



PROVIDING PATIENT INPUT INTO ACE'S TECHNICAL EVALUATIONS

The Agency for Care Effectiveness (ACE) conducts technical evaluations to assess the effectiveness, safety, and value of new treatments (such as drugs, vaccines, and medical devices) to inform funding decisions made by the Ministry of Health (MOH).

About this factsheet

This factsheet contains **tips and examples** that can help you provide useful patient input into ACE's technical evaluations. Your lived experience of your medical condition and treatments help MOH advisory committees understand what is important to **you** when they review ACE's evaluations.

Who can submit patient input?

Anyone who has, or cares for someone with, the medical condition under evaluation can provide input. You can be a **patient, carer** or **representative** from a patient or voluntary organisation.

GETTING TO KNOW YOU

Some information about you (the patient) helps ensure that we have views from a range of different patients

What is your age and sex? How long have you been living with the condition? Are you receiving treatment in a public or private healthcare institution? You do not have to share your name because responses are anonymous.

Are you a member of any patient or voluntary organisations? We would like to know about groups in Singapore that provide support to patients with your condition.

I am a 50+ year-old male and was diagnosed with prostate cancer in 2000.



My son is 6 years old and has been having eczema on and off for 3 years.



We (patient organisation) represent people above 65 years who have had fractures due to osteoporosis.



WHAT IS IT LIKE TO LIVE WITH THE CONDITION?

Explain how the condition affects your day-to-day activities

What is living with the condition like for you and the people around you? Are your symptoms so bad that you have to miss work or school sometimes? Do you need a family member to care for you?

Physical symptoms

- I feel fine generally.
- I usually feel tired, have little appetite, and will break out in cold sweat. So I need someone at home to take care of me.
- My son's eczema flares up about three days a month, it's very itchy and painful so he has to miss school. Sweat can trigger it so he is less active now.

Mental and emotional wellbeing

- I often feel down, lost and stressed, my relationships with family and friends are affected.
- I feel stigmatised and lonely, I am afraid to ask for help. I feel that I have lost confidence in myself.
- The treatments are expensive. I am always worried about not having enough money to support my family.

Which aspects of the condition affect you the most?

What is the most **challenging** thing about living with your condition? What do you hope treatment will do for you?

Quality of life

- Food was a big part of my life before I had this condition. I hope that I can regain my appetite so that I can enjoy my food again.
- I used to regularly go out and spend time with my friends and family. I hope treatment will give me more energy so I can attend social events again.
- My son is very conscious about the red patches on his skin and wants to wear long sleeves to cover them. He also can't sleep at night due to the itch. I hope treatment can help to reduce his symptoms and allow him to have better sleep.

Activity

- I am most affected by the joint pain and loss of mobility. I used to go for long walks, now I can barely walk for 30 minutes. I want to be active again so that I can exercise/travel like before.
- I am most afraid that my condition will relapse. I hope I can have a normal life again and go back to work/school.
- My immunity has weakened so I am afraid to leave the house in case I get an infection. I hope that after receiving treatment I can spend time outdoors with my family.

What type of medical information have you received about your condition?

- I am happy with the information that I receive from my clinic.
- My doctor can only give short answers to my questions because he is very busy. I ask my family, friends, or support group for more information, or look on the internet.



SHARE YOUR EXPERIENCE WITH YOUR CURRENT TREATMENT

Explain your current treatment and its impact on you

Which treatment(s) have you been taking for your condition? What **impact** has the treatment had on your condition, daily life and the people around you? How has your condition **changed** since starting treatment? Did you experience any **side effects** and are they tolerable? Have your **needs** been met and did you face any **challenges** while receiving treatment?

Benefits

- I feel less pain with this treatment and I am slowly becoming more active.
- My son's eczema has gotten better, he is scratching less and not as irritable.
- This treatment isn't really working for me, my symptoms are not getting better.

Side effects

- I don't feel any side effects with this treatment.
- Some days I get mild diarrhoea, but it goes away with medicine.
- The side effects of this treatment include nausea and vomiting, loss of appetite and constipation. They became so unbearable I have decided to stop taking it.

Ease of having treatment

- I have no problems with it, I'm used to the injections.
- My memory is not good, so sometimes I can't remember when and how to take this treatment at home if nobody helps me.
- Going to the hospital every 2 weeks to receive a drip and take blood tests is troublesome and I have to miss work. Every round trip takes 2 hours for me. I also have other medical appointments.

Other considerations

- I have to take a taxi as I can't walk too much, and I have to trouble my family to accompany me. Treatment and transport are expensive, and I am not working.
- I have to take this tablet on top of my injection, is it really necessary?
- I am concerned what will happen to me if I take this treatment long-term.

Desired benefits of a new treatment

What benefits would you like to see from a new treatment that you are not getting with your current treatment?

- I hope that the new treatment can prolong my life/slow disease progression/cure me, because I want to spend more time with my loved ones.
- Fewer side effects is better.
- I want to have a treatment available in tablets because I am afraid of needles.
- I don't want to come to the hospital so often for treatment and tests, I want to cut back on transport and free up time to do my own things.
- My current treatments are too expensive, I hope the new treatment is subsidised and affordable.

SHARE YOUR EXPECTATIONS FOR THE NEW TREATMENT UNDER EVALUATION

If you have had the treatment under evaluation before, please compare it to other treatments you have had in the past. If you have heard of the new treatment but haven't had it, how **different** do you expect it to be compared to the treatment that you are currently being prescribed? How do you think it will help improve your condition? Do you think it will be more or less difficult to take the new treatment?

Don't worry if you have not tried the treatment under evaluation before as it may not be available in Singapore yet. Your expectations about the new treatment can help the MOH advisory committees identify which treatment benefits are **important** to you and whether the new treatment can address any disadvantages with your current treatment.

- I expect it to delay chemotherapy or even be an alternative. I have bad side effects from chemotherapy.
- I heard from my friend that I don't have to go to hospital so often for the injection/drip with this new treatment, then I won't have to trouble my family so much.
- I heard from my doctor about this treatment. I expect it to be more effective, but I have not started it yet as it is too expensive.
- I read about this treatment on the internet. Since it's new, I expect it to be more effective with fewer side effects.

ACE will invite you to complete a survey to provide your input into different technical evaluations. Your input is important to ensure that recommendations made by MOH advisory committees are **relevant** to the people who are affected by them. You can write to ACE_CEE@moh.gov.sg if you need any help while you are preparing your responses.



Sources

1. Agency for Care Effectiveness, Ministry of Health, Singapore. Process and methods guide for patient involvement. January 2023.
2. Briggs L, Patient Voice Initiative. Dos and don'ts when making a PBAC Consumer Comment. July 2020.

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