing in service delivery and patient support, and between policy advocacy and development. What should we raise money for and invest in were complex questions.

This session brought three important enabling factors of patients support, advocacy and engagement:

- Supporting cancer patients in Taiwan. Gloria Lin, Chairman, Taiwan Association of Cancer Patients
- Cancer prevention and cure programmes in Japan, Dr. Yumiko Mochizuki, Japan Cancer Society
- Ageing and social support-family and carers in Taiwan, Guo Jiang Xu, Executive Director, Taiwan Elderly and Long-Term Care Social Work Association

Ms. Lin began the session by stressing that health investment, patient support and service delivery are the three sides of the same healthcare triangle. Patient advocates must see their role from start to finish and not leave after a call for the investment. They must remain to see that quality healthcare services and patient support is delivered by this investment. The mental health and wellbeing of cancer patients improves with little personal touches in after-care. We need to raise awareness in a UHC patient's rights to a high quality of life after treatment.

Dr. Mochizuki, agreeing with this approach, shared her experience and practices in Japan focused on early and upstream interventions, since prevention is just as important as early diagnosis to get the best results in successful cancer treatment, rehabilitation and palliative care. Prevention, after-care and palliative care need equal investment as the treatment itself.

Mr. Xu changed the focus on to carers, whose efforts are often underrecognized and under supported. Carers are often stretched between the love, care and the duty to care, which makes it difficult to distinguish the fine line between personal care and subsidizing the UHC. As a result, carers are damaging their own physical health and mental wellbeing, becoming patients themselves. UHC must consider investments to support carers, as important extended arm of the healthcare system in the home support and self-care services. Health and social care must be one investment package with a large component reserved for carers. The complex multimorbidity and dementia issues carers must address on behalf of their protégés pose patient safety risks. However, these are all preventable and avoidable through proper support with training, subsidies and support groups.

Room 1

Patient Safety - Way forward post World Patient Safety Day

The World marked the first World Patient Safety Day on 17 September 2019. This date is now an important part of our advocacy calendar. This session had three speakers:

- Patient Safety Champion WHO Programme, Ellos Lodzeni IAPO Board Treasurer Founder trustee of Patient and Community Welfare Foundation of Malawi
- Patient safety in Asia, Fatima Lorenzo President Philippine Alliance of Patient Organizations (PAPO)
- 1st WHO World Patient Safety Day 17 Sept and planning for the second. Kawaldip Sehmi CEO IAPO

Ellos Lodzeni started by highlighting the importance of patient safety in a UHC. As a WHO Patient for Patient Safety Programme (PFPS) member and Patient Safety Champion in Africa, he highlighted how the PFPS programme approached patient safety issues. Patient harm destroys lives and trust in healthcare systems. It is wasteful and demotivating. Patients and their relatives go through a lot in raising finance and then cheated when they get poor quality and dangerous healthcare. Patient harm damages UHC. Malawi was active in this year's World Patient safety Day 17 September 2019. He highlighted their activity. In 2020 Africa will mark a bigger WPSD 2020

Fatima Lorenzo gave a good account of how PAPO is engaged in reducing patient harm by supporting the health system map out the failing areas of healthcare where most patient harm occurs. FL highlighted that in Asia Pacific, the patient champions' voice and perspective is important to reduce patient harm and address patient safety regionally. It is important we support each other and mark a bigger World Patient Safety Day 2020.

K Sehmi gave a complete history of WHO Patients for Patient Safety programme and efforts of IAPO Designated Technical Officer Dr. Neelam Dhingra and Edward Kelly in Geneva. He went over the final World Health Assembly Resolution 72.6 and what needs to be accomplished from now onwards within UHC and health systems. He signposted all to the WHO Director General's Report Global action of patient safety that gives additional evidence base. He congratulated the WHO Patient Safety team for turning around the WHA 72.6 passed in May 2019 into a phenomenally successful 1st World Patient Safety Day 17 Sep 2019 in under 4 months.

at KOLs, key patient organizations,
based approach

Room 2

Communications and Patient Advocacy in UHC

Communications is the bedrock of patient advocacy in UHC. Asia-Pacific region has its own cultural and social styles of communication.

This session had two speakers:

- Overview on the art of communication: Making cancer the headline, Paul Perez, President Cancer Coalition Philippines
- Communication and patient advocacy in UHC: Experience of Taiwan healthcare reform Prof. Liu Mei-Jun, Director, Taiwan Healthcare Reform Foundation.

P Perez highlighted that patient advocacy relies upon good communication strategies. You first need to define the problem that you are addressing. This needs a large stakeholder patient community to define it and explain it in a simple language. People need a chewable number. Every single hour someone dies of cancer grabs attention. People then need to relate with this. You then need to develop this into simple messages for the media, politicians, patients, carers and health policy makers. Your next move is to choose which media and messengers you will use. The messenger gives a real face to the story. Articulate and well-presented patients on TV and Radio are an asset. Social Media needs continuous feeding with stories, cases and results.

Prof. Mei-Jun said that you need to constantly evaluate your UHC services. Taiwan Healthcare Reform Foundation (THRF) aims to improve the failings in the healthcare system, healthcare quality and patients' rights in Taiwan. This they do by advocacy, public education and media/ resources (publications). THRF always verifies the accuracy, timeliness and relevance of health system failure with its own observations and survey, public complaints, news stories and new research findings. You must speak truth with conviction and facts. This makes people and media trust you as source of quality information.



Closing Plenary

Universal Health Coverage is not only about health finance or acute healthcare services, it is about comprehensive joined-up health promotion, prevention, curative, rehabilitative and palliative care services. The keynote speaker on the closing plenary was:

- Dr. Ying-Wei Wang, Director General, Health Promotion Administration, Ministry of Health and Welfare Taiwan

Dr. Wang set out the patient-centred participatory approaches of Taiwan's healthcare system and its National Health Insurance scheme. For meaningful engagement, the Ministry of Health started with creating an enabling environment for patient engagement at the start of their healthcare system in the health promotion section. Then invested in improving health literacy to ensure that every citizen has accurate, relevant and timely information in an accessible format- digital, print, audio and within face-to-face settings. Good quality information that is accessible forms the bedrock of good health promotion, primary care and general health literacy.

