ACE briefing on new patient involvement processes

Consumer Engagement and Education (CEE) team Agency for Care Effectiveness (ACE) 20 February 2023



Programme

Time	Item	Presenter/ Panelists:
9:00 am	Registration	
9:30 am	Introduction to establishing the Consumer Engagement and Education (CEE) team	Ms Ping-Tee Tan
9:45 am	Process and methods for patient involvement	Ms Fiona Pearce
10:00 am	Panel discussion	Dr Lau Tang Ching Dr Ritu Jain Ms Ai Ling Sim-Devadas Ms Ping-Tee Tan Ms Fiona Pearce (moderator)
10:45 am	Closing remarks	Dr Daphne Khoo
10:55 am	Thank you and feedback	Ms Ping-Tee Tan
11:00 am	End	

Introduction to establishing the Consumer Engagement and Education (CEE) team

Ping-Tee Tan

Senior Specialist
Agency for Care Effectiveness
Consumer Engagement & Education Team



Singapore's paradigm shifts towards healthcare sustainability



ACE was formed in August 2015 as the national HTA agency in Singapore to:

- Consolidate local health technology assessment (HTA) capacity and capabilities, and
- 2. Optimise healthcare value within finite resources

Mission

- ✓ To issue objective and credible healthcare guidance
- ✓ To enable stakeholders to make better-informed choices
- ✓ To drive evidence-based practice



Working in partnership with three key stakeholders

ACE's logo is three intertwined branches which represent the three stakeholders that ACE works closely with to improve patient outcomes and keep healthcare affordable

- patients
- healthcare providers (clinicians)
- payers (government)



ACE supports healthcare providers, patients and payers make better-informed decisions about patient care

- Health technology assessments (HTA) to inform funding decisions
- 2. Clinical guidance to inform clinical practice
- 3. Healthcare professional education
- 4. Healthcare consumer education

Guidances & publications are available at www.ace-hta.gov.sg



Health technology assessments (HTA) to inform funding decisions

HTA is an **established methodology widely used internationally** (including UK, Canada, Australia, South Korea, Thailand) to inform funding decisions for health technologies (such as **drugs**, **vaccines** and **medical devices**).



HTA helps to answer:

How well health technologies work in relation to how much they cost?

The goal of HTA is to inform the development of effective health policies about the use of health technologies in a manner that is patient-focused and achieves best value.



ACE conducts an HTA by reviewing clinical and economic evidence, negotiating prices with companies, and seeking expert views



Systematic literature review of clinical evidence



Economic evaluation (cost-effectiveness analysis)



Pricing negotiations with pharmaceutical companies (Value-Based Pricing)

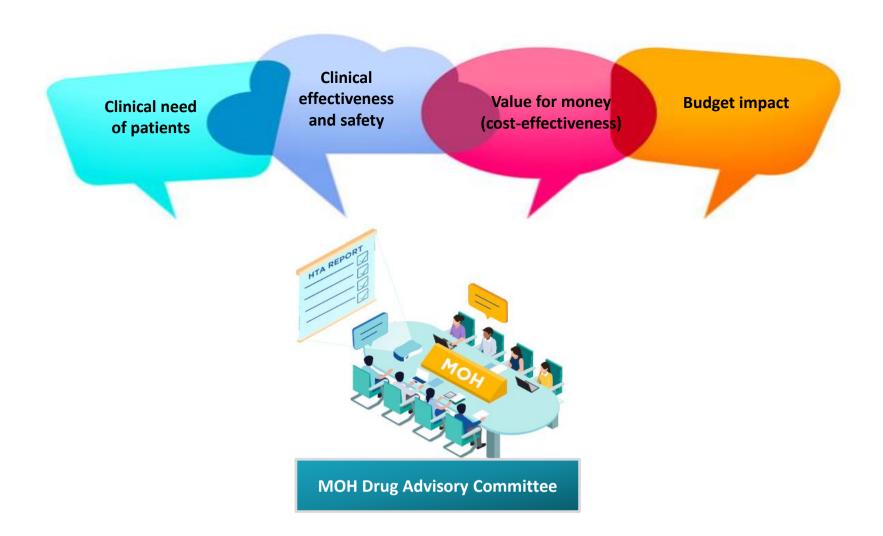


Expert opinion about local clinical practice



HTA report

MOH advisory committees use ACE's evaluations to inform their funding recommendations





