

Does Patient Input Add Value To Healthcare Decision-Making? A 2-Year Reflection On Patient Involvement Processes In Singapore

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Introduction

In 2022, the Agency for Care Effectiveness (ACE) co-developed patient involvement processes¹ with local patient organizations, to enable patients and caregivers to share their experiential knowledge about different medical conditions to inform health technology assessments (HTAs) for drug treatments. In 2023, the scope of patient input was expanded to include non-drug topics, including gene therapies and medical devices.

This poster describes the impact of patient input on decision-making committees' deliberations and ACE's processes during the first two years of patient involvement in Singapore.

Methods

- A literature search was conducted to identify frameworks and indicators used by different HTA agencies that could be contextualized to evaluate local patient involvement efforts.
- Systematic data extraction from ACE HTA reports, minutes from committee meetings, and published HTA guidance documents was performed by both authors to compare patient testimonials received from May 2022 to April 2024 and determine the impact of patient input on the committees' deliberations and funding recommendations.
- The impact of patient involvement on ACE staff, existing processes, and patient participation in future HTAs was also assessed through qualitative surveys.

Results

- During the first year (May 2022 to April 2023), ACE received 112 testimonials from 17 patient organizations for 11 HTAs. In the following year (May 2023 to April 2024), 243 patient responses from 26 patient organizations were received, informing 16 HTAs (Fig. 1).
- At least one testimonial was received for 84.6% of HTAs in the first year, increasing to 88.9% in the subsequent year. The number of patient responses varied depending on factors such as the condition under evaluation, the capacity of patient organizations to collate information from their members, and the interest of patients to participate in the process.