Patients must participate in information dissemination and augment the State's information and communication effort. This means that accurate, relevant and timely information gets through to patients and no misunderstanding occurs.

Asia-Pacific Patients' Declaration

The Delegates read through the draft Asia-Pacific Patients' Declaration (Full Declaration in Annex ###) and then endorsed it. The first APPC called on the United Nations, World Health Organization and Asia Pacific Economic Cooperation Member States in the region to scale-up, prioritize and accelerate delivery of:

- A safe, quality and patient-centred universal health coverage by 2030 that promotes protects and fulfils the patients' right to healthcare that is available, accessible, acceptable, affordable and non-discriminatory.

The APPC urged Member States to keep to their commitments as adopted within the:

- World Health Assembly Resolution 72.6 Global action on patient safety Agenda item 12.5 (WHA72.6 adopted 72nd World Health Assembly May 2019)
- United Nations Political Declaration of the High-Level Meeting on Universal Health Coverage: "Universal health coverage: moving together to build a healthier world" (Adopted at UN General Assembly 23 September 2019)

Lastly, the APPC urged Member States to create an enabling environment for effective State and patient organization partnerships to participate, engage and support in the co-planning, co-designing, co-delivery and co-evaluation of UHC 2030 above.

Closing Statements

The Chair and Board thanked all the delegates for making the 1st APPC a great gathering of delegates representing multitude experiences and patient voices from APAC countries. The Board also thanked those who made it happen like hosts (TAPO, PAT and PAPO), sponsors and partners.

The CEO then thanked the Sheraton Grand Taipei and APO's staff and volunteers who made this happen, with special thanks going to PAT and TAPO volunteers. There were plans to host the next 2nd APPC 2020 in New Delhi, India.

Conclusion

The 1st APPC has established a new patient forum within the Asia-Pacific Region where the patients from the region can develop connections and networks with regional health stakeholders like other patient organisations, academics, service providers, regulators, HTA bodies, the pharmaceutical industry and others.

The first APPC has been used by the delegates to enhance their knowledge, skills and capacity on healthcare legislation, policy, practice and standards. This empowerment will be used in advocating effectively, in partnership with their national healthcare regulatory institutions and government departments, to bring about safe and quality patient-centred UHC in the region and ensure that it is accessible, acceptable, affordable and non-discriminatory.

For sustainable universal health coverage there needs to be active patient engagement at all levels of the health system decision-making. The role of innovation and co-creation in healthcare in the region is vital. Artificial intelligence and machine learning not only make health services effective and efficient, but they also make them more patient-centred and personalised.

In pursuit of UHC, Asia-Pacific should not forget World Health Organization's principle that health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. We must bring a holistic approach to universal health coverage that reflects Asia-Pacific region's societal values of compassion and spirituality to healthcare. The role of carers and the family is important in universal health coverage. We must support and invest in carers.

IAPO and its partners will continue to build on this success and host the next APPC in New Delhi India in the fall of 2020.



OUTPUTS

Universal Health Coverage is not only about health finance or acute healthcare services, it is about comprehensive joined-up health promotion, prevention, curative, rehabilitative and palliative care services. The keynote speaker on the closing plenary was:

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Patients must participate in information dissemination and augment the State's information and communication effort. This means that accurate, relevant and timely information gets through to patients and no misunderstanding occurs.

PROGRAMME

The APPC Organising Committee crafted the final programme over two months and looked at securing the most appropriate patient-experts, policy makers, academics and regulators in the region. The Committee also succeeded in attracting the health policy elite in the region. This quite unique combination of expertise enabled cross-country and cross-sectoral exchange of experience and knowledge, ensuring vertical and horizontal exploration of issues, while focusing on the patient at the centre of healthcare, social care and wellbeing.

Patients Congress

ered Universal Health Coverage



BRANDING, VISUALS AND IMAGERY

At the outset, the APPC Organising Committee wanted a regionally sensitive branding. The Committee gave a free hand to the Taiwanese designers to come up with the branding, visuals and imagery that was culturally competent and reflected the language, script and cultural diversity of the region. The Designers used the regionally accepted design style called the Flat Design.

The Committee wanted to give delegates multiple opportunities to engage with the programme and also communicate with their communities online. For this purpose the Flat Design theme was displayed throughout the communication material. The planners produced a large 15m x 10m backdrop for speakers and general photo opportunities, four 10m x 5m side panels and entrance lobby Information Board with its daily programme for individual and small group selfies.

The delegate pack was assembled with a view to reduce paper-based resources. It supported all online resource access.

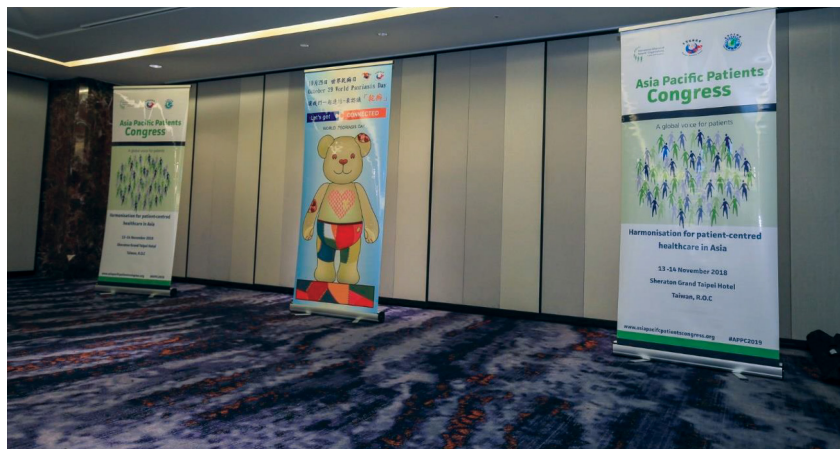
INTERPRETATION AND TRANSLATION

IAPO held discussions with the translation company at the outset as to how we could ensure that the APPC content was shared in a linguistically and culturally sensitive manner. IAPO decided to have all material translated into Mandarin and have simultaneous interpretation in two channels: Mandarin and English.