ACE started inviting patients to provide their lived experiences to inform HTAs for drug topics in 2022



Systematic literature review of clinical evidence



Economic evaluation (cost-effectiveness analysis)



Pricing negotiations with pharmaceutical companies (Value-Based Pricing)



Expert opinion about local clinical practice



Lived experiences of medical condition and treatment by patients

* coordinated by the CEE team



HTA report



CEE was established to support patient involvement in ACE's work



ACE's Consumer Engagement and Education (CEE) workstream supports patient involvement in ACE's work and co-develops educational resources with patient and voluntary organisations which encourage shared healthcare decisionmaking between patients and their doctors.



Ping-Tee TanSenior Specialist



Fiona PearceSenior Advisor



Shawn Quek Specialist



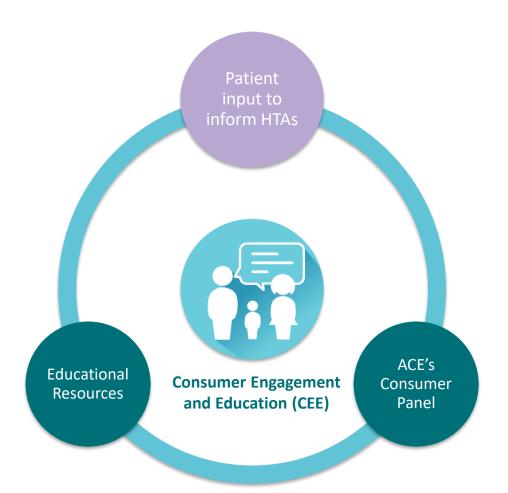
Sok Huang Teo
Specialist



Jen Hun Koh Principal Analyst



Stakeholder mapping to identify local patient and voluntary organisations

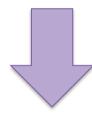


- In the absence of a centralised patient organisation database, we undertook a stakeholder mapping exercise to identify all relevant patient and voluntary groups in Singapore
- We contacted all of them to find out their remits and if they want to contribute to ACE's work

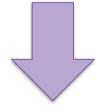
Identifying local patient and voluntary organisations

Preliminary search of all patient groups:

- Singapore Charity Portal
- Websites of healthcare service providers
- Social media platforms
- Search engines



Patient groups screened and contacted via email and cold calling



>100 local patient and voluntary organisations identified

Members from these groups can provide condition-specific input into ACE's technical evaluations and advise ACE on the needs of patients in Singapore

Regional/international networks

CEE participates in these networks to remain up to date with patient involvement initiatives taking place globally



