



3rd ASIA-PACIFIC PATIENTS CONGRESS

RECOVERING TOGETHER THROUGH COMPASSION, INSIGHT & CO-CREATION

REPORT

3rd ASIA-PACIFIC PATIENTS CONGRESS

Recovering together through compassion, insight and co-creation

16-17 November 2021

Virtual





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RECOVERING TOGETHER THROUGH COMPASSION, INSIGHT & CO-CREATION

Background

The International Alliance of Patient Organizations (IAPO) is a unique global alliance of national, regional, and international patient groups. Our mission is to help build patient-centred healthcare in the world. IAPO hosts regional congresses to build the capacity of patient groups in each of the World Health Organization regions and to strengthen IAPO's regional membership base.

The 3rd Asia-Pacific Patient Congress 2021 (APPC 2021) served as a critical platform during the pandemic to bring together members and stakeholders in the Asia-Pacific Region to address common challenges being faced by all of us as the second and third phases of the COVID-19 pandemic rolled across the region.

The APPC 2021 Congress brought together over 3800 delegates from across Asia-Pacific to share insights, experiences, and best practices on the pressing healthcare issues during the pandemic, support IAPO's mission to help build patient-centered healthcare across the region and to encourage the formation of national alliances of patient groups.

The APPC 2021 was organized by IAPO and co-presented by the Philippine Alliance of Patient Organisations (PAPO) and Duke NUS Global Health Institute Singapore. A partnership with an academic institution, Duke-NUS Global Health Institute, was an innovation to put research into practice, and patient practice and experience back into research. This academic partnership opened avenues for further collaborations and capacity building opportunities based on the learnings from the congress.

Aims and objectives

The main objective of the APPC 2021 was to gather and share a diverse perspective on the impact of the ongoing pandemic by addressing the issue of the health system recovery through collaboration, and building back better using compassion, insight, and co-creation.

Insight is defined as the ability to have a clear and deep understanding of a complicated problem or situation. This insight is attained either through deep research and development, or it is gained through experience. This congress section paired expert patient experiences, who have had long journeys along complicated care pathways, with research teams engaged in research and development of healthcare services, medicines, and health devices. Standing upon the shoulders of giants, we captured insights into developments in digital health, personalised healthcare, precision oncology and genomic medicine and pharmacogenomics generally. Asia-Pacific leads in these developments.

Compassion: this congress section addressed the fallout from the pandemic. We lost trust in our health systems. When our health systems were overwhelmed, they lost compassion. Asia-Pacific, known for being the root of global philosophy on compassion and humanitarianism, has now got to ensure that we restore confidence and trust in healthcare by delivering compassionate healthcare. This section was borrowed from the World Health Organization's respect and compassion agenda in delivering an integrated and people-centred universal health coverage 2030.

Co-creation in healthcare is about the health system, clinical trial teams, regulators, patients, and the public working together and is about:

- Sharing power
- Reciprocity
- Responsibility



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RECOVERING TOGETHER THROUGH COMPASSION, INSIGHT & CO-CREATION

- Building and maintaining relationships
- Including all perspectives and skills
- Respecting and valuing the knowledge of all

The compassion, insight and co-creation has been appreciated in Asia-Pacific by many of its health systems and leading companies and industries. Meaningful engagement of consumers in the Asia-Pacific has led to the delivery of world beating products and services that provide amazing user experience, utility, service, and value. This needs to be translated into the Asia-Pacific healthcare sector now. This section looked at how medicines and health devices manufacturers can collaborate with patients, regulators and even payers to give us great outcomes and experience.

Acknowledgments

We would like to express our special thanks to our members, collaborating partners and supporters who made the 3rd Asia Pacific Patients Congress a great success despite the difficult circumstances that they are all facing. They stepped forward to help in planning the event by joining our APPC Organising Committee and later as moderators and speakers during the congress. We thank our Industry Partners without whose partnership and resources we could not have delivered this quality virtual congress. Lastly, we would like to thank the speakers and delegates for their participation and for sharing their invaluable insights and suggestions, bringing a step closer to actualize patient-centred healthcare in the region.

Sponsors

Gold

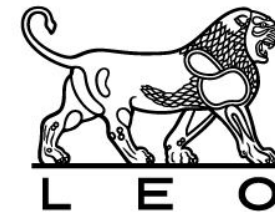
Johnson & Johnson



Silver



Bronze





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The programme and sessions

The programme was partitioned into three areas: compassion, insight, and co-creation. Each session in each of the sections was set to last one hour. Each session had one moderator and three speakers: academia/institutional speaker, patient representative, industry partner.

