

APPC



2nd Asia Pacific Patients Congress

Patient Leadership in Health Systems Strengthening REPORT

3-4 December 2020

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As we turn to the future we can build and learn from the COVID-19 pandemic by adopting a vision where health is at the core of society's values; which includes strengthened healthcare systems as part of countries' efforts to achieve Universal Health Coverage and the SDG; recognizing that there isn't a choice between economic growth and health, but that those two come hand-in-hand, and, as we increase one, the other increases, and vice versa.

*Martin Taylor, Director,
Health Systems and Services,
WHO Western Pacific Region*

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Executive Summary

The Virtual 2nd Asia-Pacific Patients Congress 2020 (APPC2020) gave us a stark reminder that health in the region must not be considered as a sovereign matter. Health was a collective regional matter and all the patients, the State, and regulators in the region must collaborate across borders.

The Virtual 2nd Asia-Pacific Patients Congress 2020 (APPC2020) gave us a stark reminder that health in the region must not be considered as a sovereign matter. Health was a collective regional matter and all the patients, the State, and regulators in the region must collaborate across borders.

The APPC2020 discussion was a lot sanguine, and the depth of engagement was deeper when compared to the 1st APPC 2019 held in-person in Taipei Taiwan.

Internally, APPC2020 gave us a big reason to push for the strengthening of our regional patient networks and health systems even further. The pandemic had given us a wake-up call that health must be prioritised as the first goal in the Sustainable Development Goals 2030 for the region.

The first sessions of the APPC 2020 gave us great insight into how COVID-19 was controlled in the region applying innovative technological and social approaches with some best practice examples from South Korean, Taipei Taiwan (ROC China) and Thailand.

APPC 2020 amplified the delegate concerns about the regional progress towards Universal Health Coverage 2030. Patient groups were expressing great concern about the collapse of current non-communicable diseases healthcare services and patient social welfare support services.

Mental health in the region was severely impacted by the COVID-19. The fear, isolation and loss of jobs and lack of access to social support networks during the lockdowns had given rise to new mental health needs.

The existing poor mental healthcare and support service infrastructure in many Asia-Pacific countries was unable to handle this new demand. This had led to a collapse of mental healthcare services in some regions.

Digital healthcare approaches in Asia-Pacific offer patients a new patient-centred approach to access healthcare. The region must invest in these technologies to address the lack of access to traditional healthcare services.

Patient safety is of great concern in the region. The region wants to work with the WHO on their global patient safety action plan when it is adopted by Asia-Pacific Member States.

Patients must work across the whole healthcare ecosystem in the region. Patient engagement in regulatory affairs and in health technology assessment is vital to ensure we have the patients' perspective into regulation and health technology assessment. Case studies from Taipei Taiwan and Thailand showed that this engagement is happening now, albeit in a few countries.

Antimicrobial resistance is now a new threat in the region. It is being considered as the next pandemic. This needs whole of society, whole of industry and whole of government response under WHO's One Health approach.

Patient engagement in clinical research and medicines development is vital for the development of patient centred medicines and therapies in the region. There is a critical need to develop pathways to encourage this engagement.

Communicable diseases like TB, HIV and Hep C are still posing a serious health burden in the region. The region has the tools and medicines needed to eliminate them. Their elimination should be prioritized.

APPC 2020 was a timely reminder to double our efforts in developing regional solidarity and strengthening both the patient movement and health systems.

Acknowledgements

We first want to thank all the health professionals and frontline health workers who have been putting themselves at great risk to take care of patients during the current COVID-19 pandemic.

Many have made the ultimate sacrifice and lost their lives in serving us. We pass our condolences to their families. In this year of the Year of the Nurse and the Midwife 2020, we acknowledge the great support given to us by the International Council of Nurses during this pandemic.

We also want to thank our members, industry partners, collaborating partners and supporters who made the 2nd 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 would also like to thank our Board Chair and Chair of the APPC Committee, Dr Ratna Devi whose strong leadership and dedication have set the new standard of quality, affluence and innovativeness in this year's programme.

We heard some exceptional speakers and got insights on what we as patients can expect from the pandemic; what and when we can expect the vaccine, country policies on who should get the vaccine first; what are the expected bottlenecks to its administration, the impact of COVID-19 on non-communicable diseases, challenges that patients faced along their journey in these uncertain times and so much more.

Thank you all once again, and we look forward to welcoming at the next 3rd Asia-Pacific Patients Congress happening in November 2021.

We would like to thank the APPC 2020 Committee:



**Dr Ratna Devi
(Chair)**



**Karen Alparce-
Villaneuva**



**Orajitt
Bumrungrakulswat**



**Kawaldip
Sehmi**



**Narendhar
R**



**Michael DC
Alzona**

Partners

Lastly, we thank our Industry Partners without whose partnership and resources we could not have delivered this quality virtual congress.

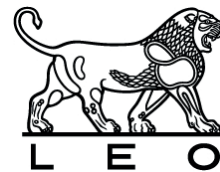
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Background

The Asia Pacific Patients Congress (APPC) was established in 2019 with the aim of serving as IAPO's platform to bring the goals of the Global Patient Congress closer to Asia. With a vision of ensuring patients are at the centre of healthcare throughout the region, the 2nd Asia Pacific Patients Congress aims to convene and coordinate patient advocates around this vision.

The Asia Pacific Patients Congress (APPC) was established in 2019 with the aim of serving as IAPO's platform to bring the goals of the Global Patient Congress closer to Asia. With a vision of ensuring patients are at the centre of healthcare throughout the region, the 2nd Asia Pacific Patients Congress aims to convene and coordinate patient advocates around this vision.

With patient advocates coming from all disease areas from across the region, APPCs are a moment that celebrates patient advocacy and patient-centred healthcare. The APPC gives the participants an enabling environment to learn how the latest global trends in healthcare will affect patient centricity, access, safety, quality, and affordability nationally.

More importantly, the APPC is a strategic cross-sector think-tank comprising expert patients and global

healthcare stakeholders willing to share their insight over two days to support patient groups in shaping their national health policy, strategies, programmes, projects, and services in order to address the challenges we face.

The Congress acts as a vital step to further the process of developing regional patient-centred healthcare by acting as a platform where patients and policymakers can discuss detailed actions to take to ensure patient-centred healthcare is a reality around the region.

Co-organized by the International Alliance of Patients' Organization, the Indian Alliance of Patient Groups and the DakshamA and Amaravati Health and Education, APPC continues to facilitate its intended outcome of fostering greater connection among delegates and collective action around urgent needs.

Aim and Objectives of APPC 2020

IAPO's overall vision is to see patient-centred healthcare institutionalised globally. APPC 2020 aimed to raise awareness of barriers and challenges faced by our regional patient community and provide patient advocates with evidence based healthcare policy and practice solutions to overcome these challenges and realise our vision.

APPC 2020's main objectives were to ensure that our delegates:

- Understood and appreciated the scale of the COVID-19 and other modern healthcare concerns and their position within their healthcare value chain.
- Participate together with the invited keynote speakers, experts, patient organizations, regulators, payers, health technology assessors, academics, and the healthcare industry in identifying the most effective, efficient and evidence-based patient centric strategies, policies, products, services and interventions that are available to our members to influence health policy and decision-makers to address these barriers and challenges.
- Engaged with our members in global advocacy to ensure that 194 heads of the WHO Member

States address the WHA Resolution 73.1 COVID-19 Response and respect, promote and protect patients' right to health and act on their political commitment and obligations.

APPC 2020 relied on the following regional policy instruments:

1. *The Declaration on Universal Health Coverage which was announced at the UN High-Level Meeting on Universal Health Coverage (UHC-UNGA 2019)*
2. *WHA 72 resolution 72.6 - Agenda item 12.5 Global action on patient safety (72 WHA 2019)*
3. *WHO Constitution (2006) Right to Health.*

We wanted every delegate to recollect that their country has ratified the WHO Constitution in 1946 and must at all time ensure that every citizen enjoys the highest attainable standard of health.

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, and political belief, economic or social condition.

APPC 2020 Theme

Patient Leadership in Health Systems Strengthening

The theme of the event Patient Leadership in Health Systems Strengthening was selected to voice the concern in the region that many health systems were showing great fault lines.

The 2nd Asia-Pacific Patients programme reflected on the impact of COVID-19 on patients and the next steps towards achieving Universal Health Coverage (UHC) in the region in the midst of COVID-19 pandemic.

We theme allowed us room to discuss how to harmonise and align agendas with national health policies in the region and the role of patient groups in advancing UHC.

Session Discussions and Takeaways

The 2nd Asia Pacific Patients Congress was held as IAPO's second fully digital congress with over 3000 delegates with 298 patient groups, who attended 20 sessions with 66 speakers from 16 countries. Patient groups and thousands of attendees drew together virtually to talk about how to reclaim a voice and space for patient rights in the wake of the COVID-19 pandemic – where patients have been more disempowered than ever before.

We heard of how COVID-19 has greatly altered the patient experience, shifting people more than ever from an active to a passive role in their health care, especially in the initial stages of the pandemic. Through discussion patients made it clear that healthcare must shift to a people-centered approach that allows patient participation and respects their needs and preferences – if goals for equity, quality and universal access are ever to be achieved. The patient community underscored the reality that for sustainable universal health coverage, there needs to be active patient engagement at all levels of the health system decision-making process.

Through presentations on topics such as digital literacy, patient registries, clinical trials and increased participation, patient safety, reducing harm, patients led research, patient co-authorship, regulatory reliance and harmonisation, and building back better healthcare systems post COVID-19, speakers flagged that patients' right to choice and their role as experts in healthcare should be acknowledged and given appropriate space and environment to contribute meaningfully.

There was consensus that the season we are in is a huge opportunity for patient groups to come together to lend their voices to the call to healthcare as “not a one size fit all”. Healthcare needs to be customized, messaging needs to be customized, and how you ask people to change their behaviours needs to be customized.

We also heard that to become more empowered, patients need to be more aware of the need to act pre-emptively when accessing health care: If patient groups integrate themselves and understand that early diagnosis, and early seeking of treatment, could be a better option, things could change for them.”

One loud message from APPC 2020 was that an effective response to COVID-19 requires that governance, health systems, populations, communities, patients, all work together. Community health leaders in the region who have succeeded in curbing transmission trends and assuring quality care have done so by building trust and engagement in solutions that worked for health workers, patients and their families, as well as the broader population.

As delegates looked ahead, it was clear that the development and rollout of COVID-19 vaccines would be the next great opportunity for new models of patient engagement. A successful rollout would be dependent on extremely effective engagement with groups, making sure that instead of misinformation, there is trust, and that vaccine supplies and delivery are carefully managed.

Delegates concluded that our vision [for the future] will only be possible if patient and patient groups, and communities are engaged, both in shaping and advocating for a vision in which health is at the core of society's values.

Day One Takeaways

Launch and Inaugural

Karen Villanueva, IAPO's Board Secretary opened the 2nd Asia-Pacific Patients Congress by welcoming delegates from across the region.

She highlighted IAPO celebrating our coming of age – 21 years of helping shape the global healthcare policy agenda and advocating that patients be at the center of healthcare systems. IAPO's unique mission and our world-wide footprint put us at a distinct advantage as a member of civil society serving as the global voice of patients. Allow me to share the IAPO at 21 Audio-Visual Presentation

She highlighted IAPO's belief that we need to strengthen the patients voice in the Asia-Pacific region where 60% of the population lives and where Universal Healthcare is still an aspiration rather than a right. She spoke of IAPO's Asia-Pacific Patient Congress as a great platform to bring together the patient movement in Asia-Pacific region closer together.

Following up was IAPO's Vice Chair Dr. Neda Milevska-Kostova who highlighted that since the first-ever Asia-Pacific Patient Congress, many things had happened. The current COVID-19 pandemic had posed diverse challenges on everyone, but the Board, the Secretariat and our Members had turned these into opportunities. She took us through the past year of our joint work and achievement.

She mentioned that in September, we managed to organize the first fully digital congress – the 9th Global Patient Congress, with record number of nearly 1200 registered delegates from over 100 countries, 338 patient groups, who attended 26 sessions with 64

speakers from 28 countries.

At that time, we also awarded 8 grants to our members to assess the situation with COVID-19 and act in the emerging crisis by helping patients and citizens where we as patient organisations are most needed.

We also worked on other topics – like, stroke where we organized a twinning programme for capacity building between peer-patient organisations from 3 countries on important topics of patient advocacy, sustainability and making the patient voice heard. We awarded 7 grants to our members to conduct a survey on the impact of COVID-19 on non-communicable diseases in collaboration with the The National Institute of Health Innovation, New Zealand. On the part of research and patient empowerment we initiated – what we believe to be two important programmes for patients and patient advocates: The Patient Academy for Innovation and Research (PAIR), aimed at providing comprehensive training and capacity building curricula for expert patients and patient advocates, so that they can equally participate in the policy and advocacy processes at national level. The PAIR Academy has already signed its first MoU with the DUKE-NUS University from Singapore.

The second initiative is the IAPO Patients for Patient Safety Observatory, aimed at improving the literacy and fluency of patients and patient advocates to become more than research subjects – to to have an equal, partner role in setting and delivering the research agenda. All of the above has been accomplished with our members and patients, as we are driven by the motto of nothing about us without us.

Following from Neda was Dr. Ratna Devi, IAPO Board Chair who spoke on the aim and the programme of the Congress. She highlighted that the Asia Pacific patient congress has a vision- To see patients and patient groups at the centre of healthcare in the Asia Pacific region.

She highlighted IAPO's Mission- To help build patient-centred healthcare throughout the Asia Pacific Region through several strategies and activities and the congress is one such means. When we built the concept of Regional Congresses as 1-1 meetings for patients and caregivers to meet and discuss, it was meant to complement our other initiatives for capacity building of patient groups- our toolkits, twinning programs, research, publications and many more.

