



The Future of Patient and Public Involvement in Health Technology in Singapore

A Dialogue with the Agency for Care Effectiveness Singapore

Event Report

18 November 2021

1. Introduction

Patient Engagement is a key focus area of the Centre of Regulatory Excellence (CoRE) at Duke-NUS Medical School. The Centre has convened like-minded partners to jointly establish the Coalition to Accelerate Patient Engagement in Asia-Pacific (CAPE) to advance systematic and meaningful patient involvement in health systems across the Asia-Pacific region. CAPE is a multistakeholder partnership hosted at Duke-NUS Medical School; this platform provides an effective, neutral and safe engagement channel for raising awareness, convening and building capacity for patient engagement among the health sector stakeholders. As we continue to build our work in Singapore, the Agency for Care Effectiveness (ACE) is an important partner to CoRE.

ACE is the national health technology assessment (HTA) agency in Singapore within the Ministry of Health (MOH). 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 MOH to make funding recommendations for the public hospitals. In 2021, the Consumer Engagement and Education (CEE) team was set up to help patients, caregivers and the public become involved in ACE's work. Moving forward, CEE will be inviting patient and volunteer organisations to provide inputs into ACE's HTA evaluations to ensure that any recommendations are relevant to the people who are affected by them.

There is growing recognition in health systems globally that patients and caregivers have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA. Involvement of patients and carers in health system decision-making contributes to equity by seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all citizens. Patient involvement in health products development, regulation and HTA is still at a nascent stage in Asia compared to other regions. The new developments at ACE signal an opportunity to enhance patient engagement in Singapore.

On 18 November 2021, ACE and CoRE co-hosted the inaugural special dialogue for members of patient and volunteer organisations in Singapore to introduce them to the work of ACE and the CEE initiatives. Over 70 participants from more than 25 patient and volunteer organisations joined the closed-door discussion which highlighted capacity building needs among volunteer organisations, healthcare professionals and other stakeholders and provided important suggestions to enhance patient and caregiver involvement in Singapore. CoRE and ACE aim to continue to partner with patient organisations other stakeholders in Singapore to raise awareness of HTA and highlight the immense potential of engaging with patients as partners to improve our health system.

2.1. Aim of the Dialogue Session

KEY OBJECTIVES

- Familiarise patient and volunteer organisations with the work of ACE and the Consumer Engagement & Education (CEE) Team.
- Share opportunities as well as support envisioned for patient and volunteer organisations to provide inputs into ACE HTA evaluations.
- Gather early feedback on the proposed Consumer Engagement & Education initiatives.
- Discuss the training and capacity-building needs of patient and volunteer organisations to meaningfully contribute to the HTA process.

2.2 Opening Remarks from CoRE

The dialogue session opened with remarks from CoRE Executive Director Professor John Lim who gave an overview of the patient engagement workstream at Duke-NUS through the CAPE platform. CAPE is a multi-stakeholder partnership, hosted at Duke-NUS Medical School, 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. CAPE have hosted several regional roundtables to start the conversation on how to accelerate patient engagement in Asia. CoRE aims to be a supportive partner to ACE, patient organisations and other stakeholders in Singapore and Asia committed to patient engagement.

2.3 Overview of Consumer Engagement at ACE

The presentation from ACE gave an overview of the Agency which was established in MOH in 2015 to support healthcare providers, payers and patients to make better informed decisions about patient care. ACE conducts health technology assessment to inform funding decisions by MOH, produces clinical guidance to inform clinical practice, and also provides education to health care professionals and healthcare consumers.

In 2021, the Consumer Engagement and Education (CEE) team was set up to help patients, carers 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 evaluations to ensure that any funding recommendations are relevant to the people who are affected by them.

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. Such insights help decision-makers understand better the benefits and risks of treatments and whether certain subgroups can benefit more from a particular treatment.

Patient and volunteer organisations play an important role by helping to identify, nominate, support and collate patients and caregivers that can give meaningful input to the MOH Advisory Committee on a particular health technology. The most useful input would be from people who have the condition under evaluation and could potentially use the health product, people who are currently using the product in question or those who have been treated in the past with the treatment.

