Process and methods guide for patient involvement

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ACE
agency for
care effectiveness

Record of updates

Date	Version	Summary of changes
January 2023	1.0	Publication of *Process and methods guide for patient involvement.*
May 2023	1.1	Guide updated to include information about process for patients to propose topics for technical evaluation. Minor additions and wording changes throughout the document have also been made to improve the clarity of the text.
April 2024	1.2	Appendix 2 (patient survey) updated to include additional questions. Minor additions and wording changes throughout the document have also been made to improve the clarity of the text.
November 2024	1.3	New funding mechanism (Cell, Tissue and Gene Therapy Products List) included. Appendix 1 (topic suggestion application form) updated to include revised questions.

Table of Contents

Acknowledgement

Patient involvement has become integral to health technology assessment (HTA) processes globally over the last decade due to an increased recognition that patients have the requisite expertise, and an important contribution to make in addressing uncertainties in the scientific evidence base and interpreting results for real-world implementation by describing their needs, preferences, lived experiences and expectations.

In this guide, we describe the contribution that patients and their carers can make to ACE's work and healthcare decision-making in Singapore by providing their experiential knowledge of different medical conditions and health technologies, and explaining which outcomes are most important to them.

This guide focuses on patient involvement in the HTA process and excludes methods on the scientific collection of patient data (that is, how to undertake formal quantitative or qualitative research on the perspectives, experiences, and preferences of patients). It has been developed by drawing on good practice examples from different HTA agencies and ACE's experience to date working with local patient organisations.

Although we explain how patients can currently be involved in ACE's work throughout the guide, it is not meant to limit involvement, and opportunities may change and increase over time. We will continue to review our processes and improve this document to ensure that it remains a useful resource for patients and carers who want to be involved in ACE's work.

We would like to acknowledge and thank the ACE Consumer Panel, local patient organisations, and patient involvement experts from overseas HTA agencies who have provided valuable advice and contributed to the development of this guide.

Abbreviations and acronyms

Term	Definition
ACE	Agency for Care Effectiveness
CDL	Cancer Drug List
CDS	Cancer Drug Subcommittee
CEE	Consumer Engagement and Education
CTGTP	Cell, Tissue and Gene Therapy Product
DAC	Drug Advisory Committee
HSA	Health Sciences Authority, Singapore
HTA	Health Technology Assessment
ISL	Implant Subsidy List
MAF	Medication Assistance Fund
MOH	Ministry of Health, Singapore
MTAC	Medical Technology Advisory Committee
PES	Plain English Summary
SDL	Standard Drug List
SVL	Subsidised Vaccine List

Introduction

About ACE

The Agency for Care Effectiveness (ACE) is the **national health technology assessment** (HTA) and clinical guidance agency in Singapore residing within the Ministry of Health (MOH). It conducts technical evaluations to assess the effectiveness, safety, and value of health technologies to inform funding recommendations made by MOH advisory committees. ACE also develops clinical guidance and educational resources to support healthcare professionals and patients achieve effective, evidence-based care.

ACE's logo is three intertwined branches which represent the three stakeholders – **patients**, **healthcare providers** (clinicians) and **payers** (government) – that ACE works closely with to improve patient outcomes and keep healthcare affordable.

In 2021, the **Consumer Engagement and Education** (CEE) team was established to support patient involvement in ACE's work, and co-develop educational resources with patient and voluntary organisations which encourage shared healthcare decision-making between patients and their doctors.

The key responsibilities of the CEE team are to:

- establish collaborative working relationships with local patient and voluntary organisations
- develop, implement, and improve methods and processes to enable patients to meaningfully contribute to ACE's work
- provide guidance and support to patient organisations whose members are involved in ACE's technical evaluations
- provide information and training to patient organisations and their members who are interested in or contribute directly to ACE's work
- co-develop educational resources with patient organisations which improve health literacy about different medical conditions and healthcare policies, and empower patients to make evidence-based decisions about their healthcare needs
- provide secretariat support to ACE's Consumer Panel

Find out more about ACE at https://www.ace-hta.gov.sg/about-us.

About ACE's Consumer Panel

In April 2022, the CEE team established a **Consumer Panel** to represent the collective voice of healthcare consumers and provide strategic advice to ACE and its 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.

The Panel comprises members who have senior appointments in local patient or voluntary organisations representing a broad range of health conditions.[i] Co-Chairs are also appointed to oversee the Panel. Although members are selected to represent their specific organisations or health conditions, they are also expected to provide their own personal views based on their range of experience engaging with the Singapore healthcare system.

[i] List of Consumer Panel members is available at: https://www.ace-hta.gov.sg/about-us/our-council-and-expert-panels

Members are appointed for a 2-year term, with an opportunity to be reappointed for a further term. The **Terms of Reference** for the Consumer Panel are stated below:

- foster effective collaboration between ACE and local patient organisations
- provide patient and/or societal perspectives to inform ACE's initiatives to improve health literacy and encourage the appropriate use of health technologies
- provide guidance on best practices that ACE can use to collect information on patients' views and experiences
- champion ACE's work and encourage meaningful patient involvement in HTAs
- support ACE to promote greater public understanding of HTA processes
- assist ACE to continuously improve how it involves patients and carers in its work
- review the format, content, and proposed communication strategies of ACE's educational resources so that they meet the needs of patients, carers, and the public
- provide guidance on opportunities to strengthen engagement with patients and the public across ACE's different workstreams
- attend scheduled meetings and provide expert advice as required

What is health technology assessment?

Before a company can sell and promote a health technology (such as a drug [medicine], vaccine, gene therapy, diagnostic test, or medical device) in Singapore, the Health Sciences Authority (HSA), Singapore's national regulatory body, assesses its **efficacy**, **safety**, and **quality**, and determines which conditions it should be used for.[ii]

However, the government does not have an unlimited healthcare budget to fund all health technologies approved by HSA, so MOH uses **health technology assessments** (HTAs or **technical evaluations**) conducted by ACE, to direct government subsidies to health technologies that are **clinically relevant**, **safe**, and **cost effective**.

