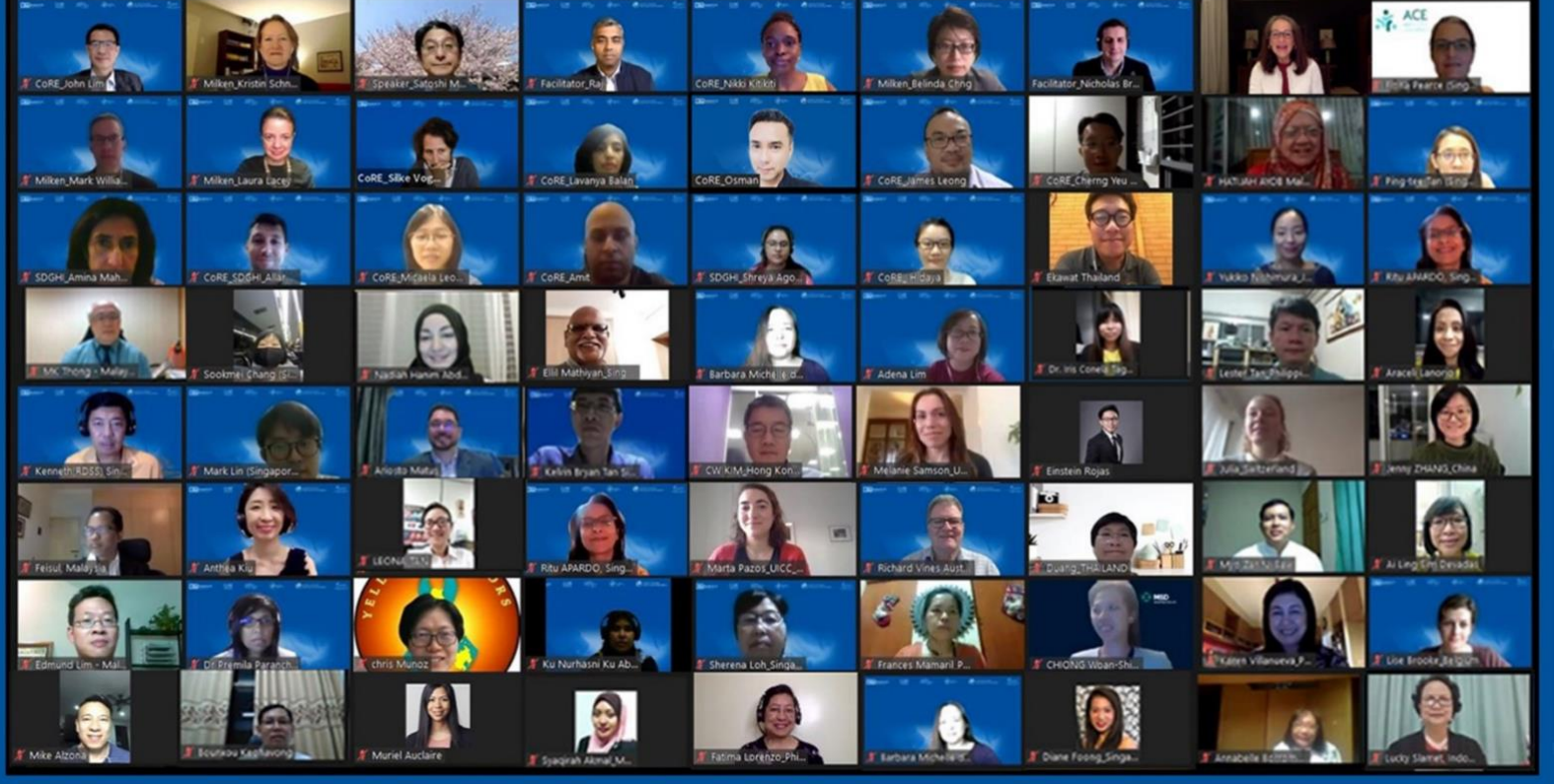


Regional Multi-Stakeholder Roundtable Report

Accelerating Patient Engagement for More Resilient Health Systems

23 - 24 November 2020

DukeNUS Medical School | CoRE Centre of Regulatory Excellence @ Duke-NUS Medical School | Rainbow Across Borders | Milken Institute | Patient Focused Medicines Development | SingHealth DukeNUS Academic Medical Centre Global Health Institute

Regional Multi-Stakeholder Roundtable: Accelerating Patient Engagement for More Resilient Health Systems

Introduction

The 2020 Duke-NUS regional patient engagement roundtable successfully launched the new Coalition to Accelerate Patient Engagement in Asia-Pacific (CAPE). CAPE is a multi-stakeholder partnership hosted at Duke-NUS Medical School (Duke-NUS) in Singapore to accelerate systematic and meaningful patient engagement in health systems across Asia-Pacific.