The interpretation system was an FM Radio System sending the interpretation feed to headsets of the APPC audience. The delegates enjoyed comfortable headphones with multi-channel receivers.

To minimise noise and for the comfort of the interpreters, IAPO had the company assemble a soundproof booth that had clear vision of the overheads on stage.

BANNERS, RESOURCES AND DELEGATE MATERIAL

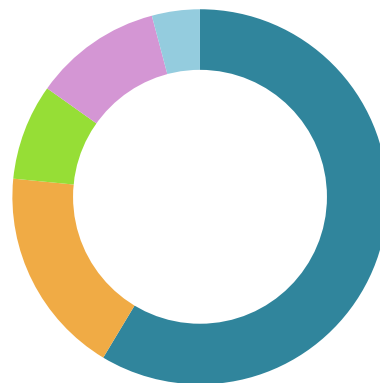
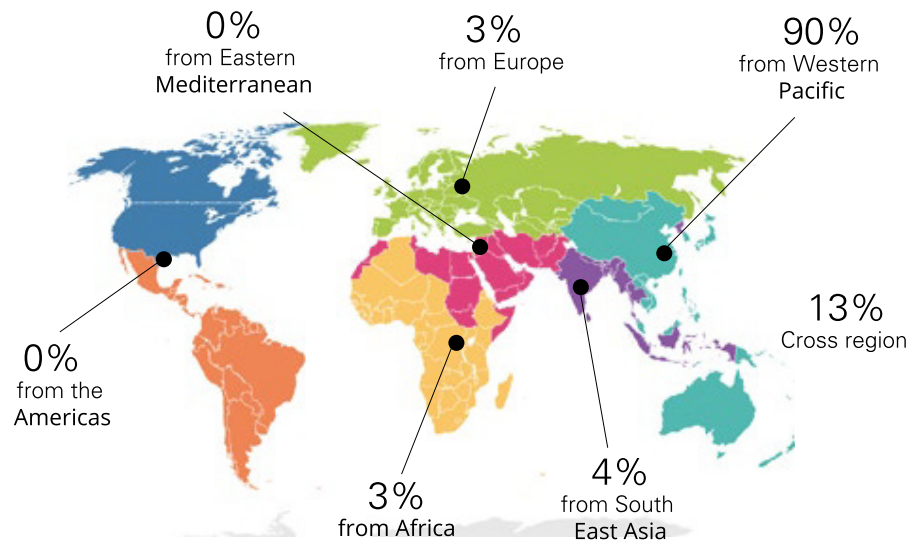


Outcome

DELEGATES WHO ATTENDED

The APPC was attended by 145 delegates registered for the entire event and about 10 additional delegates registered for one day.

Most of the delegates (90%) were from the Asia Pacific Region, as well as from USA, Europe and Africa. The majority of participants were patient representatives, and other sectors were represented by government officials, policy makers, academia and industry partners.



Delegates by field





Final Programme

Day 1: November 13, 2019 (Wednesday)

	Registration and Networking, Sheraton Grand, Taipei Hotel Zhongzheng District, Taipei City.
8:00am -8:50	Introduction and opening remarks, Kawaldip Sehmi Chief Executive Officer of IAPO Welcome address and setting the agenda Dr. Sita Ratna Devi, Chair of IAPO Board and Ya Hsin Wang, IAPO Board Member
8:50-9:10	Keynote Speech: Evolving role of patients in healthcare ecosystem Shih-Chung Chen. Ministry of Health and Welfare Taiwan
9:10-10:30	Opening plenary session - Universal Health Coverage as a driver of equity, inclusive growth and regional prosperity from the lens of healthcare financing Moderated by Karen Villa-Nueva Board Member IAPO and PAPO <ul style="list-style-type: none">Challenges and Achievement of National Health Insurance Scheme in Taiwan Prof Chiliang Yang, Taiwan Alliance of Patient OrganisationsAyushman Bharat - The National health assurance scheme of India, Dr. Sita Ratna DeviPatient perspectives on National health insurance scheme, Ya Hsin Wang, Executive Director, TAPO and IAPO Board memberNational Health Insurance Administration in Taiwan, Prof Ming-Chin Yang, Institute of Health Policy and Management, College of public health, National Taiwan University
10:30- 11:20	Patient involvement in Health Technology Assessment and Universal Health Coverage <ul style="list-style-type: none">Patient involvement in Health Technology Assessment, Prof. Ann Single, Chair Patient and Citizen Involvement interest group of HTAiMy reflection: Patient involvement and Health Technology Assessment Prof. Jasmine Pwu, co-chair of HTAi and Director of National Hepatitis C program, Ministry of Health and Welfare, Taiwan
11:20-11:30	Coffee break
11:30 - 12:40	Patient advocacy in Asia: Where is it now and where is it going? Moderated by Dr. Neda Milevska Kostova, IAPO Board member <ul style="list-style-type: none">Raising the patient voice in advoccay -PAPO Karen Villanueva, IAPO Board member, and PAPO Board MemberNAN-BYO law framework in rare diseases, Yukiko Nishimura, President ASrid- Rare Diseases patient advocacy in JapanCancer Care Advocacy in South Korea Won-young Jang, Korea Blood Disease and Cancer Association
12:40 - 13:30	Working Lunch: Speed Update and Small Group Networking
13:30 - 14:10	Disruptive technologies in Asia Pacific UHC. Can the Asia Pacific Region transform global UHC models through innovative disruptive technologies? Moderator Sabine Nick: Overview: Digitalization, artificial intelligence and machine learning healthcare. <ul style="list-style-type: none">Patient oversight and ethics in AI and machine learning, Kawaldip Sehmi, CEO of IAPOPatient Focused Medicines Development, Chi Pakarinen, The Synergist