Programme

DAY 1 : 16th November 2021

10:00AM - 10:55AM
(SGT)

Opening Ceremony & Keynote Speech



Kara Magsanoc-Alikpala (Master of Ceremonies)



Dr. Ratna Devi, Chair, International Alliance of Patients' Organizations - IAPO



Karen Alparce-Villanueva, Board Member & Congress Chair, International Alliance of Patients' Organizations - IAPO



Father Jerry Orbos, Divine Word Missionary & Cancer Survivor



Prof. Tan Kok Hian, Group Director & Senior Associate Dean, SingHealth Duke-NUS Institute for Patient Safety & Quality -

IPSQ



Fatima Lorenzo, President, Philippine Alliance of Patient Organisations - PAPO

10:55AM - 11:55AM
(SGT)

WHO Compassionate Integrated and People-Centred Universal Health Coverage. Patient journeys in a fragmented versus an integrated health system



Dr. Esperanza Cabral, M.D., former Philippine Secretary of Health (Moderator)



Prof. Lee Chien Earn, Deputy Group CEO (Regional Health System), Singapore Health Services



Leanne Wells, Consumers Health Forum of Australia



Nittita Prasopa-Plaizier, Education and Capacity Development, Maternal Child Health and Quality Safety, World Health

Organization Western Pacific Region

This session will use the WHO's agenda on the delivery of respectful, compassionate, and people-centred healthcare. It will highlight the current situation of fragmented healthcare and how to overcome the loss of trust and goodwill to restore faith in our health systems. It will require recharging the batteries of the exhausted health workers and restoring quality healthcare services again.

11:55AM - 12:05PM
(SGT)

Mobility Break

12:05PM - 01:05PM
(SGT)

Strengthening health systems through patient co-creation and re-orientation of healthcare using digital healthcare



Shanti Sharmadasani, CEO, President – Asia Pacific, Government Affairs and Market Access APAC, S. ASEAN International

Advocacy & Consultancy (Moderator)



Dr. Shekhar Potkar, Regional Chief Medical Officer – Emerging Markets & Head of Global NCD Excellence, Viatris



Netnapi Suchonwanich, Management and Technological Advisor to the Office of the National Health Commission



James O'Brien, Vice-President, International Prader-Willi Syndrome Organisation

This session will be standing on the giant's shoulder and picking out a roadmap in 'engineering in' compassionate healthcare through digital healthcare and telehealth. How is convergence of technologies and patient co-creation enhancing patient centred healthcare and compassionate healthcare? Integrating the human experience with AI and machine learning. Discussion benefits and challenges, and defining the patients' role in co-creation

01:05PM - 01:35PM
(SGT)

Lunch Break

01:35PM - 02:35PM
(SGT)

Asia-Pacific leaping forward through genomics and pharmacogenomics: Personalised healthcare, precision Oncology and precision Diabetes



Kawaldip Sehmi, CEO, International Alliance of Patients' Organizations - IAPO (Moderator)



Dr. Saumya Shekhar Jamuar, Head, SingHealth Duke-NUS Genomics Medicine Centre



Dr. Diana Edralin, MD, DPCOM, General Manager, Roche

This session looks at cutting-edge innovation in the development of personalised healthcare: precision oncology and precision diabetes. Asia-Pacific leads on developments in genomics, pharmacogenomics and digital healthcare. We will use personalised healthcare in two vertical flagship programmes to illustrate where genomics and digital healthcare disruptive technologies are being applied to improve patient centred healthcare. Precision Oncology (PO) and Precision Diabetes (PD) help us in tailoring making healthcare solutions to fit with the patient. Personalised healthcare is using PO and PD with digital disruptive innovation in diagnostics and AI to bring a unique understanding of human biology by new ways of analysing health data. PH ensures that screening, diagnosis, treatment and even prevention of diseases will ensure the right treatment for the right patient at the right time. Patients have better experience and outcomes, and even greater autonomy and faster rehabilitation, with PO, PD and PH.

02:45PM - 03:45PM
(SGT)

Patient co-creation in Asia-Pacific Safe and Quality Healthcare: WHO Global Patient Safety Action Plan 2021-2030



Fatima Lorenzo, President, Philippine Alliance of Patient Organisations - PAPO (Moderator)



Dr. Aparna Singh Shah, Scientist-Regional advisor Blood, Blood Products, products of Human Origin, WHO



Prof. Tan Kok Hian, Group Director & Senior Associate Dean, SingHealth Duke-NUS Institute for Patient Safety & Quality -

IPSQ



Dr. Socorro Escalante, Coordinator for Essential Medicines and Health Technologies, WHO Western Pacific

This session will point out that as our healthcare has become unsafe, we must take stock of the WHO Director General says patient harm has attained a public health dimension. We will be sharing insight from regional experts on patient safety as to how we can drive the WHO Global Patient Safety Action Plan 2021-30 in the region, particularly with patient safety champions defining the patients' role in co-production. This session will look at where we are and what insight can we use to drive this forward, defining the patients' role in co-production.

03:45PM - 03:55PM
(SGT)

Mobility Break

03:55PM - 04:55PM
(SGT)

Is elimination of COVID-19 using current vaccines and approaches stalling? Do patients have to engage in co-creating new vaccine platforms and finding new effective respiratory and other treatments?