She noted that second Asia Pacific Patient Congress was to be held as a face- face meeting in New Delhi but as with everyone else we adjusted due to the pandemic,

but our enthusiasm remained high. She noted that the content was carefully curated and topics chosen to cover thematic areas that will really strengthen the voice of the patient to be able to negotiate.

Topics such as Digital literacy, patient registries, clinical trials and increased participation, patient safety, reducing harm, patients led research, patient co- authorship, regulatory reliance and harmonisation were included to bring a diverse range of skills and information to the audience. She noted that we ensured that every panel had at least one patient representative, reflecting IAPO's mission of supporting patient centricity in all we do. She emphasized that the next two days will bring vibrant discussions and debates, with academia, policy makers, industry and several other experts exchanging thoughts and views.

Keynote Speech

Patients' co-creation in future proofing health systems: preparedness for next phase of the pandemic:

Martin Taylor : Director, Health Systems and Services, WHO Western Pacific Region

- The 'Ancient Indian wisdom' states that 'the world is one family', and COVID-19 has highlighted it very well: "No one is safe until everybody is safe."
- The pandemic also recalled the significance of Home and Family Care, where the contribution of women is immensely important.
- India handled COVID better than many other countries, even though it wasn't prepared for a pandemic.
- COVID-19 has brought the role of patients to the fore, while taking the healthcare system to its limits.
- "We all have the opportunity to shape a vision for the future, as we all share this responsibility: to put health as a core societal value".
- The 2nd Asia Pacific Patients Congress can help guiding principles to become a reality.

Keynote Address

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**Patients co-creation
in future proofing
health systems:
preparedness for next
phase of the pandemic**

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International Alliance of
Patients' Organisations
A global network for patients

Dr. Sanjeev Kumar
Chair, India Alliance of Patient
Groups

Martin Taylor
Director, Health Systems
and Services, WHO Western
Pacific Region

The Journey in Fighting the COVID-19 Pandemic: What can patients expect?

- The pandemic is affecting our reality in many ways, changing the way healthcare is delivered and revealing the importance of companies investing in research on the greatest health threats.
- Our new reality will impose ongoing challenges but will also provide opportunities, as many stakeholders across the health care system are now actively looking for solutions to increase patient access to innovative healthcare.
- A range of vaccines and medicines will be needed to end the pandemic. The industry has been exploring multiple pathways in an unprecedented collaboration between companies to provide access to a safe vaccine for all.
- It's important to ask what patients can expect and from whom. The government and the private sector have enormous responsibility.

Society has shown its best by spreading solidarity and information, and patients have also played their role by showing their gratitude for the health providers and, most importantly, by being kind to themselves.

Our Expert Panel

Kawalalp Sehmi
(Moderator)
CEO, International Alliance of Patients' Organizations

Dorthe Mikkelsen
President Asia Pacific, MSD

Preeti Sudan
Former Secretary Health & Family Welfare, India

Sarthak Kanade
Managing Director, Janssen India

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The Journey in Fighting the COVID-19 Pandemic: What can patients expect?

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to speak up for patients


Who gets the vaccine and how? Is there enough infrastructure and system readiness for access?

- Academia and industry have come together to identify which steps can be taken in parallel to tackle the challenges for production, storage and distribution of vaccines.
 - It's also important to prepare health systems to deliver the vaccine, to train the staff to store it, to inject it and to inform the population.
 - Dr. Raj: "Vaccines don't save lives, vaccination does" – Effective Immunization is based on the "3P construct": Product, Place and People.
 - Vaccine needs to be safe, efficacious and affordable at a place that is accessible and acceptable to the community, where trained health workers can properly work with it,
 - Dr. Satoru: 'We need to set priorities on who to vaccinate first due to limitations on vaccine supplies. Healthcare professionals should be first, then the elderly and those with underlying conditions.
- Other groups as care home workers and pregnant women should also be considered'.
- National government should take the lead in the Inoculation System and cooperate with local communities, providing information so people can make a comprehensive risk/benefit analysis.


Our Expert Panel




Dr. Amitav Banerjee
(Moderator) Professor & Head Community Medicine,
Dr. D Y Patil Medical College




Dr. Sanjiv Kumar
Chair, India Alliance of
Patient Groups



Dr. Rajshanker Ghosh
Deputy Director, Vaccine
Initiative, BMGF



Dr. Satoru Komatsu
(Moderator) President,
Asian Hospital Federation

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**Who gets the vaccine
and how? Is there enough
infrastructure and system
readiness for access?**


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International Alliance of
Patients' Organizations
to global voices for patients

Best practice emerging from Asia in COVID-19 suppression and containment. Best in test/trace; shielding; info-demic control; patient support

- The Continuity of Care Collaboration (CCC) has built a membership of 30 organisations: a multistakeholder approach seen as unique in the Australian context, which understands that the feelings and concerns of patients living with chronic diseases is critical for the continuity of care.

"We focus on communicating with patients, not at them."

- Thailand's long-term developments in fighting against other diseases is one of the background reasons for the success in fighting the COVID-19 pandemic.

Other key-measures were the:

- 1) early recognition of the virus situation;
- 2) prompt responses by tracing and tracking patients;
- 3) active surveillance: prevention and control in high risk areas;
- 4) preparedness of all hospitals; and
- 5) extensive cooperation of people worldwide.

- Of the ~6 million people living in Singapore, the country has now only 60 active cases and 29 deaths due to COVID-19. This is the result of a whole-of-society solidarity: a combination of multi-ministry COVID taskforce, transparent, clear and regular communication with citizens through a WhatsApp group, wide distribution of free reusable masks and support for migrant workers' dormitories.

Our Expert Panel



Michael Alonso
(Moderator) Patient Engagement Director, Japan/China/Asia Pacific, MSD



Jessica Bean
President and Secretary, Patient Voice Initiative



Dr. Vichai Chokvivatt
Chair Person, Heart to Heart Foundation, Thailand



Dr. Nikki Kietkiet
Senior Resident, Public Health Physician, Duke - NUS Medical School

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2nd Asia Pacific Patients Congress
Patient Leadership in Health Systems Strengthening

Best practice emerging from Asia in COVID-19 suppression and containment. Best in test/trace; shielding; infodemic control and patient support

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to speak up for patients

Mental Health, are we doing enough?

- There have been many 'faces' of the pandemic, and after 12 months, mental health is an issue in focus. Research shows spikes on anxiety and depression due to worries on economic issues and social isolation.
- The pandemic is very different from previous disasters when it comes to dealing with post-traumatic impacts.

Social distancing is the 'antithesis of all that is considered therapeutic in mental health': it takes away what people need the most in times of great distress - warmth, support and collective meaning-making.

- We haven't been doing enough, but there are many actions in course that offer good perspectives: worship and exercises online, video conferencing, social media as good alternatives to social distancing.
- National-level interventions in India to tackle the Mental Health challenges caused by the pandemic: the government is paying more attention on how the information is made available to the people.
- Psychological First Aid (PFA) should also be considered, as it encompasses practical tools already used in circumstances like natural disasters and it's proven to prevent more serious mental health issues to develop on societies affected.

Our Expert Panel



Dr. Anita Abu Bakar
(Moderator) Founder and President Mental Illness Awareness & Support Association, Malaysia



Dr. Kannan Subramaniam
Senior Medical Director, Viatris



Dr. Phil Gila Sison
Advisor Youth for Mental Health Coalition, Philippines



Dr. Nand Kumar
Professor of Psychiatry, All India Institute of Medical Sciences, New Delhi

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**Mental Health,
are we doing enough?**

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to speak up for patients

Patient engagement in research, regulation and health finance: building back a better and sustainable UHC 2030

- The pandemic has put the Universal Health Coverage in the agenda, but inequities have to be also considered when discussing UHC.
- It's important to understand the concept of inequity and keep measuring it in its multi-level aspects so we can move forwards to equity programmes.
- Dr. Chandrakant: "It's essential to combine universal actions with targeted interventions for people at the bottom, providing services for those who are left behind".
- Moving towards equity also means increasing the participation of people in policy making, as per the example of some programmes in India which are being currently proposed among rural populations.
- An alternative approach to maximize resources for health would be to recognize more explicitly that the effects of the pandemic are systemic, that is, COVID-19 impacts all aspects of people's lives: employment, housing, food security, etc. We must frame the problem as a post-pandemic health problem at a societal rather than sectoral level and build a systemic response accordingly.

Our Expert Panel



Professor Indrani Gupta
(Moderator) Head of the Health Policy Research Unit of the Institute of Economic Growth



Eduardo Banson
MD, Principal Health Specialist, Asian Development Bank



Dr. Chandrakant Lahariya
National Professional Officer, UHC, WHO India Office



Suneela Thatte
Vice President and Head, H&D Solutions India, IQVIA

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Patient engagement in research, regulation, and health finance: building back a better and sustainable UHC 2030

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International Alliance of Patients' Organizations
to deliver action for patients


NCD patient journey - Who defines it? Are we missing key touchpoints for intervention?

- The mapping of NCD patients' journey shows that treatment alone is not the solution to the problem. The treatment of NCDs will require bigger investment in awareness, prevention and screening.
- Strengthening primary care is also crucial to solve the problems within the NCD patients' journey.
- We must move away from the all-in-one approach and design awareness programmes for each cancer type so cancer patients can know more about their disease.
- The economic conditions of the patients impact their chances to have long-term treatment. The education and involvement of all members of the household is also vital to the adherence of patients to continued care.
- Pathways have to reflect patients lives and the complexities of patients' needs – in the end, it comes down to a matter of political will.
- Solutions cannot start with care providers – it has to involve patients, communities, organized civil society and other stakeholders in partnership.


Our Expert Panel




R. Narendhar
(Moderator)
Vice Chair, India Alliance of Patients Group




Fatima Lorenzo
President, Philippine Alliance of Patients Organizations



Kawaldip Sehmi
CEO, International Alliance of Patients' Organizations



Dr. Chandrasekhar Potkar
Chief Medical Officer, Upjohn Emerging Markets

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NCD patient journey - who defines it? Are we missing key touchpoints for intervention?


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International Alliance of Patients' Organizations
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Patient role in HTA and Health Economics

- Ann Single: “Health Technology Assessment is a multidisciplinary process that uses explicit methods to determine the value of a health technology at different points in its lifecycle. The purpose is to inform decision-making in order to promote an equitable, efficient, and high quality health system”.
- However, people add different values to HTA depending on their stakeholder perspective and the decision context. Therefore, patient involvement is of vital importance in HTA: the patient/citizen perspective improves HTA and offers invaluable insights to research. On the other hand, HTA agency can support the public to improve their health literacy.
- It is by involving the public that we can ensure that HTA is not disconnected from the patients’ lives.
- Public involvement and educating patient groups about HTA bodies and their function enables greater patient group participation.

Identifying context specific strategies also enables optimal engagement of patients in the HTA processes.

Our Expert Panel

Karen Alparce-Villanueva
(Moderator)
Secretary, HPO

Dr. Sukyoung Kim
PhD, Senior Research Fellow,
National Evidence-based
Health/Care Collaborating
Agency, Korea

Ann Single
Chair - HTA Patient and Citizen
Involvement Interest Group,
Australia

Dr. Oshima Sachin
Scientist F HTA, Dept of
Health Research, India

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Patients' Organisations
to deliver value for patients


Antimicrobial Resistance – What can we expect from the COVID-19 pandemic?

- Antibiotics: 20th Century miracle for medicine vs. 21st Century crisis. AMR is a major global health issue due to the overuse of antibiotics.
- As a result, resistance has increased in the past 20 years and we are losing the ability to control infections. Some diseases are becoming untreatable, costing the lives of many people worldwide.
- Dr. Jay Purdy: “One can think of this as a war, a war against the microbes – and we are outnumbered. Also, the microbes that resist are becoming better”.
- One of the challenges is the uncertainty regarding the investment of companies on AMR R&D. Increasing the investments and promoting partnerships between different stakeholders are key to address globally the issues of AMR.
- Global action needed: ensure responsible and sustainable and equitable availability of drugs, diagnostic and vaccines – using only when necessary and avoiding polluting the environment.


Our Expert Panel




Dr. Nada Milevskia-Kostova (Moderator)
Vice Chair, IAP0




Dr. Jay Purdy, M.D./Ph.D.
VP and Therapeutic Area Lead, Anti-Infectives, Global Medical Affairs, Pfizer



Dr. Tim Jinks
Head of Drug Resistant Infections Program, Wellcome Trust, UK



Dr. Sundeeep Sarin
Scientist & Advisor at Department of Biotechnology, Government of India

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Antimicrobial Resistance – what can we expect from the COVID-19 pandemic?


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to speak up for patients

Day Two Takeaways

Patients and industry participation - Global to local, Clinical trials and Patient registries in APAC. How can we ensure more participation?

- Patient organizations are still something very new in India and other developing countries. Patients still feel lost on how to organize themselves and make their voices heard. A lot of work needs to be done to really empower patients and patients' organizations.
- The industry and physicians must be key facilitators to developing patient groups by involving very early in their formation. It has to be a joint effort and all of these stakeholders must work and be seen as partners.
- Within the spectrum of stakeholders, awareness of the importance of patient engagement is key in this process.

Developing countries are still in the first stages of enjoying what patient groups can offer, but it's starting to happen. These initiatives must be identified in order to be supported.

Our Expert Panel



Dr. Alok Bhattacharya
(Moderator) Managing Trustee, World Without GNF Mysore, India



Vaishali Iyer
Communications & Patient Advocacy, Novartis India



Dr. Ajay Sharma
Head Govt. Affairs, Astra Zeneca, India



Anil Raina
General Manager and Head, Sanofi Genzyme, India

APPC
2nd Asia Pacific Patients Congress
Patient Leadership in Health Systems Strengthening

Patients and industry participation - Global to local, Clinical trials and Patient registries in APAC. How can we ensure more participation?

