

doers, users, and trainers in Ukraine, which can be an example for other countries wishing to increase HTA capacity.

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

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**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

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**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

values that could potentially be incorporated as an explicit element of the deliberative process for HTA decision-making.

## OP22 Benchmarking Of Population-Based Childhood Cancer Survival By Toronto Stage: Know The Differences To Propose Effective Interventions

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**Introduction:** Pediatric cancers are rare tumors, heterogeneous in location and biologically very different from adult cancers. Documented survival variation across European countries and Italian regions shows that there is still room for further improvement by reducing inequalities. We aim to understand why there are differences in survival. The BENCHISTA-ITA project (National Benchmarking of Childhood Cancer Survival by Stage at diagnosis), that is the Italian twin project of the International BENCHISTA, collects stage at diagnosis of solid pediatric tumors, according to the Toronto Guidelines. We will compare how far the cancer has spread at diagnosis and test if differences in tumor stage explain any survival differences between Italian regions.

**Methods:** The project study involved the stage distribution and the survival of 9 pediatric solid tumors diagnosed between 2013 and 2017 in Italy. All patients therefore had at least 3 years of follow-up in 2021 for life-stage definition. The study involves the identification of all new diagnoses of cancer, evaluation of the clinical documentation of cases eligible for research, and international classification and coding. Analyses of stage distribution and survival rates for each tumor type will be described.

**Results:** Data from 35 population-based cancer registries from 18 out of 20 Italian regions were collected covering about 84 percent of the Italian child population. In particular, data on: imaging/examination performed before any treatment; source used for staging; primary treatment defined as given within one year from diagnosis; relapse/recurrence/ progression; follow up and status of life. The study tested the applicability of the Toronto Guidelines as a tool to obtain population-level comparable stage information for childhood cancers. There were 1,343 cases collected (242 Neuroblastoma, 124 Wilms Tumour, 145 Medulloblastoma, 148 Osteosarcoma, 135 Ewing sarcoma, 115 Rhabdomyosarcoma, 54 Ependymoma, 47 Retinoblastoma, 333 Astrocytoma). Toronto stage could be assigned in more than 90 percent in the majority of tumors. Tumors in which it was more difficult to assign the stage using the Toronto staging guidelines were ependymoma, astrocytoma, and retinoblastoma. It was easier to retrieve data for patients in the 0-14 years of age range than adolescents (14-18 years). Differences in stage distribution and survival differences between regional grouping were presented.

**Conclusions:** The Italian BENCHISTA project, improving the connection between pediatric cancer registries, aims to improve care of children with cancer across the nation, reducing possible disparities. The wide adoption of the Toronto Guidelines will facilitate international comparative incidence studies, strengthen the interpretation of survival data, and contribute to more appropriate solutions to improve childhood cancer outcomes.

## OP23 Early Detection Tools For Emotional Distress In Adult Cancer Patients In Spain: A Health Technology Assessment Report

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**Introduction:** Patient-reported outcome measures are being increasingly considered both in clinical practice and in the field of health technology assessment. Although emotional distress is currently recognized as the sixth vital sign in cancer care, its early detection and screening is not yet included in routine clinical practice in Spain. The main objective of this study was to assess the psychometric properties and diagnostic accuracy of validated tools for the early detection of distress among adults with cancer in the Spanish context, at the request of the Spanish National Health System (NHS) Cancer Strategy.

**Methods:** A systematic review was carried out to analyze development and validation studies. The Quality Assessment of Diagnostic Accuracy Studies tool (QUADAS-2) was used for the risk of bias assessment, and a multicriteria global assessment was used for the tests. Ethical and organizational aspects were also addressed.

**Results:** Fifteen validation studies were included, corresponding to seven tests. The tools considered were the Distress Thermometer (DT), the Brief Symptom Inventory-18 (BSI-18), the Edmonton Symptom Assessment System-revised (ESAS-r), the Hospital Anxiety and Depression Scale (HADS), the Visual Analog Scale for Anxiety and Depression (VAS-AD), the Detection of Emotional Distress (DED) scale, and the Psychosocial and Spiritual Needs Evaluation (ENP-E) scale. Evidence of validity, reliability (internal consistency), and diagnostic accuracy (sensitivity, specificity, and area under the receiver operating characteristic curve) were summarized. Three scales were rated as poor (VAS-AD, BSI-18, and ESAS-r), the ENP-E scale was rated as acceptable, and three scales were rated as moderate (DT, DED, and HADS).

**Conclusions:** The DT (single-item measure) stands out as an appropriate tool for early detection of emotional distress in the Spanish NHS. The use of this scale could be considered a first stage, to be combined later with a longer scale to improve screening specificity. The HADS scale could be utilized for this purpose. The use of these tools should be framed within a structured screening program that ensures further evaluation and subsequent psychological care when needed.