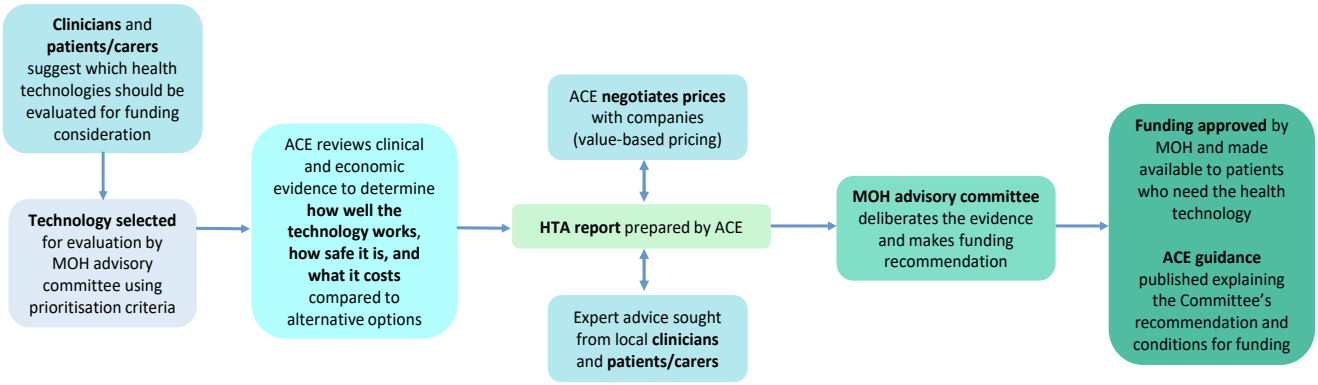
HTA is a research method used to systematically evaluate a health technology to understand its benefits, harms, and costs to determine its **value**. It helps answer questions such as:

- How well does a health technology work compared to other technologies that are already being used? (**clinical effectiveness**)
- Who does it work for?
- Does its cost justify its benefits compared to other technologies? (**cost effectiveness**)

How does ACE conduct HTAs?

ACE follows specific processes and methods when conducting HTAs for drugs and vaccines[1], and medical technologies.[2] Figure 1 shows the key steps of the HTA process.

Figure 1. Overview of HTA process



A separate process[3] (not described here) is followed by companies who want to provide an evidence submission for their drugs to be considered for funding for specific conditions.

Choosing a health technology for evaluation

Each year, clinicians in public healthcare institutions can complete an application form during ACE's annual call for topics and suggest health technologies which they would like ACE to evaluate for funding. Patients, carers, or patient organisations can also suggest topics for ACE to evaluate through a separate application process (see page 14). ACE also regularly does online searches (horizon scanning) and discusses product pipelines with companies to identify new health technologies that could be suitable for evaluation.

[ii] More information about HSA is available at https://www.hsa.gov.sg

Health technologies will usually not be considered for evaluation by ACE if:

- they are not approved for use in Singapore by HSA or
- there is not enough evidence available to conduct an evaluation

Identified health technologies are prioritised for evaluation by the MOH advisory committees (see page 10) using specific criteria including:

- the clinical need that the health technology will address for patients
- the population size and severity of the condition that the health technology will be used for
- the benefits (such as clinical efficacy or improved side-effect profile) or disadvantages of the health technology compared to other health technologies that are available
- the likely budget impact if the health technology is funded, and
- the value that ACE could add in conducting an evaluation

Health technologies are more likely to be selected for evaluation if their benefits are plausible and supported by evidence, and they address a **therapeutic gap** in clinical practice, or help fill an **unmet clinical need** for patients.

Evidence reviews

After a health technology is prioritised for evaluation, ACE reviews all available **clinical** and **economic** evidence to determine the health impacts and costs of using it for a specific medical condition compared to what is already being used in clinical practice ("the comparator"). The evidence is gathered from different sources including:

- **Literature searches** – ACE conducts comprehensive online searches to find all relevant clinical trials, reports, journal articles and clinical guidelines.
- **Expert opinion** – ACE conducts workshops or surveys with clinicians and patients (or their carers) to understand the impact of a condition on patients, how it is treated in clinical practice, the benefits and disadvantages of current treatment options, and the unmet clinical need for the health technology under evaluation.
- **Companies** – ACE negotiates prices of health technologies with companies to ensure that they are fair and good value. Sometimes companies also provide clinical and economic evidence to inform the evaluation.

For some health technologies, ACE develops an economic model (also known as a cost-effectiveness model) which uses assumptions informed by available data to make an estimate or "best guess" of all health and cost outcomes that are expected over time if a health technology is used instead of an alternative option.

ACE's evaluations typically take 3 to 6 months to complete depending on the complexity of the topic and the amount of information that needs to be reviewed. Some evaluations can take longer (e.g., if an economic model is required or price negotiations with a company are prolonged).

All evidence gathered by ACE is compiled into an HTA report to help MOH advisory committees decide whether the extra benefits from the health technology are enough to justify any extra costs to the healthcare system. HTA reports may contain sensitive or confidential information, so they are not published.

MOH advisory committees

There are two MOH advisory committees that assess whether health technologies qualify for government funding based on ACE's HTA reports:

- The **Drug Advisory Committee (DAC)** makes funding recommendations for drugs, vaccines, and gene therapies
- The **Medical Technology Advisory Committee (MTAC)** makes funding recommendations for medical technologies including devices, diagnostics, and medical services

Both committees are chaired by the MOH Director-General of Health (DGH). Committee members have a range of experience and include clinicians, pharmacists, and experts in regulatory affairs, healthcare finance, and healthcare services. Patients or lay members are not currently represented in the committees.

Vaccines and cancer drugs are also reviewed by separate committees:

- The **Expert Committee on Immunisation** (ECI) prioritises which vaccines should be evaluated by ACE for funding consideration and inclusion on the Subsidised Vaccine List (SVL)
- The **Cancer Drug Subcommittee** (CDS) provides expert advice on cancer drugs which are being considered for funding and inclusion on the Cancer Drug List (CDL)[4]

Advice from these separate committees is presented to the DAC, in addition to ACE's HTA reports, to inform their recommendations.

