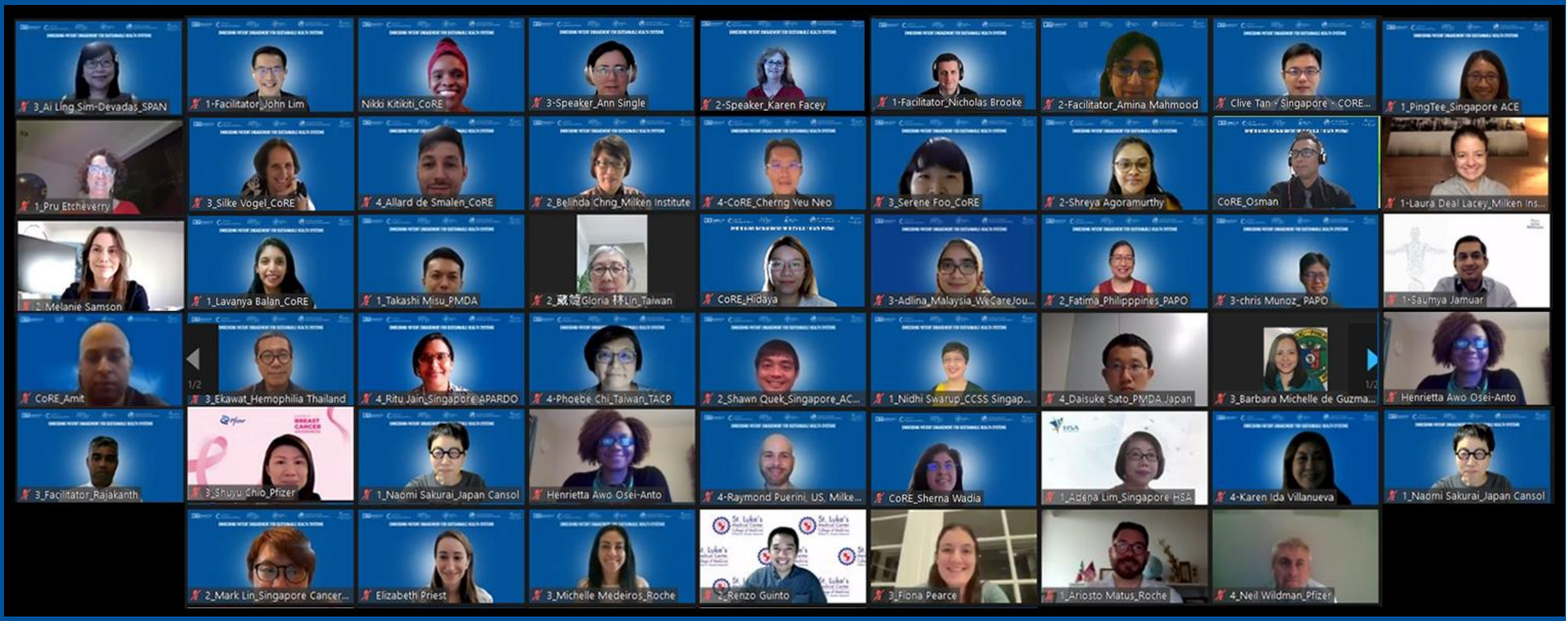


# CAPE Regional Multi-Stakeholder Roundtable Report

# Embedding Patient Engagement for Sustainable Health Systems

7 October 2021

Duke NUS Medical School
Centre of Regulatory Excellence
Rainbow Across Borders
MILKEN INSTITUTE
PATIENT FOCUSED MEDICINES DEVELOPMENT
SingHealth Duke NUS ACADEMIC MEDICAL CENTRE GLOBAL HEALTH INSTITUTE

# CAPE Regional Multi-Stakeholder Roundtable: Embedding Patient Engagement for Sustainable Health Systems

## 1. Introduction

The 2021 roundtable discussed the importance of patient engagement for sustainable health systems, which has been made even more apparent by the COVID-19 pandemic. The long-term economic impact of the current global pandemic as well as perennial issues such as ageing populations, accelerating rates of chronic disease and the rising cost of healthcare all pose significant challenges to health system durability. In this environment, patients have a vested interest in sustainable health systems and offer important perspectives that can significantly enhance access to health products, health policies and delivery of care.

This year's roundtable featured expert speakers who facilitated discussions on three key foundations for evidence-based, sustainable health systems: embedding a patient engagement culture in all health organisations, patient-centred health technology assessment (HTA) and effective use of patient experience data for decision-making.

### 1.1 About CAPE

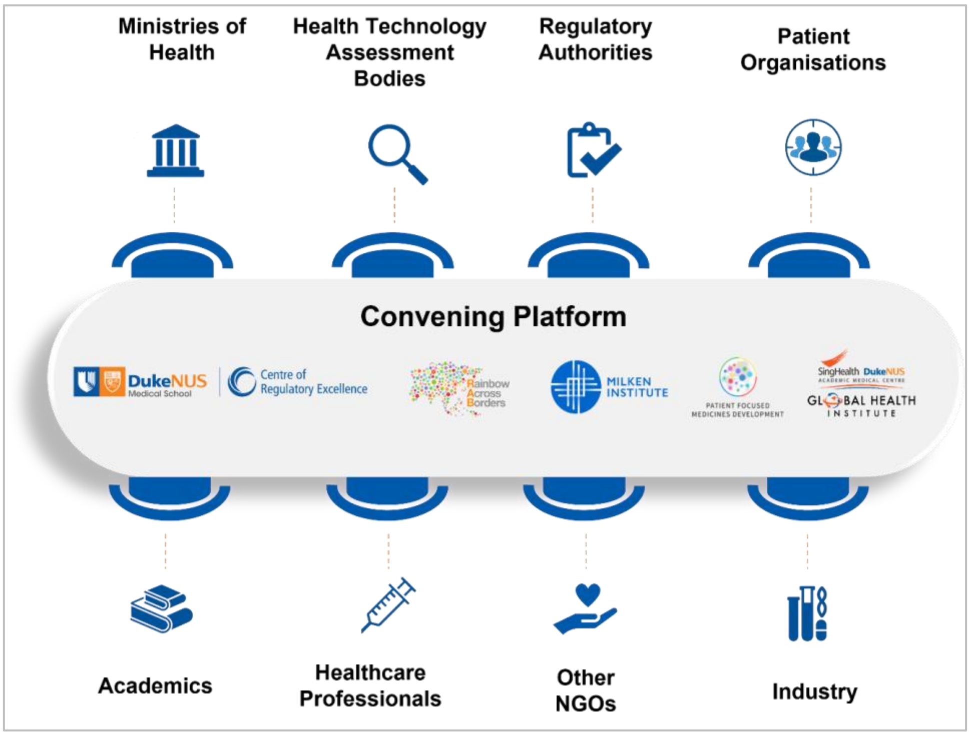
Our inaugural patient engagement regional roundtable in 2019 started an important conversation among multiple stakeholders on how to accelerate patient engagement in Asia-Pacific. At the subsequent 2020 roundtable, we successfully launched the Coalition to Accelerate Patient Engagement in Asia-Pacific (CAPE).