The inaugural CoRE-Milken Institute patient engagement regional roundtable in 2019 created a multi-stakeholder platform to accelerate patient engagement in health and access to medicines in Asia-Pacific. Building on its success, the second regional roundtable was co-hosted virtually from November 23-24, 2020 by the Centre of Regulatory Excellence (CoRE) in partnership with SingHealth Duke-NUS Global Health Institute (SDGHI)[1], Rainbow Across Borders[2], Milken Institute[3] and Patient Focused Medicines Development (PFMD)[4]. The theme of the roundtable was "Accelerating Patient Engagement for Resilient Health Systems".

The COVID-19 pandemic has brought unprecedented disruptions to our societies. Despite these challenges, this crisis has also revealed how integral patient engagement and meaningful partnerships with community groups are to the resilience of the health system. CoRE's patient engagement webinar in June 2020 highlighted how patients in South East Asia have been impacted by the pandemic and how as communities, they have come together to ensure support for those affected.

The COVID-19 crisis is an opportunity to accelerate the transformation we want to see in the health system with regard to patient engagement in healthcare and access to essential health products. It is more important than ever to continue the multi-stakeholder conversation we started at the inaugural roundtable on how to take patient engagement further in this region. The second roundtable discussed the findings from pre-roundtable informal focus groups with patient groups in five South-East Asian countries to identify the gaps and opportunities for patient engagement in each country. The focus groups also discussed the impact of the COVID-19 pandemic on patient engagement and stakeholder priorities.

The 63 participants at the roundtable included patient organisations, health policy-makers, regulators, industry and other healthcare stakeholders from 16 countries. The key discussion points of the multi-stakeholder discussion during the roundtable are summarised in this report and will guide action plans for future research and further engagement with stakeholders.

Introducing CAPE

CAPE is a multi-stakeholder partnership to accelerate systematic and meaningful patient engagement in health systems across Asia-Pacific. Duke-NUS provides an effective neutral platform and "hub" for convening, collaborating and building capacity for patient engagement among all health system stakeholders.

Currently, the pro tem steering committee members include the Centre of Regulatory Excellence (CoRE), SingHealth Duke-NUS Global Health Institute (SDGHI), FasterCures, a

[1] SingHealth Duke-NUS Global Health Institute website: https://www.singhealthdukenus.com.sg/sdghi
[2] Rainbow Across Borders website : https://www.rabasia.org/
[3] Milken Institute website with links to the participating centres of the Institute Milken Asia and FasterCures https://milkeninstitute.org/
[4] Patient Focused Medicines Development website : https://patientfocusedmedicine.org/

centre of the Milken Institute, Milken Institute Asia, Rainbow Across Borders and Patient Focused Medicines Development. Over time, broader participation in the steering committee will be sought. CAPE is the first patient engagement platform rooted in Asia and working across disease areas, while engaging all relevant health stakeholders including patient organisations, national regulatory agencies, health ministries and industry. CAPE's vision is to support development of strong and people-centred health systems in Asia-Pacific that are oriented around the needs of patients and communities. CAPE sees itself as an enabler to promote evidence-based and collaborative patient engagement in this region.

Fig 1. CAPE as a multi-stakeholder hub for patient engagement

A Growing Patient Engagement Community

Duke-NUS, as the host for CAPE, provides a neutral academic platform for this emergent community of stakeholders who are committed to meaningful, evidence-based expansion of patient engagement in health systems in Asia-Pacific. We were honoured to welcome 63 participants from 16 countries over the 2-day roundtable from Nov 23-24, 2020. We welcomed back many participants from the 2019 inaugural roundtable and connected with new patient groups and other stakeholders during the pre-roundtable focus groups.

The second roundtable welcomed patient groups from Australia, China, Malaysia and the United States for the first time, as well as additional new patient groups from Japan, Philippines and Singapore that were not represented in 2019. We also welcomed attendees from health authorities not previously represented, including Singapore's Agency for Care Effectiveness (ACE), Malaysian Health Technology Assessment Section (MaHTAS) of the Ministry of Health, Health Technology Assessment Council Philippines, Philippines Food &

Drug Administration, and Thailand Food & Drug Administration. CAPE will continue to expand our community networks within Asia-Pacific and beyond.

Learning from Global Experiences in Patient Engagement

Impact of COVID-19 on patient engagement in the United States and Europe

The inaugural roundtable in 2019 highlighted the evolution of the patient engagement landscapes in the United States and Europe over the last 30 years. Patient advocacy has contributed to many changes to involve patients in the conduct of clinical trials and regulatory decision-making processes. In recent years, as Health Technology Assessment (HTA) and value-based care has become more important, patients have also been included in decision-making around funding and reimbursement of medical treatments, appropriate use of health products as well as creation of clinical practice guidelines. Although the United States and Europe have made great strides in developing their patient engagement landscape, it is important to note that systematic, meaningful inclusion and involvement of patients in all aspects of the health system is still not the norm in any region of the world. The journey toward true patient engagement continues to develop through dialogue and collaboration among the various stakeholders.