4th December 2020, 9:00AM IST

3-4 December 2020

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International Alliance of Patients' Organizations
to global voices for patients


NCDs and COVID-19 - Understanding co-morbidities and preparing for future pandemics

- Preliminary findings of the NIHI study showed weakness in the delivery of NCD care exposed by the COVID-19 crisis. It also pointed out to the decrease of physical activity, and increase of food intake and stress to the existing mental health burden of patients.
- Partnerships are essential in addressing the NCDs current challenges. Good practices such as collaboration on mapping the patient journey, incorporating and addressing different aspects of mental health to primary care, and empowering frontline primary care workers, are vital to manage NCDs during the pandemic. The use of community pharmacists and online health assessments are also important measures to overcome the current access barriers.
- Within the NCDs framework, stroke is a time-sensitive and devastating medical emergency, as well as the leading cause of death and disability in India and around the globe.
- Since the pandemic started there has been an overall reduction in treatment due to poor public awareness (patients avoiding to continue the treatments) and the pre-existing treatment gaps in stroke care and management (especially in remote areas).


Our Expert Panel




Dr. Ratna Devi (Moderator)
Chair, IAPD




Chris Bullen
Director, National Institute
for Health Innovation



Dr. Anurita Majumdar
Senior Director and Regional
Medical Lead, ASCAN



Dr. Shraddha U. Bhure
Medical Director, Boehringer
Ingelheim India Pvt. Ltd

APPC 
2nd Asia Pacific Patients Congress
Patient Leadership in Health Systems Strengthening

**NCDs and COVID-19:
Understanding
comorbidities and
preparing for future
pandemics**


4th December 2020, 10.30AM IST

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International Alliance of
Patients' Organisations
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The Health Workforce - The role of expert patients, community pharmacists and community resilience

- Pharmacists are a valuable health workforce whose potential has remained untapped in some parts of the world. They are at the frontline; they are the first point of contact for people with symptoms and last before a patient receives medicine.
 - Underestimated, they had to transform their medicine seller role and have been extending their services during the pandemic.
- For a long period during the early stages of the pandemic, they were the only health service accessible for many communities.
- The harnessing of data is crucial to develop the expertise of patients: contributing to HTA, informing policy makers, healthcare professionals, and clinical guidelines. Within this context, patient organisations have become the trusted link between patients, hospitals and clinicians.
 - During the pandemic, rare disease patients have been suffering from double marginalization: they are marginalized by their rare conditions and by the fear of accessing healthcare facilities. However, rare disease organizations have been using their adaptation capacity to collaborate with all patient organizations, bringing various stakeholders together in creative solutions.

Our Expert Panel



Orajitt Bumrungkulawat
(Moderator)
Assistant Secretary General,
Heart to Heart Foundation



Dr. Ritu Jain
President, Asia Pacific
Alliance of Rare Disease
Organisations



Pri Etcheverry
Asia Pacific Lymphoma
Coalition



Manjiri Gharat Vice
President, International
Pharmaceutical Association

APPC
2nd Asia Pacific Patients Congress
Patient Leadership in Health Systems Strengthening

**The Health Workforce
— The role of expert
patients, community
pharmacists and
community resilience**

4th December 2020, 9:45AM IST

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International Alliance of
Patients' Organisations
to speak up for patients

Patient harm and UHC - Is data being captured well? How are we protecting patients?

- Patient safety and quality should be an integral part of UHC: it is a crosscutting component, but we're still learning to manage it properly. That results in a high global burden of unsafe care.
- Technology is key to improve patients' safety and healthcare quality and it should also be used to improve personalization of care.
- Most adverse events can potentially be avoided with effective prevention and mitigation strategies such as improved policies, data systems, environmental hygiene and infrastructure, among others.
- An important action point to strengthen the healthcare system is to inspire, educate and skill health workers to contribute to the design and delivery of safe care systems, promoting patient leadership and partnership.

Our Expert Panel



Dr Neda Milevska-Kostova
(Moderator)
Vice-Chair, IAPQ



Prof Vivekanand Jha
Executive Director, The George Institute for Global Health, India



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



Bhupendra Rana
Chief Executive Officer, Quality & Accreditation Institute

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Patient Leadership in Health Systems Strengthening

**Patient harm and UHC:
Is data being captured well?
How are we protecting
patients?**

4th December 2020, 11.30AM IST

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International Alliance of Patients' Organizations
to global voices for patients

Medical devices quality and safety regulation – How is patient voice heard in the region?

- Patient safety is a fundamental element of healthcare and it should involve all stakeholders. Increasing patient involvement at every stage benefits patient safety improvement.
- A good regulatory system is based on a fine balance between safe and fast – always ensuring every patient's voice is heard.
- Affordability and accessibility are the main challenges of the distribution of health devices: they are unaffordable to the average middle-class consumer and lower income groups don't stand a chance, and they are not easily accessible (accessibility varies from metropolitan cities to small towns) or even fully understood (many people are not completely aware of the pros and also the limitations of medical devices).

Our Expert Panel

Probir Das (Moderator)
Chairman Director, Terumo Asia Holdings & Managing Board member APACMed

Dr. Jitendra Sharma
Advisor, AP Medtech Zone

Sai Rakha
I1D Foundation and device user

Gaurav Verma
Director - Regulatory & Government Affairs, Becton Dickinson

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Medical devices quality and safety regulation – how is patient voice heard in the region?

4th December 2020, 12:45PM IST

3-4 December 2020

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International Alliance of Patients' Organisations
to speak up for patients

Build Back Better: Digital healthcare in Asia. Opportunity to integrate health systems, care pathways and personalize health care?

- Digital health innovations reflect the efforts to produce better, affordable, and convenient personalised care.
- Digital healthcare development faces important challenges towards protecting patient privacy and guaranteeing data is consistent and meaningful. It also presents incredible opportunities for health workers in terms of furthering community connectivity, data exchange and knowledge building.
- Digital healthcare is evolving and it's going to revolutionize healthcare. Artificial Intelligence is also an important tool which allows doctors to focus on human interaction and leave other concerns to AI.
- Kulbir Sandhu: "For us every patient is unique and we very much believe that every care should be a personalised care".

Our Expert Panel



Kawaldeep Sehmi
(Moderator)
CEO, International Alliance of Patients' Organizations



Siva Singh
Director EMEA, Esculap



Kulbir Sandhu
APAC Regional Head, VP of Digital Strategy, Roche Pharma



Dr. Sanjay Sood
Project Director, eSanjeevani OPD and Associate Director, C-DAC Mohali

APPC 
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Patient Leadership in Health Systems Strengthening

Build Back Better: Digital healthcare in Asia. Opportunity to integrate health systems, care pathways and personalise health care?

4th December 2020, 1:30PM IST

3-4 December 2020

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International Alliance of Patients' Organizations
to speak up for patients

Patient Academy for the region, Can EUPATI be replicated in Asia?

- “Nothing about us without us” – EUPATI has developed guidance documents for the interaction between patient organisations and stakeholders.
- Patient engagement through patient education: EUPATI has become a game changer and continue as a permanent educational programme for patients, industry, regulators and academia, tailoring the courses accordingly and being accessed worldwide.
- Asia offers a spectrum of challenges and opportunities due to the diversity of countries in terms of development and population.
- EUPATI is completely feasible in Asia and for this goal it is essential to consider the region's specificities and bring all stakeholders together.

Our Expert Panel



Dr Ratna Devi (Moderator)
Chair, IAPD



Lasse Funch Jacobsen
Senior Lead, Patient Research and Alliances LEO Pharma A/S



Tamás Bereczky
Course Coordinator, EUPATI



Nidhi Swarup
President, Crohn's & Colitis Society of Singapore

APPC 
2nd Asia Pacific Patients Congress
Patient Leadership in Health Systems Strengthening

**Patient Academy
for the region:
Can EUPATI be
replicated in Asia?**

4th December 2020, 2:45PM IST

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International Alliance of
Patients' Organizations
to speak up for patients

Communicable diseases like TB, HIV and Hep C - Have we won the war yet?


- While NCDs are the first cause of death in many developing countries, communicable diseases still affect large portions of populations, causing deaths, disability and sickness.
- The pandemic has reminded us that communicable diseases like TB and HIV need renewed focus as these patients are most at risk and very vulnerable to COVID-19.
- Despite the scaring numbers recently exposed by the pandemic, great contributions have been made to improve the public health arsenal in eliminating major communicable diseases across Asia Pacific.
- In the case of TB, one of the major challenges has been to tackle the deeply-rooted stigma attached to the disease. Arindam: "While there's an inherent fear among TB patients, stigma is still very present even within the healthcare system".

Other challenges include: poverty, malnutrition, mental disruptions, and poor access to new quality TB drugs.

Our Expert Panel




Dr. K.S. Sachdeva
Deputy Director General
at Central TB Division



Manoj Pardesi
General Secretary, National
Coalition of People Living
with HIV in India



Dr. Vandita Gupta
Lead, IDV Global Public
Health and Metabolics,
Johnson & Johnson India



Arindam Moitra
Faculty, Patient Academy
for Innovation and
Research

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Patient Leadership in Health Systems Strengthening

**Communicable diseases
like TB, HIV and Hep C -
Have we won the war yet?**


4th December 2020, 3:30PM IST

**3-4 December
2020**

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International Alliance of
Patients' Organizations
to global voices for patients

Patient led innovations

- Making insulin available for rural children: educating the population and guaranteeing appropriate storage are innovative measures which have a great impact on the lives of hundreds of children with Type 1 Diabetes in India (replicated in South Africa and Brazil).
- The Earthen Insulin Cooler is a very simple and efficient solution: is low-cost and locally available, does not require electricity and it's scientifically validated.
- The healthcare system should also take responsibility as 70% of Indian population is rural.
- Operation of Patients Platform with PGs in Japan – conducting research that cannot be done by patients alone, but with patients as partners.
- The cooperation between PPI Japan and EUPATI brings good opportunities for patient led innovations.

Our Expert Panel



Dr. Shanthipriya Shiva
(Moderator)
Young Onset Parkinsons
Warrior



Dr. Archana Sarda
Founder, UDAMAN (T1D
children)



Yukiko Nishimura
Founder and President,
Advocacy Service for Rare
and Intractable Disease



Siddharaju. K
Type 1 Diabetes Patient

APPC 

2nd Asia Pacific Patients Congress
Patient Leadership in Health Systems Strengthening

Patient led innovations
4th December 2020, 4:15PM IST

3-4 December 2020

Online:
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International Alliance of
Patients' Organizations
to speak up for patients

Resources and Inputs

In order to provide delegates with an interactive experience as close as possible to a physical conference, IAPO worked with vFairs, a virtual event platform. The event website reproduced a conference environment by providing participants with the following areas:

In order to provide delegates with an interactive experience as close as possible to a physical conference, IAPO worked with vFairs, a virtual event platform. The event website reproduced a conference environment by providing participants with the following areas:

1. Lobby
2. Exhibit Hall
3. Auditorium
4. Networking via chat
5. Downloadable resources

To ensure APPC 2020 was delivered in a successful manner, Mustard Presentations, a specialised production agency, provided IAPO with technical support before and during Congress.

On the two days of the event, we also had the support of two specialised note-takers who produced notes and summarised speakers' presentations in simultaneity with all sessions. The sessions' takeaways were then shared at the closing ceremonies on both days of the event, and used in the writing up of the present report.

APPC 2020 Information

Programme

DAY1- 3rd December

9:30AM To 10:15AM IST

Launch and Inaugural



Karen Alparce-Villanueva : Secretary, IAPO



Dr. Neda Milevska-Kostova : Vice-Chair, IAPO



Dr. Ratna Devi : Chair, IAPO

10:15AM To 11:00AM IST

Keynote Address - Patients co-creation in future proofing health systems: preparedness for next phase of the pandemic



Martin Taylor : Director, Health Systems and Services, WHO Western Pacific Region



Dr. Sanjiv Kumar : Chair, India Alliance of Patient Groups

This session reflects upon the World Health Organization Executive Board's special session on the implementation of the World Health Assembly Resolution WHA73.1 COVID-19 response. Dr Harsh Vardhan Chair WHO EB gave the Member States a platform to discuss their national and regional developments and efforts to implement the strategic preparedness and response plans.

Patients have an important role in shaping how we not only participate in our health system preparedness, but also how we co-create and build back better our health systems across the whole spectrum from promotion, prevention, treatment, rehabilitation and palliative care.

11:00AM To 11:45AM IST

The Journey in Fighting the COVID-19 Pandemic: What can patients expect?



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



Preeti Sudan : Former Secretary Health & Family Welfare, India



Dorthe Mikkelsen : President Asia Pacific, MSD



Sarthak Ranade : Managing Director, Janssen India

This session is a follow-through from our Global Patients Congress 2020 where we had IFPMA and its members share with us updates on the COVID-19 vaccine research and development. This session comes at Reaching the half-way mark in the research and development, the patient community and other stakeholders are eagerly waiting to the day when safe and effective vaccines have been approved for the greater population. We will also discuss the progress in discovering treatment options for COVID-19 patients, which is critical at this point as we wait for the vaccines to be available. We also ask the question: where Asia Pacific in all these R&D efforts and future plans is to ensure affordable and equitable access for all.

11:45PM To 12:15PM IST

Mobility Break

12:15PM To 13:00PM IST

Who gets the vaccine and how? Is there enough infrastructure and system readiness for access



Dr. Amitav Banerjee : Professor & Head Community Medicine, Dr D Y Patil Medical College (Moderator)



Dr. Satoru Komatsumoto : President, Asian Hospital Federation



Dr Raj Shankar Ghosh : Deputy Director, Vaccine Initiative, BMGF



Dr. Sanjiv Kumar : Chair, India Alliance of Patient Groups

Is Asia-Pacific prepared and have the infrastructure and health workforce necessary to distribute and administer COVID-19 vaccines to 4.3 billion people, almost 60% of the world population?

Coalition for Epidemic Preparedness and Innovations (CEPI) and GAVI are the founding members of the Access to COVID-19 Tools Accelerator (ACT-Accelerator).