CAPE is a multi-stakeholder partnership, hosted at Duke-NUS Medical School by the Centre of Regulatory Excellence (CoRE), to accelerate systematic and meaningful patient involvement in health systems across the Asia-Pacific. Duke-NUS Medical School provides an effective neutral platform for convening, collaborating and building capacity for patient engagement among all health system stakeholders.

The pro tem Steering Committee members include CoRE, SingHealth Duke-NUS Global Health Institute (SDGHI), FasterCures, a center of the Milken Institute, Milken Institute Asia, Rainbow Across Borders and Patient Focused Medicines Development (PFMD), however we aim to seek broader participation going forward. This is the first patient engagement platform that is 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. More information about CAPE is included in the Annex.

***Fig 1. CAPE as a Multi-Stakeholder Hub for Patient Engagement***



## 1.2 A Growing Patient Engagement Community

Duke-NUS Medical School, 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 involvement in health systems in Asia-Pacific. We were honoured to welcome over 50 participants from 13 economies, representing patient organisations, governments, regulatory authorities, the pharmaceutical industry, academia, and healthcare providers.

The 2021 roundtable welcomed our first patient group participation from India and New Zealand as well as additional organisations from Chinese Taipei, Philippines and Malaysia who were not represented in previous roundtables. We also welcomed first-time attendees from health authorities not previously represented, including Japan's Pharmaceuticals and Medical Devices Agency (PMDA) and Thailand's Health Intervention and Technology Assessment Program (HITAP). We aim to continue to engage all partners with the common goal of advancing patient-centred health systems in the Asia-Pacific region.

## 1.3 Defining Sustainable Health Systems and the Role of Patients

A sustainable health system means different things to different people and stakeholders. We conducted a series of interviews ahead of the roundtable to ask members of the wider CAPE community what a sustainable health system means to them, examples of how patient engagement supports sustainability and what more can be done to meaningfully involve patients in health systems. The responses revealed that there are increased efforts across countries to include patients groups in healthcare delivery and patient safety, clinical trials and health technology assessment. However, there is more that can be done to go beyond tokenistic representation to have policies that require patient engagement, to prioritise equity, to build capacity of patient organisations and enable evidence generation of the impact of patient involvement on decision-making and health system outcomes. The full collection of interviews will be posted on the CoRE website.

***Figure 2. Selected Quotes from Pre-Roundtable Interviews***

"PATIENT ORGANIZATIONS ARE USING DATA TO UNDERSTAND GAPS IN THEIR OWN SERVICES, AND WHERE THEY CAN BETTER SERVE PATIENTS. ALSO TO INFORM POLICYMAKERS, INFORM CLINICAL GUIDELINES OR HEALTHCARE PROFESSIONALS AND TO CONTRIBUTE TO HTA"

Pru Etcheverry, Patient Advocate
Regional Director
Lymphoma Coalition

"TO HAVE A SUSTAINABLE HEALTH SYSTEM YOU NEED TO UNDERSTAND WHAT MATTERS TO THE PATIENT. THE FIRST IS AT THE LOCALISED LEVEL DURING THE INTERACTION BETWEEN THE PATIENT AND THE DOCTOR OR NURSE, THEN YOU HAVE PATIENT ENGAGEMENT ON A MORE SYSTEMATIC AND ORGANISATIONAL LEVEL WHEN YOU'RE WORKING ON A PROJECT TO IMPROVE HEALTHCARE."

Ai Ling Sim-Devadas, Patient Advocate
Co-Chair SingHealth Patient Advocacy Network (SPAN)
Global Patient and Family Advisory Board, Beryl Institute

"PATIENT GROUPS HAVE A KEY ROLE IN HELPING THE INSTITUTION BE ACCOUNTABLE AND RESPONSIVE TO THE PATIENTS' NEEDS. WE CONTINUOUSLY GIVE FEEDBACK AND SOMETIMES PUSH BACK IN EXPANDING THE FRONTIERS OF THE HEALTH SYSTEM.

WE COLLABORATE."

Fatima Lorenzo, Patient Advocate
President, Philippines Alliance of Patient Organisations (PAPO)

"PEOPLE WHO HAVE BEEN AFFECTED BY LIFE-CHANGING HEALTH CONDITIONS, INJURY AND DISABILITY BRING JEWELS OF WISDOM AND INSIGHT FROM THE CAVES OF SUFFERING. ONCE YOU TAKE AN ASSET-BASED APPROACH FOR INDIVIDUALS AS WE SHOULD FOR COMMUNITIES YOUR MINDSET SHIFTS. LET'S FORGET ABOUT REPRESENTATION AND FIND WAYS OF BEING WITH EACH OTHER."

David Gilbert, Patient Advocate & Author
Inaugural Patient Director
Sussex MSK Partnership
Author, The Patient Revolution

"PATIENTS ARE OFTEN EXPERTS IN THEIR OWN CONDITION, THEY HAVE A VERY HIGH DEGREE OF KNOWLEDGE AND EXPERTISE. IN ORDER TO EFFECT CHANGE FOR PEOPLE WITH RARE DISEASES, IT IS IMPORTANT TO ENGAGE PATIENTS AS THEY KNOW MORE ABOUT THEIR OWN CONDITIONS THAN ANYONE ELSE DOES."

