1st

INTERNATIONAL

PATIENT SUMMIT

2023

REPORT

EXECUTIVE SUMMARY

The inaugural 1st International Patient Summit (IPS) was convened on 11th – 12th December 2023, in New Delhi, India at The Radisson Blu Hotel.

The summit garnered a distinguished assembly of over 200 global participants, including government dignitaries, representatives from the World Health Organization, patient advocacy groups, and a diverse array of stakeholders, hailing from more than 10 countries worldwide both online and in person, to discuss the Summit theme **'Equitable healthcare: co-planning, co-designing and co-delivery'** with the inclusion of patient voice and lived experience. The key principle behind the focus on patient-centered healthcare was the need for patient engagement in the co-creation of safe, qualitative, and equitable healthcare, as integral partners endowed with both the right and the responsibility to contribute to decisions that directly impact their health and well-being.

Co-hosted by The Patient Academy for Innovation and Research (PAIR), DakshamA Health, The Heart to Heart Foundation, and The Philippine Alliance of Patient Organizations (PAPO), IPS was meticulously crafted to provide a multifaceted and enriching experience for the participants. The summit featured a robust agenda comprising over 50 speaker sessions, interactive Q&A segments, and an immersive hands-on workshop, all designed to foster collaborative learning and knowledge exchange.

IPS aimed at discussing the "key asks" for the attainment of Universal Health Coverage (UHC) drawing insights from countries that have made significant strides towards the Target 3.8 UHC, while also taking into consideration the setbacks faced when trying to embed patient voice in the healthcare system. It created a platform to give voice to the stakeholders in the Asia- Pacific region, to help reinforce the AAA framework- Accessibility, Affordability, and Availability of healthcare. It promoted candid sharing of experiences as integral members of the healthcare community, fostering an open dialogue that critically assessed the deficiencies inherent in the prevailing healthcare systems.

The summit comprehensively addressed 9 thematic domains, such as communicable and non-communicable diseases, women's health and mental health, advanced therapies, and digital health literacy, to name a few. Deliberations within these spheres led to the formulation of pragmatic solutions, including the implementation of strategies for raising awareness, systematic capacity building initiatives, and the imperative recognition of diseases that are currently underrepresented or stigmatized within the broader healthcare discourse.

OBJECTIVES:

The International Patient Summit was structured around 3 main objectives:

- To bring together all key and high-level stakeholders to discuss important issues concerning patients specifically from the international region.
- To highlight PAIR's vision to see patients at the center of healthcare throughout the world and its mission is to help build patient-centered healthcare and UHC worldwide.
- To inspire patient groups to establish national patient alliances that will align and become members of PAIR to form a regional network.

ACKNOWLEDGEMENT:

The 1ˢᵗ International Patient Summit 2023 is grateful for the support and participation of many stakeholders to bring about the hosting of this successful event.

We wish to thank the following formally:
• The IPS Organizing Committee for the direction and successful implementation of the agenda.
• Patient organizations in the Asia-Pacific region for their participation and contribution to the summit and in providing excellent speakers.
• The Ministry of Health (India), The Ministry of Health (Thailand), and WHO India who provided excellent speakers.
• Our co-organizers DakshamA Health, The Heart-to-Heart Foundation, and The Philippine Alliance of Patient Organizations.
• Our keynote speakers Dr. Soumya Swaminathan and Dr. L Swasticharan.
• Syncline for their excellent audio-visual services.
• Our industry partners who not only provided resources, but also speakers and supported many patient advocates to attend the event:
    o MSD - Platinum Sponsor
    o Viatris – Gold Sponsor
    o BSV – Knowledge Partners
    o Bayer – Knowledge Partners

PROGRAM STRUCTURE

The International Patient Summit was a 2-day event from 9:00 to 17:00 IST consisting of 9 panel discussions and a hands-on workshop on Patient for Patient Safety Network (PFPSN). The agenda included the following topics in succession:

1. Universal Health Coverage as a driver of equity, inclusive growth, and regional prosperity from the lens of healthcare financing
2. Health literacy in the digital world: Patient empowerment with the right tools and knowledge
3. Access to advanced therapies, Genomics and Gene therapy: Is Asia Pacific ready for advanced treatments?
4. Communicable diseases: is the story over; TB, HIV and Hep C- lessons learnt for future pandemics
5. Women's health: Endometriosis, PCOS and NCDs. The double disadvantage of gender and being left behind.
6. Asia Pacific patient for patient safety networks- "Building a regional patient network to achieve GPSAP 2021-30"
7. Case studies: In-depth case studies on patients led best practices
8. Life course vaccination
9. Mental health- The need for integration into all programs

Each panel was allotted about 60 minutes and constituted one moderator and 4-5 speakers.

The 60 minutes were then delegated to the speakers for 10 minutes each, followed by 20 minutes of Q & A. The speakers delivered a mixture of presentations, videographic data, and oration, designed to follow the healthcare value-chain and find opportunities and challenges that patients in Asia-Pacific region may face when it comes to harmonizing UHC 2030 in the entire region.

OPENING CEREMONY AND KEYNOTE:

Dr. Ratna Devi opened the summit with a brief introduction into the theme and invited her two co-organizers, Ms. Orajitt Bumrungskulswat and Ms. Karen Villanueva, on stage to share their vision behind the summit. She introduced the organizing committee with a warm welcome and encouraged the participants to get ready for two days of participatory and thought-provoking sessions delivered by some of the best minds on healthcare in the region. She thanked the speakers and attendees who had given their valuable time and briefed the participants on the event logistics. The organizers, along with Dr. Amitav Banerjee, Professor of Community Medicine, Dr. D Y Patil University of Medical Sciences and Research, then proceeded with the Indian ceremony of Lamp lighting with Ganesh Vandana as a gesture of inviting positivity to the event.

Ex-Chief Scientist, WHO, Dr. Soumya Swaminathan's keynote address underscored the need for a holistic approach to healthcare namely preventive, promotive, rehabilitative, and palliative. It drew attention to the paradox of the increase in the average life span but not the quality of life which makes it imperative for the public to hold healthcare providers accountable to deliver the quality of healthcare that people deserve. Finally, she brought focus to WHO's declaration of climate change being a public

Figure 1 Keynote speaker Dr. Soumya Swaminathan and Guest of Honor Dr. L. Swasticharan joining online.

health emergency because of urbanization and deforestation, leading to the current rise in NCDs and zoonotic diseases. Dr. Soumya's take on the need for inclusion of patient voices served as a great segue for the Guest of Honor, Dr. L. Swasticharan, Addl.DDG & Director (EMR), MoH, GoI's speech in which he talked extensively about the ministry's involvement in institutionalizing Patient Safety Movement. He endorsed patient participation in universal health coverage and highlighted the health, social and economic benefits that would be brought to the healthcare system in doing so. Dr. Swasticharan also laid emphasis on the steps taken by the ministry by declaring Safdarjung Hospital, New Delhi as a Centre of Excellence and touched upon other regional centres that would serve as pillars for patient safety in the future.

