



ACE briefing on new patient involvement processes

20 February 2023



ACE
agency for
care effectiveness

1. Background

On 20 February 2023, the Agency for Care Effectiveness (ACE) Consumer Engagement and Education (CEE) team held a public briefing session for 156 attendees from patient and voluntary organisations, industry and academia on processes that have been recently implemented to encourage patients to become involved in ACE's work.



Through a series of presentations and a panel discussion, the session aimed to promote greater public understanding of ACE and its patient involvement processes, and enabled participating patient organisations to network with each other and ACE staff to establish collaborative partnerships and a shared purpose.

Slides from the presentations about the role of ACE and the CEE team, and how patients can provide their lived experiences to inform ACE's technical evaluations are available on the [ACE website](#).

2. Insights from the Panel Discussion

The panel discussion was moderated by Ms Fiona Pearce from CEE. The panellists included 3 members from ACE's Consumer Panel - Dr Lau Tang Ching, Dr Ritu Jain, and Ms Ai Ling Sim-Devadas, as well as Ms Ping-Tee Tan from CEE.

The moderator explained that ACE has begun capturing the patient voice in health technology assessment (HTA) processes to address uncertainties in the scientific evidence and interpret results for real-world implementation by enabling patients to describe their needs, preferences, lived experiences and expectations.

The key themes for the panel discussion were:

- (1) the importance of patient involvement in ACE's work;
- (2) optimal ways for ACE to collaborate with patient organisations and measure the effectiveness of patient involvement initiatives; and
- (3) training and capacity building for patient organisations.

The moderator also invited questions and comments from the audience.

(1) Importance of patient involvement in ACE's work

It is important for patients and carers to share their lived experiences and emotions, such as fear of disease recurrence and the impact that medical conditions can have on families and carers, to provide decision-makers with evidence beyond quantitative data to inform their funding decisions for new health technologies (such as drugs and medical devices). Qualitative patient inputs can lead to a better understanding of outcomes that matter most to patients and ensure that any decisions made are relevant to those that are most affected by them.

The panellists hoped that CEE's future initiatives would also help to support the Healthier SG initiative, whereby patients receive correct diagnoses early and are offered cost-effective treatment options. The

panellists also explained that patient involvement should extend beyond ACE's work into the healthcare system. Patients should have the opportunity to share their care goals with their clinicians and their care plan should be designed to meet these goals through shared decision-making.

The panellists agreed that CEE's initiatives to improve health literacy by developing factsheets and other educational resources should be continued, however, patients should also be provided with targeted training to equip them with the necessary skills required to contribute actively to ACE's work and healthcare policy decision-making. All of these efforts will enable stakeholders to work together better and be empowered to achieve a common purpose.

(2) Optimal ways for ACE to collaborate with patient organisations and measure the effectiveness of patient involvement initiatives

The panellists were pleased that the CEE team is keeping patient organisations informed of funding recommendations after each advisory committee meeting, and have been sharing how their members' inputs have helped inform the committee's deliberations. However, while this is a positive step towards including the patient's voice in health policy, the patients who provide inputs are likely to represent a younger, health literate population, so efforts are needed to engage those that are older and less literate, as they represent a sizeable proportion of patients who use public healthcare resources and subsidised treatments.

Co-creating methods with patient organisations to measure the effectiveness of CEE's initiatives are important to ensure the sustainability of patient involvement practices. The panellists shared several suggestions such as creating patients surveys that include questions about whether patients have participated in shared decision-making with their clinicians to achieve their care goals, and whether their care plans are affordable, safe and effective. Measuring quality of life indicators and healthy life-years was also suggested as well as tracking ACE website views and how

patient factsheets are used in public healthcare institutions to help inform CEE's outreach and dissemination strategies.

The CEE team is planning to conduct a formal impact evaluation of its patient involvement processes after gathering adequate case studies. The results can help inform the effectiveness of the work done to date and the necessary changes required to improve processes and continue to meet the needs of patients. Furthermore, the *Process and methods guide for patient involvement* is intended to be a living document and will be constantly updated to streamline and simplify processes according to patient feedback.

Impact stories will also be published to encourage patient organisations to continue to participate in ACE's work and to share examples where patient input has had a meaningful impact on decision-making.

Comments from the audience:

1. It would also be helpful to include the learnings and experiences of healthcare professionals who are caring for patients in this shared vision, so that they have a clear line of sight in their work and can be empowered to do better.
2. How much weight does patient input have in the overall evaluation? It would be useful for the CEE team to collect case studies and create a toolkit to share the impact of patient input. Patients can be empowered to contribute just by being involved in the process.

Panel: The way the advisory committee considers patient input depends on the evidence available. If the input provided by patients is already available in the scientific evidence, receiving patient input serves as a form of due diligence and gives certainty to the advisory committee that the evidence represents local patients' views. If there are gaps in the scientific evidence, such as for rare diseases, patient input can explain the clinical need for new treatments, and whether the treatments being evaluated can meet patients' needs and preferences. The CEE team hopes to publish case studies regularly, and provide training for patient organisations and their

members on the type of patient input that has a meaningful impact on decision-making.

3. The psychosocial support for patients and their families is a concern due to the socio-economic impact brought upon by the condition and treatments. Patients often want to know about the various funding options available. Some patients are grappling with the fear of recurrence, or losing their jobs or the ability to return to work.