Ritu Jain, Patient Advocate
Board Member, Asia Pacific Alliance of Rare Disease Organisations (APARDO)
Council Member,
Rare Diseases International

"WE WANT TO PROGRESS NEW DRUGS AND TREATMENTS. A KEY POINT IS CLINICAL TRIALS. BEFORE WE COULD NOT SEND OUR VOICE AND SHARE OUR EXPERIENCE BUT NOW WE DISCUSS ABOUT HOW WE FEEL ATTENDING THE CLINICAL TRIALS, OR WHERE IT IS DIFFICULT TO ACCESS THOSE CLINICAL TRIALS NOW WE TALK ABOUT THESE ISSUES IN JAPAN THROUGH THE PLATFORM."

Naomi Sakurai, Patient Advocate
President, Cancer Solutions
Japan

"PATIENTS DO PLAY A CRITICAL ROLE IN THE THERAPEUTIC ALLIANCE WORKING TOGETHER WITH THEIR PROVIDERS ON WHAT'S BEST FOR THEM FOR THEIR CARE. WE NEED TO EXPAND THIS CONCEPT OF A THERAPEUTIC ALLIANCE AND TURN IT INTO A HEALTH SYSTEM ALLIANCE BETWEEN POLICYMAKERS, PROVIDERS, DECISION-MAKERS AND MOST ESPECIALLY THE PATIENTS."

Renzo Guinto, Planetary Health Specialist
Director, St Luke's Medical Centre,
Planetary & Global Health Program

## 2. Embedding Patient Engagement for Sustainable Health Systems in Asia-Pacific

The roundtable speakers and discussions focused on three key foundations for evidence-based, sustainable health systems: (1) embedding a patient engagement culture in all health organisations, (2) patient-centred health technology assessment (HTA) and (3) effective use of patient experience data for decision making.

### *2.1 Embedding a patient engagement culture in all health organisations*

Patients are not only experts on their own health conditions but are also experts, by experience, in navigating the health system and they have a key role to play in identifying issues in healthcare systems and solutions. Our first speaker Karen Facey, *Evidence Based Health Policy Consultant and Editor of the book "Patient Involvement in HTA"* described concrete examples of embedding patient engagement from her experience in the United Kingdom.

*Harnessing The Power of Patient Stories*

The Scottish Patient Safety Programme has adopted a quality improvement methodology which embeds the patient experience alongside the evidence on the best practice to ensure it is being applied to the actual service delivered in the local system. This programme used patient stories where people shared their opinions and feedback on the health system. This was considered so valuable that it has since been scaled to a national system where any individual can share feedback on a specific health service and get responses from the health providers[1]. It has been expanded to social care and patient stories have led to actual change in health services.

The idea of listening to patient stories has also since been adopted by Health Boards in Scotland strategically planning health services. They  begin each meeting with a relevant patient story. For instance, if the Board was discussing reorganisation of mental health services they would hear from a mental health service user about their positive or negative feedback.

*Leadership & Accountability for Patient Involvement*

Having leadership accountable for patient involvement is key. In one Health Board in Scotland, one of the Directors was appointed as Executive Lead for Patient Involvement.  In Scotland there are also standards for patient participation that health organisations are monitored against. In the National Health Service (NHS), patient involvement is also mandated for all government funded health research and there is a guidance to researchers on how to involve patients to improve research.

*Patient Partnerships*

One example of an impactful patient partnership is the coreHEM initiative that has produced the first set of guidelines recommending a specific, minimum set of outcomes to include in hemophilia gene therapy clinical trials[2]. The outcomes were developed and agreed upon by a multi-stakeholder group, through an intensive research and formal consensus process. Participating experts and stakeholders included patients, clinicians, payers, health technology assessment groups, regulators, life sciences companies and others.

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[1] Care Opinion Patient Stories NHS Scotland website : https://www.careopinion.org.uk/services/nhs-scotland

[2] Centre for Medical Technology Policy, coreHEM website : https://www.cmtpnet.org/resource-center/view/corehem-COS/

Karen closed her presentation with key take-aways on how to make patient involvement successful from the European Patients Forum Value+ model for patient engagement which are relevant to us in Asia[3]:

- Patient involvement at the beginning and through projects for planning and decision-making
- Cooperative working and understanding each other's roles
- Providing information and support for involvement
- Monitoring and evaluation of patient involvement from perspectives of all partners
- Evaluation of project's results and impact, identifying how patient involvement has enhanced results

### *2.2 Patient-centred Health Technology Assessment (HTA)*

HTA is an important tool in the path towards achieving universal health care and sustainable health systems. Ann Single shared her presentation from her perspective as the *Chair of the HTAi Interest Group for Patient and Citizen Involvement in HTA* and *Coordinator of the Patient Voice Initiative,* an advocacy group in Australia that provides practical support to improve the way patients are heard in HTA. A health technology refers to any health intervention from a bandage, medicine, medical device or even an exercise programme. HTA is a process that ensures that medicines, medical devices, vaccines and other interventions provide value for money, are fit for purpose, and enable provision of the best care for all patients. The most recent definitions of HTA emphasise that the overall value of health technologies may vary depending on perspective, the stakeholders involved and the decision context[4]. It is key for patients' needs, preferences and inputs to be considered in assessment of value.

HTAi defines patient involvement in two streams:

1) Patient participation in the actual process of HTA through two-way communication with patients to allow committees and patients to learn from each other and solve problems before, during and after an HTA, e.g. attending meetings, submitting written patient perspectives, receiving feedback on inputs.
2) Patient-based evidence that is robust research into patients' needs, preferences and experiences

Approaches to HTA vary by country needs, budget and culture. Case studies were conducted for the book on "Patient Involvement in HTA" that mapped the different approaches towards patient engagement along two axes: the first axis was the level to which it enabled two-way communication and the second was how closely integrated patients were with the HTA researchers and committees. The analysis found that the dominant approach was one way communication such as written submission and consultation to hear what matters to patients.

Case studies also revealed that as systems got more used to patient involvement they adjusted their approaches, for example, Taiwan and Australia started with online input and evolved to include patients in committee meetings and invested heavily in training. Over time there is also an evolution in the HTA system's understanding of patients. Initially they may view patients as a mouthpiece for industry but over time they find that patients can address

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[3] European Patients Forum Value + Handbook for Project Co-ordinators, Leaders and Promoters on Meaningful Patient Involvement: https://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_handbook.pdf

[4] O'Rourke, B., Oortwijn, W., & Schuller, T. (2020). The new definition of health technology assessment: A milestone in international collaboration. *Int J Technol Assess Health Care,* 1-4. doi:10.1017/S0266462320000215

gaps in traditional evidence and add value to the process. In South Korea, the HTA agency has worked together with patients to fight disinformation and misinformation during the COVID-19 pandemic. There is also an evolution in understanding the diversity of the spectrum of patients – ranging from members of patient organisations to patients that are “hard to reach” and minority voices. There is increased attention paid to insights gained from patient involvement and that these are not lost along the product lifecycle. Patient evidence generated for regulatory decision may be better aligned with the HTA requirement at later stages of the product lifecycle.