ACT-Accelerator aims to accelerate the development, production and deployment of safe, accessible, and effective diagnostics, therapeutics, and vaccines against COVID-19. Both CEPI and Gavi want a global risk-sharing mechanism for pooled procurement and equitable distribution of the eventual COVID-19 vaccines and therapeutics/devices.

Solidarity Trial launched by the World Health Organization and partners is an international clinical trial to help find an effective treatment for COVID-19.

13:00PM To 13:45PM IST

Best practice emerging from Asia in COVID-19 suppression and containment. Best in test/trace; shielding; info-demic control; patient support



Michael Alzona : Patient Engagement Director, Japan/China/Asia Pacific, MSD (Moderator)



Jessica Bean : President and Secretary, Patient Voice Initiative, Australia



Dr. Vichai Chokvivatt : Chair Person, Heart to Heart Foundation, Thailand



Dr. Nikki Kitikiti : Senior Resident, Public Health Physician, Duke-NUS Medical School

Best practices emerging from Asia in COVID-19 suppression and containment including best in test/trace, shielding, info-demic control, and patient support. The COVID-19 experience in Asia-Pacific was a tale of two cities: It was the best of times, it was the worst of times.

Among these countries, public health measures taken in Australia, Singapore and Thailand are now acknowledged as best practice. Their multi-sectoral efforts including citizen involvement resulting to trust and compliance helped them control the pandemic and avoid the lockdowns without plan that resulted in immense suffering and noncompliance and citizen revolt elsewhere.

13:45PM To 14:00PM IST

Mobility Break

14:00PM To 14:45PM IST

Mental Health : Are we doing enough?



Dr. Anita Abu Bakar : Founder and President Mental Illness Awareness & Support Association (Moderator)



Dr. Nand Kumar : Professor of Psychiatry, All India Institute Of Medical Sciences, New Delhi



Dr. Phil Gia Sison : Advisor Youth for Mental Health Coalition, Philippines



Dr. Kannan Subramaniam : Senior Medical Director, Viatrix

This session follows the Global Patients Congress 2020 session that anticipated a mental health pandemic will follow COVID-19. In Asia-Pacific, COVID-19 has had a direct impact as most mental health services and psychiatry care (medical evaluations, care, and treatment) were restricted or collapsed during the height of the pandemic. Many countries in the region now find a backlog of missed appointments or pipeline constriction in access to medication, counselling, and psychotherapy services.

The indirect impact of COVID-19 on mental health and wellbeing in the Region will come later as COVID-19 has changed many of the social-economic determinants of health and wellbeing. COVID-19 has impacted employment, housing, cultural activity (worship/family gatherings/theatre) and the environmental conditions. This deterioration of national social-economic determinants will lead to more high-risk behaviour (misuse of alcohol, tobacco, and drugs)

14:45PM To 15:30PM IST

Patient engagement in research, regulation, and health finance: Building back a better and sustainable UHC 2030



Professor Indrani Gupta : Head of the Health Policy Research Unit of the Institute of Economic Growth (Moderator)



Dr. Eduardo Banzon : MD, Principal Health Specialist, Asian Development Bank



Dr. Chandrakant Lahariya : National Professional Officer, UHC, WHO India Office



Suneela Thatte : Vice President and Head, R&D Solutions India, IQVIA

When Member States in the Asia-Pacific affirmed the Political Declaration of the High-level Meeting on Universal Health Coverage Universal health coverage: moving together to build a healthier world 2019, they had a vision to have integrated and people centred healthcare across the Region.

Patient and citizen involvement in national health systems will ensure each Member State can setup UHC that covers more of its population, extend the range of health services it covers, and reduce the cost sharing and fees, while ensuring financial protection.

To build back better, patient engagement in UHC in the Region must not be confined to their own healthcare. Expert patient advocates must move along the health system value chain and share their insight and perspectives with research, regulation, health economics and health technology assessment.

15:30PM To 16:00PM IST

Mobility Break

16:00PM To 16:45PM IST

NCD patient journey- who defines it? Are we missing key touchpoints for intervention?



R. Narendhar : Vice Chair, IAPG (Moderator)



Fatima Lorenzo : President, Philippine Alliance of Patient Organizations



Kawaldip Sehmi : CEO, International Alliance of Patients' Organizations



Dr. Chandrasekhar Potkar : Chief Medical Officer, Viatrix

Patient journeys are often defined by providers, hospitals and clinical trial administrators who map the journey based on critical touchpoints in the healthcare system. The journey from the patients perspective however is far more complex with multiple entry and exit points specially as most patients with NCDs battle with co morbidities and complications. The session will explore the critical touchpoints from the perspective of patients and identify key gaps that can help providers and policy makers address them for better outcomes.

16:45PM To 17:30PM IST

Patient role in HTA and Health Economics



Karen Alparce-Villanueva : Secretary, IAPO (Moderator)



Sukyeong Kim : PhD, Senior Research Fellow, National Evidence-based Health Care Collaborating Agency, Korea



Ann Single : Chair - HTAI Patient and Citizen Involvement Interest Group, Australia



Dr. Oshima Sachin : Scientist F HTAI, Dept of Health Research, India

Is traditional Health Technology Assessment (HTA) missing important information from patients? How do patients get this across and incorporated into their HTA?

Clinical measurement like alleviation of symptoms or reduction of morbidity, or mortality may not be enough to help us make the most effective and efficient decisions on adopting a new health technology as Patient-reported outcomes (PRO) and Patient Reported Experience (PRE) may give more value as to adherence to the treatment and the mental health and well-being of patients.

PROs are important in decision-making when adopting of new health technologies because they can provide a patient perspective on the effectiveness of the health technology adopted to prevent, treat, or cure their disease.

PREs are equally important in decision-making as they represent patient experience of the process of care. Does the health technology promote respect, dignity, confidentiality, and health literacy? Does the technology generate trust in staff and help cleanliness and timeliness of treatments? If a health technology is invasive, complicated, creates mistrust or creates other negative health ecosystem, it may not be accepted and have uptake.

17:30PM To 17:45PM IST

Mobility Break

Antimicrobial Resistance – What can we expect from the COVID-19 pandemic?**Dr. Neda Milevska-Kostova** : Vice-Chair, IAPO (Moderator)**Dr. Jay Purdy, M.D./Ph.D.** : VP and Therapeutic Area Lead, Anti-infectives, Global Medical Affairs, Pfizer**Dr. Tim Jinks** : Head of Drug Resistant Infections Program, Wellcome Trust, UK**Dr. Sundeep Sarin** : Scientist G/Advisor at Department Of Biotechnology, Government Of India

The Asia Pacific region, home to two-thirds of the world's population and ten of the least developed countries, is highly vulnerable to the threats of the antimicrobial resistance (AMR). AMR undermines efforts in improving the health systems and health security in the region, threatening its overall growth potential.

The region is projected to be home to 27 of the world's 43 megacities by 2030, and these densely populated cities may serve as huge reservoirs for the spread of drug-resistant pathogens. One of the main drivers of antimicrobial resistance is uncontrolled consumption of antimicrobials, and antibiotics in particular.

A 2011 systematic review showed that taking antibiotics without prescription remains a practice, with large variations from 9% in Pakistan and 18% in India, to 62% in Vietnam and 86% in Bangladesh.

The ongoing pandemic and the inconclusive findings on what 'works' against the SARS-CoV-2 virus, have created additional space and self-justification of self-medication practices, the effects of which we are yet to assess on the increase of AMR and spread of drug-resistant pathogens. The session will be looking into the possible scenarios on AMR trends as consequence of the COVID-19 pandemic.

Close of Day 1

DAY 2- 4th December

9:00AM To 9:45AM IST

Patients and industry participation- Global to local, Clinical trials and Patient registries in APAC. How can we ensure more participation?



Dr. Alok Bhattacharya : Managing Trustee, World Without GNE-Myopathy, India (Moderator)



Dr. Ajay Sharma : Director Government Affairs AstraZeneca Pharma India Limited



Vaishali Iyer : Head, Communications & Patient Advocacy, Novartis India



Anil Raina : General Manager , Sanofi Genzyme, India

Early patient engagement in clinical trial design, conduct and reporting is critical in the development of patient centred medicines that improve patient outcomes and experience. Early engagement not only improves research study efficiency and cost-effectiveness, but it also successfully leverages the patient perspective to improve recruitment and retention of patients by optimising scientific objectives with patient goals. Using innovative patient centred communication and other networks, many research teams and clinical trial centres have reached out to and inspired patient advocacy groups into getting involved with the entire medicine development process from design, research, development to market. Involving patients meaningfully and sincerely ensures better communication with prospective participants and helps clinical trial centers build robust and flourishing patient communities to recruit from. Many clinical centres are struggling in recruiting and retaining patients in their clinical trials. They do not have the necessary ecosystem of good patient registers, enabling environments and national frameworks supporting them. This session looks at how we can all improve this situation.

9:45AM To 10:30AM IST

NCDs and COVID - 19 - Understanding co morbidities and preparing for future pandemics



Dr. Ratna Devi : Chair, IAPO (Moderator)



Dr. Anurita Majumdar : Senior Medical Director and Regional lead for ASEAN, Viartis



Chris Bullen : Director, National Institute for Health Innovation



Dr. Shraddha U. Bhure : Medical Director, Boehringer -Ingelheim India Pvt. Ltd.

NCD patients have borne the brunt of the Covid 19 pandemic. Evidence suggests that those with Diabetes and COPD succumbed to the virus faster and suffered more even after recovery. The health systems were ill prepared to face the challenges of the pandemic. NIHI has conducted a nine country study to understand the challenges faced by primary care physicians, pharmacists and patients themselves. This session will look at the preliminary findings and try to recommend action points for future pandemic readiness

10:30AM To 10:45AM IST

Mobility Break

10:45AM To 11:30AM IST

The health workforce- Role of expert patients, community pharmacists and community resilience



Orajitt Bumrungrakulswat : Assistant Secretary General, Heart to Heart Foundation (Moderator)



Manjiri Gharat : Vice President, International Pharmaceutical Federation



Pru Etcheverry : Regional Director, Asia Pacific Lymphoma Coalition



Dr. Ritu Jain : President, Asia Pacific Alliance of Rare Disease Organisations

At our GPC 2020 the CEO of the International Pharmaceutical Federation and the President of the Community Pharmacists Association India both shared with us the role of the community pharmacist in ensuring patient safety and resilience of their communities during the COVID-19 pandemic. During COVID-19 they were placed at considerable risk while serving patients who were shielding.

Many patients' organisations have carried out their own COVID-19 response surveys. The role of their Expert Patients in supporting the local and national COVID-19 pandemic control efforts is now well appreciated. If the Community Pharmacists are considered the 4th emergency service (after police, ambulance, and fire fighters), then Expert Patients must be the 5th emergency service during pandemics, especially in the rare diseases' ecosystem.

This session wants to raise the profile of expert patients and community pharmacists as an additional 'health worker' resource that can be tapped into to support community resilience.

11:30AM To 12:15PM IST

Patient harm and UHC- Is data being captured well? How are we protecting patients?



Dr. Neda Milevska-Kostova Vice-Chair, IAPO (Moderator)



Dr. Vivekanand Jha : Executive Director, The George Institute for Global Health, India



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



Dr. Bhupendra Rana : Chief Executive Officer, Quality & Accreditation Institute

Patient safety and quality (PSQ) is an integral aspect of every health system with successfully implemented universal health coverage (UHC). However, there is a noticeable lack of information on UHC-PSQ convergence, especially in low- and middle-income countries (LMICs).

A 2014 WHO-led consultation emphasized the importance of synchronizing political will from the top to the realities encountered at the ground level, proposing two principal approaches for its achievement: promoting political will to move from merely "access" to access with safety & quality; and pushing political action in the form of national guidelines and a regulatory framework (including accreditation processes).

The session will look into addressing the importance of PSQ in achieving UHC, discussing how PSQ considerations should be used to shape health service delivery; how can PSQ be utilized to measure UHC performance, and what are the barriers to integrating PSQ approach for achieving UHC in LMICs

12:15PM To 12:45PM IST

Mobility Break

12:45PM To 13:30PM IST

Medical devices quality and safety regulation – How is patient voice heard in the region?



Probir Das : Chairman Director Terumo Asia Holdings & Managing Board member APACMed (Moderator)



Dr. Jitendra Sharma : Advisor, AP Medtech Zone



Sai Rekha : Joint Secretary , Type 1 Diabetes Foundation of India



Gaurav Verma : Director – Regulatory & Government Affairs, Becton Dickinson

In mid-2010s the FDA and EMA adopted regulations aimed at introducing among other stricter pre-market control of high-risk devices a new risk classification system for diagnostic medical devices based on international guidance and transparency through establishment of a comprehensive databases embedding device traceability across the supply chain from its manufacturer through to the final user. This enables monitoring and follow-up of real-life use of devices including patient-reported outcomes and post-market control of devices quality and safety beyond clinical trial data.

Countries in the Asia-Pacific region are also committed to regulating the medical devices Singapore and Thailand regulated medical devices in the late 2000s India introduced a regulation in 2017 Bangladesh in 2015 and Viet Nam updated its guidance in 2019. However the quality and safety standardization in these regulations is quite varied from mere regulation of imports to ensuring devices' cyber security.

The session will explore challenges in implementation of the existing regulations on medical devices in the region and showcase best practices for patient engagement in regulatory development cross-country exchange of experience for regulation/implementation improvement

13:30PM To 14:15PM IST

Build Back Better: Digital healthcare in Asia. Opportunity to integrate health systems, care pathways and personalise health care?