Kristin Schneeman, our co-facilitator from FasterCures, shared how COVID-19 has amplified deep-rooted disparities among different groups within the United States. Patients from certain ethnicities, socioeconomic backgrounds and occupations have been disproportionately impacted by COVID-19 mortality and morbidity. Through feedback from community engagement, researchers and industry were encouraged to ensure increased diversity in clinical trials for vaccines and other therapeutics for COVID-19. There have been some positive developments in medicines development due to the COVID-19 crisis; for example, national lockdowns forced developers to rethink how to conduct clinical trials. Remote monitoring through digital technologies has become more widespread and more patient-centric changes, such as decentralised trials, have been adopted since the pandemic started. Hopefully, some of these positive developments will be preserved in the long-term.

We also heard from Nicholas Brooke, our co-facilitator from Patient Focused Medicines Development (PFMD), how COVID-19 has brought about a huge acceleration in patient engagement through increased use of digital touchpoints and decreased need for travel. On the flip side, however, COVID-19 has also revealed a crisis of public confidence in science and vaccines. Community engagement by all health authorities around the world will be key to increase acceptance of vaccines and other policies that require the public to change their behaviours to protect their health. Patient engagement is more important than ever before.

Lessons from the patient engagement journey in Japan

Satoshi Miki, Board Member at Patient and Public Involvement Japan (PPI Japan)[5], shared updates on patient involvement in Japan. PPI Japan was established in 2019 with Dr Kondo, former Chief Executive of the Japan Pharmaceuticals and Medical Devices Agency (PMDA), as its head. It is an open forum for patients, industry, academia and PMDA to promote mutual understanding and collaboration among essential stakeholders in medicines development. This non-confrontational platform aims to support patient involvement in the health system through education programs to increase capacity and coordination with other relevant bodies in Japan including the regulatory agency and medical research authorities to co-create resources. Mr Miki emphasised that while PPI Japan and other stakeholders in the patient involvement ecosystem take reference from global best practices and resources, the key to

[5] PPI Japan website (in Japanese) : https://ppijapan.org/

adoption in Japan is to adapt these resources and not merely copy and paste to the Japanese context. PPI Japan has become the first national platform of the European Patients' Academy on Therapeutic Innovation (EUPATI) outside of Europe with fully translated resources in Japanese. EUPATI is a leader in patient education in medicines research and development through their patient-friendly resources and patient expert courses.

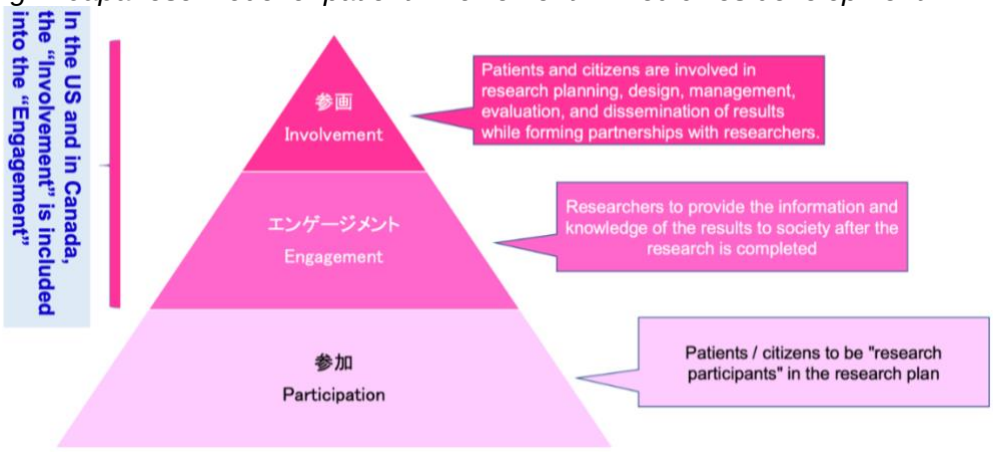
> *Simply copying and pasting EUPATI was not an option. The background and relationship of patients and medicine as well as cultural aspects in Japan are so different from those in Europe. Rather, we are fully utilising the best practice of patient engagement initiatives in the world, like EUPATI, for the benefit of patients and the general public in Japan*

Mr Miki Satoshi
Board Member
PPI Japan

Besides the activities of the PPI Japan, other stakeholders in Japan are adapting and co-creating resources for patient engagement. In May 2019, the PMDA created the Patient Centricity Working Group to discuss how patients can be more involved in their overall activities and a guidance for patient engagement is expected from this working group in 2021[6]. The Chief Executive of PMDA has also stated that Japan is looking to learn from global best practices such as EUPATI, the Patients' and Consumers' Working Party at the European Medicines Agency (EMA)[7] and the Patient Representative Program at U.S. Food and Drug Administration (FDA)[8] and adapt those to the Japanese context to provide training to healthcare professionals, patients and the public. A PPI Guidebook has also been developed by the Japan Agency for Medical Research & Development[9]. The PPI models highlighted from Japan are focused on medicines development but the principles of patient involvement are applicable to all areas of the health system.