ACE Consumer Panel established in April 2022

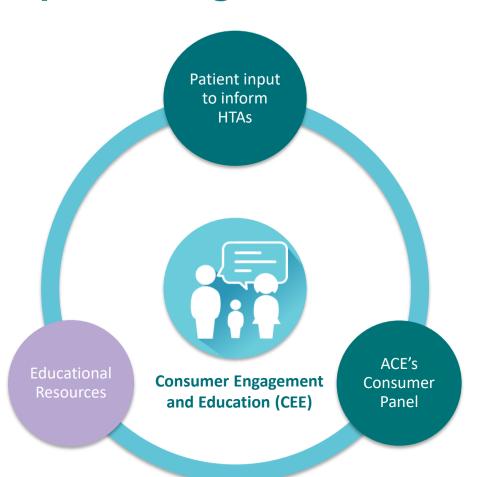


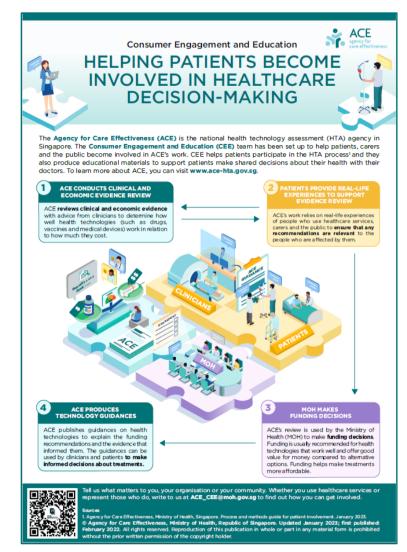
- Provides strategic advice to ACE and MOH advisory committees on opportunities to strengthen engagement efforts which meet the needs of patients, carers, and the public and ensure their views are effectively used to inform ACE's work.
- Comprises 14 individuals from local patient organisations covering a broad range of health conditions who have extensive lived experience engaging with the Singapore healthcare system.

www.ace-hta.gov.sg/about-us/our-council-and-expert-panels



Co-developing educational resources with patient organisations

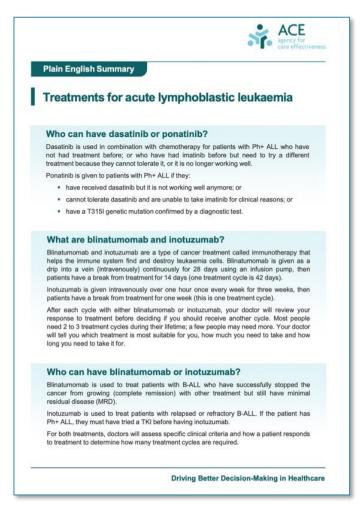






Plain English summaries

- Short plain English summaries of ACE's drug guidances have been published on the ACE website since January 2019
- Describe key funding recommendations and provide brief information about the drug(s) and condition(s) that were evaluated
- Revised when guidances are updated to ensure that they remain relevant to readers





Patient factsheets

Provides patients with key information about:

- Their health condition
- Available treatment options in Singapore
- How well treatments work compared to each other
- Which treatments are subsidised and most affordable

Facilitate patients' understanding by:

- Limiting to a 2-page summary
- Writing in plain English
- Using simple numbers
- Using pictures



https://www.ace-hta.gov.sg/Patients-And-Community/Educational-Resources





TREATMENTS FOR ALK MUTATION-POSITIVE

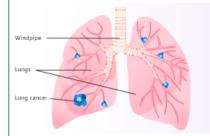
ADVANCED NON-SMALL-CELL LUNG CANCER



Around 1.600 people are diagnosed with lung cancer every year, making it one of the most common cancers in Singapore, It is also one of the leading causes of cancer-related deaths locally.1

Two in three patients1 have cancer that has spread outside of the lungs to other parts of the body, which is known as advanced lung cancer.

There are different types of lung cancer depending on which cells are affected. Non-small-cell lung cancer or NSCLC is the most common type.



Doctors may send samples of the cancer for testing to determine which treatment will work best.

Some patients with NSCLC have an abnormality (mutation) in the Anaplastic Lymphoma Kinase (ALK) gene which helps the cancer grow. This is called ALK mutation-positive NSCLC.

How is NSCLC treated?

Advanced NSCLC options include:

Chemotherapy

Radiotherapy Targeted therapy

Immunotherapy +/- chemotherapy

Targeted therapy are medicines that are effective against cancers with specific genetic mutations.

There are 5 targeted therapies approved for patients who have advanced NSCLC with an ALK mutation. These drugs are known as ALK inhibitors.

Alectinib

* ACE

Brigatinib

Ceritinib

Crizotinib

Lorlatinib

Legend: 🐔 Tablets: 🔊 Cap



Published studies show that all 5 ALK inhibitors are effective treatments for ALK mutationpositive NSCLC. They have different side effects from each other.

- For patients with newly diagnosed NSCLC, alectinib, brigatinib, ceritinib and lorlatinib are likely to be more effective than crizotinib in extending the length of time they can live without their cancer getting worse.
- If the cancer continues to grow while a patient is taking an ALK inhibitor, alectinib, brigatinib, ceritinib and lorlatinib are effective treatment options.