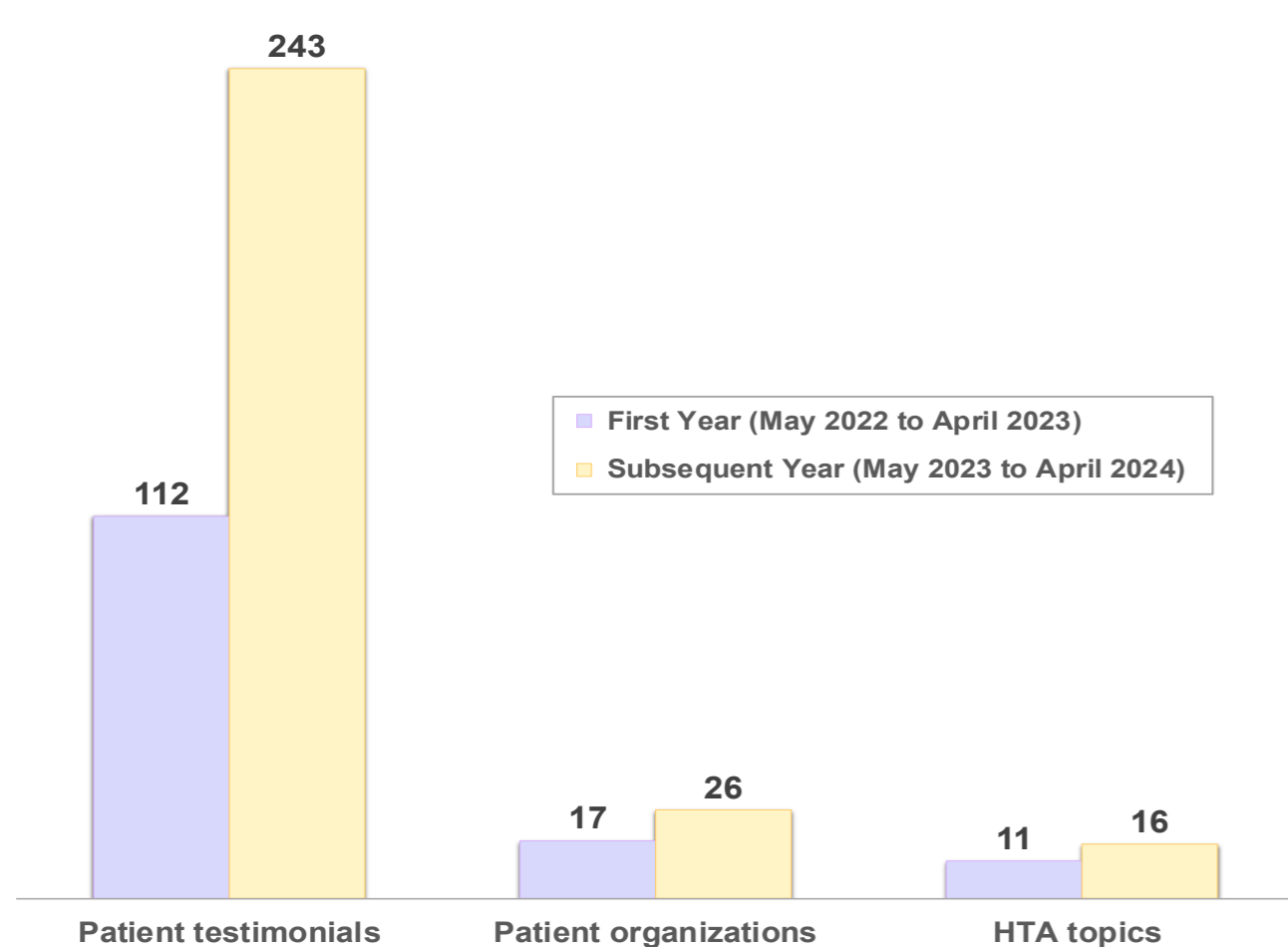


Figure 1: Chart comparing patient involvement in ACE's HTAs during the first two years

Since May 2022, patients and their caregivers have contributed important information to supplement and validate clinical and economic evidence evaluated as part of each HTA. Their insights have helped the committees understand the impact of different conditions on patients' and families' daily lives, and have informed funding recommendations for treatments which address patients' needs for:

- Blood and immune system conditions
- Cancer
- Cardiovascular conditions
- Diabetes and other endocrinal and metabolic conditions
- Eye conditions
- Infections
- Kidney conditions
- Musculoskeletal conditions
- Neurological conditions
- Respiratory conditions
- Skin conditions



Figure 2: Patient insights across 11 therapeutic areas informed 27 HTAs between May 2022 and April 2024

- Patients' lived experiences and testimonials addressed uncertainties in the scientific evidence and helped decision-making committees understand how different conditions affect patients and their caregivers, the outcomes that matter most to patients, and the benefits and disadvantages of existing and new treatments.

Testimonials were received for:

~ 85 to 89%
of HTAs



- Insights derived from patients' experiences and preferences, factors influencing patients' ability to use a new technology, and information about their educational needs, have offered valuable local context to inform funding recommendations and have been important considerations for technology guidance adoption (Figs. 2 and 3).
- During the 2-year period, industry and patient organizations have also expanded their capacity to contribute to ACE's HTAs.

"The Committee heard that axial spondyloarthritis had a significant negative impact on patients' daily lives, causing symptoms such as joint stiffness, pain, and fatigue, which limited their mobility and prevented them from exercising and working. Patients also experienced a loss of confidence and depression."

"The Committee noted that the patient experts were all receiving [drug], with or without other lipid-lowering therapies, as their primary treatment, and considered that [drug] worked well in lowering LDL-c levels, was easy to take, and generally well tolerated."

"Overall, people with atopic dermatitis preferred daily oral tablets over bi-weekly self-injections."

"Most respondents highlighted that they would like any new [device] for type 1 diabetes mellitus to be more affordable, able to automatically and frequently monitor their blood glucose level and require less frequent calibration with blood glucometers."

Figure 3: Extracts from technology guidance documents on how the committee used patient input to inform their deliberations

Discussion

- The high proportion of ACE HTAs with patient input (~89%) exceeds patient contributions made to HTA bodies in other countries such as Australia (33%)² and France (25%)³.
- This could be in part due to the implementation of a continuous feedback loop which ensures patient organizations are made aware of how their inputs have informed HTAs, while allowing them to suggest process improvements to optimize future participation from their members (e.g., providing patient input templates in other formats to support patients' different needs and having surveys in languages other than English; Fig. 4).
- Dedicated staff within ACE to oversee patient involvement processes and engage with the local patient community have also raised awareness of opportunities for patients to inform HTAs and kept them up to date on any process changes.
- Targeted patient workshops and online self-directed learning modules (Fig. 4) will continue to aid local patients' understanding of HTA and enable them to make meaningful contributions to ACE's work in the future.
- A series of impact stories currently being co-developed with patient organizations will also highlight the value patients bring to healthcare decision-making to showcase the importance of including the patient voice in HTA and encourage more patient involvement.



Figure 4: Self-directed learning module for patients and the public, and an example of a patient input survey in Chinese

Conclusion

During the first two years, building and strengthening meaningful relationships with local patient organizations; continuously evolving patient involvement processes to meet the needs of patients and caregivers; and empowering patients through HTA training have increased patient participation, improved the legitimacy of ACE's HTAs, and added value to decision-making about which health technologies should be funded in Singapore.

References:

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