OP19 Exploring The Environment/Capacity Of South African Citizen Actors To Contribute To Health Technology Assessment Processes, Policy Development And Institutionalization

Lauren Pretorius (lauren@campaign4cancer.co.za) and Debjani Muller

Introduction: Several overarching health policy reform processes are currently underway in South Africa (SA), providing an opportunity to establish health technology assessment (HTA) and value-based assessment (VBA) frameworks that foster patient and citizen involvement (PCI). A mapping of the capacity, knowledge, and skill of SA PCI advocacy actors and understanding of the ‘middle-ground’ and influencing relationships that influence advocacy strategies for PCI in HTA, will allow us to determine the needs of PCI actors to entrench PCI principles in the emerging institutionalization of HTA in SA.

Methods: An analysis of national and international legislative and policy frameworks indicates current gaps and opportunities for PCI institutionalization in HTA in SA. A survey was conducted to determine SA patient and citizen advocacy actors’ capacity, knowledge, and skill across multiple disease areas. An analysis of decision-maker’s opinions and positions about PCI in HTA and VBA policy, and their potential influence on the PCI process was undertaken.

Results: The legislation and policy review indicate that engagement initiatives are positioned at the ‘involvement’ or ‘consultation’ stages of the engagement continuum, rather than higher-level engagement. Five percent of patient advocacy groups (PAGs) interviewed have formalized PCI HTA advocacy strategies. Few PAGs indicated employing processes to actively monitor the HTA and PCI-related activities of decision-makers.

The majority of PAGs stated that collaborative efforts within larger networks would generate more success, if they engaged in PCI in HTA advocacy. Over eighty percent of civil society stakeholders face capacity constraints, such as lack of knowledge of the legislative framework and theory of HTA, funding and manpower to engage in PCI. The majority of HTA processes undertaken by funders in SA do not actively include PAGs or formalized PCI.

Conclusions: 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.

OP21 Patient Values Project (PVP): Patient Preferences For Cancer Treatments To Inform A Framework Incorporating Patient Values Into Health Technology Assessment

Deborah A Marshall (damarsha@ucalgary.ca), Karen V MacDonald and Barry Stein

Introduction: The methodology for explicitly incorporating patient preferences by expert committees engaged in deliberative health technology assessment (HTA) processes for drug reimbursement recommendations is a relatively unexplored area despite the growing emphasis on patient-reported outcomes and patient engagement. The Patient Values Project (PVP) aims to improve patient input to expert review committees and promote a better understanding of the patient perspective using quantitative data to support the rationale in assessing new cancer drugs. Using colorectal cancer as a starting point, the PVP aims to develop a framework to objectively incorporate quantitative patient values and preferences into Canada’s cancer drug HTA decision-making process. We report on results from the first phase.

Methods: In the first phase, we developed a bilingual survey informed by qualitative focus groups, literature review and feedback from clinicians, patients and experts. The survey includes background questions, general and cancer specific quality-of-life tools, two discrete choice experiments (DCE) and a best worst scaling (BWS) experiment. After pre-testing and pilot testing, the survey was administered across Canada to metastatic and non-metastatic colorectal cancer patients and caregivers, in addition to adults from the general population. In the next phases, we will use vignettes to explore how patient preferences could be incorporated explicitly into decision-making, and what approach to use in HTA submissions.

Results: DCE1 survey results (n=1,000) reflect trade-offs between health-related quality-of-life and survival; DCE2 results reflect trade-offs between treatment regimens, side effects and survival/risk of recurrence; BWS results ranked and weighted the tolerability of 25 possible side effects of treatment. We observed differences in preferences amongst the general population, patients with metastatic cancer, non-metastatic cancer and caregivers.

Conclusions: Patients have unique perspectives and preferences about what is important and of value to them, which may impact patient adherence to treatment. In the next phases, we will explore how this evidence from patient preferences can be translated into