ACE reviewed all available clinical evidence for each ALK inhibitor and negotiated prices with the companies.



Value for money (cost-effectiveness) of alectinib, brigatinib, ceritinib and lorlatinib was improved when the companies reduced the drug prices.



Cash or MediSave needed every month

after subsidy and MediShield Life for a middle-income patient receiving outpatient treatment at public

hospitals*:

Ceritinib	Around \$100	Subsidised ✓ MediShield Life: \$1000 ✓
Alectinib	Around \$200	Subsidised ✓ MediShield Life: \$2000 ✓
Brigatinib	Around \$200	Subsidised ✓ MediShield Life: \$2000 ✓
Lorlatinib	Around \$200	Subsidised ✓ MediShield Life: \$2000
Crizotinib	\$6,500 to \$7,000	Subsidised X MediShield Life X

Alectinib, brigatinib, ceritinib and lorlatinib were recommended for government funding2 because they are effective and provide the best value for money for treating ALK mutation-positive advanced NSCLC.



Crizotinib was not recommended for funding because its benefits do not justify its cost at the price offered by the company.

Talk to your doctor to discuss which treatment is suitable for you. You can also speak to a medical social worker if you need further financial assistance for any of these treatments.

* Expenses will differ according to the amount of medicine that each patient needs and does not include other costs for doctor consultations, medical tests etc. MediSave withdrawal is capped at \$600 per month for these treatments. For Singaporeans who are eligible for subsidy, treatment costs will be subsidised by 40% to 75%. For subsidised drugs, expenses have been calculated using prices proposed by the companies including patient assistance programmes. For non-subsidised drugs, prices at public healthcare institutions at the time of subsidy review were used.

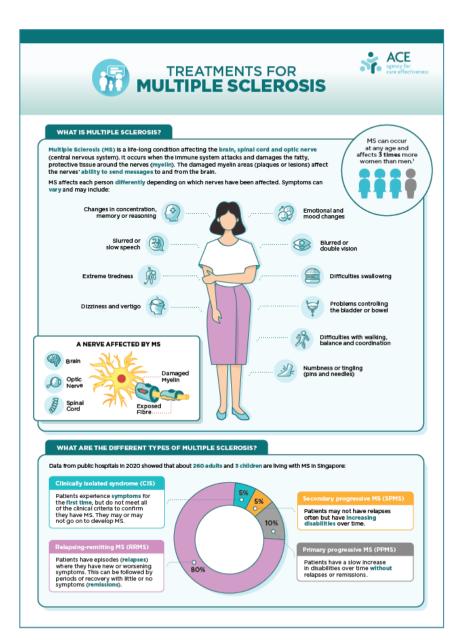
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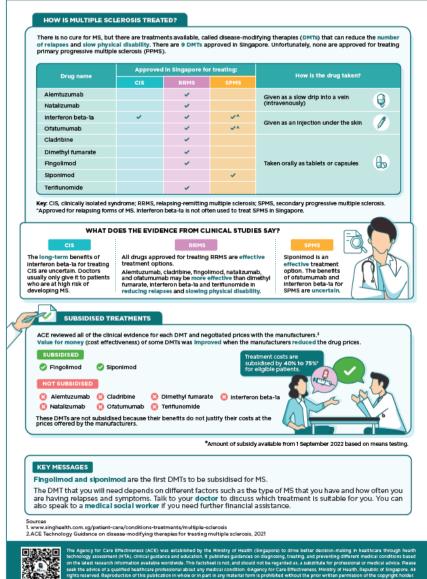


health technology assessment (HTA), clinical guidance and education. It publishes guidances on diagnosing treating, and preventing different medical conditions based on the latest research information available worldwide. This factsheet is not, and should not be regarded as, a substitute for professional on medical advice. Please seek the advice of a qualified healthcare professional about any medical condition. © Agency for Care Effectiveness, Ministry of

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CEE Updates



CEE UPDATES December 2022



CEE AND PATIENT ORGANISATIONS IN ACTION

The CEE team and the ACE Consumer Panel were privileged to participate in three recent conferences to discuss best practices and ways to encourage meaningful collaboration with healthcare consumers. The insights gathered have also helped to shape how ACE involves patients in healthcare decision-making. We look forward to future opportunities to connect with and learn from local and international patient and voluntary organisations.