Decision-making criteria

Funding recommendations are made in line with decision-making criteria which both DAC and MTAC follow. Other factors such as social, cultural, and ethical issues may also be considered.[5]

i. Clinical need of patients

The health technology should address an **unmet medical need** of patients. The committees assess this need by asking questions such as:

- How many people in Singapore have this condition?
- How does this condition affect patients? Does it significantly impact a patient's daily activities?
- Which health technologies are already available in Singapore to manage this condition?
- What are the benefits and disadvantages of the available health technologies? Are they affordable for patients?
- How will the health technology change clinical practice?

ii. Clinical effectiveness and safety

A health technology should be **effective** and **safe** for managing the health condition. The committees will consider questions such as:

- Is the health technology more effective and/or safer than alternative treatment options?
- Are the benefits of the health technology important to patients?
- What is the quality of the clinical evidence for the health technology? Is the evidence strong or weak?
- How confident are we that the benefits of the health technology seen in the evidence are likely to be realised by patients in local clinical practice?
- How relevant are the clinical trial results to patients in Singapore?

iii. Value for money (cost-effectiveness)

New or expensive health technologies may not be as good as older subsidised options. The committees assess the **value for money** of a health technology by comparing its additional benefit and cost with alternative technologies that are already being used in clinical practice. This helps them answer the following questions:

- Compared with available alternatives, does the health technology:
  - Cost less with the same or more benefit? → good value for money
  - Cost less with less benefit? → may be good value for money depending on the clinical need for additional treatment options
  - Cost more with more benefit? → may be good value for money depending on how much more benefit it provides compared to alternatives
  - Cost more with less benefit? → poor value for money

iv. Budget impact

For a health technology to be recommended for funding, its cost to the healthcare system (which includes the government, patients, and insurance providers) should be reasonable. The committees will determine this by considering:

- How many patients will need the health technology?
- What out-of-pocket costs will patients have if the health technology is funded or not funded?
- Are there specific groups of people for whom the health technology provides the best value for money?
- What could be gained if the funds were spent on other healthcare services instead?

v. Organisational feasibility

MTAC also assesses the potential impact on the healthcare system if the health technology is used in clinical practice. They do this by asking questions such as:

- Is additional staff training needed to use the health technology?
- Do existing systems or protocols in the public healthcare institutions need to be amended?
- What impact might the changes needed to use the health technology have on available resources?

Types of funding recommendations

The MOH advisory committees provide funding recommendations to MOH about which health technologies should be subsidised in the public hospitals, specialist outpatient clinics and polyclinics to ensure that patients have access to effective and affordable treatments. Table 1 shows some of the reasons why a health technology may be recommended or not recommended for funding by the MOH advisory committees.

Table 1: Reasons why health technologies may be recommended or not recommended for funding

RECOMMENDED	NOT RECOMMENDED
Health technology is **likely** to be considered suitable for funding if: ▪ There is a high clinical need ▪ There is a lack of affordable and effective alternatives ▪ There is clear evidence that it is clinically effective and safe ▪ It provides good value for money compared to existing alternatives at the price proposed by the company ▪ The annual cost to the healthcare system is reasonable if the health technology is funded	Health technology is **unlikely** to be considered suitable for funding if: ▪ There is a low clinical need ▪ Affordable and effective alternatives are available ▪ The Committee has assessed that the health technology is not more clinically effective than alternatives ▪ The additional cost of the health technology over existing alternatives does not justify its benefits at the price proposed by the company ▪ The annual cost to the healthcare system to fund the health technology is unreasonable

Based on the available evidence, the MOH advisory committees recommend:

- whether a drug should be included on the Standard Drug List (SDL)[iii] or the Medication Assistance Fund (MAF)[iv] and receive government subsidy
- whether a cancer drug should be included on the Cancer Drug List (CDL) and be eligible for government subsidy and/or claims under MediShield Life and MediSave[v]
- whether a gene therapy should be included on the Cell, Tissue, and Gene Therapy Products (CTGTP) List and be eligible for government subsidy and/or claims under MediShield Life and MediSave[vi]
- whether a vaccine should be included on the Subsidised Vaccine List (SVL) and receive government subsidy
- whether a medical technology should receive government subsidy or
- whether a medical implant should receive government subsidy and be included on the Implant Subsidy List[6] (ISL)[vii]

Implementing funding decisions

Once an MOH advisory committee has made their recommendation, funding for recommended health technologies typically occurs within 4 to 6 months once financing has been approved by MOH. ACE notifies public healthcare institutions of the recommendations after each MOH advisory committee meeting so that they can make changes to their formularies and inventories (if required) before funding is implemented. The CEE team also notifies patient organisations of any outcomes from the committee meeting if they provided patient input to inform the committee's deliberations.

ACE writes a **technology guidance** for each health technology which summarises the committee's funding recommendation, the reason for the recommendation, and the key evidence which informed it. A **Plain English Summary** (PES) is also written to explain the funding recommendation in non-technical language.

Both documents are published on the ACE website usually before or at the same time when funding becomes available for the health technology in the public healthcare institutions. An example of a technology guidance and accompanying PES is shown in Figure 2.

[iii] The SDL includes low- to moderate-cost drugs essential for the management of common diseases. Drugs on SDL are subsidised by 50% for all conditions that they are approved to treat. Patients from lower to middle income households may receive a higher subsidy of up to 75%.

[iv] The MAF includes moderate- to high-cost drugs that are not on the SDL but are clinically effective and cost effective. Drugs listed on the MAF are only subsidised for specific conditions and patients must meet clinical criteria to be eligible for subsidy. Patients receive 40-75% subsidy for drugs listed on MAF based on means-testing.

[v] If the DAC recommends a cancer medicine for funding, the DAC Chairman and Minister for Health subsequently determine how much a patient can claim from MediShield Life and MediSave each month for the medicine once it is included on the CDL.

[vi] Subsidies will be provided for CTGTPs that are assessed to be clinically effective and cost effective, for specific indications, to eligible patients.