PLENARIES:

Universal Health Coverage as A Driver Of Equity, Inclusive Growth, And Regional Prosperity From The Lens Of Healthcare Financing

The Alma-Ata Declaration of 1978 emerged as a major milestone of the twentieth century in the field of public health, as it identified primary health care as the key to the attainment of the goal of Health for All. It strongly reaffirmed that health is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity. Quality healthcare is a fundamental human right and the attainment of the highest possible level of health is the most important world-wide social goal. The current state of the world predominantly invests in health in the form of insurance that caters to the population who are in ill-health. This form of approach is very medical care centric as opposed to health care, thus hindering the 2030 goal of Universal Health Coverage. In order to raise the quality and quantity of the regions who have attained health care, it is essential for all sectors, and not just the ministry of health, to invest in reaching this goal. The key to attaining universal health coverage is to mindfully finance the healthcare systems to ensure that people get good healthcare- when they need it and where they need it.

This session was on harmonizing UHC in the Asia-Pacific region by looking at various country perspectives and learning from the experiences. The audience received insights into established UHCs in the region and how they have, through patient engagement, extended the services to cover more people and bring in innovative services for patients.

Figure 2 Mr Rehan Khan - keynote address

The keynote address preceding this session was delivered by Mr. Rehan A. Khan, the Managing Director, India MSD who walked us down the journey of his 20-year long battle with the rare disease Churg-Strauss syndrome. He drew the attention of the audience to the questions patients commonly struggle with:

- o Will I get correctly diagnosed?
- o Will I get the right treatment?
- o Will I be able to afford the treatment?
- o Will I be able to recover and have a job to go back to?

Mr. Rehan's speech set precedence to the main topic of discussion, as the moderator and Chair Dr. Sanjiv Kumar, Chairperson and Managing Trustee, Three Domain Health Leadership Foundation introduced the four panelists:

- UHC in Thailand – Orajitt Bumrungskulswat, Assistant Secretary General, Heart to Heart Foundation, Thailand
- UHC in Sri Lanka – Dhanya Wijesuriya, Vice President, Diabetes Association of Sri Lanka
- UHC in Philippines – Karen Villanueva, President, Philippine Alliance of Patient Organizations
- UHC in India – Smitha Sadasivan, Civil Society Representative for the Global South on the UHC2030 Steering Committee

Ms. Orajitt highlighted the challenges faced by Thailand in selecting the right healthcare finance models for the country and its economic system, elaborating on how the People/Patient Participation in National Health Security System was undertaken not only at the national/regional/district/provincial levels but was also regulated by 9 People/Patient Networks and funded via multiple schemes.

Mrs. Dhanya then followed with how a multi-ethnic, middle-income country like Sri Lanka has been able to achieve 66% UHC by focusing on mandating health education and creating a synergy between the public and private healthcare systems. She also gave credits to good

road network, transportation, and

Figure 3 Panel on UHC

communication aids for quick access to healthcare.

Ms. Karen shed light upon the Universal Health Care Law or The Republic Act 11223, enacted in the Philippines in 2019 to provide financial risk protection, quality health services, and equitable access to medical care for all Filipinos. She elaborated on the 6 legislative steps undertaken in collaboration with all policy makers to support the universal health care law.

Lastly, Ms. Smitha wrapped up the discussion by talking about several initiatives taken by the Indian government and how the challenges and recommendations from neighboring countries can help us attain UHC. Some of the key topics discussed by her included The Ayushman Bharat Health Insurance, NITI AAYOG & SDG framework, National Public Health Observatory (NPHO), E Health & Telemedicine (Esanjeevani, Telemanas), and many more.

Health Literacy In The Digital World: Patient Empowerment With The Right Tools And Knowledge

According to the United Nations 2030 Agenda for Sustainable Development, the spread of information and communications technology and global interconnectedness has great potential to accelerate human progress, to bridge the digital divide and to develop knowledge societies. This realization birthed the WHO's Global Strategy on Digital Health 2020-2025 which indicated that the digital transformation of health systems is critical. It emphasized on 4 action points (1) commit - for the implementation of the global strategy on

digital health (2) catalyze- generation of a cooperative environment that is conducive to the creation, introduction and scaling up of appropriate digital health technologies (3) measure- to create and adopt processes and metrics for monitoring and evaluation (4) enhance and iterate- to respond to feedback and adapt to emerging digital health technologies. Similarly, The APEC Conference on Digital Healthcare Innovation concluded that Information and Communications Technology (ICTs) currently linked to the fields of health and medical care can provide healthcare professionals with more extensive and efficient tools for healthcare delivery by applying digital health data, wearable & sensors devices and smartphones apps to disease management, telehealth, and careful monitoring. Chair and moderator Einstein Rojas, Board member, Philippine Alliance of Patient Organizations invited 5 speakers to discuss the following:

- Addressing misinformation- Dr. Usha Rani, Associate Professor and Coordinator, Manipal Health Literacy Unit
- Is digital a unifier or devisor- Pru Etcheverry, Director, Advocacy Answers, New Zealand
- Health literacy from the HCP perspective - Prof Dr. Peter Chang, President, Asian Health Literacy Association
- Tools for Health literacy: Industry perspective - Dr. Arshiya Zaheer, Patient Engagement Lead, JCAP, MSD
- Patient friendly communication- Ms. Araceli Lanorio, Patient leader, Neurofibromatosis Friends, Philippines

Dr Usha Rani opened the discussion focusing the dangers of health-related claims on social media that are either based on anecdotal evidence, are false, or misleading owing to the lack of existing scientific knowledge. She talked about the power

that public figures such as politicians hold in influencing civilians regarding facts related to healthcare and the role of social media in disseminating misinformation. Most social media platforms stress and verify the authenticity of the facts being broadcasted through their services, rather the most "sensational" content gets rewarded, which is often exaggerated or controversial.

Ms. Pru addressed the very important question of whether technology is a means to promote inclusivity, accessibility, and reduce costs or is it a place where misinformation festers. Technology, when used for the right means, leads to equity, inclusion, and helps breach geographical boundaries. Digital healthcare goes beyond social media, and includes web-based services, mobile health, wearable technological devices, telemedicine etc., all adding to patient experience, understanding patient needs, offering a choice to how patients would like to receive information, and promoting patient education, training, and support.

Figure 4 Dr Arshiya Zaheer talking about health literacy.

Prof. Dr. Peter Chang spoke about health literacy from the perspective of a health care professional. He laid emphasis on the need to

put patients and HCP at the same table when discussing healthcare to promote empathy, tolerance, and understanding amongst the HCPs. He talked about how according to NHS; 61% adults struggle to understand health information that contains both words and numbers which makes designing healthcare systems and creating health literacy tools in a way that is understandable to the layman imperative.

Dr. Arshiya Zaheer spoke about the healthcare industry's role in health literacy. The patient's voice is the most important factor in any industry's pre-clinical stage of research to ensure the research prioritizes the needs of the public. Simultaneously, the patient voice is embedded during all stages of clinical development. The use of infographics to display data regarding the products, videographic presentations for ease of understanding and the use of QR codes for dissemination of large quantities of data are some of the steps undertaken by the industry for a patient centric approach to healthcare.

