CoRE Scientific Conference 2022 Report

Patients as Partners for Health: Co-creating Equitable Access to Health Products and Services

5 – 6 October 2022

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Figure 1. From Left: Guest-of-Honour Dr Janil Puthucheary (Senior Minister of State, Ministry of Communications and Information & Ministry of Health); Adjunct Professor John Skerritt (Deputy Secretary, Australian Department of Health and Special Advisor to CoRE); Dr Lembit Rägo (Secretary-General, Council for International Organizations of Medical Sciences (CIOMS))

The Centre of Regulatory Excellence (CoRE) at Duke-NUS Medical School hosted the 2022 CoRE Scientific Conference with the theme *"Patients as Partners for Health: Co-creating Equitable Access to Health Products and Services"* from 5 – 6 October 2022. This conference builds upon previous roundtables on patient engagement in healthcare and access to medicines in 2019, 2020 and 2021, and the launch of the Coalition to Accelerate Patient Engagement (CAPE) in Asia-Pacific.

Over 250 participants from 22 economies representing patient groups and leaders, national regulatory agencies, healthcare administrators, academics, and industry attended the two-day conference. Adjunct Professor John Skerritt from the University of Sydney, Deputy Secretary at the Australian Department of Health and Special Advisor to CoRE chaired the Scientific Programme Committee. Dr Lembit Rägo, Secretary-General for the Council for International Organizations of Medical Sciences (CIOMS) was the co-chair.

Figure 2. Memorandum of understanding (MOU) between CoRE and CIOMS

During the conference, a memorandum of understanding (MOU) was signed between CoRE and CIOMS to strengthen ties and explore innovative opportunities of cooperation in promoting thought leadership and excellence in regulatory science. Preceding this conference, the CIOMS working group released a report titled *'Patient Involvement in the development, regulation and safe use of medicines'*. Key contributors to the report including Dr Juan Garcia Burgos, Dr Elisabeth Oehrlein, Dr Meredith Smith, Dr Marilyn Metcalf, Mr François Houÿez and Dr Lembit Rägo were also speakers and panellists in this conference.

Patients, consumers, and carers are at the centre of health products and healthcare systems and there is an increasing call to involve patients more throughout the product lifecycle from medical research, product development, regulation, financial reimbursement, and appropriate use of health products. In Asia, the culture and practice of patient engagement in this process are relatively nascent. It is timely to highlight the potential of engaging patients as partners in improving our health systems.

Applying and adapting emerging global best practices in patient engagement and access to health products for the Asia-Pacific region

The conference centred around three themes. The first, *'Applying and adapting emerging global best practices in patient engagement and access to health products for the Asia-Pacific region'* provided a platform for international regulators such as the European Medicines Agency (EMA) and Japan Pharmaceuticals and Medical Device Agency (PMDA) to share their wealth of experience in systematically involving patient and citizens as part of medicine regulation. Various initiatives include the EMA's Public Engagement Department and PMDA's Patient Public Involvement.

Using a patient-centred approach, clinical trials can be optimised to be more attractive and beneficial, thus increasing early enrolment by moving them into communities to facilitate participation. Early enrolment saves time, reduces dropout, and uses fewer resources. Patient engagement also increases investment in biomedical research, which is crucial to the development of health products.

Speakers highlighted that patient organisations and the pharmaceutical industry also play an important role in the development of clinical trials and regulatory approvals of medicines. Initiatives such as setting up community advisory boards for patient advocates and the inclusion of patient involvement at the beginning of clinical trials have accelerated the delivery of therapies, improved trial experience and facilitated meeting the unmet medical needs. One example of adapting global best practices could be from the Good Clinical Practice guidelines from the International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use (ICH), where stakeholders such as patients were involved to ensure stakeholders' perspectives on and experiences with clinical trials were considered in developing the guideline.

Current technological advancements have driven the rapid development of digital patient engagement tools which can improve patient engagement as well as provide faster, more accurate and targeted communication with patients. The session also discussed that digital patient engagement is often trackable at every step and enables a feedback mechanism which greatly enhances communication.

Communication in safety and healthcare delivery was another talking point at the conference. Communicating the right message at the right moment using the right language will lead to more meaningful engagement and enhanced risk minimisation. The best practices in risk communications are to use relevant, clear, and accurate messages to address any uncertainties considering the benefit of the medicine. High-quality communication with patients can have a positive effect on patient experience and behaviour, leading to better outcomes and safer use of the medicine. Engaging patients themselves in delivering the messages will help to build trust and combat misinformation.

One such example of risk communication during the COVID-19 pandemic was the communication on vaccine risk. Using targeted communications such as infographics and public safety reports with positive language and clear figures, the benefit of vaccines was communicated clearly to the public.

Other noteworthy points highlighted were that patients can also participate in the benefit and risk assessment of medicines. For example, Patient Preference Studies measure a patient's perspective on the benefits and risks, thus showing the trade-offs acceptable to patients. Patients' perspectives in Health Technology Assessment (HTA) is the process of determining the value of new health interventions and is crucial as it provides data on patient needs, preferences, experience and participation.

Practical implementation to increase the level and quality of existing patient engagement and partnership in Asia-Pacific

The second theme of the conference was *"Practical implementation to increase the level and quality of existing patient engagement and partnership in Asia-Pacific".* There are many ways in which patients can actively participate in the development of health product development and regulations. Patients can be involved as stakeholders in the process of policy development, as co-researchers in research, and as advocates in the development and dissemination of information. However, a top-down approach to effectively increase patient engagement is required. There is a need to move away from ad-hoc to a more organised, sustained, comprehensive approach to patient engagement.