[6] Presentation by PMDA Chief Executive at DIA Europe 2020 https://www.pmda.go.jp/files/000235787.pdf
[7] EMA Patients' and Consumers' Working Party https://www.ema.europa.eu/en/committees/working-parties-other-groups/chmp/patients-consumers-working-party
[8] FDA Patient Representative Program https://www.fda.gov/patients/learn-about-fda-patient-engagement/about-fda-patient-representative-program#:~:text=The%20FDA%20Patient%20Representative%20Program%C2%AE%20is%20the%20agency's%20flagship,drugs%2C%20biologics%2C%20and%20devices.
[9]Japan Agency for Medical Research and Development, PPI Guidebook (in Japanese) https://www.amed.go.jp/ppi/guidebook.html

Fig 1. Japanese model of patient involvement in medicines development[10]



Pre-roundtable Informal Focus Groups

Rajakanth R., our co-facilitator from Rainbow Across Borders, shared the results of the pre-roundtable informal survey and focus group discussions that were conducted with patient groups in the third quarter of 2020. The focus groups included patients from five South-East Asian countries (Indonesia, Malaysia, Philippines, Singapore and Thailand) to identify the gaps and opportunities for patient engagement in each country. The sessions also discussed the impact of the COVID-19 pandemic. We aim to continue the landscape mapping to feed into our future roundtable discussions and the development of plans for CAPE. Overall, we found that patient engagement is not yet well integrated in most countries but there is progress and opportunities identified within countries to accelerate meaningful patient engagement. We identified key themes that were common in focus groups across all countries around gaps and challenges, capacity building needs and recommendations of how to improve patient engagement.

[10] Mr Satoshi Miki, PPI Japan. Presentation slides at the 2nd Duke-NUS Regional Roundtable on Patient Engagement (Nov 23, 2020)

Tab 1. Summary of common findings in pre-roundtable informal focus groups in Indonesia, Malaysia, Philippines, Singapore and Thailand[11]

 Common Gaps	 Common Capacity-Building Needs	 Common Recommendations
• Need for holistic frameworks of care that integrate and equally prioritise medical, social, economic and mental health needs. • Fragmented schemes for financing the continuum of care for chronic conditions • Variation in standard of care across different regions and providers within countries • Lack of access to medical products and treatments available in other countries • Limited access to national level data to support advocacy and policy planning • No platforms for continuous engagement and dialogue with senior key decision-makers in healthcare organisations and government agencies • Negative perception of patient groups by policymakers and healthcare professional and concerns about conflicts of interest	• Patient navigation and caregiver capacity-building • Fundraising and strategic planning for the organisation • Sustaining volunteer manpower and pipeline of advocates • Capacity for data collection and evidence generation • Making the case to key decision-makers • Understanding clinical trials and regulatory process	• Create platforms for continuous, sustained patient engagement • Develop overarching frameworks for care for specific diseases with multi-ministry taskforce coordination and/or legislative oversight • Promote plain language resources to explain clinical research and scientific terminology

[11] Please note that these findings are not from a representative sample within countries but an interim pre-roundtable convenience sampling. These findings do not represent the views of the majority of patients in the countries but is a summary of the opinions of the limited specific group involved in the focus group.

Adapting Global Best Practices in Asia-Pacific

In Asia, patient engagement with health authorities, industry and academia is still in a nascent stage but at a point ripe for increased visibility and development. It is also an exciting time for innovative financing for health. Laura Deal Lacey, co-facilitator from Milken Institute Asia, shared on the increasing role of Asian philanthropic centres in supporting access to healthcare and research for lung, liver and nose cancers.

The positive developments in patient engagement in Japan and other patient engagement ecosystems such as those in South Korea, Taiwan and Australia hold many lessons for other parts of Asia-Pacific on how to effectively utilise existing global resources while contextualising them for the specific local environment. We should prioritise culturally relevant approaches for Asia-Pacific countries and seek not just to *adopt* existing global resources but rather *adapt* through a collaborative discussion with all relevant stakeholders. Leveraging existing resources from other regions gives Asia-Pacific the opportunity to even potentially leapfrog some of the lengthy journeys that have played out over decades in other regions.