Dr. Raj Shankar Ghosh, Deputy Director, Vaccine Initiative, Bill & Melinda Gates Foundation (Moderator)



Dr. Socorro Escalante, Coordinator for Essential Medicines and Health Technologies, WHO Western Pacific



Dr. Aileen Dualan, Global Medical & Scientific Affairs Asia Pacific Regional Head, MSD



Dr. Kashmira Date, Director of Global Medical Affairs for Vaccines, Johnson & Johnson's Global Public Health Organization

New Zealand is now reconsidering its decision to invest fully in interventions aimed at eliminating COVID-19 (SARS-CoV-2 Virus). Other countries are realising that vaccination using the current vaccine platforms alone cannot be the entire solution in preventing and controlling the pandemic. If elimination is impossible, then can patients engage in further innovation in COVID-19 vaccines development like use of new platforms? Do we need to change use of vaccines as long-term prophylaxis with regular booster shots to mitigate the worse symptoms of the disease? As the respiratory failure and the cytokine storm is the main cause of high morbidity, then should we look at research preventing this and finding new and repurposed treatments as with WHO Solidarity Trials, to improve survival rates in acute care. This session will look at what insight and innovation we can expect in ensuring the survival rate of COVID-19 patients.

04:55PM - 05:10PM
(SGT)

Wrap Up



Bisi Bright, Board Member, International Alliance of Patients' Organizations - IAPO

Close of Day 1

DAY 2 : 17th November 2021

10:00AM - 10:10AM
(PST)

Opening of Day 2



Kara Magsanoc-Alikpala (Master of Ceremonies)



Oranjitt Bumrungruskulswat, Board Member, International Alliance of Patients' Organizations - IAPO

10:10AM - 11:10AM
(SGT)

Meaningful patient engagement in health literacy in a digital and social media age. Learning from the COVID-19 Global Pandemic and National 'Syndemic'



Dr. Ratna Devi, Chair, International Alliance of Patients' Organizations - IAPO (Moderator)



Laurie Myers, Director for Global Health Literacy & Oncology Health Equity, MSD



Pru Etcheverry : Regional Director, Lymphoma Coalition, Asia Pacific



Kawaldip Sehmi, CEO, International Alliance of Patients' Organizations - IAPO

This session will look at the dynamic between a global pandemic and national social determinants of health in a digital and social media driven world. Can this syndemic explain the variation in outcomes in Asia-Pacific. It will also look at how expert patients can co-produce attractive and effective digital health literacy and patient education solutions fast during a pandemic. Is the day of paper-based health literacy through pamphlets, posters, and booklets over in this digital media age? Denso Japan invented the Quick Response Code (QR Code). It has taken over in many Asia-Pacific healthcare settings, including the COVID-19 test, trace, and track systems.

11:10AM - 11:20AM
(SGT)

Mobility Break

11:20AM - 12:20PM
(SGT)

Meaningful patient engagement in co-creation in medicines and health devices R&D - moving from tokenism to meaningful engagement at all levels



Neda Milevska-Kostova, Vice-Chair, International Alliance of Patients' Organizations - IAPO (Moderator)



Mariko Koh Siyue, Clinical Assoc Professor, Singhealth



Dr. Li Ying (Grace) Huang- Director of the Division of the Health Technology Assessment, Center for Drug Evaluation, Taiwan (CDE/HTA)



Satoshi Miki, Board Member, Patient and Public Involvement Japan

The COVID-19 'fast-track' vaccines development process has educated many patients on how clinical trials are conducted. Asia-Pacific patients are now more aware of the opportunities and challenges faced by R&D teams. This session will invite experts to showcase how meaningful patient engagement in clinical R&D settings is undertaken now. We will also invite PPI Japan EUPATI's national platform in Japan to show how meaningful patient engagement in clinical trials is conducted in Japan.

12:20PM - 12:50PM
(SGT)

Lunch Break

12:50PM - 01:50PM
(SGT)

Selfcare within universal health coverage 2030. Lessons from the pandemic lockdowns



Paul Perez, President, Cancer Coalition Philippines (Moderator)



Kawaldip Sehmi, CEO, International Alliance of Patients' Organizations - IAPO



Orajitt Bumrungruskulswat, Board Member, International Alliance of Patients' Organizations - IAPO



Deon Schoombie, CEO, Consumer Healthcare Products Australia

This session will look at self-care and its evolution post pandemic. It will look at a new partnership framework and sharing of responsibilities. WHO defines self-care as "the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a healthcare provider. To ensure we have sustainable UHC 2030 we must optimise how we design and use our future healthcare services. The pandemic showed us that a lot of care moved out of the official healthcare care pathways and under the health professionals, to self-care, community pharmacists and the home, supported by telehealth.