***Figure 3. Snapshot of Approaches to Patient Involvement in HTA in Asia-Pacific***

| **Country** | **Key features of approach** |
|---|---|
| **Australia** | Any group or individual can submit input online for an HTA. This may be valuable but also depends on health literacy level of patients |
| **Taiwan** | Patient members in committee meetings |
| **New Zealand** | One-way mediated public consultation on the draft recommendation |
| **Philippines** | Patient members in committee meetings. |

Ann closed by reflecting on how even among HTA agencies that are admired for their patient involvement, internal beliefs about patient engagement may become a barrier. Since patient involvement is considered so important, it may be difficult for stakeholders to raise genuine concerns about patient involvement and ask awkward questions. However, as difficult as these questions may be, hiding the concerns may do more to limit meaningful involvement and make engagement tokenistic. A good example of an organisation doing this difficult self-reflective work, that organisations earlier in their patient involvement journey can learn from, is the Belgian Health Knowledge Centre (KCE) which systematically assessed internal beliefs about patient engagement in their organisation and has developed a position statement[5].

There are several resources available on patient involvement in HTA from HTAi[6], PARADIGM[7], Patient Voice Initiative[8] and the book on Patient Involvement in HTA[9] co-edited by our guest speakers Karen Facey and Ann Single.

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[5] Belgian Healthcare Knowledge Centre (KCE) , Position of KCE on patient involvement in health care policy research : https://kce.fgov.be/en/position-of-kce-on-patient-involvement-in-health-care-policy-research

[6] HTAi Patient & Citizen Involvement website: https://htai.org/interest-groups/pcig/resources/

[7] PARADIGM, Patient Engagement in Early Dialogues: Tools and resources for HTA bodies: https://imi-paradigm.eu/petoolbox/pe-in-ed-hta/

[8] Patient Voice Initiative Resources : https://www.patientvoiceinitiative.org/pvi-publications/pvi-resources/

9 Karen Facey , Ann N V Single (Editor), Helle Ploug Hansen (Editor), Patient Involvement in HTA (2017): https://link.springer.com/book/10.1007/978-981-10-4068-9

### 2.3 Effective use of patient experience data for decision making

The development and use of patient experience data (PED) is one way to further engage patients. *Nicholas Brooke, Executive Director at Patient Focused Medicines Development (PFMD)*, shared on the global project on PED led by PFMD and National Health Council (NHC) in the US. The project seeks to bring together multiple stakeholders to clarify, integrate and streamline the design, generation, analysis and decision-making about patient experience data through, and with, patient engagement. A landscape paper has been published to describe the current status of patient engagement and patient experience data around the world[10].

The United States Food and Drug Administration (FDA) defines patient experience data as "*data that is collected by any person with the intention to provide information about patients' experiences with a disease or condition, including the impact of the disease or condition or related therapy or clinical investigation, and patient preferences with respect to treatment of the disease or condition*[11]*.*" Regulators and HTA bodies are increasingly embracing patient experience data (PED) to help with decision-making.

Feedback from consultations with global stakeholders across the health system reveals that there are still questions about how to create and use patient experience data in a meaningful way. There are several categories of challenges in effective use of patient experience data namely,

i) *Culture* - Internal organisational cultures are risk averse and unwilling to challenge the status quo.
ii) *Cross-organisational alignment* – Organisations often work in operational silos and lack cross-functional capacity to engage patients for data generation
iii) *Process* – Lack of early and dedicated communication pathways
iv) *Tools* - Many tools are available but even experts are not clear which to use and when. There is a lack of standardised instruments, platforms and techniques for patient engagement and generating patient experience data.

There is a need for a global PED taxonomy to provide a harmonized, streamlined approach for the development and use of PED and the project aims to also seek inputs from Asia-Pacific. The global project is working to address two key issues with PED:

- Globalized lack of clarity, scattered perspectives, different approaches and mixed experiences
- How to streamline guidance on PED it to make it more efficient and coherent, e.g. convergence between regulatory and HTA agencies.

Stakeholder conversations around the world continue to elicit interest in further project participation and help to broaden the use of PED.

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[10] PFMD, Patient Experience Data Project : https://patientfocusedmedicine.org/patient-experience-data-project/

[11] FDA Guidance Document, Patient-Focused Drug Development: Collecting Comprehensive and Representative Input (2020): https://www.fda.gov/regulatory-information/search-fda-guidance-documents/patient-focused-drug-development-collecting-comprehensive-and-representative-input

## 3. Challenges in Embedding Patient Engagement

During the breakout group discussions participants reflected on what aspects of the presentations resonated with their own country experiences and discussed some of the challenges they face in embedding patient engagement even though health stakeholders do have the intention to be patient-centred. Common challenges that were raised in the breakout groups included:

- No structured ways for soliciting patient input, resulting in tokenistic and ad hoc engagement
- Bureaucratic and cumbersome processes for patient involvement resulting in low uptake from the public
- Dissemination of information is challenging especially among patients who are not digitally savvy
- Varied levels of knowledge and confidence among patients and patient organisations especially for technical areas such as HTA; some groups are taken seriously by other stakeholders and involved in policymaking and HTA, while others struggle for legitimacy
- The patient group landscape is fragmented which makes it difficult to reach the patients and also may dilute the collective voice.

## 4. Opportunities to Embed Patient Engagement in Asia Pacific

There are reasons to be optimistic about embedding patient engagement in Asia-Pacific despite the current challenges faced. The breakout groups also discussed opportunities to improve patient engagement in the region.

*Supporting patient readiness*

Initiatives to improve health literacy should be prioritised as well as capacity building to build confidence of patients to participate in policymaking and other decision-making bodies. The message from the group discussions was clear that despite the gaps in some technical knowledge that patients may have, they have their own expert knowledge and are willing to learn other areas.