The second day of the roundtable welcomed an intentionally smaller group of stakeholders from the five ASEAN countries where we conducted our pre-roundtable focus groups. They were invited to reflect on what can we learn from successes and challenges in other regions to shape the direction of the patient engagement landscape in South East Asia. The group was split into breakout sessions to discuss the challenges and potential opportunities in the following areas: creating platforms for patient engagement, moving from anecdotes to evidence, and building capacity and capability for patient engagement in the region.

Platforms for Patient Engagement

The US FDA and EMA have developed formal, regular platforms to engage with patients on matters relating to medicines development. At the FDA, the FDA Patient Representative Program is the agency's flagship program that offers patients and caregivers the opportunity to provide critical advice to the agency in regulating medical products[12]. Candidates are carefully recruited and trained to prepare them for various agency-sponsored meetings and activities. FDA Patient Representatives who serve on Advisory Committees that review drug and biologic therapies are temporary members of the Committee with voting privileges. The Patients' and Consumers' Working Party (PCWP) at the EMA provides a platform for exchange of information and discussion of issues of common interest between EMA and patients and consumers. In Japan, the PPI Consortium provides a platform for the medicines development stakeholders to build mutual understanding among stakeholders. The PMDA aims to explore adopting certain elements of the FDA and EMA patient engagement platforms.

Due to historical legacies, many of the patient engagement ecosystems in Europe and the United States, have been focused on regulatory agencies. However, platforms for engagement are also emerging for other areas of the health system such as in Health Technology Assessment (HTA), Clinical Practice Guidelines (CPG), public health policymaking and in healthcare delivery. The areas of the health system with greater potential for expansion of patient engagement in the short term may turn out to be different in Asian countries than what has happened in other regions. Some insights on emerging platforms in various South East Asian countries are provided below.

[12] United States FDA. FDA Patient Representative Program website https://www.fda.gov/patients/learn-about-fda-patient-engagement/about-fda-patient-representative-program

Existing Platforms in ASEAN

Overall, the breakout discussions highlighted that there are few formal, regular platforms for patient engagement in most countries. Examples of existing platforms include those at Malaysian Health Technology Assessment Section (MaHTAS), Ministry of Health Malaysia where patients have been involved in platforms responsible for conducting value and evidence-based assessment on technologies as well as evidence-based clinical practice guidelines (CPG). Philippines Health Technology Assessment Council also includes a citizen representative. SingHealth Patient Advocacy Network (SPAN) is an example of a platform for patient engagement in healthcare delivery in Singapore's largest public healthcare cluster. The Singapore Agency for Care Effectiveness (ACE) has plans to create a consumer engagement platform.

The existing platforms are positive signs of opportunities within these countries. However, more needs to be done to formalise the structure of engagement in these platform, to move from ad hoc to regular interaction and co-creation of solutions through the platforms. Often, organisations gather patients' comments on finished projects at a later stage rather than co-creating with patients from the start. Some participants highlighted that it would be beneficial to have formal platforms that enable patients to engage at a higher level in organisations and ministries to make the most impact. It is also important to build the capacity of patients participating in such platforms to be able to contribute in a meaningful and informed way.

A key enabler for such platforms would be to increase interaction among different stakeholders. Some participants felt that health authorities may have a negative perception of patient groups having conflicts of interest, so they are wary of attempts at advocacy. As discussed during the inaugural roundtable, culturally, the term "advocacy" still has negative connotations in Asia but through increased frequency of engagements via platforms such as CAPE, stakeholders can build more trust and mutual understanding of what patient engagement done the right way looks like.

Capacity and Capability Building Needs

Information & Knowledge Gaps

The group discussions identified information gaps among all stakeholders as a major challenge. Patient groups may lack information on their conditions and on how various organisations' processes work. Patients and caregivers often have to navigate complicated health systems on their own with incomplete information. Having condition-specific information and patient journey roadmaps curated for patients would help to meet some of their knowledge needs. Some participants also felt that non-specialist healthcare professionals also need to increase their knowledge on diagnosis and management of certain conditions, especially rare diseases, that they may not have been exposed to in their training.

Skills for Multi-stakeholder Engagement

Patients need to develop technical skills to understand some aspects of healthcare delivery, clinical research, regulation and health technology assessment. Training in these technical aspects would help patients to feel more confident when engaging health authorities and to be able to better contribute to decision-making. Some participants shared that with increased online learning adoption, many global courses are now available without the need for travel. However, as most of the resources are in English, the few patients who are able to attend find it difficult to share the knowledge gained with others who are unable to take the digital courses. There is a need for resources in multiple languages that are pitched at different levels of health literacy among patients. It was encouraging to hear of emergent capacity-building initiatives

for patients in Asia-Pacific such as the Union for Cancer Control (UICC) Masters Course for oncology patient groups[13] and the upcoming Patient Academy for Innovation and Research (PAIR) supported by the International Alliance of Patient Organisations (IAPO).