01:50PM - 02:00PM
(SGT)

Mobility Break

02:00PM - 03:00PM
(SGT)

Meaningful Patient engagement in HTA and Regulatory Affairs



Ann Single, Chair, HTAi Patient & Citizen Involvement Interest Group & Coordinator Patient Voice Initiative (Moderator)



Dr. Roongnapa Khampang, Researcher, Health Intervention and Health Technology Program



Janis Bernat, Director, Scientific & Regulatory Affairs, International Federation of Pharmaceutical Manufacturers &

Associations - IFPMA



Chris Muñoz, CEO & Adviser, Yellow Warrior Society Philippines

This session will build on APPC 2019 and 2020 and show how to conduct meaningful engagement with Regulatory and HTA bodies in the region. During the in-person APPC 2019, Taiwan FDA showcased how patient engagement in medicines and health devices regulation was conducted. The European Medicines Agency and US FDA have both created an ecosystem that encourages patient engagement. This session will also look at how patients can engage with regulatory affairs and discuss developments elsewhere like the regional developments elsewhere like in African Medicines Agency and Regulatory Reliance to converge regulatory regimes to give us faster access to quality, safe and patient centred innovative medicines and health devices. During the first APC 2019 the Taiwan Centre for Drug Evaluation, a health technology assessment body, discussed how patients take part in HTA. In the United Kingdom National Institute for Health and Care Excellence (NICE) one of the earliest health technology assessment bodies set up in 1997, is now instituting a new patient centred engagement framework. The European Union is also investing in HTx, the next generation health technology assessment, to support patient centred, societally oriented, real-time decision-making on access to and reimbursement for health technologies throughout Europe.

03:00PM - 03:15PM
(SGT)

Closing Session and Call to Action



Karen Alparce-Villanueva, Board Member, International Alliance of Patients' Organizations - IAPO



Orajitt Bumrungruskulswat, Board Member, International Alliance of Patients' Organizations - IAPO



Dr. Ratna Devi, Chair, International Alliance of Patients' Organizations - IAPO



Kawaldip Sehmi, CEO, International Alliance of Patients' Organizations - IAPO

03:30PM - 05:30PM
(SGT)

[By invitation only] Consensus Building Workshop on Patient Advocacy for Patient Safety in Asia-Pacific in line with WHO Global Patient Safety Action Plan 2021 -2030

WHO SEARO and WHO WPRO have to come up with their own plan on patient engagement in the Global Patient Safety Action Plan 2021-2030. Duke NUS and IAPO will explore this along with co-production, fundraising, collaborative partnerships and digital health.

Close of Day 2



All Congress' sessions were recorded and [can be accessed online here](#).

Sessions' Main Takeaways

Keynote Speech

Father Jerry Orbos, Society of the Divine Word (Keynote Speaker)

- COVID-19 was a great equalizer. As we see it coming to an end, let's focus on what we've learned: how to be human and be kind, how to balance being personal and professional, and how to celebrate life and heal together. How to be grateful for what we have rather than regret what we have lost.

Prof. Tan Kok Hian, Group Director & Senior Associate Dean, SingHealth Duke-NUS IPSQ (Responder)

- Hippocrates, a compassionate figure in medicine, believes that holistic patient care is to care sometimes, to relieve often, and to comfort always. As we go through COVID, we need compassion and empathy to relieve the suffering of patients and health workers alike.

- Treat patients as partners. Empathy-based programs are the need of the hour.

Fatima Lorenzo, President, Philippine Alliance of Patient Organisations (Responder)

- Amidst the widened inequity brought about by the pandemic, collective recovery requires deeper compassion that inspires learning and develops new behaviours, bringing about insights and collaborative solutions to the COVID-19 crisis.

SESSION 1: WHO Compassionate Integrated and People-Centred Universal Health Coverage. Patient journeys in a fragmented versus an integrated health system

Dr. Esperanza Cabral, M.D., former Philippine Secretary of Health (Moderator)

- Let the secret of healthcare be in caring for the patient.

Prof. Lee Chien Earn, Deputy Group CEO (Regional Health System), Singapore Health Services

- In working with patient communities, co-creation begins with understanding their needs, aspirations, and what matters to them. Services should then provide holistic care with clear goals and an integrated team working collaboratively with the patient as an active co-producer.

Leanne Wells, CEO, Consumers Health Forum of Australia

- The Consumers Health Forum of Australia set a key goal to support patients in engaging with and influencing health policies, services, and research. Consumers as change makers were highlighted in all programs leading to effective use of their voice.

Nittita Prasopa-Plaizier, Education & Capacity Development, Maternal Child Health & Quality Safety, WHO Western Pacific Region

- Research has confirmed that patients with the skills and confidence actively engaged in their healthcare have better health outcomes and incur lower costs. Strengthening the capacity of patients and families to engage in health services, systems, policies, and research ensures patient safety that results in quality and universal healthcare.

SESSION 2: Strengthening health systems through patient co-creation and re-orientation of healthcare using digital healthcare

Shaanti Shamdasani, CEO, President, S. ASEAN International Advocacy & Consultancy

- Technology and compassion must jointly address patient challenges moving forward in this technology-driven world.