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



Siva Singh : Director EMEA, Escalla



Dr. Sanjay Sood : Project Director, eSanjeevani OPD and Associate Director, C-DAC Mohali



Kulbir Sandhu : APAC Regional Head, VP of Digital Strategy, Roche Pharma

COVID-19 pandemic revealed major fault lines in our health systems. One such flaw was that most health system did not know their patients and their conditions well, nor where they lived and how they accessed healthcare. This had a huge impact on shielding programmes and support services for patients with multimorbidity and high support needs. Fragmented healthcare and teams working in silos prevented timely, appropriate and effective response. Many health systems had to use digital solutions to start delivering services. Many have scaled-up digital healthcare. This session sees how digital healthcare can integrate health systems, encourage patient participation and bring about personalised health care (PHC)

14:15PM To 14:45PM IST

Mobility Break

14:45PM To 15:30PM IST

Patient Academy for the region, Can EUPATI be replicated in Asia



Dr. Ratna Devi : Chair, IAPO (Moderator)



Lasse Funch Jacobsen : Senior Lead, Patient Research and Alliances LEO Pharma A/S



Tamás Bereczky : Course Coordinator, EUPATI



Nidhi Swarup : President, Crohn's & Colitis Society of Singapore

Patient advocacy and involvement in drug development , research and inclusion in national formularies has been greatly enhanced with institutions like EUPATI supporting patient training and enhancing skills and knowledge for patients to be actively involved in policy dialogues. EUPATI fellows are recognised by governments and included into government committees as well as industry forums. Can a similar initiative be successful in APAC given the diversity and vast differences in health systems and policies

15:30PM To 16:15PM IST

Communicable diseases like TB, HIV and Hep C- Have we won the war yet?



Dr. K S Sachdeva : Deputy Director General at Central TB Division (Moderator)



Manoj Pardesi : General Secretary, National Coalition of People Living with HIV in India



Dr. Vandita Gupta : Lead, IDV Global Public Health and Metabolics, Johnson & Johnson India



Arindam Moitra : Faculty, Patient Academy for Innovation and Research (PAIR)

While NCDs have now become the No 1 cause of death in many developing countries, communicable diseases still affect large portions of the populations and cause loss of life, disability and sickness. The recent Covid 19 pandemic has reminded us that communicable diseases like TB and HIV need renewed focus as these patients are most at risk and very vulnerable both to infections as well as poorer outcomes if infected with SARS Covid 19

16:15PM To 17:30PM IST

Patient led innovations



Dr. Shanthipriya Shiva : Young onset Parkinsons Warrior (Moderator)



Dr. Archana Sarda : Founder, UDAAN (T1D children)



Yukiko Nishimura: Founder and President, Advocacy Service for Rare and Intractable Disease



Siddaraju. K : Type 1 Diabetes Patient

User-led innovation has now been instituted within all economic sectors around the globe. Users are the first to experience the latent design and delivery failures of products and services, and they are also the first to identify potential solutions or innovations that can improve these products and services.

Patients as users are not being engaged fully by the health sector to contribute to health innovation to improve the reach, efficacy and impact of health products (medicines and devices) and services.

In order to build back better, we will need to institute patient led innovation and create an appropriate forum and framework of policies and practice standards to encourage patient-led innovation. This session celebrates a few cases.

17:30PM To 17:50PM IST

Closing Keynote - Industry role on building back better



Thomas B. Cueni : Director General, IFPMA

17:50PM To 18:05PM IST

Closing Session



Dr. Ratna Devi : Chair, IAPO



Dr. Neda Milevska-Kostova : Vice-Chair, IAPO



Karen Alparce-Villanueva : Secretary, IAPO



Kawaldip Sehmi : CEO, International Alliance of Patients' Organizations

Close of Day 2

List of Speakers

Listed in alphabetical order using first name



Dr. Anita Abu Bakar

Founder and President Mental Illness Awareness & Support Association

Puan Anita Abu Bakar is the Founder and President of the Mental Illness Awareness & Support Association (MIASA), a peer-led advocacy NGO. As Anita was born and raised overseas, she subsequently pursued her tertiary education in the United States. She obtained a Bachelors Degree in Computer Information Systems, with a minor in Management Information Systems.

Upon her return to Malaysia, Anita pursued a career path as an investment banker, and worked in the corporate field for over 10 years. She also holds an MBA in Islamic Banking and Finance from the International Islamic University of Malaysia (IIUM). She has appeared on the Islam Channel UK Show, BernamaTV, Astro, NTV7, RTM, NXNow, Bernama Radio, Sinar, NST, Berita Harian, the Star and more.



Karen Alparce-Villanueva

IAPO Secretary

Karen Alparce-Villanueva is currently a Board Member and Secretary of the International Alliance of Patient Organizations (IAPO) as well as Board

Member and Treasurer of the Philippine Alliance of Patient Organizations (PAPO). She has over thirty years' experience in the private sector, specializing in communications and policy work, twenty of which were spent in the healthcare industry. Karen left her corporate job in 2015 to devote her long experience in health advocacy to advancing patient rights.

Karen also served in government as Board Member of the Philippine Health Insurance Corporation (Philhealth) and as consultant for the Health Promotions and Communication Services of the Department of Health (DOH). She was previously External Affairs Director of MSD and was also Corporate Affairs Director of Pfizer Philippines.

Karen runs a communications consulting firm called Health PRx Communications Inc.



Michael Alzona

Patient Engagement Director, 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.

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.

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.



Dr. Amitav Banerjee

**Professor & Head Community Medicine,
Dr D Y Patil Medical College**

Dr. Banerjee joined DY Patil Medical College, Pune in Oct 2005 after taking voluntary retirement from the Indian Armed Forces. In the first six and a half years he undertook teaching, and the occasional research paper. In January 2012, he took over as Editor of Medical Journal of Dr D Y Patil Vidyapeeth.

This is challenging work as it involved providing a platform for sharing experiences and advances in medical sciences on a global scale. Striving to encourage young researchers to showcase their work for a global audience is the mission of the journal which has over 4000 reviewers from over 90 countries.



Dr. Eduardo Banzon

**MD, Principal Health Specialist,
Asian Development Bank**

Dr. Eduardo P. Banzon is a Principal Health Specialist in the Sustainable Development and Climate Change Department of the Asian Development Bank. He champions Universal Health Coverage and has long provided technical support on UHC to countries in Asia and the Pacific.

Before joining ADB in 2014, he was World Health Organization (WHO) regional adviser for health financing for the Eastern Mediterranean region and WHO health economist in Bangladesh, President and CEO of the Philippine Health Insurance Corporation, World Bank senior health specialist for the East Asia and Pacific region, and faculty member of the University of the Philippines' College of Medicine and Ateneo Graduate School of Business.



Jessica Bean

**President and Secretary,
Patient Voice Initiative, Australia**

Jessica Bean is a medicines access advocate, international speaker, consultant and empowerment coach for young women living with chronic illness.

Informed at age 21 that she would need a double lung transplant to survive the damage caused to her lungs by the genetic condition cystic fibrosis, Jessica fought hard to change her trajectory. Over a decade later, Jessica continues to breathe through her own lungs and live a life beyond her diagnosis.



Tamás Bereczky

Course Coordinator, EUPATI

Tamás Bereczky currently works as the Courses and Contents Coordinator of the European Patients' Academy on Therapeutic Innovation EUPATI (www.eupati.eu), while also coordinating the national platform of EUPATI in Germany. HIV positive since 2003, he served as a

member of the board of directors of the European AIDS Treatment Group (EATG) for almost 4 years, and also served as the co-chair of the European Commission's Civil Society Forum on HIV/AIDS between 2013 and 2015; and has been involved in many EU and global projects.

Tamás has been a member of the BMJ Patient Panel since 2017. A linguist and psychologist, Tamás obtained a PhD based on research into the significance and perspectives of patient organizations in Europe in 2020. In addition to his work as a psychodrama practitioner, he also works as an advisor to several international and European institutions concerning HIV, HCV, men having sex with men, substance use, and health policy. Tamás lives with his partner in Berlin, Germany and is a proud grandfather.



Dr. Alok Bhattacharya

**Managing Trustee,
World Without GNE-Myopathy, India**

Dr. Bhattacharya is currently a professor of biology at Ashoka University. He was trained at the Indian Institute of Technology Kanpur, Jawaharlal Nehru University New Delhi, National Cancer Institute, USA and Harvard Medical School, USA. He has nearly four decades of experience in teaching and research. His scientific interest has been in the area of infectious diseases, biology of parasitic pathogens and genomics.

Alok is credited with helping to set up one of the first teaching and research programmes on Bioinformatics and Computation Biology in India. He has published over 200 research papers, review articles, and book chapters, some of these are in highly reputed Journals.



Dr. Shraddha U. Bhure

**Medical Director, Boehringer-Ingelheim
India Pvt. Ltd.**

Dr. Bhure is a trained post graduate medical professional in clinical pharmacology with an industry experience of over 15 years in medical affairs, clinical operations, regulatory affairs and pharmacovigilance, across multiple segments of the biopharmaceutical value chain.

She has been responsible for the designing and implementation of the pre-launch, launch, and post-launch strategies of innovator products like Pradaxa® (dabigatran etexilate) across indications, Jardiance® (empagliflozin), Trajenta® (linagliptin), Glyxambi® (empagliflozin + linagliptin), Jardiance Met® (empagliflozin + metformin), Xovoltib® (afatinib) as well as Cyendiv® (nintedanib) in Boehringer Ingelheim and Multaq® (dronedarone) in Sanofi and for the life cycle management of the various innovator brands like Metalyse® (tenecteplase) and Actilyse® (alteplase) in BI and Lantus® (insulin glargine), Amaryl® (glimepiride) Clexane® (Lovenox-enoxaparin) and Plavix® (clopidogrel) in Sanofi.

She drove strongly the risk mitigation strategies around many innovator compounds, with specific focus on information dissemination and training; working closely with Pharmacovigilance; ensuring controlled adverse event rate and right product use in Indian market.

She has delivered numerous presentations in many prestigious departments/institutes across India and has to her credit various research publications in indexed journals.

She has been felicitated by the Organization of Pharmaceutical Producers of India (OPPI) as one of the key women achievers of the Indian Pharmaceutical Industry. She is also a member of the OPPI Medical and Regulatory Committee, as well as the Ethics and Business Integrity task force.



Prof. Chris Bullen

Director, National Institute for Health Innovation NZ

Professor Chris Bullen is a public health physician and Professor of Public Health at the University of Auckland's School of Population Health, where he is Director of the National Institute for Health Innovation.

He is a leader in non-communicable diseases research, with expertise in tobacco control and cardiovascular intervention trials, and has a growing interest in the use of digital tools for supporting people to improve their health.

Chris is passionate about the democratization of healthcare and health knowledge, patient empowerment and health equity.



Orajitt Bumrungkulswat

Assistant Secretary General, Heart to Heart Foundation

Orajitt brings 41 years of experience in policy and plan analysis, civil society and community development, Social Investment Fund of the World Bank, Local and Community Health Fund, Long Term Care Fund,

Community Healthcare System, People and Patient Engagement and Consumer Protection in Health Insurance System, Local Authority Engagement in Health Insurance System. Patient centred-healthcare Development and Patient Support Group and Network Development.

She is an expert in local and community development / strategic planning and advocacy, local and community fund management, people and patient engagement and empowerment, civil society development/networking, participatory monitoring and evaluation.

She is the former- Senior Director, Bureau of Community Health Service System, National Health Security Office, Present- Committee member and Assistant Secretary General, Heart to Heart Foundation. Health Promotion Fund Committee Member, Formal and Informal Labor Strategic Development.

Orajitt has a Bachelor in Economics from Chulalongkorn University, Master of Science in Human Settlement Planning and development at Asian institute of Technology.



Dr. Vichai Chokvivatt

Chair Person, Heart to Heart Foundation, Thailand

Dr Vichai is a Physician with the Institute for the Development of Human Research Protections (IHRP), Thailand. He currently serves as the Chairman, Ethics Committee, IHRP; National Science & Technology Development Office, Chairman, Ethics Committee for Thai Traditional & Alternative Medicine, MOPH, Member, Quality Control Committee, National Health Security Fund, Thailand, President, Senior Citizen Council of Thailand.

He has previously worked as Director General, Dept. for the Developments of Thai Traditional & Alternative Medicine, MOPH, Thailand, Secretary General, Food and Drug Administration, MOPH, Thailand, Secretary General, Thai Medical Council, Member, National Health Security Committee.



Thomas Cueni

Director General of International Federation of Pharmaceutical Manufacturers

Thomas B. Cueni is Director General of International Federation of Pharmaceutical Manufacturers (IFPMA), the global association of research-based pharmaceutical companies and associations. Based in Geneva, IFPMA has official relations with the United Nations and contributes industry expertise to help the global health community find solutions that improve global health.

Mr. Cueni is Secretary of the Biopharmaceutical CEO Roundtable (BCR), a policy forum of the global CEOs of IFPMA member companies. He is also Chair of the Business at OECD Health Committee, and also serves on the Board of Directors of the City Cancer Challenge (CCan), an initiative aiming to improve cancer care in major cities in low- and middle-income countries.

In addition, Mr. Cueni serves as Industry Co-Chair of the APEC Biopharmaceutical Working Group on Ethics and Chair of the Board of the cross-sectoral AMR Industry Alliance, a group comprising more than 100 companies and associations representing Rx pharma, generics, biotech, and diagnostics committed to tackling the threat of antimicrobial resistance.



Probir Das

Chairman Director Terumo Asia Holdings & Managing Board member, APACMed

Probir Das has been with Terumo since 2012 and is responsible for running its operations across Asia Pacific and India. In this role, Probir oversees all of Terumo's Business Units and Functions.

Probir has three decades of medical technology industry experience and has extensively worked across medical surgical, interventional, diagnostics, infectious diseases, ophthalmology, and nutrition domains.

Given his keen interest in policy shaping, he is actively engaged in advocacy as Director on Board for Medical Technology Association of India (MTAI), Past Chairman of Federation of Indian Chamber of Commerce and Industry's (FICCI) Medical Devices Forum, and past Senior Vice President of Healthcare Federation of India (NATHEALTH). Additionally, he also works with international advocacy fora such as AdvaMed, USISPF, APACMed.