Ms. Araceli Lanorio, a Type 1 Neurofibromatosis patient, shared her experience as a healthcare receiver and emphasized on the need for the other healthcare stakeholders to be empathetic and invest in interactive methods and visual aids to help the patient understand their ailment and work towards recovery. Digital health literacy has a vast scope in equipping the public with the right knowledge, community building, promoting communication, addressing FAQs, simplifying scientific terminology, and increasing accessibility to a broader audience.

Access To Advanced Therapies, Genomics And Gene Therapy: Is Asia Pacific Ready For Advanced Treatments?

The emergence of commercial cell and gene therapies (CGTs) revolutionized the way we think about treating diseases. These advanced therapies have the potential to cure a range of illnesses that previously had limited treatment options, with the Asia Pacific region being at the forefront of this field, with several countries such as India, Japan, China, Korea, and Singapore, investing in their research and development.

The keynote speaker Dr. Claus Runge, Global Head, Market Access, Public Affairs & Sustainability, Bayer, opened the panel by acknowledging the rapid development of CGTs in the Asia Pacific region and emphasizing the importance of pharmacovigilance and safety aspects of this swift growth. He shed light on Bayer's role in ensuring availability, accessibility, affordability, and safety of CGTs, as one of the pioneering companies in the field.

The Chair and Moderator Dr. Madhulika Kabra, HOD, Medical Genetics, All India Institute of Medical Sciences, New Delhi, called upon 3 speakers to deliberate on the topics as follows:

o Promoting patient and patient groups led research- Dr. Saumya Jamuar, Director, SingHealth Duke-NUS Institute of Precision Medicine

o Access to innovative medicines and gene therapies- Dr. Ritu Jain, President of DEBRA International and DEBRA Singapore

o Data, registries, and technology- Have we really moved forward- Jeyaseelan Jeyaraj, Senior Director, Asia Pacific, Life Sciences Global Industry Unit Oracle Corporation

Dr. Saumya Jamuar opened the session by sharing the success story of gene therapy, not only offering treatment to patients, but also relieving them from the agony of not having the

right diagnosis. He talked extensively about the journey of patients suffering from PURA syndrome who found solace in research and support groups centered around CGTs in the Asia Pacific region. He mentioned the need for patient voices to be embedded in the stakeholder meetings to ensure a holistic approach to this digital transformation of healthcare. Certain challenges faced by the system such as ensuring data safety and receiving timely funding were also referred to.

Dr. Ritu Jain brought to light a much-needed consideration on the supposed transformation of

advanced therapies transform the healthcare system as we know it by working on low priced models and affordable therapies.

Mr. Jeyaseelan Jeyaraj brought a non-medical perspective into the discussion and emphasized the need for the general population to be aware of technical information to participate as active stakeholders in the development of advanced therapies. The emergence of CGTs brings about a customized focus towards healthcare, however, to ensure the steady rise of quality of medical facilities, digitalization needs to be parallel. Authenticated data sits at the core of all

Figure 5 Showcasing the opportunities and challenges associated with introducing and developing advanced therapies

healthcare due to CGTs. She questioned the affordability of such treatments, whether they are accessible to the public from medium to low income countries with conflicting health priorities and small health budgets. She expressed optimism for the future generations and reflected upon the need for skilled professionals and high specialty facilities to make

innovation due to which there is an urgent need of the establishment of one database, following one set of scientific technology, consisting of medical information of the entire population that is accessible to the right people.

Communicable Diseases: Is The Story Over; TB, HIV And Hep C- Lessons Learnt For Future Pandemics

According to WHO, communicable diseases, including tuberculosis (TB), viral hepatitis, sexually transmitted infections such as HIV/AIDS, and neglected tropical diseases (NTDs), are among the leading causes of death and disability in low-income countries and marginalized populations. HIV continues to be a major global public health issue, having claimed 36.3 million lives so far. 1.5 million people die from TB each year – making it the world's second top infectious killer after Covid-19. In addition to the high proportion of deaths and suffering that they cause, communicable diseases hinder social and economic development and can pose significant threats to international health security.

As documented in the WHO Results Report - Programme Budget 2018-2019, new recommendations on HIV testing services have been developed for the elimination of mother-to-child transmission of HIV. Furthermore, the WHO Director-General's Flagship Initiative has been fast-tracked to progress towards ending TB, over the period 2023-2027 with a focus on ensuring universal access to prevention, care and the latest tools and technologies to combat TB on the road to Universal Health Coverage (UHC). Similarly, WHO's global hepatitis strategy aims to reduce new hepatitis infections by 90% and deaths by 65% between 2016 and 2030.

Dr. Amitav Banerjee, Professor of Community Medicine, Dr. D Y Patil University of Medical Sciences and Research opened the session and called upon 3 esteemed speakers to share their experiences as follows:

o   Tuberculosis- Dr. Kuldeep Singh Sachdeva, Regional Director - The Union, Southeast Asia at International Union Against Tuberculosis and Lung Disease

o   HIV - Manoj Pardeshi, General Secretary, National Coalition of People Living with HIV in India (NCPI+)

o   Hepatitis - Danjuma K. Adda, President, The World Hepatitis Alliance

Dr. Kuldeep Singh Sachdeva pointed out how tuberculosis, a 20,000 old disease, finally has tools that can be used for its containment and elimination owing to the inclusion of patient voices and needs, along with the accessibility of free of cost healthcare facilities. The last 5 years have seen the cases of drug resistant TB go down from 40% to 90% due to the availability of managerial and public health tools such as sensitive and specific drugs. Furthermore, TB preventive therapy and the TB vaccines bring India a step closer to reaching its goal of going TB free by 2027.

Mr. Danjuma K. Adda shared his experience of losing his mother to hepatitis and being a survivor himself in a world where only 2% of people living in low-medium income countries have been diagnosed with hepatitis B and 0.1% have been placed on treatment. He underscored the need for the state and central governments to work with the WHO in reaching the 2030 hepatitis goal of 90% diagnosis and 80% treatment. He shed light on how the wide gap between the number of people diagnosed and the number of people put under recovery poses the biggest threat in reaching the 2030 goal.

Mr. Manoj Pardeshi introduced the idea of how treating bearers of sexually transmitted diseases such as HIV as "patients" can cause a lot of stigma to develop in society and directly hinder

people from seeking comfort and treatment at the right time. With the help of desensitization of STDs via support groups and awareness programs, emotions such as fear and despair have now turned to hope and courage. By

keeping human rights at the center, forming, and strengthening state and district level networks have helped strengthen people's voices to attain universal access to treatment.

Women's Health: Endometriosis, PCOS And NCDs. The Double Disadvantage Of Gender And Being Left Behind.

While poverty is an important barrier to positive health outcomes for both men and women, poverty tends to put a higher burden on women and girls' health due to decreased access to information and finances combined with malnutrition and use of unsafe cooking fuels (COPD). Women are often the caregivers in a family, yet when it comes to their own healthcare, they face several challenges, including barriers to access and quality. Most reproductive health programs do not go beyond maternal and child health and with the increasing trend of Endometriosis, PCOS and women cancers, there is an urgent need to address this very important issue of women's health, especially from the gender lens.