It is not just patients that need capacity building. Healthcare professionals also need training to increase their confidence in technical aspects of health economics and regulation beyond clinical care. And health authorities need more guidance and case studies on how to use best incorporate patient experience data in their work. Also, besides the technical skills, it is important for all stakeholders to develop their communication skills to facilitate effective and constructive conversations. Soft skills for patient engagement are as important as technical skills as we develop capacity and capability for patient engagement.

Organisational Development

Strong patient leadership comes from strong patient organisations that are able to manage their governance, fundraising and strategic communications well. Developing the organisational capacity of patient groups strengthens their ability to achieve their primary objective of supporting their patient and caregiver beneficiaries in a sustainable fashion. Patient organisations in the region face challenges in long-term strategic planning as they are often focused on short-term survival due to lack of sustainable funding and manpower. During the roundtable discussion we heard of new programmes such as the Pinnacle program by Rare Cancers Australia which provides important multilingual resources focused on organisational development for patient organisations across disease areas[14].

Moving Beyond Anecdotes to Evidence

One common challenge for meaningful integration of patient involvement in health systems is that health professionals are more comfortable evaluating data based on clinical and quantitative data while many patients wish to share their stories and experiences. A combination of quantitative and qualitative data is important to give the full picture and understanding of the impact of any treatment or programme on the real-world quality of life of patients. Legislation such as the 21st Century Cures Act [15] in the United States now requires the FDA to include patient experience data in any evaluation of health products which has rapidly developed the science of patient engagement through the use of patient experience data. The FDA has published its first guidance on how to collect both qualitative and quantitative patient experience data and EMA is also expected to release its guidance soon[16,17]. There is also increased use of patient experience data for Health Technology Assessment and in clinical care.

Use of patient experience data in Asia

The roundtable discussion revealed that use of patient experience data is still limited in Asia, especially among regulators and policymakers. Although emergent frameworks for patient involvement and use of patient experience data are available through international

[13] UICC Master Course https://www.uicc.org/what-we-do/capacity-building/online-learning
[14] Pinnacle Program: https://pinnacle-patient.org/
[15] FDA.gov summary slides "Collecting Patient Experience Data: How You Can Best Help the FDA" https://www.fda.gov/media/112163/download
[16] FDA Guidance on Collecting Comprehensive and Representative Input (June 2020) https://www.fda.gov/regulatory-information/search-fda-guidance-documents/patient-focused-drug-development-collecting-comprehensive-and-representative-input

[17] EMA Summary slides (Nov 2019) EMA's Regulatory Strategy to 2025 Human Stakeholder Workshop "Reinforce Patient Relevance in Evidence Generation" https://www.ema.europa.eu/en/documents/presentation/presentation-ema-regulatory-science-2025-reinforce-patient-relevance-evidence-generation_en.pdf

organisations like FDA, HTA International[18], and the Council for International Organisations of Medical Sciences (CIOMS) [19], further work is needed to familiarise stakeholders in Asia-Pacific with these available resources. It is important to increase awareness of the value of structured approaches to collecting patient data that can be used by healthcare professionals, industry and even patient groups themselves. Once there is awareness of these frameworks, the next step is to discuss with stakeholders if these frameworks are relevant in their setting and how they may be adapted to be more culturally relevant if needed.

Health system stakeholders should shift their thinking from focusing on the potential risks of patient engagement to highlight the risks of not engaging patients, as well stated by Nicholas Brooke. The COVID-19 pandemic has magnified the risks of not communicating, coordinating and collaborating with patients and community organisations. We were honoured to have Dr Margaret Hamburg, former U.S. FDA Commissioner to close the first day of the roundtable and her message on the increased importance of patient engagement during this crisis is worth keeping in mind as we launch the next stage for the CAPE community.

> *If the people are not engaged and if people don't trust the system, science, medical product innovations, and health systems, then even the best innovation becomes useless. Patient needs and engagement should not be an after-thought but should be the central driver of all efforts.*

Dr Margaret Hamburg
Former Commissioner
U.S. Food And Drug Administration
Interim Chair, CoRE

The Potential Role of CAPE in Advancing Patient Engagement in Asia-Pacific

Create awareness about the value of the patient voice in health systems

- Promote holistic, culturally relevant approaches to patient engagement in our region
- Landscape mapping within countries for local understanding of ecosystem challenges and opportunities
- Highlighting global trends and best practices, case-studies and trends through publications, webinars and special events

Convene stakeholders who normally would not have the opportunity to dialogue to co-create local solutions