As the Regional Leader of Asia Pacific & India, Probir is spearheading Terumo's investments into these emerging markets for purposeful business strengthening, health system scale-up through educational interventions, and cost leveraged manufacturing across several Asian sites.

Probir also has over a decade's teaching experience, specifically around strategy, leadership development, coaching and performance management.



Dr. Ratna Devi

IAPO Chair

Dr. Ratna Devi 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.

She leads a cross disease Patient Alliance in India called Indian Alliance of Patient Groups (IAPG), Board member HIA (Healthy India Alliance – the National NCD Alliance in India) and 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. Dr. Devi also holds advisory positions at several NGOs and has contributed to research as well as publications.



Pru Etcheverry

Regional Director, Asia Pacific Lymphoma Coalition

Pru is currently regional director for the global non-profit organisation, the Lymphoma Coalition. She has over 25 years of executive, and governance experience in a range of organisations in the healthcare sector. As previous CEO of Leukaemia & Blood Cancer New Zealand (LBC) she grew the organisation to a prominent NGO developing national services and sustainable income streams generating \$50 million USD.

Prior to working in the NGO sector Pru had a corporate career in the multinational healthcare industry. Pru works to strategically build capacity for patient organisations. She has a passionate interest in using credible evidence-based data as a powerful way for patient input to be valued, both in decision-making and improving outcomes.



Manjiri Gharat

Vice President, International Pharmaceutical Federation

Pharmacy education, Community Pharmacy and Consumer Medicine Education are the main areas of Manjiri's work. She advocates for a larger role of practicing pharmacists in healthcare and is instrumental in establishing a public-private partnership engaging community pharmacists in TB DOTS programme. She leads IPA's Responsible Use of Medicines Campaign (CARUM) and is involved in professional development of pharmacists through training and projects.

Manjiri works with Academia, Pharmacy Councils, Chemist Associations, Consumer Organizations, NGOs and IPA Branches all across the country. She is a regular pharma columnist in regional newspapers and has a book "Äushadhbhaan" (Medicine awareness) to her credit. She uses media (print and electronic) to improve public knowledge of medicine awareness and the role of the pharmacist. She involves pharmacy students in public health activities and works to prepare students for social aims of the profession.

Manjiri is the recipient of two global awards, one is Fellow of International Pharmaceutical Federation (FIP) in year 2016 and Ishidate Award of Federation of Asian

Pharmaceutical Associations (FAPA) in year 2018 in recognition of her services to the community pharmacy and pharmacy profession (first Indian Woman Pharmacy Professional to receive any of these awards, 2nd and 3rd Indian respectively to receive these awards).

She is also a recipient of the fellowship of IPA and several other awards from social and professional organizations in the country.



Prof. Indrani Gupta

Head of the Health Policy Research Unit of the Institute of Economic Growth

Professor Gupta has a PhD in Economics from the University of Maryland, USA. Her work experience includes teaching and academic institutes, the World Bank and the Government of India.

Her focus of work is mainly in the area of health economics and policy, and includes health financing and coverage, poverty and health, costing and cost-effectiveness and economics of diseases.



Dr. Vandita Gupta

Lead, IDV Global Public Health and Metabolics, Johnson & Johnson India

A physician by education followed by an MBA, Vandita has 17 years of experience in drawing on leadership, strategy and commercial roles to lead and support businesses. She is currently responsible for leading Global Public Health efforts, Infectious Diseases and Vaccines and Metabolics Business at Johnson & Johnson.

She also leads the Bedaquiline Access Project globally to help build access pathways for expanded indication.

With the introduction of the first novel drug, Bedaquiline in TB in 40 years, Vandita closely worked to build health programmes that led to sustainable access for Bedaquiline.



Vaishali Iyer

Head, Communications & Patient Advocacy, Novartis India

With a Bachelor in Pharmacy and Masters in Marketing Management Marketing, Communications and Advocacy Vaishali is a specialist with over two and a half decades of experience across the Pharmaceutical (Cipla, Sanofi, Pfizer and Novartis) and Advertising (Ogilvy and DDB) industries. Her experience includes developing and implementing communication and advocacy strategies for brands across Healthcare (Hospitals, Pharma, Devices, Diagnostics, DTC and OTC) and FMCG categories.

Her greatest assets encompass the fusion of science, business and emotional intelligence, which enables her to be culture conscious, narrate stories and build sustainable networks.

Elevating stakeholder voice in decision-making and driving conversations through insight-driven communication strategies, based on data and that revolve around a central core idea has been her forte; and she believes that that large goals can be achieved through capability building and forging partnerships with diverse stakeholders.



Lasse Funch Jacobsen

**Senior Lead, Patient Research and Alliances
LEO Pharma A/S**

Lasse brings ten years of experience from working in pharma – the last four years in Patient Engagement teams across two different pharma companies. Lasse has helped establish functions that ensures 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.



Dr. Ritu Jain

**President, Asia Pacific Alliance of
Rare Disease Organisations**

Dr Ritu Jain is the President of the Asia Pacific Alliance of Rare Disease Organisations (APARDO), the voice of the rare disease organisations in the Asia Pacific region. She is also founder and current President of Dystrophic Epidermolysis Bullosa Research Association (DEBRA) Singapore, the Epidermolysis Bullosa (EB) patient advocacy and support organization, and on the councils of advocacy organisations such as Rare Diseases International (RDI) and the International Rare Diseases Research Consortium (IRDiRC).

In her various roles, Ritu remains committed to strengthening and extending the rare disease network in

the Asian regions and ensuring that rare diseases remain a priority in their national health care plans. She is also invested in fostering collaboration of local and international clinicians/ researchers as well as pharmaceutical organisations, for enhanced research initiatives and clinical trials for improvement in the quality of lives of individuals living with rare diseases.

Beyond these volunteer roles, Ritu is a sociolinguist and works as an academic at an autonomous university in Singapore.



Dr. Tim Jinks

**Head of Drug Resistant Infections Programme,
Wellcome Trust, UK**

Timothy Jinks is the Head of the Drug Resistant Infections Priority Programme leading Wellcome Trust's strategic plan to address antimicrobial resistance. In his preceding role in Wellcome's Innovations Division, he was responsible for a portfolio of over a dozen early stage product development projects covering therapeutics, diagnostic and devices spanning across therapeutic areas such as infectious diseases and oncology.

Prior to joining the Trust in 2012 he has over a decade of industry experience in drug development, most recently as a consultant providing business development, licensing and commercial research services.



Sukyeong Kim

PhD, Senior Research Fellow, National Evidence-based Health Care Collaborating Agency, Korea

Dr. Sukyeong Kim is Senior Research Fellow and International Cooperation Advisor of National Evidence-based Healthcare Collaborating Agency (NECA), Korean governmental agency for Health Technology Assessment.

She plays the leading role in the field of health policy regarding local evidence generation and RWE, HTA system, R&D planning, optimal use of drugs and DUR, and patient safety.

Since 2013 she joined NECA, she undertook several research projects focusing on HTA system, patient safety system and R&D for RWE.

For more than ten years before she joined NECA, Dr. Kim played the leading role in the Korean pharmaceutical benefit policy making, drug utilization researches planning and new health technology assessment programme development in Health Insurance Review and Assessment Service (HIRA) as the principle investigator and director of Pharmaceutical Benefit Division and Research Department.

As a representative of National HTA Agency of Korea, she is the Chair of ISPOR HTA Roundtable Asia Pacific (2016-2019), one of the regional body composing ISPOR HTA Council. She has been participating regional and international meetings and workshops on HTA, medicine policy and UHC in Asia Pacific countries.



Dr. Nikki Kitikiti

Senior Resident, Public Health Physician, Duke-NUS Medical School

Nikki is a Public Health specialist physician based at Duke-NUS Medical School in Singapore at the Centre for Regulatory Excellence (CoRE) and the Singhealth Duke-NUS Global Health Institute (SDGHI) Policy Core. Her work involves building multistakeholder alliances to support research, policy dialogue and capacity building to contribute to equitable global systems for access to essential health services, vaccines, medicines, and digital technologies.

Nikki is involved in the creation of the Coalition to Accelerate Patient Engagement in Asia-Pacific (CAPE) at Duke-NUS. In prior roles, Nikki has worked in clinical practice, outbreak management, health promotion and healthcare administration.



Dr. Satoru Komatsumoto

President, Asian Hospital Federation

Dr. Satoru Komatsumoto is currently the President of Asian Hospital Federation and the Vice-President of Japan Hospital Association. He got his M.D from Keio University in 1975 and his Ph.D from the Tokyo Medical and Dental University. He also teaches at esteemed universities including Kio University, Dokkyo Medical University and Gunma University.



Dr. Nand Kumar

Professor of Psychiatry, All India Institute Of Medical Sciences, New Delhi

Dr. Nand Kumar is a Professor of Psychiatry and Prof In-Charge of Neuromodulation in mental health. He has experience of more than 20 years as a clinician, researcher with interest in community mental health and spirituality. He has delivered talks in various national and international conferences and published scientific papers in reputed international journals. He has delivered educational talks regarding health on All India Radio & National Televisions for improving public awareness regarding Mental Health.



Dr. Sanjiv Kumar

Chair, India Alliance of Patient Groups

Dr Sanjiv Kumar is a public health physician with 44 years of experience across 33 countries. He has been in academics and programme Implementation. He worked in UNICEF for 22 years. He worked as Director, International Institute of Health Management and Research in New Delhi and Executive Director at National Health Systems Resource Centre providing technical support to Government of India. He led development of many policy and strategic documents to improve health in India including National Health Policy 2017.

Dr Sanjiv Kumar has published more than 125 papers in scientific and popular magazines and chapters in books. He has been conferred twelve international and national fellowships and Awards for his professional contribution. He is currently Professor, Leadership, Global Health &

Strategic Management at INCLEN Institute of Global Health, Chair of Indian Alliance of Patients Group, Indian Academy of Public Health and Institutional Ethics Committee of Gautam Budh University, member Governing Board of National Institute of Health and Family Welfare, Advisor, India Health and Wellness Council and Indian Cancer Society and Member Core Committee of Government to prepare Health Research Policy in India.



Dr. Chandrakant Lahariya

National Professional Officer, UHC, WHO India Office

Dr Lahariya is a medical doctor and public policy and health systems expert. Dr Lahariya joined the World Health Organization in early 2008, and been engaged in WHO's work on immunization programme, health systems strengthening as well as universal health coverage. Over these years, he has been engaged in drafting of a number of policies and programmes including the National Health Policy 2017 and launch of Ayushman Bharat programme in 2018.



Fatima Garcia-Lorenzo

President, Philippine Alliance of Patient Organizations

Maria Fatima Garcia-Lorenzo advocates for patients' rights and is engaged in health policy development. Ms. Garcia-Lorenzo is the president of the Philippine Alliance of Patients' Organization (PAPO), an umbrella organization of at least 32 disease-specific patient

groups, representing about a million patients nationwide. She is a member of the Department of Health's Technical Working Group on Patient Safety and is an Adviser of Hospice Philippines.

She was chosen by the Union of International Cancer Control as one of the patient leaders in their Asia-Pacific Patient Leaders Mentoring Programme.

Fatima is also the Philippine representative to the Duke-NUS /Center of Regulatory Excellence Coalition to Accelerate Patient Engagement in the Asia-Pacific region.



Dr. Anurita Majumdar

**Senior Medical Director and
Regional Lead for ASEAN, Viatrix**

Dr. Anurita Majumdar is an Oncologist with over 20 years in the pharmaceuticals and Medical R&D sectors leading medical affairs, regulatory affairs and clinical development programmes. She is currently the Senior Medical Director and Regional lead for ASEAN, within the emerging markets division for Pfizer Upjohn.

In her current role she is responsible for leading Non communicable disease (NCD) strategies in the ASEAN region, working with her diverse team across 8 countries and drives strategic partnerships with Academia, Government and Patient organizations in leading the conversation on NCDs.

In her over 20 years of career she has held various country and regional leadership medical R&D roles in global MNCs including Pfizer and Eli Lilly as well as an academic stint as a practicing Oncologist at the Tata Memorial Hospital, Mumbai, India. She has worked on various public private partnerships in ASEAN and South

Asia towards improving public health in NCD care and Antimicrobial Stewardship.

She is a certified clinical researcher and has led early and late phase drug development programmes in diabetes and oncology. She is a strong advocate for women leadership in science and health and was recently on the judges panel for the METRODORA awards.



Dorthe Mikkelsen

President Asia Pacific, MSD

Dorthe Mikkelsen is the President of MSD in Asia Pacific, based in Singapore. Ms. Mikkelsen began her career at Novo Nordisk. She joined MSD in Denmark in 1997 within Sales, Marketing & External Affairs, and was appointed Managing Director of MSD in Denmark & Iceland in 2006. After since, Ms. Mikkelsen held several regional leadership roles.

Ms. Mikkelsen then became Senior Vice President for the global Diversified Brands Customer Business Line (CBL), based at the Merck & Co., Inc. Kenilworth HQ in the USA, from 2016-2017. The Diversified Brands CBL managed a multi-billion-dollar portfolio of mature brands and the commercial center for life cycle management.

Ms. Mikkelsen held several board member roles including Chairman of the Board of the Danish Industry Association for the pharmaceutical industry from 2010 to 2016. Most recently, Ms. Mikkelsen joined the Board of Directors for the US-ASEAN Business Council (USABC) for a two-year term and also serves on the USABC Nomination Committee. In November 2019, Ms. Mikkelsen was named one of the 100 Most Influential Women in Denmark by Berlingske. She is an Executive Ambassador for MSD for Mothers.



Dr. Neda Milevska-Kostova

Vice-Chair, IAPO

Dr Neda Milevska-Kostova is president of Studiorum, a regional think-tank working on research and policy aspects of health and wellbeing in Europe. Neda has over 20 years experience in health research, policy and patient advocacy. She holds a MSc in functional pharmaceuticals (University of Tokyo), MA in public policy (University of Pittsburgh, USA), and a PhD in public health (University of Sheffield, UK).