The health of women and girls is of particular concern since, in many societies, they are disadvantaged by discrimination rooted in sociocultural factors. Some of these factors include:

- unequal power relationships between men and women

- social norms that decrease education and paid employment opportunities

- an exclusive focus on women's reproductive roles

- potential or actual experience of physical, sexual, and emotional violence.

This end-of-the-day session was moderated by Dr Ratna Devi and was particularly important brought together 4 women from 3 different countries to share their perspectives on:

o HPV and Cx Cancer- Sutapa Biswas, Co-founder, Executive Director, Cancer Foundation India
o PCOS and Metabolic syndrome- Chand Kaur, Founder & Chief Executive of PCOS Relief, UK
o NCDs and Gender- Ranjit Pritam Kaur, Board Member, Reach to Recovery International, Breast Cancer Support, Malaysia
o Endometriosis and Lifelong diseases- Surita Mogan, President, Endometriosis Society of Malaysia (My Endosis)

Figure 6 The panel on Women's Health

Ms. Sutapa Biswas highlighted the importance of paying equal levels of attention to all types of cancer susceptible to women such as cervical

cancer, breast cancer, etc. She talked about her 23 year long journey of raising awareness on cervical cancer and emphasized on how people are still ignorant regarding the fact that Cx cancer is treatable. Elimination and eradication are two peas in a pod and only by vaccination, screening, management, and treatment, can cancer be eliminated, and along the 2030 target, eradicated.

Ms. Chand Kaur brought to attention how the frequency of PCOS is high among Indian women, compared to the global average. She talked in detail about the early onset and increased risks that women in the Asia-Pacific region are susceptible to. Social stigma, limited access to information, and language barriers lead to delayed diagnosis and treatment, increased risk of complications, and emotional distress. Access to healthcare services, including diagnosis and treatment for PCOS, varies significantly across different regions and socio-economic backgrounds making it imperative for the voices of women to be integrated in healthcare policies.

Ms. Ranjit Pritam Kaur shed light on the societal expectations of women which often leads to perceived stigma, prejudice & discrimination due to spread of misinformation- NCDs being "contagious". She touched upon the different barriers to prioritizing women suffering from NCDs, such as shortage of women HCPs closer to home, time away from responsibilities, limited access to health info, and out of pocket healthcare and other expenses. Changing the narrative from healthcare expenditure to healthcare investment would help harness local resources and offer possible solutions to move beyond gender norms and societal views in the healthcare sector. WHO's Framework for Meaningful Engagement for People Living with NCDs and Mental Health and Neurological Conditions is one of the many steps taken to overcome this travesty.

Ms. Surita Mogan shared her arduous journey of raising awareness regarding endometriosis, challenges in its diagnosis and the physical, emotional, and mental pain associated with it. She uncovered the myth that endometriosis can be cured using surgical means and questioned the quality of life that women led when suffering from the diseases. She urged the promotion of awareness campaigns, incentivization of organizations that support womens' health and validation of menstrual leave to those in need

Asia Pacific Patient For Patient Safety Networks- "Building A Regional Patient Network To Achieve GPSAP 2021-30"

The first session of day 2 of the summit opened with the importance of having patient networks to collectively embed patient voice into the healthcare system. Patient Safety is a health care discipline that aims to prevent and reduce risks, errors, and harm that occur to patients during the provision of health care. Patient participation and empowerment can play a major role in enhancing patient safety practices and are possibly the most effective tools for improving patient safety. Patients, families, and other informal caregivers provide insights from their care experiences that physicians, managers, and researchers cannot replace or reproduce.

WHO Patients for Patients Safety (PFPS) engages and empowers patients and families and facilitates their partnership with health professionals and policymakers to make health

care services safer worldwide. The decade of Patient safety 2021-2030 aims to provide Member States and other stakeholders with an action-oriented framework to facilitate the implementation of strategic patient safety interventions at all levels of health systems globally over the next 10 years i.e. 2021–2030. The Chair and Moderator Dr. Ratna Devi, Director, Patient Academy for Innovation and Research, called upon the stage, 5 speakers from the WHO, the pharma industry and patient advocacy to discuss the means to translate the PFPS 2030 plan in the Asia-Pacific region as follows:

o   The need for a regional Alliance of patient groups and way forward- Dr. Parminder Gautam, National Professional Officer, Patient Safety and Quality, WHO India
o   Ensuring right product at point of care using QR code - Dr. Gaurav Sharma, Head Regulatory Affairs and Safety, Reckitt Benckiser, (INDIA) Ltd and Dr. Mohammed Anwar, Risk Management & Vigilance Manager, Consumer Safety, Reckitt.
o   Patient reported safety incidents: building the metrics and creating the system- Manvir Victor, Chairman, Patient for Patients Safety Malaysia
o   Empowering patients to identify and report patient harm- Arshia Bhandari, Pharmacovigilance expert, Patient safety advocate, PhVFIt

Dr. Parminder Gautam opened the session by addressing the necessities of engaging patients as stakeholders in the healthcare system. He mentioned the key strategies of the Strategic Objective 4: Patient and Family Engagement and stressed upon the significance of establishing patient-centered care and involving patients as partners in their own care. WHO has several

Patient safety Networks and collaboratives in place such as The Global Patient Safety Network (GPSN), Global Patient safety Collaborative (GPSC), and The Global Medication Safety Network. A regional Alliance and 'Patient for patient safety network' would enable efficient and effective knowledge and experience sharing across the region, stimulate dialogue, promote continuous learning, and create unique opportunities for contributing to patient and family engagement. It is also the key to hosting a repository of resources for low-cost and easy-to-implement interventions.

Dr. Gaurav Sharma, shared Reckitt's initiative of using QR codes to direct the users at point-of-care services to the right platform. The use of QR code technology is the driver behind replacement of paper leaflets, taking a multidisciplinary approach in stakeholder management. Although theoretically sound, the implementation of QR codes faces hurdles in the form of varying acceptance levels by stakeholders, supply chain readiness, country-wise different legislative requirements, data management and IT readiness, and cost/resources needed by company to set up hosting platform.

Dr. Anwar Mohammed echoed Dr. Gaurav's take and demonstrated the scope of QR code technology with the help of an animated video presentation. The evolution of healthcare is of utmost importance to ensure digital literacy, provide open access to information, promote accessibility, combat counterfeit and encourage collaborations amongst different stakeholders.

Mr. Manvir Victor dwelled on a glimpse of the struggles of patients in Malaysia, where the healthcare workers often overlook the capabilities of patients in understanding their ailment. This gap comes from a place of underrepresentation and reinforces the need for the public to have a voice in the healthcare system. The Asia-Pacific is a region of complex cultures and societies due to which regional

Ms. Arshia Bhandari stressed upon the need for empowering patients to identify and report patient harm. As a patient safety advocate, she gave voice to patients across the region and implored the system to be empathetic and understanding. It is imperative that the healthcare system learns, corrects, and prevents future harm to patients, and that is the significance of patient stories. Patients journey

Figure 7 Dr. Anwar Mohammed showcasing the scope of animated informative videos for ease of understanding for people from non-medical backgrounds

patient advocates need knowledge and skills to understand the social and cultural setting to put forward contextualized approaches and solutions. In such a setting, where health is a sovereign matter, one-size-fits-all approaches will fail unless all the stakeholders sit at the same table to discuss policy changes.

through the entire health system and have a holistic understanding needed to build a strong foundation of the healthcare system. Hence, their perspective on how healthcare can be made safer is very valuable.