	HTA & Health Economics
	Patient role in HTA and Health Economics: Are we missing 'economic consideration' of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience (PREMs)?
14:10- 14:50	<ul style="list-style-type: none"> • How Taiwan is engaging patients? Dr. Po-Chang Lee, Director General, NHIA Ministry of Health and Welfare, Taiwan • CDE experience on HTA and Health Economics, Dr Li-Yin Huang, Director, Division of HTA, Taiwan • Patients' perspectives on HTA and Health Economics, Harry Yi-Mou Ko, Chairman of Psoriasis Association Taiwan and Secretary General of PsorAsia in IFPA
	Patient engagement in research, regulation and UHC economics in the region
14:50 - 15:30	<ul style="list-style-type: none"> • Patient engagement in research to improve medication safety, pharmacovigilance and pharmacy, Prof. Hsiang-Wen Lin, College of Pharmacy Vice Dean, China Medical University School of Pharmacy, Taiwan Society for Pharmacoeconomics and Outcome Research (TASPOR) • Putting patients first MSD, Dr. Michelle Vichnin , Global Lead, Patient Advocacy and Strategic Alliances at Merck Speaker • Patient engagement in good manufacturing and regulatory practice to improve patient safety and pharmacovigilance, Shou-Mei Wu, Director General, FDA Taiwan • Patient and family engagement in developing innovative stroke rehabilitation services and support, Tracy Chan & Ivan Tan, NASAM (National Stroke Association of Malaysia)
15:30 - 15:50	Coffee Break and exhibition
	Public Policy: Role of patients in extending UHC in covering new populations, introducing innovative services and reducing out-of-pocket expenses (financial protection)
15:50 - 16:30	<ul style="list-style-type: none"> • Maintaining momentum on 30 Baht Reforms-covering more people, with innovative services, medicines, Orajitt Bumrungruskulswat, Assistant Secretary General, Heart to Heart Foundation, Thailand • Extending the basic coverage to cancer education, advocacy, cancer family service and building a cancer resource network, Margaret Chang Consultant Hope Foundation HOPE Foundation Taiwan
16:30 - 17:00	Discussions on Asia Pacific Regional Survey: Patient perceptions Summary and close of Day 1
18:30	Dinner and fellowship night with authentic cultural shows



Agenda Day 2: November 14, 2019 (Thursday)

6:30 - 8:00	Tai Chi & Breakfast	
8:15 - 9:15	AGM	
9:15 - 9:20	Agenda for day 2 and recap of day 1	
9:20 - 10:30	Plenary: IAPO Strategy and plans for the Asia-pacific region Discussions on Asia Pacific Regional Survey: Patient perceptions on access	
	Dr Sita Ratna Devi, Chair, IAPO Board Dr Neda Milevska Kostova, Secretary, IAPO Board Ellos Lodzeni, Treasurer, IAPO Board	
10:30 - 11:00	Coffee break	
6:30 - 8:00	Plenary session (panel with industry global leaders/ main patient representatives from Pharmaceutical and health devices companies	<p>Industry Best Practices - Patient Engagement in UHC Innovation</p> <ul style="list-style-type: none"> • Patient education and involvement in R&D Lasse Jacobsen, Senior Lead of patient research & Alliances, LEO Pharma. • Building capacities for patient engagement, Michael Alzona, Regional Director for Patient Engagement MSD Asia Pacific • Patient and societal perspectives in biotechnology innovation to improve health for patients and society, Kylie Park, Amgen. • Physician and service provider training, Dr Kannan Subramaniam, Senior Medical director, NCD R&D Upjohn, Pfizer
12:30 - 13:30	Lunch	
Afternoon breakout sessions		
13:30 - 14:30 Room 1	Case studies	<p>In-depth case studies on patient led UHC best practice Moderated by: Kawaldip Sehmi</p> <ul style="list-style-type: none"> • Patient advocacy and the Universal Health Care Law (Republic Act No. 11223), Fatima Lorenzo, President, Philippine Alliance of Patients' Organisations (PAPO) • Patient Shouting Cafes, Gi-jing An, President, Korea Alliance of Patients' Organizations (KAPO) • Self-Care in Type 1 Diabetes and impact upon UHC –opportunities and challenges, Dr. Apoorva Gomber, IAPG/DIYA India
13:30 - 14:30 Room 2	Fundraising and Investment	<p>Patient organizations striking a balance between investing in service delivery and patient support, and policy advocacy and development- what should we raise money for and invest in? Moderated by Dr Neda Milevska Kostova, IAPO Board Member</p> <ul style="list-style-type: none"> • Supporting cancer patients in Taiwan Gloria Gloria Lin, Chairman, Taiwan Association of Cancer Patients • Cancer prevention and curative programmes working together in Japan Dr. Yumiko Mochizuki, Japan Cancer Society • Case Study Autoimmune Disease Societies, Guo Jiang Xu, Executive Director, Taiwan Elderly and Long-Term Care Social Work Association