One of the ways to practically increase patient engagement is to collect data pertaining to their health and medical conditions. Data such as symptoms and outcomes are important to patients. The impact of their treatment and conditions on their quality of life can help both researchers and patients build active, meaningful collaborations across all stages of the research process.

The session discussed that patient organisations are also effective platforms to bring patients to the forefront and increase the level of patient engagement. It can create awareness among patients on how they can contribute to healthcare, collaborate with training providers, and facilitate potential partnerships.

Speakers also shared that patient-generated health data (PGHD) are powerful data that can increase the quality of patient engagement. Health data can be used in prevention where data captured can inform and guide behaviour. It can also be used in diagnosis, where data can trigger patients to seek healthcare. Health data can also incentivize patients to take charge of their health maintenance and monitor treatment impact.

Examples of patient engagement efforts in the Asia-Pacific were shared. For example, the Patient Public Involvement (PPI) in Japan is a consortium that incorporates the perspective of patients and citizens into medical research and development. In Singapore, the Agency for Care Effectiveness, the national HTA agency has set up a workstream called the Consumer Engagement and Education (CEE) to support patients' involvement in ACE's technical work and development of educational resources.

Speakers also shared the importance of training and capacity building for those who engage with patients, as well as for patients themselves for patient engagement activities. This training is important as patient engagement requires specific knowledge, skills, and experience as well as an understanding of the nature of patient organisations, and the importance and value of patient involvement. Using tools and metrics, the impact of patient engagement can be assessed. Training in communication skills to convey patient engagement concepts, to engage in the medicines lifecycle and health technology assessment (HTA) is also important.

Figure 3. Panel Sessions during the Conference

Collaboration to promote and establish regional multi-stakeholder platforms for sustained engagement

The third theme of the conference was *"Collaboration to promote and establish regional multi-stakeholder platforms for sustained engagement".* Speakers shared on the Innovative Medicines Initiative (IMI) in the European Union (EU) which was set up with a mandate to improve health by increasing the development of innovative medicines as well as access to these medicines. An example of an IMI-funded project with strong patient involvement is the Patients Active in Research and Dialogues for an Improved Generation of Medicines (PARADIGM). PARADIGM provides a framework for structured, effective meaningful and ethical patient engagement.

The European Patients' Academy (EUPATI), another project by the IMI, is a public-private partnership representing patient organisations, NGOs, pharmaceutical industry, and academic institutions. EUPATI's mission is to provide accessible, innovative, and inclusive education that empowers patients and patient representatives with the knowledge and skills to engage with other stakeholders.

Figure 4. Networking Sessions during the Conference

The session concluded that it is important to establish multi-stakeholder platforms for greater health literacy for all stakeholders to increase patient engagement and shift from paternalistic to patient-centric health systems. Multi-stakeholder platforms have the potential to enable diversity in funding to improve sustainability and trust. It also encourages better data collection and sharing of disease registries, genomic studies, and clinical trials, leading to greater efficiency in efficacy and effectiveness studies. Ultimately, it promotes a better quality of life for patients through these platforms.

The conference ended with a closing session to collectively develop a conference statement. This statement brought together key points of the discussions over the two days of active exchanges. There is room to further institutionalise patient engagement in Asia-Pacific and this statement is a call for action to continue to do so. The statement reflects the recommendations from diverse stakeholders represented at the conference and recognises the common goal to advance patient engagement despite the diversity of social, cultural and health systems across the region.

The statement:

1. Support sharing of best practices in patient engagement from Asia-Pacific & globally to increase patient involvement in the development, regulation & access to health products

2. Encourage active steps to increase the level & quality of patient engagement & partnership for equitable access to health products & services in Asia-Pacific

3. Support efforts towards meaningful collaborations through multi-stakeholder platforms to facilitate regional capacity building in patient engagement.

Patient engagement remain a key focus for CoRE in 2023 and beyond. Together with CAPE, a multi-stakeholder platform hosted at the Duke-NUS Medical School, priority areas in the patient engagement landscape have been identified following this conference. CoRE and CAPE will continue to serve as a neutral platform to convene stakeholders and key opinion leaders locally and globally to generate important dialogue and discussion to advance patient engagement initiatives.

ANNEX

Scientific Committee for the CoRE Scientific Conference 2022

	Name	Designation and Organisation
1	Adj Prof John Skerritt	Adjunct Professor University of Sydney Deputy Secretary, Australian Department of Health Special Advisor, CoRE Advisory Board
2	Dr Lembit Rägo	Secretary-General Council for International Organizations of Medical Sciences
3	Dra Lucky Slamet	Former Head National Agency of Food and Drug Control Indonesia
4	Dr Meredith Smith	Senior Director Implementation Science Group Lead Patient-Centered Research Evidera, Inc. PPD, a part of Thermo Fisher Scientific Adjunct Professor, School of Pharmacy University of Southern California
5	Dr Elisabeth Oehrlein	Founder and CEO Applied Patient Experience, LLC
6	Ms Nidhi Swarup	Founder and President Singapore Crohn's and Colitis Society
7	Ms Fiona Pearce	Senior Advisor HTA and Consumer Engagement and Education Agency for Care Effectiveness (ACE) Ministry of Health, Singapore
8	Dr Juan Garcia Burgos	Head of Public and Stakeholders Engagement Department Stakeholders and Communications Division European Medicines Agency
9	Mr Nicholas Brooke	Executive Director Patient Focused Medicines Development
10	Mr Rajakanth R	Executive Director Rainbow Across Borders Ltd

Acknowledgements

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The views presented in this report are those of individual contributors and do not represent formal consensus positions of the authors' organisations or CoRE.

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