[vii] The ISL is a list of implants that are subsidised in public healthcare institutions when they are used in line with specific clinical criteria.

Figure 2: Example of a technology guidance and the accompanying Plain English Summary

Technology Guidance

Ixekizumab and secukinumab

for treating active non-radiographic axial spondyloarthritis

Technology Guidance from the MOH Drug Advisory Committee

Guidance Recommendations

The Ministry of Health's Drug Advisory Committee has recommended:

- ✓ Secukinumab 150 mg/mL solution for injection in prefilled pen for treating adults with active non-radiographic axial spondyloarthritis.

Funding status

Secukinumab 150 mg/mL solution for injection in prefilled pen is recommended for inclusion on the MOH Medication Assistance Fund (MAF) for the abovementioned indication from 1 August 2023.

Secukinumab should be used in line with additional clinical criteria for initial and continuing prescriptions for adult patients with active non-radiographic axial spondyloarthritis.

MAF assistance **does not** apply to ixekizumab, or any other formulations or strengths of secukinumab.

Published: 1 June 2023

Plain English Summary

Ixekizumab and secukinumab for treating non-radiographic axial spondyloarthritis

What does the guidance say?

Secukinumab is recommended for listing on the Medication Assistance Fund (MAF) for government subsidy for adults with non-radiographic axial spondyloarthritis.

Ixekizumab is not recommended for government subsidy for this condition.

What is non-radiographic axial spondyloarthritis?

Axial spondyloarthritis is a type of arthritis which causes long-term inflammation of the joints in the spine. Joints in other parts of the body, such as the hips, knees, ankles and fingers may also be affected. Early symptoms include joint stiffness and back pain, which is usually worse in the morning but improves with exercise or activity. It typically occurs in adults less than 45 years of age.

Doctors use scans to detect any changes to the joints in the lower back. When symptoms are present but joint changes are not seen on an X-ray scan, this is known as non-radiographic axial spondyloarthritis.

What is secukinumab?

Secukinumab belongs to a group of medicines called biologics which reduce inflammation and relieve symptoms. It is given as an injection.

Your doctor will regularly assess if secukinumab is working for you and if you are likely to benefit from continued treatment.

Who can have secukinumab?

Adults with non-radiographic axial spondyloarthritis can have secukinumab if their condition has not improved with, or they are unable to take non-steroidal anti-inflammatory drugs.

Your doctor can advise if secukinumab is a suitable treatment for you.

Driving Better Decision-Making in Healthcare

The full guidance document and Plain English Summary for this example is available at: https://www.ace-hta.gov.sg/healthcare-professionals/ace-technology-guidances/details/ixekizumab-and-secukinumab-for-treating-active-non-radiographic-axial-spondyloarthritis

Opportunities for patient involvement in ACE's work

Patients are in a unique position to challenge presumptions about their health aspirations, and describe their perspectives and lived experiences of how their condition impacts them, the outcomes that matter most to them, and the potential benefits and disadvantages of different health technologies on their health and daily lives. ACE is committed to understanding the priorities and preferences of patients and their carers, to improve the quality of our work and ensure that it remains relevant for the people most affected by it.

The **Consumer Engagement and Education** (CEE) team provides opportunities and support for healthcare consumers (patients, carers and members of the public) in Singapore who want to contribute to ACE's work.[7] Currently, there are three main activities that healthcare consumers are involved in at ACE:

1. **Suggesting which health technologies (topics) should be evaluated** by ACE to fill an unmet clinical need for patients
2. **Providing lived experiences** about their condition, treatments, and unmet needs to inform ACE's technical evaluations and funding recommendations made by the MOH advisory committees for different health technologies
3. **Providing feedback on educational resources** which CEE co-develops with patient organisations and clinicians about different medical conditions, health technologies, and healthcare policies

Anyone who would like to be involved in ACE's work or find out more about CEE can write to ACE_CEE@moh.gov.sg.

Suggesting topics for ACE to evaluate

Each year, usually from October, clinicians, patients, carers, and patient organisations are invited to suggest which drugs or medical devices they would like ACE to evaluate for different conditions. This is known as the "annual call for topics" and is an important step in ACE's HTA process to ensure that the health technologies chosen for evaluation address priority issues and therapeutic gaps which will help improve the health of the population.

When the call for topics begins, all patient organisations receive an application form (Appendix 1) via email from the CEE team. Patient organisations can distribute the form to their members to complete individually or they can collate their members' suggestions and prepare application forms on their behalf. All applications should be submitted to ACE_CEE@moh.gov.sg by the due date stated on the form.

A factsheet - *How to suggest health technologies for ACE to evaluate?*[8] - is available which explains how patients, carers and patient organisations can suggest which health technologies ACE should evaluate for different conditions.

The CEE team reviews each application to ensure that the health technologies suggested are suitable for evaluation. The following health technologies are usually outside the remit of ACE's evaluations:

- Health technologies that are still in the research stage of development or do not have approval for use in Singapore yet from the Health Sciences Authority (HSA)
- Dental technologies
- Dialysis solutions
- Fertility technologies

- General Sale List items (health products that can be purchased from retail outlets without prescription)
- Homeopathic medicines
- Lifestyle drugs (such as medicines to treat impotence, baldness, or wrinkles)
- Proton beam therapy
- Traditional Chinese medicines
- Vital sign monitoring devices (such as devices to monitor body temperature, blood pressure or breathing rate)
- Wound dressings

After filtering, specific selection criteria (see page 9) are used by ACE to rank each topic in order of priority for evaluation. This information is then presented to the MOH advisory committees who decide which topics should be added to ACE's work plan.

After the MOH advisory committee meetings, CEE will advise the patient or patient organisation who submitted the application form if the topic they suggested has been selected for evaluation, and provide an explanation why a topic has not been selected in the event of a negative outcome. CEE is unable to confirm the evaluation timelines for topics that have been selected but will be in contact with the patient organisation once the evaluation begins to seek their input.