14:30 – 15:00	Coffee Break and Exhibition	
15:00 - 16:00 Room 1	Communications and Patient Advocacy in UHC	<p>The choice of message, messenger and medium: Who and how do they tell our story, and tell it well? Moderated by: Harry Mou TAPO Board Member</p> <ul style="list-style-type: none"> • Health Promotion and Communication in Taiwan- innovation and patient community engagement, Dr. Ying-Wei Wang Director General, Health Promotion Administration, Ministry of Health and Welfare, Taiwan • Overview on art of communications, Paul Perez, President Philippines Cancer Coalition • Research, evaluation, advocacy, public education and media/ resources in Taiwan. Prof. Liu Mei-Jun, Director Taiwan Healthcare Reform Foundation
15:00-16:00 Room 2	Patient Safety	<p>Post World Patient Safety Day - The Global action on patient safety Moderated by Kawaldip Sehmi, IAPO CEO</p> <ul style="list-style-type: none"> • Quality and Safety are not mutually exclusive, Ellos Lodzeni, IAPO Board member • Fight the Fakes campaign and falsified medicines in the Philippines, Fatima Lorenzo, President, Philippine Alliance of Patients' Organisations (PAPO) • World Patients Safety Day 2019
16 :00- 17:00	Summary and close of Day 2 Congress take-home messages Adoption of Asia-Pacific Patients' Declaration CLOSING CEREMONY	







Speaker Appreciation

One of the outcomes envisaged was that the conference has a comprehensive content that is matched by attracting subject-expert speakers in the region. The International Alliance of Patients' Organization (IAPO), Psoriasis Association Taiwan (PAT) and the Taiwan Alliance of Patients' Organization (TAPO) established the APPC Committee to bring these experts to the APPC who had experience within the Asia-Pacific healthcare settings. The committee wanted patient advocates to understand the current healthcare challenges faced in UHC delivery in the region and then participate in addressing these with their national healthcare systems to co-design and co-create future patient-centric interventions.

As planned, the APPC committee was able to attract major external State and non-State institutions. More importantly, the APPC also secured exceptionally good regional speakers who had long experience in healthcare overall. The speakers brought much specialised experience in specific areas of the healthcare value chain and supported fully to develop their presentation and sessions based upon this experience.

Ann Single

Chair, HTAi Patient and Citizen Involvement Interest Group

Ann Single is an experienced practitioner in and advocate for patient involvement. Currently the Coordinator and a Steering Committee Member of the Patient Voice Initiative (Australia), Ann began in this field in Scotland directing patient involvement and communication in the country's first Health Technology Assessment (HTA) body in 2001, followed by the Scottish Medicines Consortium in 2002. As part of

the Health Technology Assessment international (HTAi) Patient and Citizen Involvement Interest Group (PCIG), she has been involved in the development of numerous tools and resources to support patient involvement in HTA. In June this year, she became Chair of PCIG which has more than 400 members internationally from a range of stakeholder groups. Ann is a co-editor of the first book in the field, Patient Involvement in Health Technology Assessment (2017), a lay reviewer for several journals and has worked in a patient group as well as science and corporate communication. Her most recent publication focuses on stories of impact in patient involvement in HTA.

Maria Fatima Garcia-Lorenzo

President, Philippine Alliance of Patient Organizations, Co-Founder and Executive Director, Kythe Foundation Inc.

Fatima Garcia-Lorenzo is the president of the Philippine Alliance of Patients' Organization (PAPO), an umbrella organization of 32 disease-specific patient groups, representing about a million patients nationwide. Fatima advocates for patient's rights and is engaged in health policy development. Ms. Garcia-Lorenzo also holds the distinction of being the First Filipino Ashoka Fellow. Ashoka is a global organization based in the USA, which recognizes outstanding achievements of social innovators. Fatima was chosen because she co-founded Kythe Foundation, an organization which addresses the needs of more than 17,000 children with cancer and other chronic illness in eight partner government hospitals nationwide. Ms. Garcia-Lorenzo is recognized as a patient group thought-leader in the Philippines and in the Asia-Pacific region.

Kawaldip Sehmi

CEO of the International Alliance of Patients' Organizations (IAPO)

Kawaldip is a patient who is championing for the rights of vulnerable patients globally. He has extensive experience in paediatric healthcare and children and adolescents mental health services. He previously held the position of CEO at Richmond Psychosocial Foundation International and worked as Managing Director of Coram Children's Legal Centre. He has European and international public health experience as Director of the Global Health Inequalities Programme and as Chairman of the European Network of Qitlines

during the successful negotiations and ratification of the WHO Framework Convention on Tobacco Control. Kawaldip's qualifications include an MSc in the Public Health International Programme from the London School of Hygiene and Tropical Medicine, a Master's in Business Administration and an LLB (Hons).

Kannan Subramaniam

Director, Non-communicable Disease Strategy for Research, Development & Medical (RDM) at Upjohn

Kannan Subramaniam leads the non-communicable disease (NCD) strategy for Research, Development & Medical (RDM) at Upjohn in the Emerging Markets. He is a physician with specialist training in psychiatry, and has over a decade of clinical experience across emerging and developed nations. Prior to joining Pfizer in 2010, he was chief executive of a biotechnology venture of Fonterra, a global leader in dairy ingredients. Kannan has served on boards of health care, biotechnology and health information technology organizations fostering the growth of innovative companies that aim to improve health outcomes. As a member of Upjohn's RDM team, Kannan's focus is to understand and bridge knowledge and practice gaps through scientific transformation of NCD care. Partnerships are key to executing the transformation in both public and private health sectors. Technology is a key enabler of beyond the pill solutions to improve health outcomes.

Lasse Funch Jacobsen

Senior Lead of Patient Research and Alliances, LEO Pharma

Lasse bring 10 years of experience from working in pharma – the last 3 years in Patient Engagement teams across two different pharma companies. He has helped establish functions that ensure that the patient's voice is not only heard, but also implemented throughout the value chain from early research to product. Lasse has been part of numerous initiatives and coalitions across Academia, Patient Organisations and Industry working together to help improve the lives of people living with chronic diseases.