Dr. Shekhar Potkar, Regional Chief Medical Officer – Emerging Markets & Head of Global NCD Excellence, Viatris

- The pandemic can be seen as a crisis of opportunity that allows us to leverage digital disruption to improve patient care. Digital strategies have been pivotal in offering information and innovation to address the pandemic's disruption across the patient journey.
- In reimagining the new normal, solutions can be developed within the strategic themes of the customer and patient journeys, organizational preparedness, and policy.

Netnapis Suchonwanich, Management and Technological Advisor to the Office of the National Health Commission, The National Health Commission Office of Thailand

- Thailand utilized big data to develop a patient-centered information system that allows precision medicine per patient and provides tech-based solutions across the patient's entire life story.

James O'Brien, Vice-President, International Prader-Willi Syndrome Organisation

- Project ECHO democratizes knowledge on complex and rare diseases across the world. Doctors and healthcare providers are trained in an "all teach, all learn" model that employs amplification, sharing best practices, case-based learning, and monitoring outcomes to bring care where it is needed most.

SESSION 3: Asia-Pacific leaping forward through genomics and pharmacogenomics: Personalised Healthcare-Precision Oncology, Precision Diabetes

Kawaldip Sehmi, CEO, International Alliance of Patients' Organizations - IAPO (Moderator)

- With knowledge accumulating over time, we must evolve from generalized healthcare into personalized health systems.

Dr. Saumya Shekhar Jamuar, Head, SingHealth Duke-NUS Genomics Medicine Centre

- Significant social, emotional, and economic burdens to the individual, the family, and the healthcare system can be connected to genomics. Personalized healthcare can use genomics as a starting point to identify clinically actionable diseases, promote the practice of pharmacogenomics at the point of care, and offer personalized therapy.

Dr. Diana Edralin, MD, DPCOM, General Manager, Roche

- Witnessing the convergence of science and technology, Roche puts patients at the center of healthcare solutions and not the disease alone. High quality of individual data is also associated with broader data of patients around the world to provide more comprehensive and personalized healthcare solutions. Furthermore, value-based outcome healthcare aims for proactive instead of reactive results.

SESSION 4: Patient co-creation in Asia-Pacific safe and quality healthcare: WHO Global Patient Safety Action Plan 2021-2030

Fatima Lorenzo, President, Philippine Alliance of Patient Organisations - PAPO (Moderator)

- Echoing the call of the WHO, patient safety is of primary concern in the context of the pandemic. Patients and Patient groups need to be an integral part of this ecosystem of Quality and Safety

Dr. Aparna Singh Shah, Regional Advisor, WHO South-East Asia

- Patient safety is vital to deliver maximum reduction of harm to all facets of healthcare. With WHO as the forefront of this initiative, patient safety is prioritized, which makes patient and family engagement crucial to continually promote betterment of healthcare systems.

Prof. Tan Kok Hian, Group Director & Senior Associate Dean, SingHealth Duke-NUS - IPSQ

- The WHO outlines strategic objectives to bring about patient safety. Applying such strategies, co-creation in healthcare empowers patients and families, allows improved quality and patient safety, and increases efficiency. It is thus important to evolve toward a model in which patients and clinicians work in partnership to improve clinical safety and outcomes.

Dr. Socorro Escalante, Coordinator for Essential Medicines and Health Technologies, WHO Western Pacific

- To embed patient safety into the values of primary healthcare, WHO Western Pacific Region focused on universal coverage for quality health services. They also ensure safety in medical products by integrating scientific development to guarantee quality of medicines. Patient safety systems should be built upon the unique context of each country.

SESSION 5: Is elimination of COVID-19 using current vaccines and approaches stalling? Do patients have to engage in co-creating new vaccine platforms and finding new effective respiratory and other treatments?

Dr. Raj Shankar Ghosh, Deputy Director, Vaccine Initiative, Bill & Melinda Gates Foundation

- The context around the COVID-19 vaccine covers centers on 4 Ps: People, Products, Process and Places where they can be accessed. Vaccine confidence will depend on these parameters.

Dr. Socorro Escalante, Coordinator for Essential Medicines and Health Technologies, WHO Western Pacific

- The ACT-A initiative developed worldwide successful technologies to fight COVID-19 which strengthens health systems. Led by WHO, solidarity trials on vaccines aim to rapidly evaluate promising new COVID-19 vaccines to save lives with a focus on primary and secondary endpoints.

Dr. Aileen Dualan, Global Medical & Scientific Affairs Asia Pacific Regional Head, MSD

- The COVID-19 pandemic allowed various industries and sectors to collaborate at an unprecedented scale. Initiatives involve the development of therapeutics including, co-manufacturing vaccines and oral agents.
- Research in the UK has shown a drop in the involvement of patients and the public in health policy and programs amid the COVID-19 pandemic, therefore involving patients is the key to success.

