EXPLORING THE ENVIRONMENT/CAPACITY OF SOUTH AFRICAN CITIZEN ACTORS TO CONTRIBUTE TO HTA PROCESSES, POLICY DEVELOPMENT AND INSTITUTIONALIZATION



Lauren Pretorius – Campaigning For Cancer, Debjani Muller – HTAi, Anke Peggy Holtorf – HTAi



Introduction

Definitions

Reference: Htai.org

According to a joint Health Technology Assessment international (HTAi) & ISPOR initiative:

Health Technology Assessment (HTA) is a multidisciplinary process that uses explicit methods to determine the value of a health technology at different points in its lifecycle. The purpose is to inform decision-making in order to promote an equitable, efficient and high-quality health system

Whereas Health Technology is an intervention developed to prevent, diagnose or treat medical conditions; promote health; provide rehabilitation or organize healthcare delivery. The intervention can be a test, device, medicine, vaccine, procedure, program or system.

Patient and Citizen Involvement (PCI) is when patients, caregivers and/or their representatives directly participate in discussions at different stages of the HTA and that is supported by evidence on patient value and experience collected directly from patients and their caregivers that incorporate the principles of relevance, fairness, equity legitimacy and capacity building.

Background

In South Africa's journey towards the institutionalization of HTA, there is very little exploration of the current capacity of patient and citizen actors to contribute to HTA processes, policy development and eventual institutionalization. In stark contrast to international territories, there currently exists limited country specific tools and resources to both aid and capacity-build patient and citizen actors in HTA and reimbursement models.

Objectives

- 1. A legislative, regulatory and policy review of the current limited South African legislative framework of HTA for opportunities to advocate for the required legislation reform and development to entrench the principles and processes for PCI.
- 2. A review and mapping of the capacity, knowledge and skill of the South African patient and citizen advocacy actors to actively advocate in the development of the regulatory and policy for the transparent and evidence-informed approach to healthcare prioritization and HSP formulation through HTA and methods of value-based reimbursement in the new NHI landscape.

Methods

Literature scan and analysis of relevant national and international documentation including reports through primary and secondary data analysis to aid in the identification of current gaps in, and opportunities for, PCI in HTA in South Africa. Data sources included resolutions, legislation, regulations, government policy and technical reports gleaned from websites of relevant agencies e.g. the WHO, NDoH, academic and research institutions, and national and international HTA associations and contacts with experts in the field.

Electronic survey distributed to 213 patient and citizen actors. Survey aimed to establish the capacity, knowledge and skill of South African patient and citizen advocacy actors and organisations across multiple disease areas, predominately NCDs.

Results

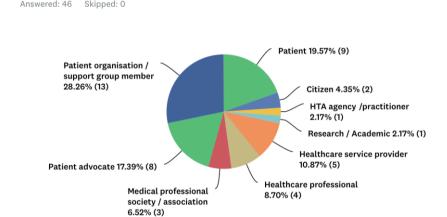
Objective 1:

Outcomes from legislative and policy review:

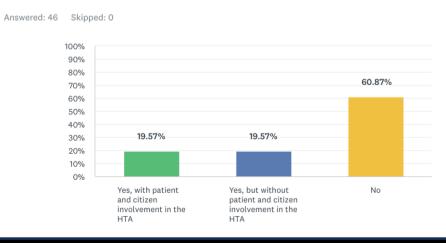
- The legislation and policy documents indicate that the engagement initiatives are located at either the 'involvement' or 'consultation' stages of the engagement continuum, rather than higher-level engagement.
- It has been noted that patient advocacy groups typically participate in raising awareness of the disease burden, advocating for the adoption of specific technology, or utilising legal channels to compel coverage arrangements for specific therapies.
- Some of the barriers and challenges observed in individual-level engagement are:
 - Lack of appropriate skills, training, and education
 - Insufficient information regarding roles and responsibilities
 - Lack of logistical and/or financial support for work
 - Lack of integrated strategy
- However, there are many possible dimensions of a capacity-building strategy for HTA for
 patients and citizens: the key will be to select appropriate starting points that build on research
 partners' strengths, meet some of the immediate needs of the country governments and
 contribute to longer-term goals.

Objective 2: Survey Outcomes

Surveyed audience: Which Stakeholder group do you represent? (Select the answer that most describes your day-to-day engagement)

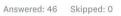


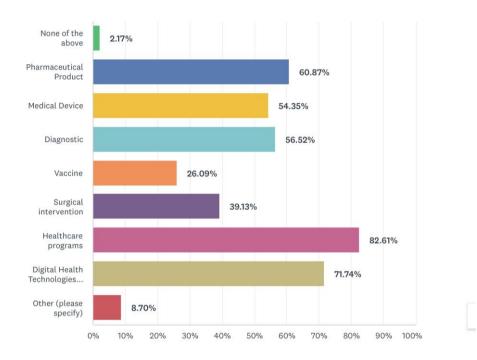
HTA Involvement: Have you participated in/contributed to a health technology assessment?



HTA Involvement continued:

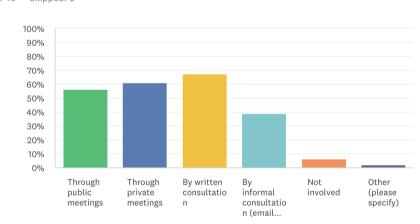
Which type of HTA with patient involvement do you feel your organisation and patient members could be included in? Check all that apply





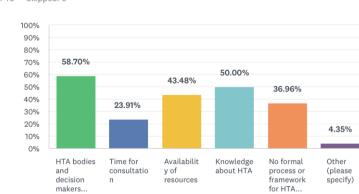
In your opinion, how would you or your organisation take part in the HTA process?

Answered: 46 Skipped: 0



In your opinion, which factor poses the most significant barrier for you and your organisation to influence HTA effectively?

Answered: 46 Skipped: 0



ALL FIGURES ARE AUTHOR"S CONTRUCT

Conclusion

These results are indicative of non-involvement of key actors in crucial health care processes. Further questions lean towards gleaning from participants how and what stages they could add value during the assessment process. Actors were adamant that it is at government (provincial and national government level) that they would effect greater influence in order to make meaningful contributions.

Existing legislative and policy frameworks do not include PCI capacity-building strategies. This is impacted by the lack of coordination amongst patient and consumer groups, the willingness of existing HTA structures to formalize PCI, and the resources of the country's PCI advocate actors to influence existing HTA processes.

It should be noted that this conversation is ongoing and thus the research. We can only conclude once health care processes are inclusive, and patient and citizen involvement is mandatory. In addition to comprehensive training, sensitization prior to PCI engagement implementation in local HTA to boost people's knowledge and confidence to contribute in PCI