Michael Alzona

Asia Pacific Regional Director for Patient Engagement, MSD

Michael "Mike" Alzona is the Asia Pacific Patient Engagement Director for MSD. In this role, Mike is responsible for building and maintaining close relations with patient organizations across the region. In line with the company's increased focus on integrating patient perspective, Mike works together with patient organizations to ensure that their voices are heard on critical issues such as access to innovative drugs, headroom for innovation, and health care budget allocation. Prior to this regional role, he was MSD Philippines Director for Market Access, External Affairs and Women's Health. He also worked with Pfizer as its senior manager for public affairs and corporate social responsibility. Mike earned his BA in Social Sciences major in Behavioral Studies cum laude from the University of the Philippines Manila and completed his MA in Health Policy Studies from the same university.

Orajitt Bumrungkulswat


Assistant Secretary General, Heart to Heart Foundation

Orajitt has over 30 years' experience working in patient centred-healthcare development and support group and network development in Thailand where she is based. She has served as Senior Director at the Bureau of Community Health System, National Health Security Office. She is currently working at the Heart to Heart to Heart Foundation where she leads on the community development and advocacy work.

Dr. Ratna Devi

IAPO Board Chair & CEO of DakshamA Health & Founder of the Indian Alliance of Patient Groups (IAPG)

A medical doctor, public health and management professional, Dr. Ratna Devi brings more than 28 years of experience working to improve health outcomes in India. She spent her initial 10 years in the government and for the past 18 years, she has worked with national and international NGOs on public health initiatives. Dr. Ratna has demonstrated experience managing large-scale programs for success and scaling-up innovative pilot programs across India, at national and state levels. A versatile leader, she combines clinical qualifications to support high-quality service delivery and management experience. She is the CEO and Co-founder of DakshamA Health and Education, an organisation that is dedicated to working for access to health, patient education and advocacy. DakshamA aims to create a network of caregivers and patient groups, and work with them on knowledge sharing as well as providing



essential feedback for managing long term and chronic diseases. Dr. Devi works towards achieving these objectives by collaborating with the government and other vital stakeholders. She leads IAPG, a cross disease Patient Alliance in India and is a Board member of I-ORD (Indian Organisation for Rare Diseases). She holds an MBBS degree from Sambalpur University and a dual MBA from SYMBIOSIS and Manipal Institute of Distance Education. She has experience in working with the government and development sector, and has worked towards policy change, human resources capacity building and system strengthening. She is the WHO Technical Expert on the working group for Global Coordinating Mechanism for NCDs on “meaningful involvement of people with NCDs”. Dr. Devi also holds advisory positions at several NGOs and has contributed to research as well as publications.

Neda Milevska-Kostova

IAPO Board Member & Executive Director of the Centre for Regional Policy Research and Cooperation “Studiorum”

Neda holds MA in public policy and management, and PhD in public health. She has participated in a number of advocacy and legislative processes, including the promotion of patients’ rights in South East Europe, the creation and the passing of patients’ rights law in Macedonia, and is a strong supporter of patient-centred health systems. She has been the team leader and researcher of many projects related to rights to health, health care reforms, and promoting health as a contributor to economic growth and societal development. She has experience in implementing national health policies; strengthening networks; supporting newly established patient organizations in South East Europe; public policy development and advocacy at governmental level, professional associations and scientific congresses and symposia; and fundraising.

Wonyoung Jang

General Manager, Korea Blood Disease Cancer Association

Wonyoung is a lymphoma survivor who leads the advocacy programs at Korea Blood Disease Cancer Association. He has over 9 years’ experience championing patients’ needs.

Yang Ming-Chin

Professor, Department of Public Health / Institute of Health Policy and Management, College of Public Health

Professor Ming-chin has over 30 years experience working in the health education sector in Taiwan. He’s currently serving as the Associate Dean, College of Public Health, National Taiwan University. He has served as the Associate Editor at Value in Health Regional Issue, as the Scholar Representative at the Joint Establishment of the NHI Drug Items and Fee Schedule, Chairperson, National Health Insurance (NHI) Medical Expenditure Negotiation Committee and Director, Department of Planning and Management, NTU Hospital. He was also the Founding President Taiwan Society of Pharmacoeconomics and Outcomes Research.

Gloria Lin

Founder, Taiwan Association of Cancer Patients

Ms. Gloria Lin was diagnosed with breast cancer in 1995, and later she joined the volunteer work, hence began her impressive career as a volunteer and advocate for breast cancer. She was the founding president of Taiwan Breast Cancer Alliance, a platform that consolidates all the breast cancer patient support groups in Taiwan. After her two terms of presidency were complete, Gloria continues to work as CEO in TBCA. Her work and dedication to bring the awareness of patient’s rights, and improvement of quality of life were not unnoticed. In 2015, with successful experiences in breast cancer patient supports, she founded Taiwan Association of Cancer Patients, aiming to empower patients to engage in health policy decision making.

Dr. R.-F. Jasmine Pwu

Director, National Hepatitis C Office, Ministry of Health and Welfare, Taiwan (R.O.C.)

Dr. Raoh-Fang (Jasmine) Pwu, is Director, National Hepatitis C Program Office, Ministry of Health and Welfare, in Taiwan. She also is adjunct Assistant Professor at the Taipei Medical University and Fu Jen Catholic University. Trained as an epidemiologist, Dr. Pwu has picked up the expertise in research designs and analysis of large/claims database early in her career. Along the research path she found that

economic evaluations in healthcare quite interesting and determined to pursue a career in this field. She is one of the first researchers who are exceling modelling cost-effectiveness of medicines and public health interventions in Taiwan. During the time when she worked in the HTA unit of CDE, Taiwan, she and her team have built up many good examples of HTA system and research. Dr. Pwu has been involved in many regional and global HTA activities. She served on the INAHTA Board from 2010-2012. She and her HTA colleagues from Thailand and Korea created HTAsiaLink in 2010 and she served as their President from 2014 to 2016. She is the ISPOR Board of Director (2018-2021).