Dr. Kashmira Date, Director of Global Medical Affairs for Vaccines, Johnson & Johnson's Global Public Health Organization

- Unique partnerships brought together international health organizations which made COVID-19 vaccines accessible for everyone. J&J is committed to provide equitable access to low- and middle-income countries.
- Learning from these experiences is essential to be prepared for another pandemic.

SESSION 6: Meaningful patient engagement in health literacy in a digital and social media age. Learning from the COVID-19 Global Pandemic and National 'Syndemic'

Dr. Ratna Devi, Chair, International Alliance of Patients' Organizations - IAPO (Moderator)

- "Digital is the way, moving forward. Digital is here to stay."
- With digital converging into healthcare, it made patients happy, but also challenged the equality and equity of health systems.

Laurie Myers, Director for Global Health Literacy & Oncology Health Equity, MSD

- A world where patients are fully empowered should be what we all strive for. In this pursuit, health literacy is front and center as a stronger predictor of health than other demographic variables.
- Improving health literacy begins by communicating in ways that resonate with the patients and learning from listening to patients and caregivers.

Pru Etcheverry, Regional Director for Asia Pacific, Lymphoma Coalition

- “Digital equity enables considerations of who has the ability and accessibility of technologies. Patient and organization engagement are needed to be there from the very start. Understand what really is needed by the people.”
- Construct something new that patients can participate in. If patients understand actions they undertake, it empowers them and they adhere to their treatment.

Kawaldip Sehmi, CEO, International Alliance of Patients' Organizations - IAPO

- Health literacy can now be personalized. With the personalization of health communication, patient organizations are able to leverage on their narrow and deep reach.
- Simplify healthcare pathways and make them seamless through tech solutions. When you start reaching patients and the public early, you are able to shift beliefs into science literacy. Visualization of health information can also be very powerful to grab patients’ attention and get to them.

SESSION 7: Meaningful patient engagement in co-creation in medicines and health devices R&D - moving from tokenism to meaningful engagement at all levels

Neda Milevska-Kostova, Vice-Chair, International Alliance of Patients' Organizations - IAPO (Moderator)

- COVID-19 has educated patients on how they can get engaged, but we need to do more to further involve patients across the continuum of care.

Mariko Koh Siyue, Clinical Associate Professor, Singhealth

- “Did we consider what patients want in research? Not enough.” “Research has really accelerated because of COVID-19.”

- “Patients are at the heart of all we do.” With patient-oriented trial design, patients' mental and well-being support improved tremendously. Patient revolution demonstrates the value of experience-based and knowledge empowered patients.

Dr. Li Ying (Grace) Huang- Director of the Division of the Health Technology Assessment, Center for Drug Evaluation, Taiwan (CDE/HTA), Taiwan CDE

- Patient involvement in the interdisciplinary HTA process in Taiwan has shown that results can be delivered even when resources are limited.
- The initiative outlines ways of involving patients, ensuring that the patient voice is heard. Patients are involved in developing a platform that aims to collect their opinions and experiences, patient group representatives are present at key meetings, and patient input is incorporated in relevant reports.

Satoshi Miki, Board Member, Patient and Public Involvement Japan

- PPI Japan aims to realize the true meaning of “industry-patient-government-academia” collaboration. Health authority, Academia, and Industry are the focus of practical PPI activities in Japan.
- “We traditionally rely on academia information. We don’t pay attention to patient journey.” Hence, the patient journey workshop transformed the patient's public involvement. Accurate information dissemination is PPI Japan’s purpose.

SESSION 8: Self-care within universal health coverage 2030. Lessons from the pandemic lockdowns

Paul Perez, President, Cancer Coalition Philippines

- The pandemic showed how healthcare shifted into self-care.

Kawaldip Sehmi, CEO, International Alliance of Patients' Organizations - IAPO

- “Self-care is about empowered individuals. Consumers and patients must be empowered.” We must have legal policies promoted actively around self-care where all stakeholders can understand.
- Looking at self-care, we ask: what can a patient work on themselves, what is the healthcare system responsible for, and what should they work on together?

Orajitt Bumrungruskulswat, Board Member, International Alliance of Patients' Organizations – IAPO

- Embedding self-care into the healthcare system brings about various benefits. During the pandemic in Thailand, self-care plays an essential role and costs are included in the healthcare system and in health insurance coverage. This includes health education, digital health, and self-care practice programs.
- Good collaboration between patients and healthcare providers builds a more effective continuum of care. Public-private and community partnerships are also essential.

Deon Schoombie, CEO, Consumer Healthcare Products Australia

- “Self-care is prevention.” To establish self-care for global healthcare, pursuit of universal healthcare coverage is needed. Ensure diversity across multiple international jurisdictions.
- Three themes on SCRI: Launch a global advocacy campaign to universalize the definition of self-care which will inspire action. Individual empowerment through legislation. Power of digital technologies to reach multidisciplinary health solutions worldwide. Recommendation: Forge broader self-care reach for healthier patients and lower healthcare costs.
- Four enablers: First enabler is **Stakeholder support & adoption**. The second enabler is **Consumer & patient empowerment**. The third enabler is **Self-care in health policy**. “Right legislation must be leveraged to promote self-care.” The fourth enabler is **Regulatory environment**.