Life Course Vaccination

Vaccination is widely recognized as one of the most cost-effective public health interventions. Immunizations have significantly diminished the incidence of diseases, disabilities, and fatalities stemming from various infectious ailments. The development and administration of vaccines against COVID-19 proved to be a key element in the fight against the pandemic as national implementation plans and vaccination strategies

ensured the immunization of large segments of the population in the shortest time.

A recent economic assessment of 10 vaccines across 94 low- and middle-income countries indicated that a $34 billion investment in immunization programs yielded savings of $586 billion by curbing illness-related expenses, and when factoring in broader economic advantages, the savings amounted to a staggering $1.53

trillion. Given the aging global population, the resurgence of infectious diseases, and the heightened susceptibility of individuals with underlying health conditions, there is an escalating urgency to extend the benefits of vaccinations beyond childhood and throughout the entire lifespan.

The Chair and Moderator Chitra Gupta, Lead Patient Advocacy, Pfizer Inc., invited 4 excellent speakers from the government, patient organizations, and the industry to discuss:

o Vaccines as a life-saving measure- Dr. Raj Shankar Ghosh, Senior Advisor, Immunization, PATH
o Adult vaccination and challenges for uptake - Neelima Dwivedi, Executive Director, Market Access, MSD
o Vaccines for all: improving access- Dr. Supharerk Thawillarp, Division of Epidemiology, Department of Public Health, Ministry of Public Health, Thailand
o Patient-led Vaccination Campaign- Nelia Medina, Board Member, Philippines Alliance of Patient Organizations

Dr. Raj Shankar Ghosh deliberated upon the importance of physician awareness over public awareness and where to prioritize efforts: Policy leading to practice or Practice leading to policy. Ensuring UHC calls for a multifaceted approach combining both public and physician awareness to educate the population regarding the importance of immunization beyond childhood and ensure active promotion and administration of vaccines during patient visits. Establishing comprehensive immunization policies at the national and regional levels helps create a framework that guides healthcare practices to mandate vaccination protocols, set standards for healthcare professionals, and allocate resources

effectively, thus reinforcing "Policy leading to practice".

Ms. Neelima Dwivedi spoke a life-course immunization approach to ensure optimal vaccine uptake across adults of all ages as the first step to reduce morbidity and mortality in later life. However, lack of knowledge, myths and provider ignorance pose as threats to this mission. India has recognized the value of immunization and its consequences and added HPV vaccination to the National Immunization Plan. HPV is the only cancer that is preventable with potent treatment, however the effectiveness of this feat depends largely upon patients being rightly diagnosed and getting the cure.

Figure 8 Neelima Dwivedi, speaking on HPV Vaccination and challenges

Dr. Supharerk Thawillarp continued the conversation on the importance of timely diagnosis by sharing his experiences from the Ministry of Health in Thailand. He talked extensively about the Department of Disease Control's initiative- Thailand National Vaccination Act. The introduction of The National Personal Health Record brought the diagnosis, laboratory results, medications, and treatment history to one place for ease of access and follow-up for all patients. Digitalization of records

is the future of healthcare as seen in the successful story of Thailand and should be implemented in all countries.

Ms. Nelia Medina shed light on how patients and patient groups can support vaccination awareness and help improve uptake of vaccines.

She talked about her experience on the engagement of patient groups and their role in public awareness and policy building to replicate the success of Covid. For this, patient groups serve as a strong and active network to empower people to advocate for their rights and become productive members of society.

Case Studies: In-Depth Case Studies On Patients Led Best Practices

The inclusion of case studies in healthcare discussions enriches the overall experience, promotes learning, and contributes to a collaborative and informed community dedicated to managing and improving health outcomes. IPS brought together individuals with a common health condition, caregivers, healthcare professionals, and experts who got the real-world context and examples of how individuals have navigated and managed their health conditions. These discussions contribute to patient education by providing detailed accounts of the patient's journey, including diagnosis, treatment options, and lifestyle modifications and can empower people to make informed decisions about their own healthcare. By facilitating communication and collaboration, it can create a supportive community where individuals feel heard, validated, and connected with others who may be facing similar challenges.

This was an important session as patients from 5 countries shared their insights on the importance of advocacy inittiatives, successes and challenges for including interventions and treatment plans to meet the unique needs of each patient, taking into consideration, the environment, and socio-economic conditions they live in.

The session was moderated by Dr. Mahen Wijesuriya, Founder, Diabetes Association of Sri Lanka who invited four speakers to share their expertise and views:

o The Philippine Alliance of Patients Organization Patient Advocacy- Marimel Lamsin, Trustee, Philippine Alliance of Patient Organizations

o Building a National Alliance- Nidhi Swarup, Chair, Alliance of Patients' Organizations Singapore (APOS)

o Organization of Rare Diseases- Prasanna Shirol, Co-Founder Organization of Rare Diseases India (ORDI)

o Patient Educators of the comorbidity diseases: Diabetes, Heart, Kidney- Chuensuk Rerkngarm, Committee member, Heart to Heart Foundation

Ms. Marimel Lamsin, a member of a coalition of 52 patient groups in The Philippines, talked about various patient led activities such as The Philhealth Orientation, Universal Healthcare Capacity Building Workshops, Pandemic Response: Bakuna Now Na Webinars, and AIM Healthcare Leadership and Management Post Graduate Course to build patient capacity and equip them with knowledge on understanding the UHC Law, policy evaluation & monitoring, and patient safety.

Ms. Nidhi Swarup walked us down her long fight against Crohn's disease that started in 2009 when she experienced recurrent symptoms that left her incapacitated in Singapore. She talked about the arduous journey of going through numerous tests and exploring alternate methods to try to find a cure, all the while managing mixed emotions and questioning "why me?" She further briefed upon how patients like her cope with the diagnosis and struggle with going back to life, in an attempt to focus on things they can do, instead of those that they cannot. She dwelt on the steps to creating a National Network – The Alliance of Patient Organisations Singapore and the challenges in bringing various patient groups to a common platform.

Mr. Prasanna Shirol highlighted the shift in the Indian landscape of rare diseases since the emergence of a cohesive patient group. The existence of helplines has helped over 12,000

healthcare from their country

patients navigate to the right healthcare provider. When suffering from a long-term illness, it is often more important for the patient to be connected to the local/ nearest HCP as opposed to going to the specialist occasionally. The National Policy for Treatment of Rare Diseases helps mitigate the exorbitant costs borne by patients seeking treatment. It aims at lowering the incidence and prevalence of rare diseases based on an integrated and comprehensive preventive strategy encompassing awareness generation, premarital, post-marital, pre-conception and post-conception screening and counselling programmes to enable access to affordable health care to patients of rare diseases.