*Stakeholder mapping and tailored engagement*

Those wishing to engage patients should conduct comprehensive stakeholder mapping to understand who they want to reach so as to customise the approach and ensure they do not leave the “hard to reach” behind. The Agency for Care Effectiveness (ACE) in Singapore has started mapping all patient organisations in the country as there is no existing central database. During the pandemic, minority groups who are harder to reach, have fallen behind in vaccination rates. This highlights the importance of tailored and purposeful engagement for equity.

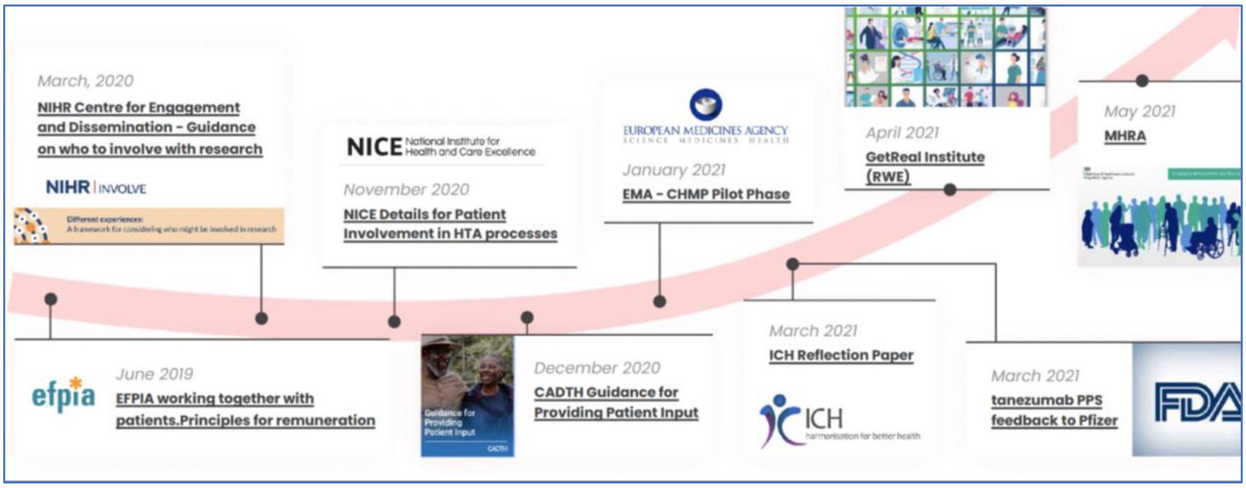
*Leverage data and technology*

Data emerged as an important theme among breakout groups with discussions highlighting the importance of including qualitative alongside quantitative data to better capture the entire patient experience. There is an opportunity to enhance patient contributions to data collection through patient registries. The discussion highlighted that data collection by patients does not need to be complex to be impactful. Facilitator *Kristin Schneeman from Milken Institute* shared an example of how a simple contact registry for patients with a rare disease can be extremely valuable to developers conducting research. Simple data can be very meaningful and valuable. Organisations should leverage data and technology to enhance engagement with patients using customised tools.

Participants also shared examples of patient engagement in the region that are making an impact. Japan’s PMDA has published guidelines on patient engagement in medicines development and regulation which are providing needed structure to patient input. As shared during the 2020 roundtable, Japan has also adapted the European Patients’ Academy on Therapeutic Innovation (EUPATI) curriculum to provide structured training for patient advocates. The World Health Organisation is partnering the SingHealth Duke-NUS Institute for Patient Safety and Quality (IPSQ) to set up a regional Patient Academy. We followed up on case studies of other impactful emerging models of embedding patient engagement in Asia-Pacific that were shared during the roundtable breakout discussions and these are expanded on in the next section.

Nicholas Brookes closed his presentation on an optimistic note by sharing how rapidly patient engagement has accelerated in the last few years with agencies around the world announcing guidances for patient involvement. There is a huge movement among regulators, HTA agencies and healthcare providers and Figure 4 illustrates that patient engagement is increasingly adopted as a critical practice across stakeholder groups. Patients should be encouraged by the increasing momentum for patient engagement in our region and we should take advantage of this growing interest to “ride the wave” and partner with like-minded early adopters.

***Figure 4. Patient Acceleration in the Last 2 Years***



## 5. Case studies

The three case studies in this section demonstrate emerging models of patient engagement around Asia and the key takeaways.

### Case study 1: Building a Strong Patient Advocacy Network in a Healthcare System

**SingHealth Patient Advocacy Network (SPAN), Singapore**

SPAN is a network of advocates established in 2015 at SingHealth, Singapore's largest public healthcare cluster. It is similar in concept to the Patient and Family Advisory Councils found in some North American hospitals. SPAN patient advocates are patients and caregivers who want to make a positive impact on healthcare by bringing forward the patient and family perspective to healthcare teams. Patient and family advocacy was a relatively new concept in Singapore and Asia when SPAN started. There were no models to harness the patient voice and lived experience. Another challenge they faced was lack of effective engagement tools and training for advocates and healthcare professionals. Fortunately, there was strong buy-in and support for SPAN from SingHealth leadership and the network has made progress on transforming patient involvement in the cluster from passive feedback to active involvement and proactive contributions.

SPAN advocates have been involved in several successful initiatives to improve quality, safety and patient-centricity such as:

- Co-designed and co-developed a Plain English Glossary for healthcare professionals comprising 150 commonly used medical jargon and the plain language alternative to improve communication between patients and clinicians
- Bright Vision Hospital (BVH) redesign of care process and the environment
- Patient Advocate Communication Training (PACT)
- Partnered with healthcare teams during COVID-19 by creating posters, flyers and videos aimed at improving communication with the health team and allaying concerns of foreign workers in dormitories who were greatly affected by the first wave in Singapore.