CEE will provide administrative support to patients giving input to the ACE Advisory Committee. Formal support would include process guides, templates for patient input and testimonials, trainings and workshops and other patient support tools. ACE CEE team would also provide day-to-day informal support to patients giving input with preparation meetings, emails, and help to answer any queries to help patients prepare their inputs.

The process of patient input would be a two-way conversation- after patients provide their inputs, they would receive early feedback from ACE on the usefulness of their input and suggestions for specific information to close gaps if necessary. After the decision on funding is made, ACE would share with the patients how their input was used for the deliberation and what types of input were most useful for the Committee. This could then be shared with other organisations who would be providing inputs in the future. ACE will be appointing a Consumer Panel to help guide ACE towards meaningful patient involvement. The panel would consist of senior members of patient and volunteer organisations with lived experience of the Singapore healthcare system.

The full slides presented by CoRE and ACE and educational collateral ‘Helping Patients Become Involved in Healthcare Decision-Making’ providing an overview of ACE’s HTA and decision-making processes for health technologies involving three core stakeholders (clinicians, patients, and the payer) are available [here](#).

2.3 Insights from the Panel Discussion and Q&A

Critical Role of Patients Perspectives and Experiences

A two-way communication between patients & care providers and healthcare providers has been advocated worldwide. Patients’ perceptions can play a crucial role in shaping quality care and patient involvement. In the same vein, it is critically important for patients and caregivers to communicate openly about the disease, understanding that while frustrations will arise, an open line of communication about physical and role changes will help them in living with the disease.

Health Literacy as a Foundation for Informed and Shared Decision-making

ACE appreciates that improving health literacy is key to moving consumer engagement forward. Health literacy is complex and the ACE CEE initiative may not be able to address health literacy in the whole population but rather target improving literacy specific to certain medical conditions. ACE is in the process of developing educational materials for patients and the public on managing specific medical conditions. The information will include basic information, such as the disease information, the available treatment options, as well as some of the out-of-pocket expenses and available subsidized drugs. The material being developed by ACE is intended to serve as a starting point to support patients to initiate conversations with their healthcare providers and increase understanding of their condition. At the moment, the

input required from patients would be based on their own lived experience so they would not be expected to give technical inputs. ACE encourages interested patient organisations to register as stakeholders to give input on materials developed for patients by ACE.

The Importance of Plain Language

Language plays a critical role in patient engagement. Studies suggest that language and communication of expectations is clearly an issue that is found across all forms of patient engagement¹. Participants emphasised that there is need for clarity in communication during patient engagement. Use of plain language would be more effective as patients come from diverse backgrounds and cultures. Patient information should be simple, so it will be easy for the patients and caregivers to understand and use in their care journey.

Optimising Organization of Patient Advocacy Groups

The patient advocacy landscape in Singapore is still very fragmented and it is difficult to even identify the groups active in Singapore to reach out to. ACE has started an initial mapping of groups in Singapore and estimate there are approximately 150 patient or volunteer groups related to health. The panel discussion highlighted that as there is an increasing recognition of patient groups, it would be best that these patient groups are better coordinated in order to maximize the outreach to groups and enhance the patient input. There may be benefits to organizing individual groups in umbrella organisations for similar conditions (e.g. auto-immune conditions) or conditions using the same health technology (for example, the same biologics may be used across different conditions).

Capacity-Building for Patient Organisations

Most groups are focused on the day-to-day work, and they may need additional training to learn to speak the same language as the decision-makers. The Patient Academy being set up at the SingHealth Duke-NUS Institute of Patient Safety and Quality was given as an example of a platform to provide additional capacity-building for groups. The discussion emphasised that a mindset shift is necessary at every level from patients, healthcare providers, researchers and policymakers. It is important for the relevant organisations to support ACE.

Rare Conditions May Require Special Considerations

It may be challenging to collect trial data for rare conditions with the small population affected. Therefore, patient input for such conditions would be extremely relevant to fill data gaps and there may need for unique considerations in the assessment of evidence to support subsidies for orphan drugs that tend to be prohibitively expensive.

¹ Gallivan J, Kovacs Burns KA, Bellows M, Eigenseher C. The many faces of patient engagement. J Participat Med. 2012 Dec 26; 4:e32.