Mrs. Chuensuk Rerkngarm talked about Dr. Sanguan Nittayarumpong, the first Secretary General of The National Health Security Office in Thailand's attempt to bring together patients with chronic diseases, that require high-cost treatment, in order to empower them. She emphasized the necessity of providing correct knowledge to each patient to help them understand their body and the severe consequences of not taking proper care of it. Health behavior is difficult to change, due to which awareness building workshops such as The Cardio-Renal-Metabolic Patient Educator Workshop are of immense importance to build CRM patient educators networks and encourage cooperation and support among patient groups to give voice to patients collectively.

Mental Health- The Need For Integration Into All Programs

WHO defines health as "a state of complete physical, mental and social well-being", health has both physical and mental implications. However, many primary healthcare systems in countries around the world focus on physical care, failing to provide mental healthcare to their populations, leading to failure in addressing the holistic well-being of individuals. Today, 45 years after the adoption of the Alma Ata Declaration, the world seeks to re-affirm primary healthcare

as essential healthcare, universally accessible to individuals, presenting an important opportunity to integrate mental health as a priority in the system to stimulate awareness and acceptance.

Mental health conditions across all age groups are highly prevalent, affecting a significant portion of the global population due to factors such as work stress, relationship and familial obligations, heightened expectations, and domestic violence. The World Health Organization estimates that one in four people will experience a mental health issue at some point in their lives, leading to profound effects on the person's quality of life, productivity, and overall functioning.

The last session of the day brought together the Moderator Dr. Nand Kumar, Prof. In charge ICMR CARE in Neuromodulation for Mental Health and some of the most diverse representations of mental health advocates in the form of 4 esteemed speakers:

o Access to Mental Health in Asia Pacific- Dr. Vinay Kumar, President, Indian Psychiatric Society
o Mental Health for young people: challenges and opportunities- Dr. Harshita Umesh, Mental Health Advocate, Internal Lead, YOUNGO Health Working Group, UNFCCC
o Mental Health and end-of-life care- Smriti Rana, Head, Strategic Programs and Partnerships, Pallium India
o NCDs and Mental Health- Lopa Ghosh, Country Coordinator, Global Health Advocacy Incubator, India

Dr. Vinay Kumar brought to attention how the mental health chart is extremely skewed, due to a lot of the lesser-known disorders being neglected since they remain at the sub-clinical/ non-clinical or sub-syndromal levels. The Global

Burden Diseases of 1990 showed that mental health disorders remain at the top 10 hidden or neglected health challenges, with Asia-Pacific contributing to almost half the global population. India is a pioneer in removing the negative connotations from mental illness and raising awareness and voice via the establishment of initiatives such as the Asia-Pacific Community Mental Health Development Project. This project aims to illustrate and inspire best practice in community mental health care in the Asia-Pacific region through exchange of practical experience and current evidence through a high-level network of government mental health officials, leading psychiatrists, and research leaders from 17 countries/regions.

Dr. Harshita Umesh raised the point of how mental health is often viewed from an "individualistic" perspective, questioning the fortitude of the patient, when it should in fact be seen as a consequence of a lot of environmental, social and health complications. She talked about how the WHO Determinants of Adolescent Health proposed The Ripple Effect which states that a majority of low mental health cases stem out of factors at multiple levels such as the individual, family, community, environment, and society. There is ambiguity in the way of addressing a patient of mental health disorders and a person struggling with low mental health, often leading to desensitisation, negligence and dismissal of warning signs and symptoms. Furthermore, in the age of connectivity, the content on social media showcases a glamourized reality that puts pressure on the youth to meet unrealistic standards to feel a sense of belonging, leading to depression, panic attacks, burn-outs, and dissociations. Youth-led initiatives such as The Youth Mental Health Challenge aim to find innovative solutions to

reduce the stigmatization of mental health and empower youth today, to create a better world tomorrow.

Ms. Smriti Rana shed light on the other end of the spectrum by talking about the importance of palliative care once a person is diagnosed with a mental illness. Catastrophic out-of-pocket health expenditure pushes people to end their lives in an attempt to relieve their burdens. When interacting with patients, it is crucial to listen to them, understand what they know, help them gain clarity and support them through their struggles. Low mental health leading to lack of energy, change in appetite and body weight, impaired concentration and sleep disturbances not only impacts the quality of life of the patient but can also directly affect their treatments of other physical illnesses.

Ms. Lopa Ghosh echoed the previous sentiment and talked about how mental illness is one of the major risk factors for NCDs since low mental health has been associated with the consumption of tobacco and alcohol. She shared her experience as a cancer survivor who went through immense stress over financial stability, job security, and obligations towards family, all of which contributed to lowering her physical and mental health. She emphasized the role of peer and family support, with the accompaniment of cancer support groups, in preventing her from sinking into depression. NCDs and mental illnesses are shrouded in stigma which makes it necessary for awareness to be spread regarding the diagnosis, treatment, and management of the diseases without apportioning blame. It is important to advocate for stronger health systems and policy changes using insights from the lived realities of people living with NCDs or those who are victims and survivors of public health concerns.

Figure 10 Figure 10 A hearty discussion on various topics of mental health

WORKSHOP ON PATIENT SAFETY- PATIENT AND FAMILY ENGAGEMENT:

Figure 11 workshop on patient for patient safety network India

Patient Safety is a health care discipline that aims to prevent and reduce risks, errors, and harm that occur to patients during the provision of health care. Patient participation and empowerment can play a major role in enhancing patient safety practices and are possibly the most effective tools for improving patient safety. Patients, families, and other informal caregivers provide insights from their care experiences that physicians, managers, and researchers cannot replace or reproduce. This is especially true for people who have been harmed.

Today, patient harm due to unsafe care is a large and growing global public health concern and is one of the leading causes of death and disability worldwide. Collaboration with patients lays a solid foundation for the advancement of the health-care system as patients are more likely than health workers to have a holistic picture of the health care system rather than a focus on one specific aspect of it since they move through the entire system.

The objectives of our workshop included:

- Raising awareness on patient safety amongst stakeholders.
- Bringing together a diverse group of stakeholders from varied backgrounds in order to build a common understanding of patient safety.
- Engaging and educating patients and families to become the patient advocates.
- Strengthening awareness of the Patient for Patient Safety Flagship Initiative of WHO.

- Launching the Patient for Patient Safety Network India

The workshop was moderated by Dr. Parminder Gautam, National Professional Officer, Patient Safety and Quality, WHO India as he called upon the stage, 2 eminent speakers to discuss:

o Medication safety- Dr. Mahesh Devnani, Additional Professor and Joint Medical Superintendent, Dept. of Hospital Administration, Office of Medical Superintendent, Post Graduate Institute of Medical Education and Research
o Community involvement in patient safety- Dr. J N Srivastava, Advisor, Quality Improvement, NHSRC, GOI

The workshop targeted a diverse audience of approximately 40 participants, bringing them together to agree on a consensus statement as well as chart a way forward to actively engage with the government and WHO's initiatives on patient safety. Participant information slides and the WHO GPSAP document were disseminated to participants for their reading and preparation before the workshop. A pre-workshop briefing session was organized for the facilitators to align the objectives, expected deliverable outcomes, and roles and responsibilities.

