

Conclusions. ACLR procedures in Indonesia are underbudgeted. Adjustment of reimbursement prices for ACLR procedures is needed to facilitate access for the Indonesian people. This study showed varying cost estimates for ACLR in Indonesia, necessitating a new reimbursement system that takes various clinical and patient factors into account.

PD50 Value Of Healthcare Journey For Patients With Rare Diseases In The Brazilian Public Healthcare System: Methods And Preliminary Results

Ludmila Gargano (ludgargano@gmail.com),

Bianca Caroline Salvador, Luiz Carlos Santana-da-Silva, Gabriel Ogata, Marcelo Eidi Nita, Têmis Maria Félix and JAV-Raras Study Group

Introduction. Implementing value-based healthcare (VBHC) services requires the ability to assess and integrate evolution of patient-centered outcomes (PCO), clinical/epidemiological data and resource consumption. Aligned with Porter's framework of value, the "Value of Healthcare Journey for Patients With Rare Diseases Project" (JAV-RARAS) was implemented to evaluate the value of the healthcare journey of patients with rare diseases (RD) in the Brazilian Public Healthcare System (SUS). The goal of this project is to identify the value (clinical outcomes and costs) associated with the management of RD in the SUS.

Methods. Patients diagnosed with eight pre-defined RD under active clinical follow-up in SUS medical centers were invited. Retrospective data on diagnosis and assistance carried out after diagnosis were collected from medical records. Prospective follow-up of one year will be collected through validated clinical questionnaires on three visits, with an average interval of 6 months. Clinical outcomes include exams and disease-specific features, quality of life, productivity loss, treatment adherence and satisfaction. Total cost of patient's journey in each medical center will be assessed through Time-Driven Activity-Based Costing method. All data collection is being carried out through the Think Patient Value (TPValue®), a computerized management support system, based on Porter's paradigm of value.

Results. Thirty-five medical centers currently assisting patients with RD were enrolled, representing all macro-regions in Brazil: Midwest (n=4), North (n=5), Northeast (n=10), South (n=5) and Southeast (n=11). Recruitment started in March, and until November 2021, 28 centers had reported retrospective data of at least one RD. So far, JAV-RARAS recruited patients with osteogenesis imperfecta (number of patients=106), phenylketonuria (n=52), familial amyloidotic polyneuropathy (n=32), classical homocystinuria (n=25), Prader-Willi syndrome (n=30), acromegaly (n=33), hereditary angioedema associated with C1 esterase-inhibitor deficiency (n=42) and mucopolysaccharidosis type-II (n=17).

Conclusions. Future results of JAV-Raras real-world evidence study will bring PCO and costs according to Porter's Value, bringing insights for decision-makers in SUS. This study was funded by National Council for Scientific and Technological Development – CNPq and Ministry of Health of Brazil – MoH.

PD51 Patient Perspective: A Preliminary Analysis Of The First Year Of The Patient Involvement in CONITEC Meetings

Clarice Portugal (clarice.portugal@saude.gov.br),

Andrea Brigida de Souza, Adriana Prates, Andrija Almeida, Bruna Cabral de Pina Viana, Luiza Losco and Vania Canuto

Introduction. The Patient Perspective is an initiative to include the testimonials of patients or their representatives at the time of the initial recommendation of health technology assessment (HTA) processes developed by the National Committee for Health Technology Incorporation in the Brazilian Public Health System (CONITEC). It allows these actors to be involved prior to the public consultation. This action is articulated with a framework of strategies to encourage patient and public involvement (PPI) in HTA in Brazilian Public Health System (SUS). This paper aims to analyze the first year of its implementation.

Methods. This is a descriptive study, based on document analysis (minutes of meetings, technical and society reports, videos of CONITEC meetings, tables for internal control, etc.) and systematic observation of the activities related to the initiative. Field notes were taken and their contents were coded, following content analysis criteria.

Results. From December 2020 to November 2021, 1,052 subscribers were registered in 75 public calls, which resulted in the participation of 42 people. The testimonials presented information about the illness experience, its impact on quality of life, use of technologies, and difficulties of accessing and adherence to treatment. The patient perspective has been useful to give visibility to specific dimensions of experiences regarding not only the health conditions but SUS as well. Furthermore, some testimonials produced tensions and repercussions about HTA processes, such as the consideration of aspects or technologies not covered in the clinical studies and thus the HTA, as well as the need of reviewing some results of the technical report.

Conclusions. The patient perspective has had the support of the target audience. Additionally, it has been successful in including various types of participants and different aspects of the experience with the health condition and/or the technologies under evaluation. In general, it has been possible to observe the diversification of modes of PPI and institutional learning towards the improvement of HTA in SUS.