Panel: These aspects are taken into consideration in the development of the patient survey. Patients often share that their treatment expectation is to be able to return to work or school, and they also feel the stress on their family and carers. Carers' perspectives are important and they can also submit testimonials to ACE. Additionally, the CEE team considers the emotional aspect when developing educational resources by paying attention to the writing tone, and including relevant patient organisations in the factsheets as a source of emotional and social support for patients.

4. Is CEE planning any patient education on proton beam therapy, a new technology for patients with a brain tumour?
5. Will there be another chance for patients to provide their input on drugs and devices that have already been evaluated by ACE without patient engagement?

Panel: The CEE team co-develops educational resources and invites patient input for topics that ACE has been asked to evaluate for funding consideration. For topics that were evaluated before the new patient involvement processes were established, it is not necessary to retrospectively seek patient input if the topic has already received a positive funding decision. For negative funding decisions, there are appeal processes and companies may resubmit proposals for the advisory committee's consideration, and patients can be asked for inputs at this point.

6. Which HTA framework is ACE working towards? Is there a particular benchmark for the CEE team?

Panel: The scientific methodological frameworks for conducting HTAs that are used in Singapore and by overseas agencies are similar, but there are differences in the healthcare systems, value preferences, and decision-making processes across different jurisdictions. ACE keeps abreast of overseas practices and often references Australia, the UK, Taiwan, Belgium, South Korea and Canada when establishing new processes. The patient involvement processes that have been set up by CEE are largely aligned with practices in Canada at this stage, but with notable differences such as the inclusion of a feedback process to enable CEE to advise patients and patient organisations on how their input has informed funding decisions, and to recognise their contributions.

(3) Training and capacity building for patient organisations

Different academic institutions and companies in Singapore are preparing training packages for patients to help them narrate their clinical insights and disease journeys to inform clinical trial development, policy decisions or HTAs. However, patient organisations have different capabilities, capacities and education needs. Developing a collective approach to training and capacity building can prevent duplicative effort and stop patient organisations from being overwhelmed by the amount and type of training they should be undertaking.

The panellists agreed that there is no one-size-fits-all approach to training and it is important to get patients' inputs about their training needs and aims before rolling out any training initiatives. Courses should be categorised from basic to intermediate to advanced to tailor to the informational needs of each patient organisation, and techniques such as adaptive learning can be used to customise training resources for each competency level. The panellists highlighted that all training initiatives need to be evaluated after implementation to determine if they are effective in changing behaviours and meet the aims of patient organisations.

Enhancing capacity in patient engagement, especially to inform HTAs, is currently an area of interest for many healthcare organisations, pharmaceutical companies and medical schools. However, it is not straightforward to provide meaningful patient perspectives, even with training. A long-term commitment from all stakeholders is needed to ensure that patients are well equipped to communicate effectively and are adequately informed of healthcare policies and engagement opportunities to ensure that the patient voice is heard.

Comments from the audience:

7. A toolkit from ACE on how patients can co-design training packages would be useful to help patient organisations build capacity, tailor resources to meet their needs and gather better input from members.
8. Is CEE planning to run campaigns such as “Choosing Wisely Australia” in the future? How can patient organisations help?

Panel: While condition-specific factsheets have been helpful, CEE recognises the potential to develop educational campaigns for select conditions. While CEE is not directly implementing Choosing Wisely campaigns at this time, the team can support patient organisations drive these initiatives.

3. Closing Remarks

Dr Daphne Khoo, Executive Director of ACE, closed the session by emphasising that patients are important stakeholders that help to improve the legitimacy of ACE's work, improve patient outcomes and keep healthcare affordable. Establishing the CEE team is a transformational step that ACE is taking to ensure that the patient perspective helps shape healthcare policies. Furthermore, including patient input in ACE's HTAs is an important initiative to advance patient engagement in Singapore and ACE looks forward to working more closely with patient organisations going forward.

Acknowledgement

The ACE Consumer Engagement and Education team would like to thank the panellists and all attendees for their participation during the briefing session and for their ongoing support of ACE's work.

Moderator and Panellists

| Name | Designation & Affiliations |
|--|---|
| Ms Fiona Pearce (Moderator) | Senior Advisor Consumer Engagement and Education Agency for Care Effectiveness (ACE) Ministry of Health, Singapore |
| Ms Ping-Tee Tan | Senior Specialist Consumer Engagement and Education Agency for Care Effectiveness (ACE) Ministry of Health, Singapore |
| Dr Lau Tang Ching | Chairman, The National Arthritis Foundation Chair, ACE Consumer Panel |
| Dr Ritu Jain | President, Dystrophic Epidermolysis Bullosa Research Association, Singapore (DEBRA Singapore) Co-Chair, ACE Consumer Panel |
| Ms Ai Ling Sim-Devadas | Patient Mentor, SingHealth Patient Advocacy Network Member, ACE Consumer Panel |

Resources



To view the slides presented at the session, or the *ACE Process and methods guide for patient involvement* and supporting factsheets, please scan the QR code or visit

<https://www.ace-hta.gov.sg/Patients-And-Community/opportunities-for-patient-involvement>

The Agency for Care Effectiveness was established by the Ministry of Health Singapore to drive better decision-making in healthcare through health technology assessment, clinical guidance, and education.

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