Dr. Mahesh Devnani opened his speech with an emphasis on the importance of having the right knowledge regarding health and medical care to prevent the dissemination of misinformation. He talked about the dire consequences of medical errors with the help of a few examples such as taking the wrong medication, having the wrong dosage, and not adhering to prescriptions. As stated by WHO, around 1 in every 10 patients is harmed in health care and more than 3 million deaths occur annually due to unsafe care and 50% of patient safety issues are related to

medical errors. Some of the common adverse events that may result in avoidable patient harm are medication errors, unsafe surgical procedures, health care-associated infections, diagnostic errors, patient misidentification, etc. It is the responsibility of the patient to know each medicine prescribed, dispensed, and administered to them, and be aware of potential errors with Look Alike Sound Alike (LASA)

medicines to equip themselves with the right tools to lower medical errors.

Dr. J. N. Srivastava talked in depth about the community's involvement in patient safety, an approach that is highly underrepresented. There is a plethora of factors that need to be regulated at the societal level to prevent people from falling ill due to malnutrition, unsafe drinking water, poor sanitation, unhealthy lifestyle, and substance abuse. It is imperative for the

Collaboration

Communication

Consultation
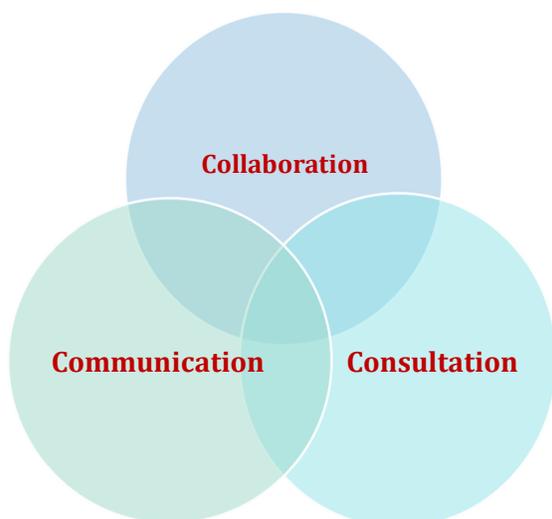
Figure 12

1. **Working with community structure and local leaders for nutrition and other forms of support**
2. **Engaging with staff at health facilities to assess feasibility of establishing PSGs**
3. **Mobilizing patients with the help of frontline health workers**

community to mobilize its resources and take responsibility for its own developmental activities to ensure shared decision-making for the overall improvement of the healthcare system. Several initiatives such as the National Quality Assurance Standards, a facility that ensures health promotion and disease prevention activities through community mobilization, and Platforms like Jan Arogya Samitis (JAS), Mahila Arogya Samitis (MAS), and Village Health Sanitation & Nutrition Committee (VHSNC) enhance patient knowledge and communication, while improving treatment adherence.

CLOSING STATEMENTS:

The Organizer, Dr. Ratna Devi thanked all the delegates for making the 1st IPS a great gathering, representing multitude experiences and patient voices from countries across the Asia-Pacific region. They also thanked those who made this event a success- the organizers: PAIR, DakshamA Health, HTH and PAPO, sponsors and partners, and the volunteers.

OUTCOME

Figure 13 pictographic representation of countries

The International Patient Summit was attended by over 200 delegates, comprising of both online and in-person attendants. Most of the delegates were patient representatives, and other sectors were represented by government officials, policy makers, academia, and industry partners.

We had over 50 speakers representing over 5 countries in the Asia- Pacific region. And from other parts of the world.

The event successfully concluded discussions across 10 topics and launched the Patient for Patient Safety Network India.

FINAL PROGRAMME

TIME (IST)	SESSION	SPEAKER
	DAY 1 11.12.2023	
9:00-9:20	**Inaugural session** **Opening remarks by the Organising Committee Karen Villanueva, Orajitt Bumrungskulswat, Dr. Ratna Devi** **Lamp lighting**	
9:20-10:00	**Opening keynote speakers**	
	Asia Pacific Region as the growing economy of the world. Investments in healthcare are urgent if the benefits of this growth have to be reaped and sustained. How is India leading the way?	**Dr. Soumya Swaminathan** (virtual) Chairperson of M S Swaminathan Research Foundation (MSSRF), Ex Chief Scientist WHO Inaugural address (virtual) (9:20-9:40) **Dr. L Swasticharan** (virtual) Addl.DDG & Director (EMR) Directorate General Health Services, MoH, GOI Guest of honour (9:40- 10:00)
10:00-11:15	**Universal Health Coverage as a driver of equity, inclusive growth, and regional prosperity from the lens of healthcare financing**	
	Chair & Moderator	**Dr. Sanjiv Kumar** (virtual) Chairperson and Managing Trustee, Three Domain Health Leadership Foundation, Chair, Indian Alliance of Patient Groups
	Opening address	**Rehan A. Khan** Managing Director, India MSD
	Speaker 1- Thailand	**Orajitt Bumrungskulswat** Committee member, Assistant Secretary General, Heart to Heart Foundation, Thailand

	Speaker 2- Sri Lanka	**Dhanya Wijesuriya** Vice President, Hon. Secretary, Board of Trustees – Diabetes Association of Sri Lanka, Director Administration - NCD Alliance Lanka
	Speaker 3 - Philippines	**Karen Villanueva** President, Philippine Alliance of Patient Organizations, Board Member, Philippine Tuberculosis Society Inc.
	Speaker 4 - India	**Smitha Sadasivan (virtual)** Civil Society Representative for the Global South on the UHC2030 Steering Committee
11:15-11:30		**Coffee break**
11:30-12:30	**Health literacy in the digital world: Patient empowerment with the right tools and knowledge**	
	Chair & Moderator	**Einstein Rojas** Board member, Philippine Alliance of Patient Organizations, Certified Innovation Professional – GIMI, Innovation Venture Architect and Foresight Consultant, Web 3 Marketing Consultant
	Addressing misinformation	**Dr. Usha Rani** Associate Professor and Coordinator, Manipal Health Literacy Unit, India Country office Head, Asian Health Literacy Association, Prasanna School of Public Health, Manipal Academy of Higher Education (MAHE), Manipal, India
	Is digital a unifier or devisor	**Pru Etcheverry** (virtual) Director, Advocacy Answers, Chair of the Auckland Regional Biobank, Chair of Grandparents Raising Grandchildren, Trustee with SkyCity Community Trust and Chair of Patients Representatives Roundtable, Asia Pacific ISPOR.
	Health literacy from the HCP perspective	**Dr. Prof Peter Chang** (virtual) President, Asian Health Literacy Association, Vice President, International Health Literacy Association, Adjunct Professor, Tufts University School of Medicine, former Ombudsman, Taiwan.