Members of SPAN

### Key Take-Aways from SPAN on How to Initiate a Patient Advocacy Network in Your Health System

01 Strong Leadership Commitment

02 Partner with a small group of keen & passionate patients

03 Build a guiding coalition with key partners within the organisation to champion the patient advocacy network

04 Empowerment and co-creation with patient advocates as the guiding principle

05 Support vigorously and spread the ideas, pilots and growth of network and advocate leads

### Key Take-Aways from SPAN on How to Sustain a Patient Advocacy Network

06 Build a dedicated group of Patient and Family Advocates who possess key attributes

07 Effective onboarding and competency development of patient advocates

08 Learning best practices and sharing generously

09 Communicate actively throughout the organisation

10 Develop meaningful and impactful activities and programmes for patient advocates and health care staff

11 Don't forget to Make patient advocacy fun

**What's Next for SPAN?**

- Collaborating with IAPO to develop an Asia Pacific Patients Consensus on the WHO Global Safety Action Plan
- Collaborating with WHO to create a Patient Academy for the region
- Working towards their vision of a new partnership in 10 years where :
  - Healthcare professionals will involve patients throughout their care journey and educate and empower patients to take charge.
  - Patients will be an active and responsible member of the care team, influence care delivery through dynamic feedback mechanisms and shape policy through engagement

**Source: SPAN**

## Case study 2: Consumer Engagement in HTA in Singapore

### Agency for Care Effectiveness (ACE), Singapore

ACE is the national HTA agency in Singapore. ACE reviews clinical and economic evidence to determine how well health technologies (such as drugs, vaccines and medical devices) work in relation to how much they cost. This information is then used by the Ministry of Health (MOH) to make subsidy recommendations for the public hospitals.
In 2021, the Consumer Engagement and Education (CEE) team was set up to help patients, care takers and the public become involved in ACE's work. Moving forward, CEE will be inviting patient and/or volunteer organisations to provide inputs into ACE's HTA projects to ensure that any subsidy recommendations are relevant to the people who are affected by them. Patient and public involvement in HTA and other areas of the health system is a relatively new concept in Singapore.

From 2022, patients will be invited to provide input and testimonials into HTAs. These inputs will provide lived experiences and help decision-makers understand what is important to patients and their families. The process of patient input would be a two-way conversation; after patients provide their inputs they would also receive feedback from ACE on if the input was useful and how it was used in the HTA deliberation. ACE does not want this engagement to be tokenistic and will be appointing a Consumer Panel to guide meaningful patient involvement at ACE. The Consumer panel will be made up of senior members of patient and volunteer organisations with lived experience of the Singapore healthcare system.

The Consumer Panel is being set up to:

- identify opportunities for consumer involvement in ACE's work
- advise on appropriateness of tools/templates developed by ACE to encourage meaningful patient involvement in our projects/HTAs
- review the format, content and communication strategies of consumer educational materials
- provide guidance on initiatives to strengthen ACE's relationships and engagement opportunities with consumers

### Key Lessons from ACE:

- Patient involvement in HTA adds value for all stakeholders.
- Patients can contribute important lived experiences that are not part of the evidence found in clinical research.
- Improving health literacy is key for meaningful involvement

### What's next for ACE Consumer Engagement & Education?

- CoRE and ACE co-hosted a special dialogue for members of patient and volunteer organisations in Singapore with an interest in contributing to HTA on November 18.
- CEE is developing educational collaterals for healthcare consumers to improve health literacy
- CEE aims to provide formal and informal support to patients involved in HTA in the form of training, resources, support tools and day-today support through meetings, emails and addressing queries to help patients as they draft their input

**Sources: Ping-Tee Tan, ACE Presentation Slides**

Top row from left: Prof John Lim (Executive Director, CoRE); Ms Fiona Pearce (Senior Advisor, Agency for Care Effectiveness (ACE), Ministry of Health Singapore (MOH)); Dr Ritu Jain (Director, Asia Pacific Alliance of Rare Disease Organisation (APARDO)); Bottom row from left: Mrs Nidhi Swarup (Founder & President, Crohn's & Colitis

## Case study 3: The Power of Patient-Led Surveys in China

### House 086 Lymphoma Patient Survey, China

House 086 is a community for Lymphoma patients in China with over 47,000 registered members. Since 2017, House 086, has been conducting a nationwide survey on the survival status of Lymphoma patients in China and producing a whitepaper with academic partners. In 2018, the group joined the Lymphoma Coalition Global Patient Survey with other Coalition members around the world while continuing to focus on Chinese-specific data that is locally relevant on T-cell and Follicular Lymphoma patients. In 2020, The China Lymphoma Patient Survey had over 3,000 responses, an impressive feat given that it was conducted at the height of the COVID-19 pandemic in China[12].

Recognising the power of a data and evidence-based approach, the data and content in the whitepaper have been used many times for advocacy in the media and by medical experts. This whitepaper has amplified the patient's voice to key decision-makers. Many in China, including policymakers, had the impression that Lymphoma is an incurable disease. House 086 were invited to a closed-door discussion with health officials to present their report. They were able to educate decision-makers that, actually, half of Lymphomas have a treatment available but these are not currently covered in the national insurance scheme.

Beyond these closed-door meetings, the group has also been featured in the People’s Daily which is the official state media outlet and this will increase their reach as they advocate for reforms to the national insurance scheme for Lymphoma patients. Currently, patients are not involved in the HTA processes in China but this is being considered. In the meantime, House 086 is building relationships with health officials and building their knowledge on HTA to share with their members.

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[12] The China Lymphoma Patient Survival Survey reports can be downloaded here: https://www.house086.com/thread-222638-1-1.html

**Key Lessons from House 086 Case**:

- Rigorous, evidence-based advocacy can have great impact to change policy and improve services and access to treatments
- Even in the absence of formal structures for patient involvement, patient generated data can open the door to building key relationships with health officials
- Combination of local survey items with ones from a global survey can led to new insights and enable benchmarking and comparison across countries to identify local gaps
- For patients organisations just getting started in building their data collection capabilities, Jenny from House 086 advises groups to keep learning from larger groups with more experience with surveys, attend and learn from global patient meetings and partner with health professionals and academics as they can give important scientific input to ensure their surveys are of high quality.

**What's next for House 086?**

- Currently translating the book "Patient Involvement in Health Technology Assessment" [co-incidentally edited by our two guest speakers Karen Facey and Ann Single] into Chinese. They believe it will be an important resource for and patient training and pharmaceutical companies in China to learn about patient-centred HTA.
- House 086 will be conducting a more detailed survey is also working with smaller groups affiliated with them to help them improve their survey standards and help them with their communication strategy

**Sources: Jenny Zhang, House 086 and Pru Etcheverry, Lymphoma Coalition**

House 086 Lymphoma Patient Survey, China

## The Way Forward

We have convened roundtables and focus groups with a wide range of stakeholders over the last three years. These engagements, along with case studies we have collated, have provided rich insights and recommendations from stakeholders on how to enhance patient engagement in the region. Through our analysis, we have distilled the insights into three key foundations to move from the current state to the desired future where patient engagement is truly embedded in health systems: **culture, structure** and **data**. These three areas are interconnected and mutually reinforce one another and help us to better partner patients for sustainable health systems.