Ellos Lodzeni

IAPO Board Member & Patron and Founder trustee of Patient and Community Welfare Foundation of Malawi

Ellos is Governance, Health and Social Justice advocate and also a Patient for Patient Champion having been a victim of a medical error and also suffering from a range of chronic diseases with an enormous passion on health matters. He is the patron and founder trustee of Patient and Community Welfare Foundation of Malawi, the only cross-disease patient movement in Malawi which articulates and amplifies the patient voice and drives the crusade for patient-centered health care in Malawi. He has over 34 years public sector work experience advancing the protection and promotion of respect to human rights. Currently, he is also serving in the Office of the Ombudsman as an Executive Secretary. Ellos is involved in lobbying and advocating for implementation of more humane, equitable, passionate Patient centered health and social service delivery, and also ensure that Malawi has a robust vibrant Patient movement that is informing health policy and practice.

Ya Hsin Wang

IAPO Board Member & Secretary-General of Psoriasis Association Taiwan & Executive Director of Taiwan Alliance of Patients' Organizations

Ya-Hsin is a graduate of Taipei Medical University with a degree in nutrition and health sciences and has worked as a dietician for many years. 22 years ago, she was diagnosed with psoriasis which for her, came with a lot of pain. However, her patient journey allowed her to develop a deep sympathy for other suffering patients and now as a patient representative,

she strives to ensure that the core values of patient-centered healthcare are implemented in the real world. She has served as a member of national health insurance committee, the ministry of health and welfare. She has served as a national health insurance committee representative in Medical Service Payment of Pharmaceutical Benefit and Reimbursement Scheme Joint committee. She is a Member of HTAi (HTA international) interest Group on patient and citizen involvement

Karen Villanueva

IAPO Board Member & Vice-President of the Philippine Alliance of Patient Organizations & founder of Rare Cancers Philippines

Karen has as over 30 years experience in the private sector specializing in communications & policy work in the healthcare industry, where she spent the last 20 years. She has served in government as a Board Member of the Philippine Health Insurance Corporation (Philhealth), worked as a consultant for the Health Promotions and Communication Services of the Department of Health and as Corporate Affairs Director of Pfizer Philippines. Currently, Karen is the Chairperson of the International Public Relations Association Philippine Chapter and also runs a communications consulting firm called Health PRx Communications Inc.

Dr Li-Yin Huang

Director, Division of Health Technology Assessment Center for Drug Evaluation (CDE/HTA), Taiwan

Before joining CDE/HTA in 2008, she worked for almost ten years as a clinical pharmacist in a leadership role in the department of pharmacy in one of the major medical centres in Taipei. She completed her Ph.D. degree in Graduate Institute of Health Policy and Management, College of Public Health, National Taiwan University and Master's degree in pharmaceutical science from the National Taiwan University as well. She has authored and co-authored articles published in several international journals and also serves as a reviewer of manuscripts. Her current research focuses on comparative efficacy of new drugs, applying mixed treatment comparison methods, patient involved HTA and therapeutic inertia among adult DM patients in Taiwan.

From 2016 to 2018, she was on the International

Network of Agencies for Health Technology Assessment (INAHTA) board of directors. Since then, she has been involved in INAHTA activities; she has joined the INAHTA several Task Groups and participated in webinars on Hot topics in HTA. She has also worked with the HTAi Interest Group for Patient and Citizen Involvement in HTA (PCIG) and INAHTA Patient Involvement and was invited to the HTAi Asia Policy Forum in 2018 to share the experience of Taiwan's HTA.

In 2019, Dr. Li Ying (Grace) Huang currently serves on the board of Directors for the International Board of Directors for the INAHTA.

Dr Lanka Jayasuriya Dissanayake

Director, NCD Alliance, Sri Lanka

Dr Lanka has worked as the World Health Organization focal person responsible for Non Communicable diseases, elderly, Disability, Injury prevention, Road Safety and Tobacco Free Initiative. Having worked in the Government and Private Hospitals as well as the NGO sector, Dr Lanka has witnessed many gaps in the health system and hardships faced by patients were noted. In addition having worked in the UK where he faced the issue of his sister having breast cancer and how the UK system managed her disease and her final stages prior to her death in 2006 enabled Dr. Lanka to understand the components of an ideal patient centered treatment. The work he has done at the

World Health Organization as the National Professional Officer for NCD, Elderly, Disability and Road Traffic Injuries also enabled him to understand the needs, gaps and possible solutions.

Harry Yi-Mou Ko

Chairman, Psoriasis Association Taiwan and Secretary General of PsorAsia in IFPA

Harry is chairman Psoriasis Association of Taiwan and advocate patients' rights for many years. In addition, he is also the chief of secretary, Asia Pacific Region in IFPA (International Federation of Psoriasis Associations). About psoriasis, he can know how much the torture is, especially, he experienced psoriasis and psoriatic arthritis lonely when he studied at University of Southern California in USA as a graduate student long time ago. Right now, Harry is also patient representative of PBRS committee in medical device as well as the committee member

of the medical device committee. Before this, I was also deputy Committee Member, National Health Insurance Committee and Medical Service Payment of PBRS. Therefore, he is glad and thank to have chance to accumulate important practical experiences about total amount budget in the healthcare system as a patient representative. As a patient suffering from much torture with patient journey and patient representative for a long period of time, he hopes that he can contribute more related experience to the healthcare system by the perspective of patient representative and he thinks that we can make effort to make healthcare systems better and better together. He also hopes that the "patient-centered" can come true through global cooperation in our human society.