Neda is also a Vice-president of Health First Europe, an umbrella organization based in Belgium working on improving access to innovative health technologies in Europe. In 2018, she was awarded the title Primarius by the Minister of Health for exceptional and long-term commitment to the advancement of health system and population health in Macedonia.



Arindam Moitra

Faculty, Patient Academy for Innovation and Research



R. Narendhar

Vice Chair, IAPG

Mr. R. Narendhar is the Executive Director, with Alzheimer's Related Disorders Society of India-ARDSI, since 2009, he is actively engaged in public policy and advocacy for a comprehensive country strategy on Dementia. He has worked with two working committee sub groups of Ministry of Health and Ministry of Social justice and empowerment representing ARDSI and cause of elderly including Dementia for 12th five year plan (2012-17).

He is the Vice Chair of the Indian Alliance of Patients' Group-IAPG which is affiliated to International Alliance of Patients' Organization and is also the Governing Board member of Healthy India Alliance.

He is also the Vice President of a Delhi based largest NGO Society for All Round Development-SARD (which is working on primary and secondary education through implementing remedial models addressing learning gaps and ensuring learning enhancement through teachers capacity building and evolving appropriate learning resources in over 400 schools of North and South Municipal corporation of Delhi).

He is a post-graduate in social sciences and has a PG diploma in NGO management besides being qualified in electronics engineering.



Yukiko Nishimura

Founder and President, Advocacy Service for Rare and Intractable Disease

Yukiko Nishimura is President and founder of NPO ASrid (Advocacy Service for Rare and Intractable Diseases' stakeholders in Japan). Yukiko has worked and collaborated with patients/patients' families and stakeholders in the rare and intractable diseases and orphan drug field for over 10 years.

She has been a Vice Chair of PACC, IRDiRC since 2017, and a Secretary of ICORD since 2010.

Yukiko is currently organizing the 2021 ICORD Tokyo, which will be the first time the event has been held in Asia.

Yukiko had worked as a Chief Secretariat of International Relations, Japan Patients Association (2011-2016), as an Assistant Professor of Research Center for Advanced Science and Technology, The University of Tokyo (2007-2015), Visiting lecturer at the Institute for Integrated Cell-Material Science, Kyoto University (2009-2012) as a technical consultant at MEXT (Ministry of Education) (2005-2009).

Yukiko obtained her BSc and MSc from Meiji University. Yukiko also graduated from The University of Tokyo, Graduate School of Science.



Manoj Pardesi

General Secretary, National Coalition of People Living with HIV in India

Having worked in the field of HIV for over 24 years Manoj has been able to collectivise PLHIV, work with government, non-government, bilateral and funding agencies, and facilitate policy and legal change to protect rights and meet community needs. He has had the opportunity to work at the international, national, and community level, which has helped him understand the epidemic from a range of perspectives.

He has worked on various aspects of the HIV response, including conceptualizing, designing, financial oversights, and programme management. He has been involved in a number of research projects with institutions like NARI, ICMR, the Population Council, and the National Institutes of Health in the United States.



Dr. Chandrasekhar Potkar

Chief Medical Officer, Viatris

Dr. Chandrasekhar Potkar is the Chief Medical Officer for Pfizer's Upjohn business in Emerging Markets. He is currently responsible for the medical organization in Emerging Markets and setting up the medical & scientific strategy for Upjohn across Asia, AfME and LatAm regions.

Previously, he was the Regional Medical Affairs Lead APAC for Pfizer's Established Health business, where he led the medical team across the region and provided strategic medical support.



Dr. Jay Purdy, M.D./Ph.D.

**VP and Therapeutic Area Lead, Anti-infectives,
Global Medical Affairs, Pfizer**

Dr. Purdy is an Infectious Disease physician who also holds a Ph.D. in the field of Microbiology where he studied gene regulation in the human pathogens *Entamoeba histolytica* and *Leishmania chagasi*. He currently serves as the Vice President and Therapeutic Area Lead for Pfizer's Anti-Infectives Global Medical Affairs team.

He moved from a professorship at the University of Chicago 13 years ago into pharmaceuticals and has since led research and development programmes from pre-clinical to post-approval in both antibiotics and vaccines as well as leading the medical/scientific team on external acquisitions.



Anil Raina

General Manager, Sanofi Genzyme, India

Currently the India & South Asia head of Sanofi Genzyme, Anil joined Genzyme in 2007 and has pioneered the development of the field of rare diseases in India & South Asia over the last 13 years. Anil's got a cross functional experience in the biopharma sector – marketing and sales, business planning and operations, new product launches.

Anil has worked across sectors in companies like Larsen & Toubro, Ranbaxy Laboratories Limited, Dr. Reddy's, spanning manufacturing, sourcing, business

development and planning, sales & marketing etc. He is a mechanical engineer from National Institute of Technology (Kurukshestra) and an MBA in International Business from Indian Institute of Foreign Trade, New Delhi.



Dr. Bhupendra Rana

**Chief Executive Officer,
Quality & Accreditation Institute**

Dr. B.K. Rana is the CEO of Quality & Accreditation Institute (QAI) and former Director & CEO-In-charge of NABH, Quality Council of India. He is a Former Board Member of the International Society for Quality in Health Care (ISQua) & Chairman of Accreditation Council of ISQua. Board Member of Asian Society for Quality in Healthcare (ASQua) & served as President of ASQua in 2011 & 12. Founding Member of the International Academy of Quality & Safety (IAQS) and Scientific Advisory Board, International Alliance of Patients' Organisations (IAPO).

He is an International Consultant and Expert for the WHO, World Bank, ADB, USAID, ISQua, UNFCCC, GIZ and several other national and international organisations. His expertise is establishing Healthcare Accreditation Body, Laboratory Accreditation Body, implementing Quality Management Systems, accreditation requirements and Standard Development in the field of quality improvement and patient safety. His passion for doing different things differently keeps him motivated to innovate and create new standards and programmes.

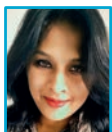


Sarthak Ranade

Managing Director, Janssen India

As Managing Director of Janssen India, Sarthak oversees the Company's operations in India and the South Asian markets of Sri Lanka, Bangladesh & Nepal. Sarthak is a member of the Johnson & Johnson (J&J) India President Council, as well as the Janssen Asia Pacific Leadership Team.

Sarthak joined Janssen as General Manager – Marketing in 2007. He went on to hold a variety of roles with increasing responsibility, including leadership roles at regional and country level. From 2011-2014, he worked in the Janssen Asia Pacific Strategic Marketing team as Regional Commercial Director for Immunology, Metabolics and Established products and played a pivotal role in ensuring timely access to important medications for patients across the region.



Sai Rekha

Joint Secretary , Type 1 Diabetes Foundation of India

Sairekha Sureshkumar is a lawyer with 14+ years of corporate legal experience. She has been living with type 1 diabetes for 25 years. She is an evangelist for the use of med tech in diabetes management. She had created and produced a YouTube series called “Tech Talk” for Club 1 to demystify medtech. She is a keen advocate for non-discrimination and the mainstreaming and inclusion of persons with type 1 diabetes in workplaces and society at large.

She is the Mumbai practice head for Cohere Consultants – a boutique diversity and inclusion practice. She co-founded Club 1 diabetes with the KEM Hospital, Pune in 2017, which was one of the first patient driven support communities in India that focused on education, outreach and quality of life for persons with Type 1 diabetes. Club 1 KEM is currently partnered with the Hinduja Foundation. She is the Joint Secy of Type 1 Diabetes Foundation of India, a non-profit that focuses on policy advocacy for persons with type 1 diabetes.



Dr. K S Sachdeva

Deputy Director General at Central TB Division

Dr Sachdeva is a public health physician, presently working as Deputy Director General at Central TB Division. He had worked in the programme earlier for a period of 8 years looking after multiple portfolios including Drug Resistant TB, Laboratory, TB-Comorbidity etc. Prior to the present position, he worked in National AIDS Control Organization overseeing HIV counseling & testing services, STI, TB-HIV collaborative activities, research and Global Fund activities implementation.

He has also served as the Chief District Medical Officer, South Zone, for the Govt of NCT, Delhi and a Nodal Officer for the National Rural Health Mission as well as Chief Medical Officer for the Essential Drugs Programme within the Directorate of Health Services, Govt of NCT, Delhi.

As Chief Medical Officer for the Essential Drugs Programme, Dr Sachdeva was in charge of the central procurement agency and essential drug programme. This included developing an Essential Drugs List and Quality Assurance mechanism of drugs and surgical

consumables. He was also the resource person for capacity building in rational use of drugs, procurement, and logistics management.

Dr Sachdeva obtained his MBBS degree from the Maulana Azad Medical College, University of Delhi and has additional training in TB & chest diseases from the VP Chest Institute at the University Of Delhi.



Dr. Oshima Sachin

Scientist F, HTAIn, Dept of Health Research, India

Dr. Oshima Sachin is a scientist in the HTA body of India-HTAIn (Health Technology Assessment India). Her interests include Evidence based policy, Health Economics, Healthcare costing and Financing.



Kulbir Sandhu

APAC Regional Head, VP of Digital Strategy, Roche Pharma

Kulbir Sandhu is APAC regional head of Digital Strategy and Innovations with Roche Pharma. Kulbir is an experienced leader with a track record of new product creation and strategic solution development for innovative healthcare technologies and consumer electronics products across Asia Pacific Japan region and Silicon Valley.

Most recently, Kulbir was the Medtech Practice head for Life Sciences with A*STAR. Previously, he was the Sr. Director and Co-inventor of digital portfolio management at Earlens Corporation, where he led the team to develop first cloud-connected photonic based hearing aid system.

Kulbir also spent eleven years with St. Jude Medical (acquired by Abbott) in designing award winning fully connected Implantable ICDs and cardiac pacemakers. He is a co-author on more than 50 patents in healthcare and connected devices. He enjoys golf, 4x4 off-roading and spending time with family.



Dr. Archana Sarda

Founder, UDAAN (T1D children)

Dr. Archana Sarda is a Diabetes specialist who founded UDAAN 15 years ago with a mission to empower underprivileged children with Type 1 Diabetes. Having actively adopted more than 800 kids from rural area of Marathwada, she believes in education and policy change as the core gamechangers.

Her work includes invention of an earthen pot to store insulin, a globally unique DMOM to DCOACH programme, rural teaching tools, and a first ever visual learning book for families with T1D. She currently leads the National RSSDI T1D Task force. Having led India's first T1D challenge, she is working on creating a positive ecosystem for every child with T1D in India.

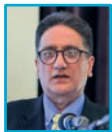


Dr. Sundeep Sarin

Scientist G/Advisor at Department Of Biotechnology, Government Of India

Dr. Sundeep Sarin is Scientist G/ Advisor at Department of Biotechnology, Ministry of Science & Technology, Govt. of India. He has more than 25 years of experience in Public and Private Sectors.

He was involved in Strategic planning, design and effective implementation of more than 30 programmes to advance innovative scientific and technological research to address product development needs. He established Indian Innovation Ecosystem for Antimicrobial Resistance.



Kawaldip Sehmi

CEO, International Alliance of Patients' Organizations

Kawaldip is the chief executive officer of the International Alliance of Patients' Organizations. He has an academic background in public health and law and has a passionate belief in improving access to services through digital health and justice services. As the managing director of an international children's legal center, he led a team of international lawyers improving the rights of the child, including right to health, by applying Remote Courts.

He has also served as the chief executive officer of an international mental health charity, specializing in niche mental health services supporting young people and adults with complex mental health, personality disorder and substance misuse problems access telehealth and digital mental health services.

Kawaldip is a passionate advocate of the WHO's human rights based approaches to health and strengthening of the institutional, legislative, policy, practice and standards framework. He believes this support is needed to achieve the health goals outlined in the Sustainable Developmental Goals 2030, specifically in SDG 3.8, to ensure universal health coverage for all.



Dr Raj Shankar Ghosh

Deputy Director, Vaccine Initiative, BMGF

Raj Shankar a physician with public health training. Over the past 28 years he has worked in multiple organizations that include Governmental health services (India), multinational technical organizations (World Health Organization- National Polio Surveillance Project; PATH; Institute for OneWorld Health) and donor agency (Bill & Melinda Gates Foundation).

His work has primarily been on primary health care (programme planning; service delivery; monitoring & evaluation) and infectious diseases (Polio; Japanese Encephalitis; Visceral Leishmaniasis; Rota virus diarrhoea and Pneumonia). He was awarded honorary fellowship by Indian Public Health Association in 2013 for his work in public health in India and South Asia. Currently, Raj Shankar is Senior Advisor, Vaccine Delivery at India office of Bill & Melinda Gates Foundation.



Dr. Ajay Sharma

Director Government Affairs AstraZeneca Pharma India Limited

As the Government Affairs Director, Ajay is responsible for supporting AstraZeneca's science-led strategy in India. Ajay started his journey in AstraZeneca in 2020 and is part of the India Leadership team. He has led AZ's donation drive during ongoing COVID-19 pandemic where in AZPIL has donated more than 130k N95 masks to 12 State & Central Governments amid the lockdown in March/April and our employee contribution of approx.

100K USD to PM CARES fund. He currently is part of AZPIL COVID Vaccine Strategy team for India.

Prior to AstraZeneca, Ajay has worked with Organisation of Pharmaceutical Producers of India, Frost & Sullivan, 3M and HMCC Kuwait. Ajay holds a Masters degree in Management from SP JAIN and a Bachelor's degree in Medicine & Surgery from Nagpur University. In addition he also holds a WIPO sponsored certificate course on IPR from George Mason University, Washington DC.



Dr. Jitendra Sharma

Advisor, AP Medtech Zone

Dr. Jitendar Sharma is a Healthcare Technologist and specializes in application of technology and innovations in health products and manufacturing sector. Having started his career at Sri Sathya Sai Institute of Higher Medical Sciences, his experience includes at AIIMS, New Delhi, at The World Bank and at WHO headquarters, Geneva Switzerland.