Providing lived experiences to inform technical evaluations

Lived experiences of patients and their carers provide important evidence to inform ACE's technical evaluations and help ACE and MOH advisory committees:

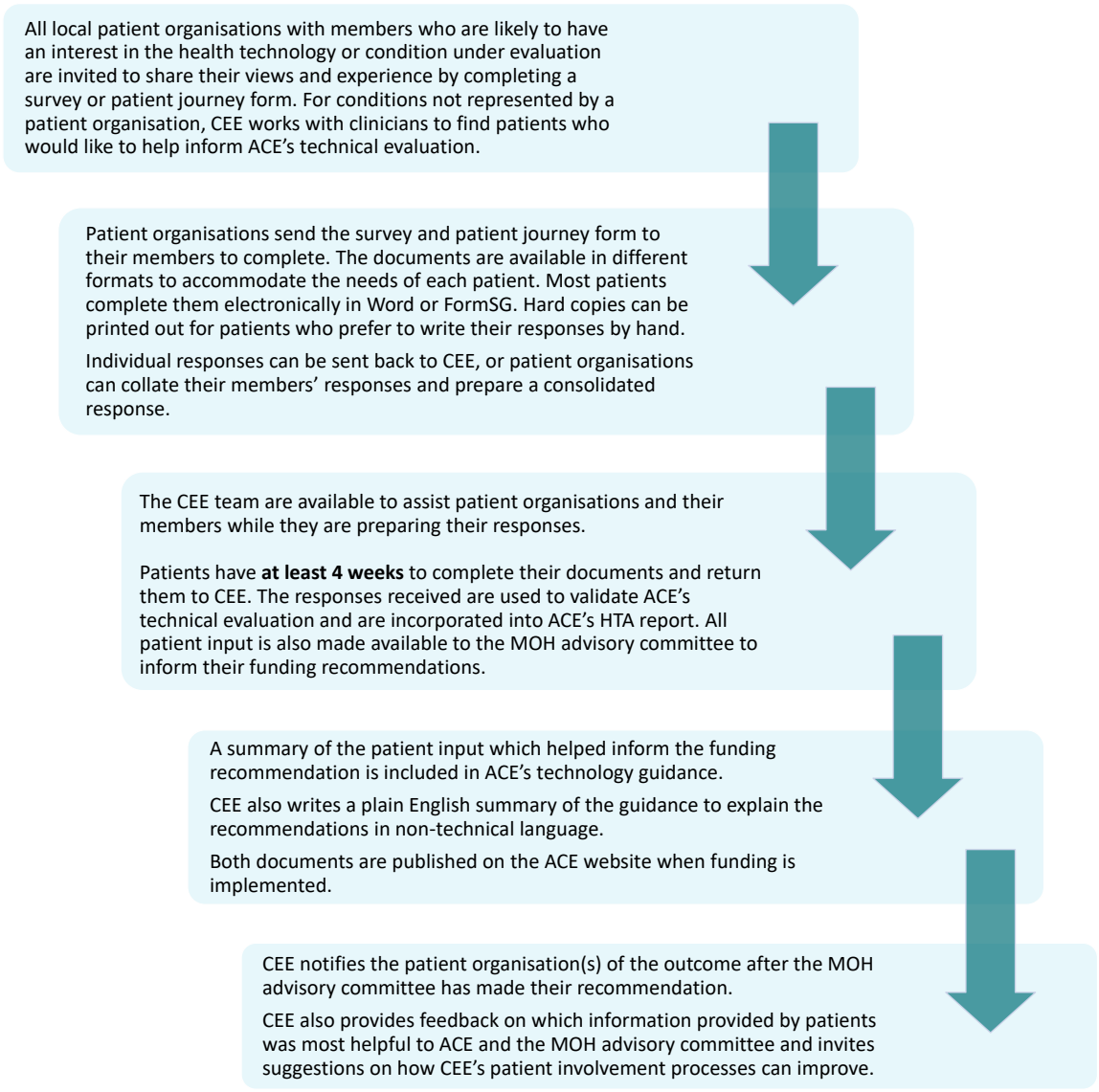
- understand the nature of different medical conditions and how they affect patients, their carers, and families
- identify unmet needs and preferences of patients
- understand benefits and disadvantages of different health technologies
- understand patients' expectations of the health technology under evaluation
- identify health outcomes (such as prolonging life, symptom improvement, avoiding future illness, improving quality of life, ease of use etc.) that are important to patients
- determine if the outcomes measured in clinical trials and economic models are relevant to the Singapore context
- fill gaps or address uncertainties in the evidence
- identify potential issues around patients' abilities to use and access the health technology under evaluation

The CEE team coordinates all patient involvement in ACE's technical evaluations of drugs and wearable or home-based medical devices. Once an evaluation begins, any patient, carer, or patient organisation can provide evidence ("**patient input**") to ACE by completing a **survey** (Appendix 2) about the health technology and condition under evaluation. If a patient does not want to complete the survey but would like to share some information about their condition or treatment, they can complete a **patient journey form**. This form can also be used by patient organisations that want to summarise survey responses from their members and provide a collated submission to ACE.

CEE staff draft the surveys and patient journey forms and distribute them to relevant patients and patient organisations and collate responses once they are received. They also support patients who contribute to each technical evaluation and can answer any questions or provide advice about the type of information that is most useful to include in their responses to inform decision-making.

The key steps for patients, carers or patient organisations that would like to provide evidence to inform ACE's technical evaluations are shown in Figure 3.

Figure 3: Key process steps to provide patient input into ACE's technical evaluations



ACE will use information received from a patient, carer, or patient organisation solely for the purpose of conducting its technical evaluation. ACE follows the Ministry of Health's policies and procedures to ensure the appropriate management of sensitive information.

The information received by ACE is stored in the Ministry of Health IT system. Access to this information is limited to ACE staff involved in the evaluation and to MOH advisory committee members who are all aware of their obligations to safeguard information.

Advice on how to complete a survey and the type of information that is useful to inform ACE's technical evaluations is described later in this document (pages 18-20).

Providing feedback on educational resources for patients

CEE co-develops targeted educational resources, such as factsheets and infographics, with clinicians and patient organisations to improve health literacy about different medical conditions and policies, and equip patients with helpful, evidence-based information that they can use when making shared decisions with their doctors about their healthcare needs.