Hsiang-Wen Lin

College of Pharmacy Associate Dean Dean, China Medical University School of Pharmacy

Dr. Hsiang-Wen (Margaret) Lin got her Bachelor degree of pharmacy from College of Pharmacy (COP), China Medical University (CMU), Taichung, Taiwan, master degree in clinical pharmacy from National Taiwan University, and doctoral degree of Pharmacy Administration from University of Illinois at Chicago, U.S.A. She is currently the Associate Professor and Associate Dean in COP, CMU. She has made a lot effort on the following research areas: clinical pharmacy, evidence-based medicine, outcomes research, health service research, patient-reported outcomes research, drug safety and geriatric medication use. Overall, Dr. Lin has emphasized her researches on the evidence-, patient-centered outcomes, effectiveness-, safety-, and economic-related topics, including patient-reported outcomes, medication health literacy, on both western and Chinese medications in Taiwan and nationally. As a result, Dr. Lin has been sponsored for several patient-centered, drug safety, risk assessment and outcomes research projects by Department of Chinese Medicine and Pharmacy, Ministry of Health and Welfare, Ministry of Science and Technology, and National Health Research Institute, Center for Drug Evaluation (CDE) in Taiwan and EuroQol Research Foundation for the past few years. The corresponding project outcomes were compiled and submitted for several conference presentations, more than 28 journal articles, one English book chapter and 4 books in Chinese

Margaret Chang

Consultant, Hope Foundation Taiwan

Margaret Chang is consultant of Hope foundation, she was senior and excellent reporter ,composing commissioner.,onvener.as well as Margaret has come to public affair and involving patient filed over 20 years. She is also an writer ,her publication has Amazon Tracing China Times publishing co., 2002. This Book described all author saw and heard when author were stringing along with Taiwan Root Medical Peace Corps to provide free medical care for one month in Amazon region and Human Subject of Gene Science , China Times publishing co., 2001. This Book collected professional contentions of Gene Science elaborated by worldwide scientists, and also collected the opinions of its probable impact on society expounded by jurists and sociologists.

Dr. Apoorva Gomer

IAPG/DIYA India

Dr. Apoorva Gomer, is a patient advocate for type one diabetes mellitus. She is currently working as Partnerships Development Consultant at IAPO and Policy Advocacy officer at Dakshama Health. She co-founded a non-profit organization “Diabetes India Youth in Action” (DIYA) in Delhi, India and is handling the functioning of the organization with an aim of setting up diabetes camps for people living with type one diabetes in India. She has been passionate for working in the field of diabetes & research and has been working as South East Asia Regional Representative at Young Leaders programme by International Diabetes Federation. She has been advocating for improved care for patients living with type one diabetes and to ensure accessible & affordable insulin for all. With keen interest in advocacy and diabetes research she has been working at national & international level with other eminent non- profit organization like Beyond Type 1 , League of Advocates and T1International.

Prof. Liu Mei-Jun

Director Taiwan Healthcare Reform Foundation

Prof. Liu is the Board Director of Taiwan Healthcare Reform Foundation. She leaded THRF as Executive Director and Board Chairperson to enhance public engagement on health care policies from 2001 to

2015. Prof. Liu is also dedicated to higher education reform as Chairperson of Taiwan Higher Education Union and Professor of Graduate Institute of Labor Research, National Chengchi University.

Prof Chiliang Yang

Taiwan Alliance of Patient Organisations

Prof. Yang is a public health scholar, he was the Minister of the Department of Health of the Executive Yuan from 2009 to 2011. He obtained his bachelor’s degree from the Department of Health Promotion and Health Education of the National Taiwan Normal University

and master’s degree in public health from National Taiwan University as well as his doctoral degree in the same field from the University of Michigan in the United States.

Yukiko Nishimura

NPO ASrid

Yukiko Nishimura is President/Founder of NPO ASrid (Advocacy Service for Rare and Intractable Diseases’ stakeholders in Japan). ASrid is very unique organization and committed to providing the valuable services/system for “connecting” and “creating” with/ among multi-stakeholders related to its field, as an Intermediate Organization. Based on Yukiko’s effort, ASrid and JPA (Japan Patienets Association) has contracted MOU about research promotion and drug development area, and also collaborated with Pediatric NANBYO network, the biggest Pediatric Rare Diseases network in Japan. Yukiko has worked/collaborated with the patients/patients’ families and among stakeholders in rare and intractable disease and orphan drug field for about 10 years. Yukiko had worked as a Chief Secretariat of International Relations, JPA (2011-2016), as an Assistant Professor of Reaseach Center for Advanced Science and Technology, The University of Tokyo (2007-2015), visiting lecturer of Institute for Integrated Cell-Material Science, Kyoto University (2009-2012) as a technical consultant of MEXT (Ministry of Education (2005-2009. Yukiko has a board member of ICORD committee since 2010, and her team was a main organizer of ICORD Tokyo.

Kylie Park

Amgen

Kylie Park is the Director of Advocacy and Government Relations for Amgen in the Asia Pacific where she leads Amgen's external engagement strategy. Kylie is focused on ensuring that Amgen delivers on its mission to serve patients through the establishment of successful multi-stakeholder collaborations to improve individual patient, and health system outcomes. Throughout her 20+ year career in public affairs, Kylie has been a television reporter, political media advisor, communications and public affairs leader in both the NGO and MNC sectors. Prior to joining Amgen Kylie managed her own consultancy where she provided strategic counsel to Pfizer, Novartis, Abbott and Amgen in Australia and the Asia Pacific region. She holds a Bachelor of Arts - Journalism from Charles Sturt University and a Master of International Studies from the University of Sydney. Kylie lives in Hong Kong with her husband and three children.



Social Media Output

IAIPO had set up a unique webpage to funnel traffic towards our registration, Eventbrite Ticketing system and our Social Media.

IAIPO used IAPOVoice accounts on Twitter and Facebook, with the hashtag #APPC2019

Using the following we measured our social media presence:

- Google Analytics
- Twitter Analytics
- Facebook Analytics

We reached 2434 unique accounts on Twitter with 155,500 impressions. On Facebook, we reached 151,400 across the Asia-Pacific Region.

In the months leading up to APCC2019 i.e September, October and November, the following activity was recorded on our twitter page (@IAPOvoice) all following the event hashtag #APPC2019.





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