	Tools for Health literacy Industry perspective	**Dr. Arshiya Zaheer** Patient Engagement Lead, JCAP, MSD
	Patient friendly communication	**Araceli Lanorio** Secretary, Philippines Alliance of Patient Organizations, Patient leader, Neurofibromatosis Friends, Philippines
12:30-13:30	**Access to advanced therapies, Genomics and Gene therapy: Is Asia Pacific ready for advanced treatments?**	
	Chair & Moderator	**Dr. Madhulika Kabra** (virtual) Additional Professor, Genetics subdivision, Department of Pediatrics, HOD, Medical Genetics, All India Institute of Medical Sciences, New Delhi
	Keynote speaker	**Dr. Claus Runge** Global Head, Market Access, Public Affairs & Sustainability, Bayer
	Promoting patient and patient groups led research	**Dr. Saumya Jamuar** (virtual) Director, SingHealth Duke-NUS Institute of Precision Medicine; Inaugural Head, SingHealth Duke-NUS Genomic Medicine centre; Co-founder Global Gene Corp
	Access to innovative medicines and gene therapies	**Dr. Ritu Jain** (virtual) President of DEBRA International and DEBRA Singapore
	Data, registries, and technology- Have we really moved forward?	**Jeyaseelan Jeyaraj** Senior Director, Asia Pacific, Life Sciences Global Industry Unit Oracle Corporation
13:30-14:30	**Lunch**	
14:30-15:30	**Communicable diseases: is the story over; TB, HIV and Hep C- lessons learnt for future pandemics**	
	Chair & Moderator	**Dr Amitav Banerjee** Professor of Community Medicine, Dr. D Y Patil University of Medical Sciences and Research
	TB	**Dr Kuldeep Singh Sachdeva** Regional Director - The Union, Southeast Asia at International Union Against Tuberculosis and Lung Disease

	HIV	**Manoj Pardeshi** General Secretary, National Coalition of People Living with HIV in India (NCPI+)
	Hepatitis	**Danjuma K. Adda** (virtual) President, The World Hepatitis Alliance, Executive Director, Founder CFID, CCT Taraba
15:30-16:30	**Women's health: Endometriosis, PCOS and NCDs. The double disadvantage of gender and being left behind. How can we prioritize women's health?**	
	Chair & Moderator	**Dr Ratna Devi** Director, Patient Academy for Innovation and Research
	HPV and Cx Cancer	**Sutapa Biswas** (virtual) Co-founder, Executive Director, Cancer Foundation India
	PCOS and Metabolic syndrome	**Chand Kaur** Founder & Chief Executive of PCOS Relief, UK
	NCDs and Gender	**Ranjit Pritam Kaur** Board Member, Reach to Recovery International, Breast Cancer Support, Malaysia
	Endometriosis and Lifelong diseases	**Surita Mogan** President, Endometriosis Society of Malaysia (My Endosis)
Close of day 1 and wrap up **16:30-16:45**		
Day 2 **12.12.2023**		
9:00-9:30	Recap of day	
9:30-10:30	**Asia Pacific patient for patient safety networks- "Building a regional patient network to achieve GPSAP 2021-30"**	
	Chair & Moderator	**Dr Ratna Devi** Director, Patient Academy for Innovation and Research
	The need for a regional Alliance of patient groups and way forward	**Dr Parminder Gautam** National Professional Officer, Patient Safety and Quality, WHO India
	Ensuring right product at point of care using QR code	**Dr Gaurav Sharma** Head Regulatory Affairs and Safety, Reckitt Benckiser (INDIA) Ltd

		Dr Anwar Mohammed Risk Management & Vigilance Manager, Consumer Safety, Reckitt
	Patient reported safety incidents – building the metrics and creating the system	**Manvir Victor** (virtual) Chairman, Patient for Patients Safety Malaysia, Board member of Malaysian National Patient Safety Council, WHO
	Empowering patients to identify and report patient harm.	**Arshia Bhandari** Pharmacovigilance expert, Patient safety advocate, Founder PhVFIt
10:30-11:30	**Life course vaccination**	
	Chair & Moderator	**Chitra Gupta** Lead Patient Advocacy, Pfizer Inc.
	Vaccines as a life saving measure.	**Dr. Raj Shankar Ghosh** Senior Advisor, Environment Health, Public Health Foundation of India, Senior Advisor, Immunization, PATH
	Adult vaccination and challenges for uptake	**Neelima Dwivedi** (virtual) Executive Director, Market Access, MSD
	Vaccines for all- improving access	**Dr. Supharerk Thawillarp** (virtual) Division of epidemiology, Department of Public Health, Ministry of Public Health, Thailand
	Patient-led Vaccination Campaign	**Nelia Medina** Board Member, Philippines Alliance of Patient Organizations
11:30-11:45	**Coffee break**	
11:45-12:45	**Case studies: In-depth case studies on patients led best practices**	
	Moderator	**Dr. Mahen Wijesuriya** Founder / Honorary Secretary – Diabetes Association of Sri Lanka, Founder/ Honorary Secretary – NCD Alliance Lanka
	The Philippine Alliance of Patients Organization Patient Advocacy	**Marimel Lamsin** Trustee, Philippine Alliance of Patient Organizations
	Building a National Alliance	**Nidhi Swarup** Chair, Alliance of Patients' Organizations Singapore (APOS)
	Organization of Rare Diseases	**Prasanna Shirol** Co-Founder Organization of Rare Diseases India (ORDI)

	Patient Educators of the comorbidity diseases- Diabetes, Heart, Kidney	**Chuensuk Rerkngarm** Committee member, Heart to Heart Foundation
12:45-13:45	**Lunch break**	
13:45-14:45	**Mental health- The need for integration into all programs**	
	Moderator	**Dr. Nand Kumar** Prof. In charge ICMR CARE in Neuromodulation for Mental Health, Department of Psychiatry, AIIMS, New Delhi
	Access to Mental Health in Asia Pacific	**Dr. Vinay Kumar** (virtual) President, India Psychiatric Society
	NCDs and Mental Health	**Lopa Ghosh** India country coordinator for Global Health Advocacy Incubator
	Mental Health for young people- challenges and opportunities.	**Dr Harshita Umesh** (virtual) Youth Ambassador, Mental Health Advocate, Internal Lead, YOUNGO HWG (Health Working Group), United Nations Framework Convention on Climate Change (UNFCCC)
	Mental Health and end-of-life care	**Smriti Rana** Head - Strategic Programs and Partnerships, Pallium India, India Advocacy Focal Point for the International Association of Hospice and Palliative Care, Board Member, International Drug Policy Consortium.
14:45- 16:45	**Workshop on Patient Safety (patient and family engagement)**	
	Moderator	**Dr. Parminder Gautam** National Professional Officer, Patient Safety and Quality, WHO India
	Medication safety	**Dr. Mahesh Devnani** Additional Professor and Joint Medical Superintendent, Dept. of Hospital Administration, Office of Medical Superintendent, Post Graduate Institute of Medical Education and Research
	Community involvement in patient safety	**Dr J N Srivastava** Advisor, Quality Improvement, NHSRC, GOI
	Group work consensus building on SO4	**All facilitators**
	Closing remarks and way forward	Dr. Ratna
16:45- 17:00	Wrap up of day 2	

GALLERY

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