- Regional multi-stakeholder roundtables to share best practices and experiences across countries
- Country multi-stakeholder roundtables to initiate platforms to build regular engagement among stakeholders with a long-term view that this will spark locally-driven platforms geared toward the local needs.
- Events focused on specific themes with the relevant stakeholders

18 HTAi. Patient Engagement in Early Dialogues: Tools and resources for HTA bodies https://imi-paradigm.eu/petoolbox/pe-in-ed-hta/

19 CIOMS. Working Group XI: Patient Involvement in Development and Safe Use of Medicines https://cioms.ch/working-groups/working-group-xi-patient-involvement/

Collaborate to build capacity and networks

- Establish collaborative capacity building programmes for all stakeholders in effective communication and multi-stakeholder engagement
- Support networks of global and regional organisations to provide training for evidence-based approaches to patient engagement

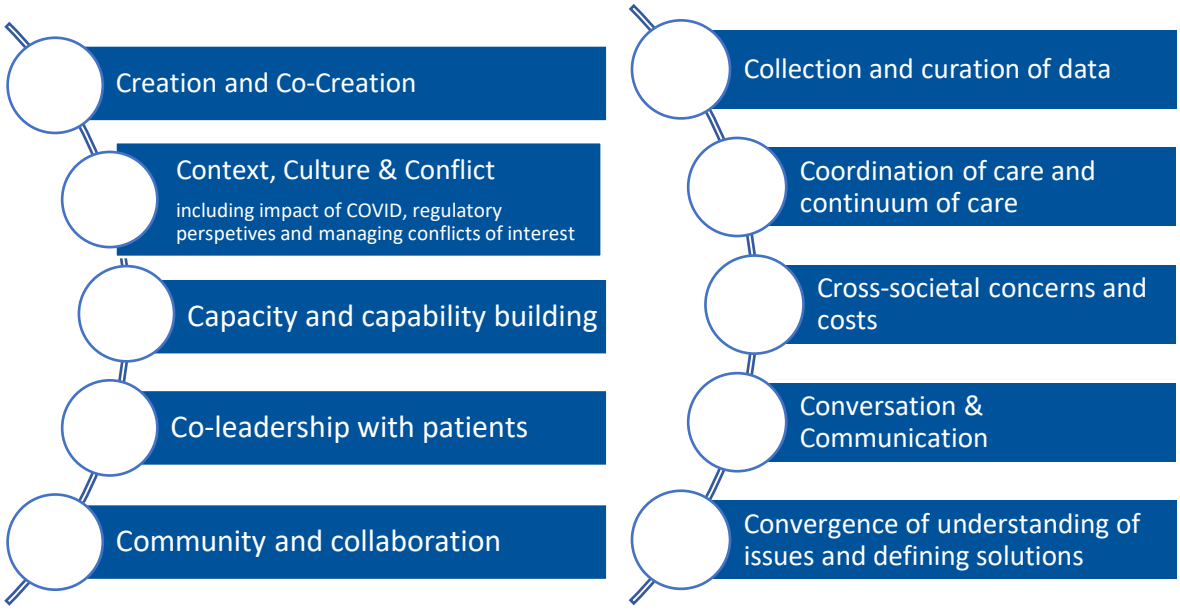
Patient engagement is relevant to all aspects of the health system and there is an opportunity for CAPE to engage along a spectrum of activities. For the inaugural year of CAPE, the priority areas will be expanding the landscape mapping within ASEAN countries to include more stakeholders, focusing on patient engagement in access to medicines (inclusive of regulation, HTA and health financing) and collaborating with partners for capacity-building for all stakeholders.

As we launch CAPE not all topics relevant to patient engagement more broadly can be prioritised and led by CAPE beyond creating awareness. However, we encourage any members of the community with a keen interest to drive programme activities in any area through the CAPE platform to contact us to discuss further.

Fig 2. A Snapshot of Areas Relevant for Patient Engagement

The overall essence of the roundtable discussion was captured by John Lim, Executive Director at CoRE, who summarised the key take-aways in 10Cs as described below.

Snapshot of Major Themes of the 2020 Regional Roundtable: The 10 Cs [20]



Next Steps for CAPE: Priority Areas for 2021-2022

- **Co-create platforms for patient engagement**
  - Host regular regional multi-stakeholder roundtable as a platform for learning and sharing best practices among the community
  - Host and seed country-specific versions of multi-stakeholder roundtables to co-create country relevant solutions and increase regular interaction among diverse stakeholders within countries to foster trust and mutual understanding.