1. ACE's Value-based Healthcare Conference, 29 to 30 September 2022



2. Duke-NUS Centre of Regulatory Excellence (CoRE) Scientific Conference: Patients as Partners for Health: Co-creating Equitable Access to Health Products and Services, 5 to 6 October 2022



3. SingHealth Patient Advocate Connection (SPACe), 29 October 2022



PATIENT ENGAGEMENT

ACE'S DRUG EVALUATIONS WERE GATHERED FROM



PATIENT ORGANISATIONS FOR

TOPICS PRESENTED TO THE MOH DRUG ADVISORY COMMITTEE IN AUGUST 2022

Patients and carers were invited to provide their lived experiences about medical conditions and treatments to include in ACE's technical evaluations. A big thank you to the patient organisations that helped to gather input from their members! The insights we received were very helpful to inform the MOH Drug Advisory Committee's funding recommendations.

COMING SOON

CEE is developing the following documents to guide patients who want to provide input into ACE's work and describe subsidy decision-making processes in plain English. The drafts will be sent to Consumer Panel members and select patient organisations for comment in September 2022:

- · Process and methods guide for patient involvement
- · Quick tips for meaningful patient input in ACE's work
- Tips to provide patient input into ACE's technical evaluations
- Factsheet on 'How are funding decisions made for new treatments?'

Your comments are greatly appreciated to help us improve our processes and ensure that the resources we produce are useful for patients, carers, and patient organisations.

Duke-NUS Centre of Regulatory Excellence (CoRE) Scientific Conference

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

5 to 6 October 2022

CEE is excited to be involved in this important conference to discuss ways to encourage patient involvement in policy development and healthcare decision-making.

The Agency for Care Effectiveness (ACE) Consumer Engagement and Education (CEE) team supports patient involvement in ACE's work and develops plain English summaries and educational resources to improve health literacy and encourage shared healthcare decision-making



https://www.ace-hta.gov.sg/Patients-And-Community/cee-updates



82 patients contributed comments for 7 topics in 2022

- DAC meets ~3 times per year
- From Aug 2022 onwards, patients and carers have been invited to provide their lived experience about medical conditions and treatments to inform ACE's technical evaluations and the DAC's recommendations about new drugs being considered for funding.
- All patient inputs received are collated by CEE and included in ACE's technology evaluation reports and drug guidance.
- Patient Responses About ACE's Drug Evaluations Were Gathered From
 - 4 Patient Organisations For
 - Topics For Aug 2022 DAC Meeting



- Patient Responses About ACE's Drug Evaluations Were Gathered From
 - **6** Patient Organisations For
 - 4 Topics For Nov 2022 DAC Meeting



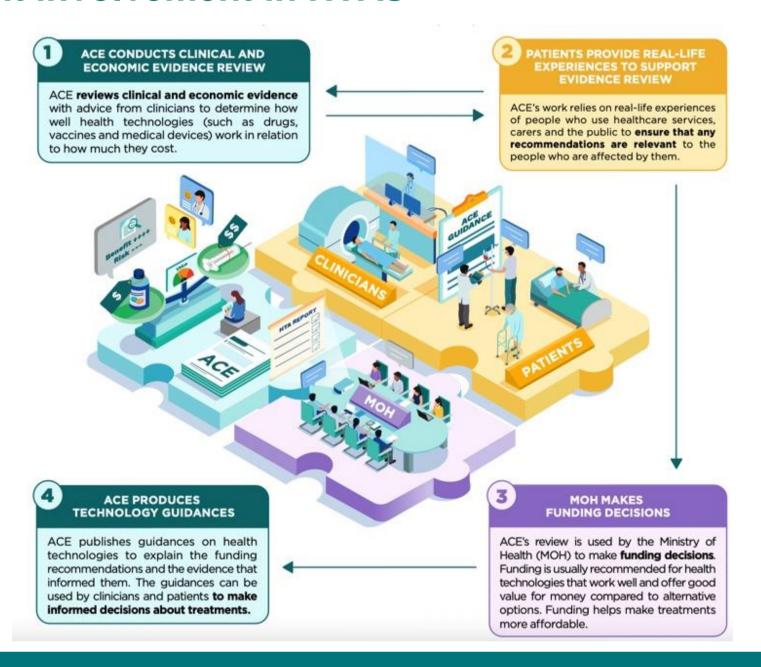
Process and methods for patient involvement