Factsheet topics are suggested by ACE staff, patient organisations, or clinicians and then prioritised according to need. Usually, factsheets or other educational resources are developed if:

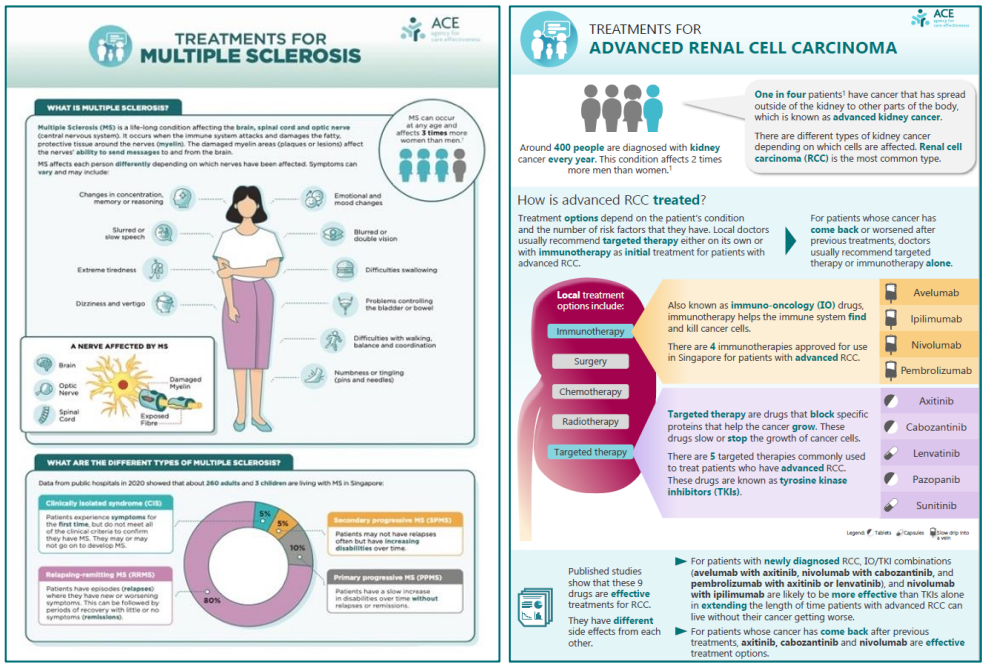
- the topic is about a new health policy or process that impacts patients
- there is limited information about the topic currently available
- there is a clinical need to raise awareness about a specific medical condition, or
- there is a need to keep patients informed about their treatment choices or changes to the way that a condition is being managed in clinical practice

Factsheets are drafted by CEE and sent to all patient organisations that may have an interest in the topic by email for comment and input. Patient organisations can distribute them to their members to provide feedback to CEE on whether the factsheets are:

- helpful for patients and carers
- easy to understand, and
- visually appealing and interesting to readers

Patients and carers can also provide comments on how CEE can improve the factsheets and advise if there is any missing information which they would find helpful. All feedback and suggestions are greatly appreciated and ensure that the factsheets are **useful** and **relevant**. Examples of factsheets are shown in Figure 4.

Figure 4: Examples of patient factsheets co-developed with local patient organisations and clinicians



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

All educational resources are published on the ACE website and sent via email to public healthcare institutions and relevant patient organisations to distribute to patients and include on their websites, if appropriate.

Advice for completing patient surveys

ACE wants to learn from your experience living with a condition (or caring for someone with a condition) and hear your opinion about how health technologies will **make a difference** to patients' daily lives. The information that you provide can help us better interpret clinical trial results, address any gaps or uncertainties in the evidence, and understand the **true value** of a health technology and what matters most to patients and carers like you.

Helpful resources

In addition to this guide, there are three resources available which describe how patients can provide input and give examples of helpful information that patients can include in their survey responses to inform ACE's technical evaluations:

- Steps to provide patient input into ACE's technical evaluations[9]
- Providing patient input into ACE's technical evaluations[10]
- Quick tips for meaningful patient input in ACE's work[11]

While they are useful to refer to, you should not feel restricted by the examples in these resources or this guide and should include what is most important to you in your survey responses.

Completing patient surveys

To inform ACE's technical evaluations, patients or their carers will be asked to complete a survey containing questions about:

- living with a specific condition
- benefits and disadvantages of current treatments
- expectations for new health technologies

You can answer as many questions as you want, depending on what is most relevant to you and what you would like to share with ACE and the MOH advisory committees. While there is no restriction on response length, it is helpful to provide detailed responses where possible, to enable MOH advisory committees to consider **all aspects that are important to patients** when making funding recommendations.

Getting to know you

All survey responses are anonymous, however, some details about you are useful for us to know so that we can make sure we have responses from a range of different patients. Information that we would like to know about you includes:

- if you are a patient or a carer
- your sex and age
- how long you have had a condition for (if you are a patient)
- if you are being treated at a public or private healthcare institution

Describing what it is like living with a condition

Everyone's experience living with a condition is different. Explaining the **physical**, **emotional**, and **social** impact of a condition can help us better understand how it affects your daily activities and the people around you. We want to hear your **positive** and **negative** experiences to find out:

- What is it like to live with the condition and how it impacts daily activities such as
    - self-care - ability to get dressed, wash, eat and live independently
    - mobility - overall or specific parts of the body
    - work, education, sports, hobbies, social activities?
- How does the condition affect your family and friends?
- What are the most challenging things about your condition that affect you the most?
- What is it like to care for someone with the condition?
- How does the condition affect your (or your carer's) quality of life, emotional health, and well-being?
- Which patients are more likely to be affected by the condition?
- Are there any patients who might benefit more or less from treatment than others?

You do not have to look for published information about the condition from the internet or journal articles to answer the survey questions. ACE already reviews all published evidence for each condition and health technology that they evaluate. Your personal experience, in your own words, can help identify critical issues that may be missing from published sources, and enable MOH advisory committees to understand the **impact** of the condition on patients and their carers, and the **clinical need** and **patient preferences** for health technologies to manage the condition.