- Integrating self-care into the healthcare systems allows for better resource allocation and ultimately improves care.

SESSION 9: Meaningful patient engagement in HTA and Regulatory Affairs

Dr. Roongnapa Khampang, Researcher, Health Intervention and Health Technology Program

- There are annual public hearings of civil society organizations, patient organizations, and lay people on the development process of topic nomination.
- Patient engagement is vital in conducting HTA Studies to inform policy coverage decisions.
- The program enabled sharing of experiences of patients to policy makers which aided the topic selection process. However, the challenge is to ensure that all concerns were included in the process. The way forward is capacity building for patient organization and civil society.

Janis Bernat, Director, Scientific & Regulatory Affairs, International Federation of Pharmaceutical Manufacturers & Associations – IFPMA

- Regulatory reliance is an opportunity for patient engagement.
- Empowerment and change on a national level is necessary for implementing regulatory reliance in medical products. It should be applied where it makes sense for the national context, to which products make up public health need, and for what the priorities of the country are.
- Regulatory reliance can help streamline and reduce redundant activities so that countries can focus on national level activities. It encourages regulators to work together, allows for broader participation in initiatives, and increases efficiency.

Chris Muñoz, CEO & Adviser, Yellow Warrior Society Philippines

- “Patient centricity is about placing patient needs in the center and in order to achieve it, patient engagement is needed.”
- “Real world data is equivalent to real world evidence.” Heterogeneity of data gives additional information not captured in our cities which can lead to effectiveness of intervention in the real world.

- Patients expect to be included in every step of the process inclusive of voting power. There must be training patient experts.
- “If you are not an involved patient, you are not an HTA.”

Final Remarks

Our 3rd Asia-Pacific Patients Congress gave our regional patient community a strategic opportunity to share their patient experiences and patient perspectives with healthcare policy makers through a global platform. It opened a door for us to join the whole-of-government and whole-of-society effort to control the pandemic and rebuild our health systems as a whole-of-patient community.

We heard that in the past, patients and families played a passive role in their course of treatment and understanding of medicines and devices, technology used are limited. Healthcare professionals however now welcome the active role of patients and families as it promotes self-care management and improves the clinical and patient safety outcomes.

It was clear that we should embrace and enhance this partnership with patients and families to create a safe and holistic healthcare system. Involvement from patients and families comes in various forms - being more engaged in their own care as a partner, sharing and speaking up from past experiences, participating in the review and co-production of policies, services and co-design of healthcare infrastructure and patient safety systems when necessary. Partnership with patients provides an excellent platform for exchange of information, knowledge and experiences while maintaining transparency and openness in the care process.

With the partnership and empowerment of patients and families, it becomes important to educate, train and build their knowledge and capability, so to contribute and play the functional role in the whole care process and journey. The training should encompass different aspects and domains of patient

safety discipline such as patient safety, healthcare quality improvement, root cause analysis, safe culture, design thinking, human factors and self-care mindfulness.

Delegates felt reassured and gained clarity as a result of the awareness raising that was done by speakers on recovering together through compassion, insight and co-creation. The entire Congress was a moment to remind ourselves of WHO Director General's words that health is not a cost; it is an investment. Health is not a reward for development; it is a prerequisite. Health is a pathway to security, prosperity, and peace. We must address this common problem through national unity and global solidarity.

Patient Organizations' Participation

At IAPO, we are always committed to broadening the participation and contribution of patient organizations to our congresses. For this purpose, we worked hard to create opportunities to increase patients' representation at APPC 2021, and give visibility for them to showcase their best practice in patient insight, compassion, and co-creation by sharing it with a regional and global multi-stakeholder audience.

We invited IAPO Members, members of IAPO Members and other patient organizations in the Asia-Pacific region to act as speakers and moderators at the Congress:

- Fatima Lorenzo, President of the Philippine Alliance of Patient Organisations – PAPO (IAPO Member), responded to Father Jerry's Keynote speech at the Congress' "Opening Ceremony" and moderated the session "Patient co-creation in Asia-Pacific Safe and Quality Healthcare: WHO Global Patient Safety Action Plan 2021-2030".