Fiona Pearce

Senior Advisor Agency for Care Effectiveness Consumer Engagement & Education Team



Patient involvement in HTAs



Providing lived experiences to inform HTAs

- Patients and their carers provide important evidence to inform ACE's evaluations and help MOH Advisory Committees to:
 - Understand how different medical conditions affect patients, their carers, and families
 - Identify unmet needs and treatment preferences of patients
 - Understand the benefits and disadvantages of different health technologies
 - Understand patients' expectations for new treatments
 - Identify health outcomes that are important to patients
 - Determine if the outcomes measured in clinical trials and economic models are relevant to patients in Singapore
 - Fill gaps or address uncertainties in the scientific evidence
 - Identify if there are any issues affecting a patient's ability to use or access treatments



Process and Methods Guide for Patient Involvement

CEE has developed a range of resources to improve our ability to consult, engage and listen to patients and ensure that our work better meets their expectations and needs

- A Process and Methods Guide for Patient Involvement was co-developed with local patient organisations to clearly explain what ACE does and how patients/carers can become involved in ACE's HTAs
- Guide also explains other opportunities for patients to be involved in ACE's work (e.g. developing educational resources)

Process and methods guide for patient involvement

Version 1 January 2023



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

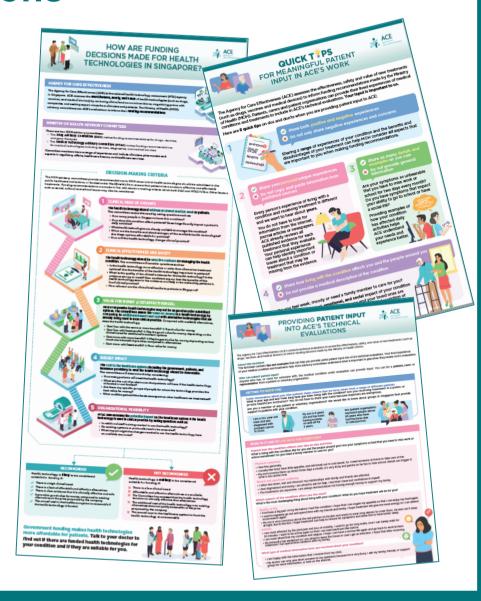


Support tools for patients who want to provide input into ACE's technical evaluations

Accompanying Factsheets:

- 1. Quick tips for meaningful patient input in ACE's work
- Providing patient input into ACE's technical evaluations
- 3. How are funding decisions made for health technologies in Singapore?

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





Co-developing resources with patients

To ensure that patient involvement processes included in the guide are in line with best practices and address local patients' needs we co-developed all resources with:

- ACE Consumer Panel
- local patient organisations (not represented by the Panel)

We also received comments from:

- AusDoH Consumer Evidence and Engagement Unit, and HTA Consumer Consultative Committee
- Patient Voice Initiative, Australia
- CADTH Patient Engagement team
- NICE Public Involvement Programme team
- Singapore Association of Pharmaceutical Industries (SAPI)



Local patient organisations and international patient involvement groups are supportive of our work

This is an excellent document about the work ACE is doing and how patients can be involved. The infographics are well-done.