Try to be as specific as possible when describing your condition. Saying that you feel tired is less meaningful than explaining that your fatigue is so severe that you need to lie down all day and cannot work. Including numbers in your responses to describe, for example, how long it takes you to get dressed in the morning, or how many hours you spend for each treatment session, can also help us determine how relevant clinical trial results are to patients in Singapore.

We are also interested to find out what type of information you would like, to learn more about your condition or treatment, and if you had any misconceptions about your condition that you wish someone had clarified earlier? This can help us identify if additional educational resources need to be developed to support patients with your condition.

Describing the benefits and disadvantages of current treatments

By describing the **benefits** and **disadvantages** of health technologies that are available to prevent, manage and treat your condition, you can help MOH advisory committees understand if there is an **unmet clinical need** that current treatments are not addressing. Even if you think the benefits of a treatment are small, they could make a large difference to patients' and their families' lives, and we want to hear about them.

Some of the important things that are helpful for us to know about current treatments include:

- Which treatment are you currently receiving?
- Is your current treatment effective?
    - How does it improve your condition and symptoms?
    - Is it easy and convenient to take?
    - Is it affordable? Do you have out-of-pocket costs?
    - What impact has it had on your daily life and the people around you?
    - Are there any aspects of the condition that the treatment cannot help, or might make worse?
    - What are the most important benefits of your treatment? (e.g., longer life, reduced dependency on oxygen, increased mobility, ability to return to work, reduction in pain, reduction in side effects that are difficult to manage etc.)
- Have you experienced any side effects from your current treatment?
    - How severe are the side effects and how long do they last?

    - Are they manageable or difficult to tolerate? Do they cause you to stop treatment?
- Do you have any concerns about where your current treatment is used (e.g., in hospital rather than at home)?
- Do you have any concerns about how often you have treatment, testing and check-ups?
- What would happen if you couldn't have this treatment?

Sharing your expectations for new treatments

Even if you haven't had the health technology that ACE is evaluating before, you can still provide useful views about what you would like from a new treatment. Your insights can help identify which treatment outcomes are **important to you** and whether the new health technology will address any disadvantages with your current treatment. Your insights can help us understand:

- How do you think the new treatment will improve your condition?
- What benefits would you like from the new treatment that you are not getting with your current treatment?
- What are the disadvantages or limitations of the new treatment?
- Are you willing to accept the risks of the new treatment for the potential benefit?
- Are there specific factors that would convince you to switch to the new treatment (e.g., less invasive than current treatment, easier to use, provides greater improvement of symptoms)

Conflict of interest declaration

We understand that patients or the organisations that they belong to often receive donations or financial remuneration from companies who have an interest in the health technology that is being evaluated.

To maintain the transparency and credibility of ACE's HTA processes, all patients or carers who provide patient input are asked to declare if they have a financial conflict of interest. This may include, but is not limited to, any of the following involvement with companies or other organisations engaged in the development, manufacture, marketing, or distribution of health technologies over the last 12 months:

1. free treatment from the company (compassionate use, patient assistance programmes, clinical trials, etc.)
2. current shareholdings
3. payment or travel grants for participating in sponsored conferences or meetings

Even if you have declared a conflict of interest, you can still complete the survey and your responses will be considered by ACE and the MOH advisory committees.

Every input is valuable to ACE and the MOH advisory committees and the effort that you put in to complete the survey and share your experiences is appreciated. However, sometimes the health technology under evaluation that you provide input for may not be recommended for government funding. This is because funding decisions are based on a range of factors, informed by clinical and economic evidence and advice from clinicians, and not just patient input. Your decision on whether to provide input and how much information to share is respected.

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Appendix 1 Topic suggestion application form

Application Form to Suggest Health Technologies for Evaluation by the Agency for Care Effectiveness

Instructions

This form should be used by patients, carers, or patient organisations who would like to suggest which health technologies (i.e., drugs or medical devices) the Agency for Care Effectiveness (ACE) should evaluate for funding.

Health technologies should be approved for use by the Singapore Health Sciences Authority (HSA) if you would like ACE to evaluate them. You can search for approved drugs on the *Register of Therapeutic Products* or approved medical devices on the *Singapore Medical Device Register*.

The following health technologies are outside ACE's remit for evaluation and should not be included in the form:

- Dental technologies
- Dialysis solutions
- Fertility technologies
- General Sale List items (health products that can be purchased from retail outlets without prescription)
- Homeopathic medicines
- Lifestyle drugs (such as medicines to treat impotence, baldness, or wrinkles)
- Proton beam therapy
- Traditional Chinese medicines
- Vital sign monitoring devices (such as devices to monitor body temperature, blood pressure or breathing rate)
- Wound dressings

A separate form should be completed for each health technology that you would like ACE to consider. Sections 1 and 2 should be completed for all applications. Section 3 only needs to be completed if you have used the health technology before. All forms should be returned via email to ACE_CEE@moh.gov.sg by [DATE].

More information about the criteria that ACE uses to select topics for evaluation is available in the *Process and Methods Guide for Patient Involvement* or in the factsheet – *How to Suggest Health Technologies for ACE to Evaluate?*. If you need any assistance completing the form or have any questions, please contact the ACE Consumer Engagement and Education (CEE) team at ACE_CEE@moh.gov.sg.

Personal Information (Compulsory)	
Are you a patient or carer?	☐ Patient ☐ Carer ☐ Others: _____
How did you get to know about this application form?	
Section 1 – State the health technology you would like ACE to evaluate for funding	
Name of health technology	
Type of health technology	☐ Drug ☐ Vaccine ☐ Medical device ☐ Gene therapy ☐ Other: _____
Details of the suggested health technology - Dosage form (such as tablets, injection, vial, etc.) - Brand name or model number of the medical device, and the components	
Clinical indication (i.e., which condition(s) do you want it funded for?)	
How did you get to know of this health technology?	☐ It was recommended by a clinician Please provide: - Name of clinician: _____ - Name of hospital or clinic: _____ ☐ It was recommended by a patient support group ☐ Other: _____
Section 2 – Clinical need	
Why do you want this health technology funded? (Explain how this health technology will help patients in Singapore. If relevant, please describe if current treatment options are unavailable or ineffective.)	
Section 3 – Your experience with the health technology	
Are you already receiving this health technology? If yes, please describe:	☐ Yes ☐ No
- How long have you been receiving the health technology for?	