- ☐ **Culture**
  - Adapt patient engagement to the local cultural context, shift organizational cultures and professional mindsets to be patient-centric, value patient input and build trust
- ☐ **Structure**
  - Move from ad hoc to formal, sustained platforms for engagement best suited to the local context
  - Emerging models of engagement structures in Asia in healthcare delivery (e.g. SPAN), regulation (PMDA in Japan) and HTA (Consumer Engagement & Education initiative at ACE)
- ☐ **Data**
  - Move beyond anecdotes to evidence by using structured patient experience data to inform health system decision-making
  - Empower patient organisations to use data and evidence-based approaches

## 6. Next Steps for CAPE in 2022

- ☐ **CoRE Conference 2022 themed “Patients as Partners for Sustainable Health Systems”**
  - 5-6 October as a hybrid event in Singapore and online
  - 4 October , Pre-Conference Seminar

- ☐ **Health Technology Assessment**
  - HTA will be an area of focus given its importance in UHC implementation and increased momentum of patient engagement in HTA in Asia.
  - CAPE will convene relevant stakeholders to dialogues to co-create the roadmap for patient partnership in HTA and collaborate with stakeholders to support capacity-building

- ☐ **Capacity and capability building for all stakeholders**
  - Curate and create resources and tools for patient engagement in medicines development, regulation and HTA
  - Explore partnering with stakeholders conducting training to share components related to patient engagement for medicines development, regulation and/or HTA

- ☐ **Ongoing Landscape Mapping**
  - Surveys, focus group discussions and interviews with key stakeholders in the patient engagement landscape

# Acknowledgements

The organising committee would like to extend our appreciation to our distinguished speakers, participants and all the members of the CAPE community who were involved in the pre-roundtable interviews and shared information for the case studies.

We consider all our past participants as part of the CAPE community and we will continue to share updates through our mailing list. Please spread the word to others you think may be interested to join this community. We will keep you posted on ways that you can contribute to our plans and programmes.

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Finally, a special thank you to our valued sponsors, Roche and Pfizer, for supporting this roundtable.

**CoRE CN: 2021_R001_CoRE_ CAPE Regional Multi-Stakeholder Roundtable Report- Embedding Patient Engagement for Sustainable Health Systems**

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## Annex A. Roundtable Participants

| Category | Name | Designation & Organisation | Economies |
|---|---|---|---|
| **Facilitators & Organising Committee** | Prof John Lim | Executive Director<br>Centre of Regulatory Excellence (CoRE) | Singapore |
| | Mr Rajakanth R | Executive Director<br>Rainbow Across Borders | Singapore |
| | Ms Laura Deal Lacey | Executive Director<br>Milken Asia | Singapore |
| | Ms Kristin Schneeman | Director<br>FasterCures<br>a Center of the Milken Institute | USA |
| | Dr Henrietta Awo Osei-Anto | Director<br>FasterCures<br>a Center of the Milken Institute | USA |
| | Mr Raymond Puerini | Associate Director<br>FasterCures<br>a Center of the Milken Institute | USA |
| | Mr Nicholas Brooke | Executive Director<br>Patient Focused Medicines Development; The Synergist | Belgium |
| | A/Prof Silke Vogel | Deputy Director<br>CoRE | Singapore |
| | Ms Amina Mahmood Islam | Deputy Director<br>Singhealth Duke-NUS Global Health Institute (SDGHI) | Singapore |
| | Ms Belinda Chng | Director<br>Milken Institute Asia Center | Singapore |
| | Mr Neo Cherng Yeu | Associate Director<br>Strategy<br>CoRE | Singapore |
| | Asst Prof James Leong | Head<br>Regulatory Science Programme<br>CoRE | Singapore |
| | Dr Nikki Kitikiti | Public Health Physician<br>CoRE | Singapore |
| | Ms Lavanya B | Business Development Lead<br>CoRE | Singapore |
| **Speakers** | Ms Ann Single | Chair<br>HTAi Patient and Citizen Involvement Interest Group<br>Coordinator<br>Patient Voice Initiative | Australia |
| | Dr Clive Tan | Adjunct Assistant Professor<br>Saw Swee Hock School of Public Health | Singapore |
| | Dr Karen Facey | Consultant<br>Evidence Based Health Policy | Scotland |
| **Patient/Patient Advocate/ Patient Representative/Patient Organisation** | Ms Jyoti Patil Shah | Chief Operating Officer<br>V Care Foundation | India |
| | Ms Naomi Sakurai | President<br>Cansol Cancer Solutions | Japan |
| | Dr Adlina Ab Rahim | Project Lead<br>We CARE Journey | Malaysia |
| | Ms Pru Etcheverry | Regional Director<br>Lymphoma Coalition | New Zealand |

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|---|---|---|---|
| | Mr Chris Munoz | Vice President<br>Philippine Alliance of Patients' Organisations (PAPO) | Philippines |
| | Ms Fatima "Girlie" Lorenzo | President<br>Philippine Alliance of Patient Organizations (PAPO)<br>Philippines | Philippines |
| | Ms Ai Ling Sim-Devadas | Co-Chair<br>SingHealth Patient Advocacy Network (SPAN)<br>Singapore | Singapore |
| | Mr Ellil Mathiyan Lakshmanan | President<br>Ostomy Association of Singapore | Singapore |
| | Mr Mark Lin | Manager<br>Singapore Cancer Society | Singapore |
| | Ms Melissa Lim | President<br>Brain Tumour Society (Singapore) Limited | Singapore |
| | Mrs Nidhi Swarup | Founder & President,<br>Crohn's & Colitis Society of Singapore | Singapore |
| | Dr Ritu Jain | Director<br>Asia Pacific Alliance of Rare Disease Organisation (APARDO)<br>Singapore | Singapore |
| | Ms Gloria Lin | Founder, Taiwan Association of Cancer Patients | Chinese Taipei |
| | Ms Phoebe Chi | Chief Executive Officer, Taiwan Association of Cancer Patients | Chinese Taipei |
| | Mr Ekawat Suwantaroj | Director<br>Hemophilia Foundation of Thailand | Thailand |
| **International Non-Governmental Organisation (INGO)** | Dr Mélanie Samson | Senior Manager<br>Capacity Building<br>Union for International Cancer Control (UICC) | Switzerland |
| **National Regulatory Authorities (NRA)** | Mr Daisuke Sato | Coordinator, Pharmaceuticals and Medical Devices Agency (PMDA), Japan | Japan |
| | Dr Takashi Misu | Senior Reviewer,<br>Pharmaceuticals and Medical Devices Agency (PMDA), Japan | Japan |
| | Ms Adena Lim | Deputy Director, Vigilance & Compliance Branch<br>Health Sciences Authority (HSA), Singapore | Singapore |
| | Dra Lucky Slamet | Visiting Expert, CoRE | Indonesia |
| **Ministries of Health/Policymakers** | Ms Barbara Michelle De Guzman | Supervising Health Program Officer<br>Health Policy Development and Planning Bureau<br>Department of Health, Philippines | Philippines |
| | Ms Rosa Gonzales | Chief Health Program Officer<br>Department of Health | Philippines |
| | Dr Kelvin Bryan Tan | Director (Future Systems),<br>Ministry of Health | Singapore |
| **HTA Agency or Division** | Dr Annabelle Borromeo | Core Committee Citizen's Representative<br>Health Technology Assessment Council (HTAC) Philippines | Philippines |

