



Helping patients become equal stakeholders in healthcare decision-making: The challenges and successes of patient involvement in Singapore

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INTRODUCTION

- The Agency for Care Effectiveness (ACE) was established in August 2015 as the national health technology assessment (HTA) agency in Singapore to guide health policy, drive appropriate use of treatments and inform technology subsidy decisions.
- To encourage meaningful patient input in HTAs, patient involvement processes were established in 2021. This presentation describes the challenges and successes of encouraging patients to share their experiential knowledge to inform ACE's work.

METHOD

- In the absence of a centralized database, stakeholder mapping was conducted to identify all local patient and volunteer groups (n=106), determine their interest in participating in ACE's work and identify any resources or support that they may need (Tab. 1).
 - A Consumer Panel comprising 15 patient representatives was appointed as the collective voice of patients who have experience engaging with the Singapore healthcare system, to provide strategic advice on priority-setting, communication activities, and opportunities for ACE to foster collaborative working relationships with patient organizations.
 - Plain English resources, a patient glossary, training materials, and a process and methods guide¹ (Fig. 1) to encourage patient involvement in topic selection, HTAs, guidance production and the development of educational resources were co-developed with local patient organizations, drawing upon international best practices contextualized to local patients' needs.



Figure 1: ACE's process and methods guide for patient involvement

RESULTS

- In 2022, 82 patient responses informed 7 HTAs, while 273 responses informed 25 HTAs in 2023. However considerable resource was required to find patients to participate and collate their responses.
- In response to feedback, ACE has continually evolved its processes to meet the needs of patients and encourage broader patient participation.



Table 1: Conditions supported by patient organizations

Conditions	Groups
Cancer	27
Neurological conditions	17
Mental health/behavioural conditions	14
Diabetes and other endocrinal, nutritional and metabolic conditions	7
Cardiovascular conditions	6
Blood and immune system conditions	5
Kidney conditions	4
Non-disease specific	4
Respiratory conditions	4
Digestive tract conditions	3
Neonatal/infant/paediatric conditions	3
Eye conditions	2
Infections	2
Skin conditions	2
Congenital malformations and chromosomal abnormalities	1
Gynaecological conditions	1
Injuries, accidents and wounds	1
Liver conditions	1
Oral and dental health	1
Rare diseases	1
Total	106

DISCUSSION

- Patient input addressed uncertainties in the scientific evidence and informed funding decisions by helping decision-making committees understand how different conditions affect patients and their carers, the outcomes that matter most to patients, and the benefits and disadvantages of different treatments.
- Continuous process improvement in response to feedback; providing patient input templates in different formats and languages to improve accessibility; and regular feedback to patient organizations on how their inputs have informed HTAs increased patient participation and improved the legitimacy and acceptance of ACE's work.
- The Consumer Panel's contributions and impact on ACE's work serve as an example for other decision-makers on how to meaningfully involve patients at the organizational level to understand their priorities and preferences and ensure healthcare policies remain relevant for the people affected by them.

CONCLUSION

- Patient involvement has become integral to ACE's HTAs. By describing their needs, preferences, experiences, and expectations, patients and carers make important contributions interpreting results for real-world implementation.



Reference: 1. ACE Process and Methods Guide for Patient Involvement, v1.1 May 2023.