Patient Engagement and Data

Some participants raised questions on potential for bidirectional sharing of data between patient organisations and ACE on specific health conditions. At the moment, formal data collection is not being requested from patient organisations as there would be data collected in the trials. Patient input on their lived experience would be more valuable to the MOH Advisory Committee as this data would not be available through the trials and studies in the literature. An exception may be rare disease where there may be a need to ask for patient data. There may be a role for collection of real-world data, for selected conditions or health products, in addition to trial data but this should not delay the HTA assessment which MOH aims to give a decision on as close as possible to the regulatory decision. On the issue of patient confidentiality, ACE clarified that all patient input would be anonymous, however, patient characteristics such as age, gender, duration of illness would be needed in order to interpret the patient input correctly.

Managing Conflicts of Interest

Industry is an important stakeholder for access to health products however it is important to manage conflicts of interest among patient organisations contributing input to HTA. ACE is working with individual companies as well as local industry associations to develop standardised guidelines for companies to appropriately work with patients. Participants shared that it may be beneficial to explore an independent body or platform with resources and mandate to facilitate engagement with industry.

2. The Way Forward

The Consumer Engagement and Education initiative and this first dialogue are important first steps to bring the patient voice into health policy decision-making in Singapore. Patient input provides context and assurance to decision-makers in combination with the study data. Patients are critical stakeholders in their health care and decision making and patient engagement is increasingly recognised as having a major role in improving quality and safety of health care interventions, service delivery, and promoting personalised health care. During the discussion, the panellists reiterated that a critical factor in fostering meaningful patient engagement in Singapore is a mindset shift at every level of the health system, from the clinicians to researchers, patients, caregivers and industry. To summarize the key takeaways from this discussion session are:

- Patient involvement in HTA adds value for all stakeholders and should be two-way conversation.
- Patients can contribute important lived experiences that are not part of the evidence found in clinical research.
- Mutual trust between different stakeholders is foundational to such an initiative.
- Improving health literacy is key for meaningful involvement.
- Although the patient advocacy landscape in Singapore is fragmented, there is opportunity to innovate ways of working together.
- Data confidentiality remains crucial in any patient input provided for HTA.

Next Steps from ACE

- CEE is developing educational collaterals for healthcare consumers to improve health literacy for patients and their caregivers.
- CEE aims to support patients involved in HTA in the form of trainings, resources, online tools and day-to-day support through meetings, emails and addressing queries.

Next Steps from CoRE

- CoRE will continue to work closely with ACE, patient organisations, and other stakeholders to convene further dialogues on the future of patient and public involvement in HTA
- CoRE will support capacity building for patients and other stakeholders along with other partners of ACE
- CoRE will host a conference on 5-6 October 2022 themed “Patients as Partners for Sustainable Health system” where HTA will be an important focus

Give us your feedback:

If you were not able to attend the event and provide live feedback during the dialogues please do use this link to provide your feedback to ACE on the Consumer Engagement & Education initiative and let them know if you would like to be involved.

Acknowledgements

The views presented in this publication are those of individual contributors who attended the event and do not represent formal consensus positions of CoRE or ACE.

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Annex A

Panelists and Moderator

	Name	Designation & Organization
1	Professor John Lim (Moderator)	Executive Director, CoRE, Duke-NUS Medical School Senior Advisor, Ministry of Health (MOH) Singapore
2	Ms Tan Ping-Tee	Senior Specialist Agency for Care Effectiveness (ACE) Ministry of Health (MOH) Singapore
3	Ms Fiona Pearce	Senior Advisor Agency for Care Effectiveness (ACE) Ministry of Health (MOH) Singapore
4	Mr Shawn Quek	Specialist Agency for Care Effectiveness (ACE) Ministry of Health (MOH) Singapore
5	Dr Ritu Jain	Director, Asia Pacific Alliance of Rare Disease Organisation (APARDO) President, Dystrophic Epidermolysis Bullosa Research Association (DEBRA)
6	Ms Nidhi Swarup	Founder & President Crohn's & Colitis Society of Singapore Co-Chair Designate (International Collaboration) SingHealth Patient Advocacy Network (SPAN)



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