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|---|---|---|---|
| | Mr Shawn Quek | Specialist (Drug Evaluation)<br>Agency for Care Effectiveness (ACE)<br>Ministry of Health (MOH) Singapore | Singapore |
| | Associate Professor Fiona Pearce | Senior Advisor,<br>Agency for Care Effectiveness (ACE)<br>Ministry of Health (MOH) Singapore | Singapore |
| | Ms Tan Ping-Tee | Senior Specialist,<br>Agency for Care Effectiveness (ACE)<br>Ministry of Health (MOH) Singapore | Singapore |
| | Mr Kris Promphrasid | Senior Communication Strategist,<br>The Health Intervention and Technology Assessment Program (HITAP) | Thailand |
| | Ms Kanchanok Sirison | Project Associate,<br>The Health Intervention and Technology Assessment Program (HITAP) | Thailand |
| **Healthcare Institution (Hospital, Clinic, Healthcare Group, Academic Medical Centre)** | Ms Sookmei Chang | Director, Group Office of Patient Experience, SingHealth;<br>Director, Office of Patient Experience | Singapore |
| | Professor Thong Meow Keong | Senior Consultant<br>University of Malaya Medical Center | Malaysia |
| | Dr Jake Bryan Cortez | Associate Professor<br>St. Luke's Medical Center College of Medicine | Philippines |
| | Dr Renzo Guinto | Director, Planetary and Global Health Program<br>St. Luke's Medical Center College of Medicine | Philippines |
| **Industry** | Mr Neil Wildman | Senior Director<br>Patient Advocacy – APAC Lead<br>Pfizer Inc | Australia |
| | Ms Shuyu Chio | Director, Policy& Public Affairs, Emerging Asia, Pfizer | Singapore |
| | Mr Ariosto Matus | Regional Policy & Public Affairs Lead, Asia-Pacific, Roche | Singapore |
| | Ms Anthea Kiu | Patient Access & Policy Lead<br>Roche | Singapore |
| | Ms Michelle Medeiros | Health Policy and Patient Access Head, Asia Pacific<br>Roche Diagnostics Asia Pacific Pte Ltd | Singapore |
| **Duke-NUS Medical School (CoRE & SDGHI)** | Dr Paul Pronyk | Deputy Director, Global Programmes and Research<br>SDGHI | Singapore |
| | Mr Allard de Smallen | Research Associate<br>CoRE/SDGHI | Singapore |
| | Ms Shreya Agoramurthy | Research Associate<br>SDGHI | Singapore |
| **Event Organisers** | Ms Sherna Wadia | Associate Director, CoRE | Singapore |
| | Ms Nurhidaya Ismail | Assistant Manager, CoRE | Singapore |
| | Mr Amit Pritam | Executive, CoRE | Singapore |

## Annex B. About CAPE

### CAPE's Vision

Strong, person-centred health systems enabled by multistakeholder coordination and empowered stakeholders with the skills and tools for effective engagement.

### CAPE's Mission

- Map and define the current regional landscape for patient engagement
- Promote awareness of best practices in patient engagement in access to health products, policymaking and healthcare delivery
- Enhance coordination and collaboration among patient engagement efforts in the region
- Capacity building to strengthen implementation of evidence-based approaches to embed patient perspectives in health product development, HTA and reimbursement

### Domains of Interest

- **Overall environment for patient engagement**: shifting attitudes and organisational culture in the health system to value and integrate the patient voice
- **Access to Health Products**: patient perspectives in product development, regulation and health technology assessment
- **Access to Quality and Value-based Care**: patient perspectives in healthcare delivery and policymaking

### Approach

In each of the domains of interest, CAPE works at both country and regional level in three main ways :

- **Raise awareness** through landscape mapping, publications, events and community engagement
- **Convene and connect** a wide range of stakeholders through roundtables, symposia and conferences
- **Capacity building** through CAPE-created and curated resources and tools and workshops targeting technical and soft skills for patient engagement in health products development, regulation, health technology assessment and health policy

*Fig 1. How CAPE currently works in each domain area*

| | Access to Health Products | Access to Quality and Value-based Healthcare | Overall Environment for Patient Engagement |
|---|---|---|---|
| **Raise Awareness** | • Landscape mapping and publication of findings and recommendations<br>• Events<br>• Website and community engagement | | |
| **Convene & Connect** | • CAPE Multi-stakeholder Regional Roundtable<br>• CAPE Country-Level Roundtables and Dialogues<br>• CoRE Patient Engagement Conference 2022 | | |
| **Capacity-Building** | Develop and curate resources and tools on best practices for PE in health products development, regulation and HTA<br>Regional workshops on advancing the science of patient engagement | CAPE does not currently lead capacity-building in this area but raises awareness of others in the CAPE community building person-centred health care delivery services | Events, resources and tools for learning important "soft skills" for patient engagement such as multi-stakeholder communications. |

## Contact us

**Tel:** +65 6601 5147
**Email:** cape@duke-nus.edu.sg

Duke-NUS Medical School
8 College Road
Singapore 169857
www.duke-nus.edu.sg/core

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