- How does this health technology compare to previous treatment(s) that you have received? (i.e., how is it better or worse?)	
- How has the health technology improved your condition?	
- Is the health technology easy and convenient to take or use?	
- Do you have any side effects? If yes, what are they and how do you manage them?	☐ Yes _____ ☐ No
Section 4 – Contact details	
Are you a member of a patient or voluntary organisation in Singapore? If yes, please list the organisation(s) or support group(s) so we can notify them of the application outcome.	☐ Yes _____ ☐ No
Please provide your email address (We will only contact you if we need to clarify your application)	

Appendix 2 Example of a patient survey

An example of some of the questions that patients and carers may be asked to inform ACE's technical evaluation of a new drug is shown below. Questions vary in each survey depending on the type of health technology under evaluation and any gaps in the evidence that ACE hopes patients may be able to address. Responses are anonymous and help MOH advisory committees understand what is important to patients and their carers when they make funding recommendations about new treatments. Patients can answer as many questions as they want and do not have to complete the entire survey if they have limited time or there is information they do not want to share.

Consent

1. Before completing the survey, please indicate your consent below: ☐ I consent to my responses being used by ACE as part of their technical evaluations to inform funding recommendations by the MOH Drug Advisory Committee

Patient or carer

2. Are you a patient with [CONDITION] or a carer of a patient with this condition?	☐ I am a patient ☐ I am a carer
3. How did you get to know about this patient survey?	☐ From patient or voluntary organisation or support group Name of the organisation(s) or support group(s): _____ ☐ Referred by my doctor Name of doctor: _____ ☐ Others: _____

Getting to know you (referring to patient)

Your responses will be anonymous but some details about you are useful for us to know so that we can make sure we have responses from a range of different patients.

4. Please state your sex	☐ Male ☐ Female
5. Please state your age	
6. How long have you had [CONDITION]?	
7. Are you receiving treatment at a public or private healthcare institution?	☐ Public healthcare institution (e.g. polyclinics or public hospitals) ☐ Private healthcare institution (e.g. private clinics or hospitals) ☐ Other: _____

What is it like to live with [CONDITION]?

Everyone's experience living with a condition is different. Explaining the **physical**, **emotional**, and **social** impact of a condition can help us better understand how it affects your daily activities and the people around you. Please share your **positive** and **negative** experiences with [CONDITION] when answering the following questions that are relevant to you:

8. How does [CONDITION] affect you each day? Try to be as specific as possible including impacts on your everyday activities, work, education, family, friends, mental and emotional health.	
9. Which aspect of [CONDITION] affects you the most?	
10. What information would you like to learn more about your condition or treatment? Did you have any misconceptions about your condition that you wish had been clarified earlier?	

Share your experience with your current treatment(s) for [CONDITION]

By describing the **benefits** and **disadvantages** of treatment(s) that you are currently receiving for [CONDITION], you can help us understand if there is an unmet clinical need that your treatment(s) is not addressing. Please describe your treatment experience by answering the following questions that are relevant to you:

11. Name of treatment(s)	
12. Effect of the treatment(s) you are receiving - Do you feel that your current treatment(s) is working well? - How does it improve your condition and symptoms? - Are there any symptoms which cannot be controlled with the current treatment(s)? - What would happen if you couldn't have this treatment anymore?	
13. Side effects of the treatment(s) you are receiving - What side effects have you experienced with current treatment(s)? Are they mild or severe? - Do you need to take treatments to manage them? - Do they cause you to stop treatment?	
14. Ease of having treatment - Is the treatment easy and convenient to take? - Is it hard to remember when you need to have your treatment?	
15. Any other considerations - Is cost of treatment a concern? - Do you have out-of-pocket costs? - Do you have any concerns about how often you have treatment, testing or check-ups? - Are there any disadvantages of your current treatment that you would like to share?	

16. What benefits would you like to see in a new treatment for [CONDITION] that you are not getting with your current treatment(s)? - What are the specific positive impacts that you hope a new treatment will have on your health condition? (For example, reducing pain) - What impact would you like it to have on your quality of life? (For example, enabling you to return to work)	

Share your expectations for the drug(s) under evaluation

ACE is currently evaluating [DRUG] for treating [CONDITION], to inform funding recommendations by the MOH Drug Advisory Committee. Even if you haven't had [DRUG] before, you can still provide useful views about what you would like from a new treatment.

17. Have you heard of this treatment before? - If yes, compared to previous or current treatments that you have received, please describe how [DRUG] is expected to improve your [CONDITION]? - What are the expected benefits or disadvantages of this treatment compared to current treatment options?	

Other considerations and suggestions

18. Are there any other considerations related to [CONDITION] that you would like ACE or the MOH Drug Advisory Committee to know?	
19. We aim to continually improve this questionnaire to meet the needs of patients and carers in Singapore. If you have any suggestions on how we can improve this questionnaire, or if there are questions that you feel should be included, please let us know.	

Declaration of interest

The purpose of this declaration is to discover any financial interest on the part of a person, or on the part of their immediate family, who is providing input to ACE and MOH. A conflict of interest is declared so that information provided to ACE can be assessed in a transparent manner. All survey responses you provide will still be considered by ACE and the MOH Drug Advisory Committee even if you have declared a conflict of interest.

A financial interest may include, but is not limited to, any of the following involvement with companies or other organisations engaged in the development, manufacture, marketing or distribution of drugs, vaccines, or medical devices over the last 12 months:

1. free treatment from the company (compassionate use, patient assistance programmes, clinical trials, etc.)
2. current shareholdings
3. payment or travel grants for participating in sponsored conferences or meetings

20. Do you have a financial conflict of interest relating to your condition or treatments that you are receiving? If yes, please state the name of the drug or company and the type(s) of financial interest.	

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.

Consumer Engagement and Education team
Agency for Care Effectiveness
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