In 2012, he was established the Healthcare Technology Division at NHSRC, Ministry of Health, Govt. of India and was the Founder Director of India's first and only WHO Collaborating Centre for Medical Devices.



Dr. Shanthipriya Shiva

Young onset Parkinson's Warrior

Dr Shanthipriya is a patient advocate for Parkinson's. A consultant ophthalmologist by profession, a young onset Parkinson's warrior since 2011, a self taught artist

and founder of SAARfoundation (To make a difference in the life of a person with Parkinson's). The foundations objectives are based on the acronym of SAAR SUPPORT- Creating a supportive ecosystem, AWARENESS- conduct awareness camps, ACTION – influence actions and rally support, REHABILITATE- state of art rehabilitation center.

She is the ambassador for world Parkinson congress 2020-22. My aim in life is not merely to survive, but thrive and to do so with Some humor compassion and style.



Siddaraju. K

Type 1 Diabetes Patient

Mr. Siddaraju works as tech operator in Accenture. He has been living with type one diabetes for over 14 years.



Siva Singh

Director EMEA, Escalla

Siva has worked in the healthcare sector for over 25 years and has a wealth of knowledge from a UK perspective and internationally. He worked directly with foreign Government agencies, the Department of International Trade and also in collaboration with global consultancies this was to develop truly bespoke role specific learning programmes in support of change and transformation.

The programmes incorporated leadership and cultural changes aside learning interventions to change behaviours and embed change. Led on the Sepsis recognition and treatment programme in the Kingdom of Saudi Arabia. This won the Global Sepsis award in

2018 and is forecast to save 32,000 lives annually. Led on various projects in Egypt to develop bespoke solutions for family physicians, nursing teams and other healthcare engagements. Leadership and management learning models in Egypt and Saudi Arabia.

Siva has also delivered guest lectures on healthcare leadership and patient safety in the UK and overseas, including Saudi Arabia, Egypt.



Ann Single

Chair - HTAi Patient and Citizen Involvement Interest Group, Australia

Ann Single is the Coordinator and a Steering Committee Member of the Patient Voice Initiative (Australia) and Chair of the HTAi Patient and Citizen Involvement Interest Group (PCIG). She began in this field directing patient involvement and communication in Scotland's first Health Technology Assessment (HTA) body. In PCIG she has been involved in the development of numerous tools and resources to support patient involvement in HTA.

Her experience includes co-editor of the book Patient Involvement in Health Technology Assessment (2017), lay reviewer for several journals, work in a patient organization, and science and corporate communication for government and research institutions.



Dr. Phil Gia Sison

Advisor Youth for Mental Health Coalition, Philippines

Dr. Gia B. Sison is a practicing medical doctor specializing

in Occupational Medicine and is a graduate of the University of Sto. Tomas. She herself is a breast cancer survivor for almost four (4) years now and is currently the Philippine Leader for Livestrong Foundation and the National Adviser of the Youth for Mental Health Coalition.

She is the former Chief Medical Officer of Global Telehealth Incorporated and a co-founder of #HealthXPh which promotes the responsible use of social media in healthcare amongst others.

She was a previous project consultant to the World Health Organization Western Pacific Regional Office on Health Lifestyle in the Workplace. She is currently the Head of Makati Medical Center's Wellness Center. She is a staunch mental health advocate and life and leadership blogger at her personal page entitled Sand and Stone at www.giasison.com and her brainchild Unsaid Feelings at www.unsaid-feelings.com which serves as a platform where individuals can write and let their feelings out with no judgment.

Dr. Sison also hosts her own digital series on CNN Philippines, G Talks which talks about life, love and anything mental-health related. She has also launched a project called Padayon PH at padayonph.com which aims to serve as a mental health resource hub hoping that more people gain access to.



Dr. Sanjay Sood

Project Director, eSanjeevani OPD & Associate Director, C-DAC Mohali

Dr. Sood is presently the Project Director of eSanjeevaniOPD – India's largest telemedicine platform that is poised to be the world's largest telemedicine platform. Dr. Sanjay Sood is a 2014 State Awardee (Chandigarh, India).

Dr. Sood's rich experience spans various geographies. With a global outlook, he is one amongst telemedicine pioneers in South-east Asia.

He has been a Telemedicine Consultant with World Health Organisation and an eHealth expert with United Nations Office for Outer Space Affairs. Dr. Sood is actively into world-class telemedicine / Digital Health large scale national and international implementations, including cutting-edge research & development. In 2002, he and his team developed India's first indigenous telemedicine technology. He is also leading development on Govt. of India's pan-Africa telemedicine project –eArogyaBharti and for the Ministry of Defence Services eHealth Assistance and Teleconsultation (SeHAT).



Nidhi Swarup

President, Crohn's & Colitis Society of Singapore

Founder and President, Crohn's & Colitis Society of Singapore (CCSS), Consultant for Foundation of Rotary Clubs (S) Ltd. Nidhi has an M.Sc. in Finance from the University of Leicester, United Kingdom and an M.Sc. Operations Research, University of Delhi, and a Graduate Certificate in Professional Counselling, Swinburne University of Technology, Australia.



Dr. Kannan Subramaniam

Senior Medical Director, Viatrix

Kannan Subramaniam is a physician with specialist training in psychiatry. After a decade in clinical medicine, he provided leadership and governance to ICT and biotechnology companies. He has been leading the

Noncommunicable Disease strategy in emerging nations for Upjohn, which has now merged with Mylan to become Viatrix, empowering people worldwide to live healthier.

His charter is to foster patient centricity, and bridge gaps in knowledge and clinical practice to reduce the burden from NCDs. Prior to Upjohn, Kannan led a biodiscovery venture for Fonterra, a global dairy company. His current focus is to address NCD care amid the pandemic.



Preeti Sudan

Former Secretary Health & Family Welfare, India

Ms. Preeti Sudan belongs to the Civil Service in India and has been an IAS Officer of 1983 batch from Andhra Pradesh cadre. She retired as Secretary, Ministry of Health & Family Welfare, Govt. of India, on 31st July, 2020, after nearly three fruitful and successful years, especially the last six months, during which she was at the forefront in tackling the COVID-19 pandemic.

She has in the past, successfully handled outbreaks of diseases like Nipah and Zika in different parts of the country.



Prof Kok Hian Tan

Group Director & Senior Associate Dean, SingHealth Duke-NUS Institute for Patient Safety & Quality

Prof Tan is Group Director & Senior Associate Dean, SingHealth Duke-NUS Institute for Patient Safety & Quality. He is Chair of the National Quality Council which

serves as national advisory panel to Singapore Ministry of Health on health quality priorities & strategies. He initiated the SingHealth Patient Advocacy Network (SPAN) and currently serves as a co-advisor to SPAN. He serves as a WHO consultant in patient safety and quality.

He received the WHO UAE Health Foundation Prize 2009 as KKH Integrated Perinatal Care Project Team Leader; and Singapore Inaugural National Outstanding Clinical Quality Activist Award 2010.



Martin Taylor

**Director, Health Systems and Services,
WHO Western Pacific Region**

Martin Taylor has worked as strategist, adviser and manager on global health and development assistance for health for 20 years – with a strong focus on supporting countries to strengthen health systems.

He has worked for the UK Department for International Development (including four years in Beijing as lead on UK cooperation with China on health systems, HIV/AIDS and TB) and was part of the team that established the Global Fund to fight AIDS, TB and Malaria.

He studied at the University of Cambridge and the London School of Hygiene and Tropical Medicine. From 2013 to 2017, Martin was the Head of the Division for Health Systems and Health Security in WHO Office in Beijing, China. In November 2019, Martin joined the WHO Western Pacific Regional Office in Manila as the Director of Health Systems and Services.



Suneela Thatte

VP and Head - R&D Solutions India, IQVIA

Suneela is an industry leader with significant experience in clinical research, operations, business management and policy advocacy with over 25 years stint in the Biopharma industry. She is currently VP and Head – R&D Solutions, IQVIA India and is responsible for managing IQVIA's Clinical development business in India to achieve business financials, exceed customer expectations and ensure employee engagement, motivation and retention. Suneela has worked extensively to establish clinical research in India and has led policy advocacy for clinical research in the country.

She has been the President of Indian Society for Clinical Research, a professional body representing the interests of all stakeholders of clinical research in India, for two terms – 2013-15 and 2015-17. She is also an active member of the Clinical Research / Pharma committees of several industry associations such as Confederation of Indian Industries (CII), Federation of Indian Chambers of Commerce (FICCI), and Organization of Pharmaceutical Producers of India (OPPI).

As a recognition of Suneela's contribution to clinical research sector in India, she has been honoured by Healthcare Businesswomen's Association, USA, as "Healthcare Luminary" in 2017. and by the Indian Society for Clinical Research by a "Lifetime Achievement Award" in 2019. She has been quoted by various health media and general press as a key opinion leader.



Gaurav Verma

Director – Regulatory & Government Affairs, Becton Dickinson

Currently heading regulatory and government affairs function for Becton Dickinson and has been since May 2017. He has 20 years of experience in Regulatory Affairs with Leading Medical Technology Companies. Prior experience includes working with Boston Scientific; Covidien.



Prof. Vivekanand Jha

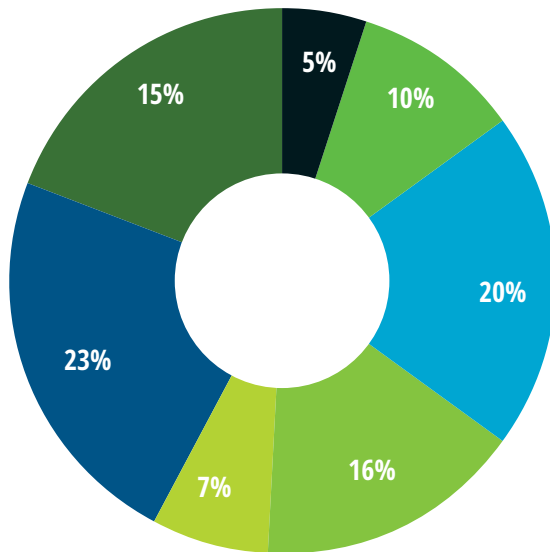
Executive Director, The George Institute for Global Health, India

Professor Vivekanand Jha is the Executive Director at The George Institute for Global Health, India, Chair of Global Kidney Health, Faculty of Medicine, Imperial College of London and the President of the International Society of Nephrology.

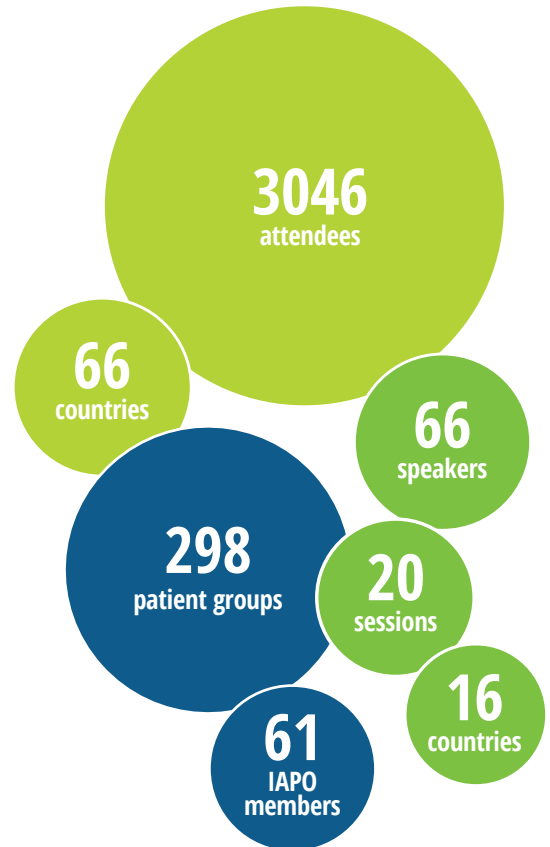
Professor Jha has wide-ranging research interests, including understanding the health and societal impact of kidney diseases around the world and development of affordable, scalable and sustainable primary and secondary prevention tools. He has worked with many organizations including with WHO to develop clinical practice guidelines and advocacy papers, has lectured extensively around the world, and is a prolific writer and editor.

Delegates' Attendance

The Congress brought together 3046 delegates from 66 countries, 20 times more than our 1st Asia Pacific Patients Congress, which was held face to face in Taiwan in 2019. In total, 298 patient groups attended APPC 2020, being 61 organizations members of IAPO.



- Patient Organizations
- Not-for-profit Organizations
- Others
- Industry
- Academia
- Government
- Other For-profit Organizations



Booth Visits

By walking into the conference Exhibit Hall, delegates and speakers had the opportunity to visit a number of booths with different resources and relevant information about healthcare.

APPC Exhibit Hall had 19 booths open to visitors during the 2-day live event and on-demand over one month after that.

More than 1700 delegates explored the resources provided in the following booths:

Stroke Rehabilitation Twinning Programme
Yellow Warriors Society of the Philippines
Cell and Gene Therapy Toolkit
Fight the Fakes Campaign
Global Health Progress
IAPO Members' booth
IAPO-Patients For Patients Safety Observatory
Indian Alliance of Patients Groups
International Alliance of Patients' Organizations (IAPO)
International Alliance of Dermatology Patients' Organizations (IADPO)
Korean Alliance of Patients' Organizations
LEO Pharma
MSD
Novo Nordisk India
Patient Solidarity Day
Patients Shouting Café
Philippine Alliance of Patient Organizations
Roche: Advancing Personalised Healthcare
World Patient Safety Day

IAPO Staff



Kawaldip
Sehmi, Chief
Executive
Officer



Dani Mothci,
Member
Engagement
Manager



Rachel Githinji,
Communications
Manager



International Alliance of
Patients' Organizations

A global voice for patients



International Alliance of
Patients' Organizations

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