Ai Ling Sim-Devadas, Mentor of SingHealth Patient Advocacy Network, ACE Consumer Panel member

I really commend you on the work you have done to introduce patient involvement into HTA in Singapore and explain it clearly and meaningfully to the public in these documents. I think they will inspire other HTA bodies.

Ann Single, Patient Voice Initiative Coordinator (Australia) and Chair of Health Technology Assessment international (HTAi) Patient and Citizen Involvement Interest Group Our patient advocates were impressed and happy with the documents.



Patient Advocacy and Support Office, National University Health System

The 3 supplementary documents are visually appealing and use clear, everyday language, images and colours to explain key aspects of the process and the role of patient organisations. I consider them to be exceptional examples.



Victoria Thomas, Public Involvement Programme, NICE (UK).



Future revisions to our processes

Some suggestions on our processes were not implementable immediately but we hope to include them over time:

- Allow patient organisations to propose topics for ACE to evaluate
 starting this year
- Invite patients to provide inputs into HTAs for technologies other than drugs – starting to seek inputs for medical devices and gene therapies this year
- Include a patient/lay member on MOH Advisory Committees
- Provide ACE's documents in languages other than English to reach a broader segment of patients
- Develop materials in other formats to support patients with aphasia or visual impairment



Key steps for patients to provide their lived experiences



1. Survey and support tools developed to help patients provide their experiences about their condition and treatment(s)





2. CEE invites inputs from all patients who have an interest in the health technology or condition under evaluation. Patient groups or clinicians circulate survey to patients.





7. CEE thanks **patient organisations** and provides feedback on which comments from their members were most helpful to the Committee. CEE also welcomes feedback to improve our processes.



3. CEE answers questions and provides clarification to help gather information that is likely to be helpful to decisionmaking



6. ACE guidance and plain English summary explaining the funding recommendation published on ACE website



4. Patient inputs included in ACE's **evaluation report**



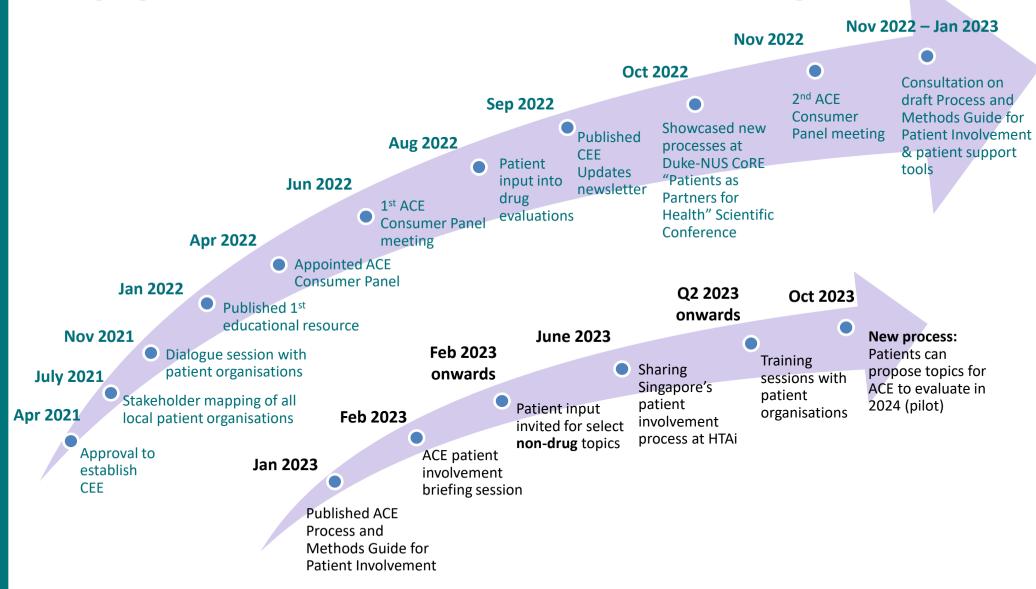


5. Deliberation and **funding recommendations** made by MOH Advisory Committee





CEE is committed to advancing patient engagement in healthcare decision-making



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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