- **Patient engagement in access to medicines**
  - Increase awareness of the value of the patient perspective throughout the lifecycle of health products from clinical research, regulation, health technology assessment, and safety monitoring
  - Host focused symposia series to update on the best practices in the use of patient experience data in health planning and decision-making frameworks for regulation and HTA

- **Capacity and capability-building for all stakeholders**
  - Curate global best practices and existing resources that may be relevant to Asia-Pacific with a long-term view to facilitate discussions on how to adapt and adopt in our region
  - Collaborate with existing and planned capacity-building initiatives in the region

[20] As summarized during the 2nd Regional Patient Engagement Roundtable on Nov 23, 2020 by Prof John Lim, Executive Director at CoRE

- **Expansion of landscape mapping**
    - Expand survey and interviews to other stakeholders, beyond patients, in ASEAN countries to hear their views on challenges and opportunities to enhance patient engagement in their countries. We will also expand representation of patients surveyed
    - Curate case studies and trends in patient engagement through publications and social media
    - Roundtable attendees and others may continue to share on topic areas discussed during breakout groups here

Stay in Touch with CAPE

The organising committee would like to thank all the participants who were involved in the pre-roundtable focus group and survey for helping us prepare a programme for this year's roundtable under such unique circumstances. Thank you to all participants for making this virtual roundtable as engaging and impactful as our inaugural in-person roundtable in 2019. We consider all our past roundtable participants as part of the inaugural CAPE community and we will continue to share updates with you.

Finally, a special thank you to our valued sponsors for the event Johnson & Johnson, Roche and MSD for jointly supporting this roundtable.

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Category	Name	Designation & Organisation	Country
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	Ms Laura Deal Lacey	Executive Director Milken Asia	Singapore
	Ms Kristin Schneeman	Director, FasterCures a Center of the Milken Institute	USA
	Mr Nicholas Brooke	Executive Director Patient Focused Medicines Development; The Synergist	Belgium
	A/Prof Silke Vogel	Deputy Director, CoRE	Singapore
	Ms Amina Mahmood Islam	Deputy Director Singhealth Duke-NUS Global Health Institute (SDGHI)	Singapore
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	Dr Nikki Kitikiti	Public Health Physician CoRE	Singapore
	Ms Lavanya B	Business Development Lead CoRE	Singapore
Opening & Closing Remarks	Mr Satoshi Miki	Board Member, PPI Japan	Japan
	Dr Margaret Hamburg	Former Commissioner, U.S. Food and Drug Administration Interim Chair, Advisory Board, CoRE	USA
Patient Organisations	Mr Richard Vines	Founder & Chairman Rare Cancers Australia	Australia
	Ms Tiffany Petre	Director Collective Action on Obesity	Australia
	Ms Jenny Zhang	Director of International Affairs House086 (Lymphoma Association of China)	China
	Ms Naomi Sakurai	President Cansol Cancer Solutions	Japan
	Ms Yukiko Nishimura	President NPO Asrid	Japan
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	Mr Einstein Rojas	Project Manager, New Voice Association of Philippines	Philippines
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	Mr Christopher Knight	CEO Everett Knight (Asia Pacific) Alliance for Safe Medicines	Singapore
	Ms Ai Ling Sim-Devadas	Co-Chair, SingHealth Patient Advocacy Network (SPAN)	Singapore
	Mr Elil Mathiyan	Co-Chair SingHealth Patient Advocacy Network (SPAN)	Singapore
	Ms Melissa Lim	President Brain Tumour Society of Singapore	Singapore
	Mr Mark Lin	Head of Department Psychosocial Services Singapore Cancer Society	Singapore
	Dr Ritu Jain	President, Asia Pacific Alliance of Rare Disease Organisations (APARDO)	Singapore
	Mr Kenneth Mah	Vice President and Co-Founder Rare Disease Society (Singapore)	Singapore
	Ms Sherena Loh	Co-Founder and Director of the Muscular Dystrophy Association (Singapore) or MDAS	Singapore
	Ms Ya Hsin Wang	Executive Director, Taiwan Alliance of Patient Organisations (TAPO) Board Member, IAPO	Taiwan
	Mr Ekawat Suwantaroj	Director Hemophilia Foundation of Thailand	Thailand
	Mr Seth Ginsberg	Co-Founder and President, Global Healthy Living Foundation	United States

	Dr Melanie Samson	Senior Manager, Capacity Building, Union of Cancer Control (UICC)	Global
	Ms Marta Pazos Belart	Manager, Capacity Building, UICC	Global
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	Dr Thin Zar Thike	Deputy Director Drugs Section, FDA	Myanmar
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	Dr Beverly Lorraine C. Ho	Director IV Health Promotion and Communication Service DOH	Philippines
	Dr Lester M. Tan	Division Chief, Bureau of Local Health Systems Development, DOH	Philippines

	Ms Barbara de Guzman	Supervising Health Program Officer, Health Policy Development and Planning Bureau	Philippines
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