- James O'Brien, Vice-President of the International Prader-Willi Syndrome Organisation (IAPO Member), spoke at the session "Strengthening health systems through patient co-creation and re-orientation of healthcare using digital healthcare".
- Chris Muñoz, CEO & Adviser of the Yellow Warrior Society Philippines (Member of an IAPO Member), spoke at the session "Meaningful Patient engagement in HTA and Regulatory Affairs".
- Leanne Wells, Consumers Health Forum of Australia, spoke at the session "WHO Compassionate Integrated and People-Centred Universal Health Coverage. Patient journeys in a fragmented versus an integrated health system".
- Pru Etcheverry, Regional Director at the Lymphoma Coalition, Asia Pacific, spoke at the session "Meaningful patient engagement in health literacy in a digital and social media age. Learning from the COVID-19 Global Pandemic and National 'Syndemic'".
- Satoshi Miki, Board Member of the Patient and Public Involvement Japan, spoke at the session "Meaningful patient engagement in co-creation in medicines and health devices R&D - moving from tokenism to meaningful engagement at all levels".
- Paul Perez, President of the Cancer Coalition Philippines, moderated the session "Self-care within universal health coverage 2030. Lessons from the pandemic lockdowns".

- Ann Single, Chair, HTAi Patient & Citizen Involvement Interest Group & Coordinator Patient Voice Initiative, moderated the session "Meaningful Patient engagement in HTA and Regulatory Affairs".
- Kara Magsanoc-Alikpala, Founder and President of I Can Serve (Member of an IAPO Member), was the Congress Masters of Ceremony.
- Orajitt Bumrungskulswat, Secretary of the Heart to Heart Foundation (IAPO Member) & IAPO Board Member, introduced the second day of the Congress and spoke at the session "Self-care within universal health coverage 2030. Lessons from the pandemic lockdowns".
- Dr. Ratna Devi, CEO and Co-Founder of the Dakshayani & Amaravati Health and Education (IAPO Member) & IAPO Chair was a moderator at the session "Meaningful patient engagement in health literacy in a digital and social media age. Learning from the COVID-19 Global Pandemic and National 'Syndemic'".
- Dr. Neda Milevska-Kostova, Executive Director of the Centre for Regional Policy Research and Cooperation "Studiorum" (IAPO Member) & IAPO Vice-Chair moderated the session "Meaningful patient engagement in co-creation in medicines and health devices R&D - moving from tokenism to meaningful engagement at all levels".
- Karen Alparce-Villanueva, Treasurer of the Philippine Alliance of Patient Organisations – PAPO (IAPO Member) & IAPO Board Member and the Congress Chair



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- Bisi Bright, 1st Vice Chairman and CEO of LiveWell Initiative LWI (IAPO Member) & IAPO Board Member, offered the closing remarks of the first day of the Congress.

At APPC 2021, we also offered the opportunity for patient organizations to showcase their work via videos which were broadcasted during the event breaks:

- [Painaustralia](#)
- [Advocacy Service for Rare and Intractable Disease](#)
- [Thalassaemia International Federation](#)
- [International Alliance of Dermatology Patient Organizations – GlobalSkin](#)

Delegates' Attendance

Being a virtual event allowed us to reach out to delegates who wouldn't otherwise be able to travel to attend a face-to-face event, whether due to health issues or financial restrictions. APPC 2021 was the widest Congress audience that we have ever had and brought together 3828 delegates from 60 countries, 800 more than our 2nd APPC and 26 times more than our 1st APPC. As part of the attending delegates who included patient organizations, not-for-profit organizations, industry, academia, government and other for-profit organizations, we had 402 patient groups, 61 organizations of whom were IAPO members. Additionally, APPC 2021 had the highest numbers of nursing professionals out of any IAPO Congress with over 1100 nursing professionals attending the congress.



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Event Delivery

Resources and Inputs

APPC 2021 was delivered via an interactive event platform managed by Pin Crowd Events. This all-in-one platform provided the delegates with a unique and interactive experience to simulate a face-to-face event. The platform had the following features:

- Lobby Area
- Auditorium
- Photo Booth
- Networking via chat
- Downloadable resources

During the two days of Congress, we also had the support of two note-takers who summarised each speaker presentation and recorded the main event takeaways. These were then presented at the closing session at the end of day 1, introduction of day 2, and the event closing ceremony. These notes were also used for the elaboration of the present report.

3rd Asia Pacific Patients Congress Programme Committee

- Karen Alparce-Villanueva, IAPO Board Member and the Congress Chair
- Dr Ratna Devi, Board Chair, International Alliance of Patients' Organizations (IAPO)
- Orajitt Bumrungruskulwat, Board Member, International Alliance of Patients' Organizations (IAPO)



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- Professor Tan Kok Hian, Group Director and Senior Associate Dean, SingHealth Duke-NUS Institute for Patient Safety & Quality (IPSQ), Singapore
- Zann Foo, Deputy Director (Admin), SingHealth Duke-NUS Institute for Patient Safety & Quality (IPSQ), Singapore
- Mabel Sim, Senior Executive, SingHealth Duke-NUS Institute for Patient Safety & Quality (IPSQ), Singapore

Committee Secretariat

- Kawaldip Sehmi, Chief Executive Officer, International Alliance of Patients' Organizations (IAPO)
- Dani Mothci, Member Engagement Manager, International Alliance of Patients' Organizations (IAPO)
- Rachel Githinji, Communications Lead, International Alliance of Patients' Organizations (IAPO)