OP29 Building A Global, Public Repository Of Patient Experience Data

Catherine Holliday (cmholliday@cc-dr.org)

Introduction. The Patient Experience, Expectations and Knowledge (PEEK) protocol was developed so that a holistic, comprehensive, independent, proactive and systematic approach could be taken to inform decisions made in the context of health technology assessment and other parts of the health sector. Each PEEK study is made publicly available which over time will result in a global repository of patient experience data.

Methods. The PEEK protocol is a single protocol that can be implemented across disease areas and includes a quantitative and qualitative component. The quantitative component is based on a series of validated tools that provide baseline health and demographic data for the study population. The qualitative component is the result of two years of protocol testing to develop a structured interview that solicits comprehensive and holistic patient experience data, and provides participants with the opportunity to provide advice on their future expectations.

Results. PEEK studies in breast cancer, bladder cancer, lung cancer, spinal muscular atrophy, atopic dermatitis, chronic kidney disease, chronic heart failure and mitochondrial disease have been completed in the Australian context (www.cc-dr.org/peek). Holistic patient experience themes are presented commencing with symptoms and diagnosis experience, through to communication, information, treatments experienced and quality of life. Information is also available in relation to participant's expectations of future treatment, care, information and communication. The result is a freely available repository of patient experience data that anyone in the sector can access to complement clinical and economic evidence.

Conclusions. The process of providing patient feedback and real-world evidence in the context of health technology assessment is often ad-hoc. The lack of consistency means that it has been difficult to assess the impact of patient engagement and feedback in the context of health technology assessment. The PEEK protocol and program is an example of a systematic, independent and holistic approach to patient experience and real-world evidence data collection that provides the sector with an opportunity to proactively engage the community in decisions that are made about treatment, care and support.

OP30 Impact Of Patient Reported Outcomes Data On Health Technology Assessments Of Acute Myeloid Leukemia

Manasee Shah (manasee.shah.contractor@astellas.com), Rianne Ernst, Stefan Holmstrom and Inge van Hooijdonk

Introduction. Patient-reported outcomes (PRO) data are important in understanding patients' experience of disease and treatment; however, PRO data are not universally collected or consistently included as part of a Health Technology Assessment (HTA) submission. Additionally, the HTA bodies' response to PRO data vary, making the impact unclear. To understand the impact of PRO data on reimbursement decisions for Acute Myeloid Leukemia (AML) indications, an in-depth analysis of HTA bodies' appraisals of AML and analogous indications was conducted.

Methods. This analysis was conducted using IQVIA's HTA Accelerator, which contains HTA appraisals from ≥100 HTA agencies in thirty-nine countries. Included in the analysis were single-technology assessments (original submissions, resubmissions, extensions of original indications, and renewals); relevant regulatory approvals and pivotal trials were also analyzed.

Results. Of the 185 AML appraisals from sixteen HTA bodies, 66 (36%) included PRO data. Within these, thirteen different PRO instruments were identified, none of which have been validated in patients with AML. For seven of twenty in-scope products, PRO evidence positively impacted ≥1 of the HTA decisions. Although the same HTA bodies (i.e., Scottish Medicines Consortium, pan-Canadian Oncology Drug Review, and the National Institute of Health and Care Excellence) generally accepted the PRO evidence, others were critical of the evidence (i.e., Haute Autorité de Santé and the Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen). The most common concerns raised by the HTA bodies regarding the PRO evidence included trial design and low patient response rate.

Conclusions. Of the products that included PRO evidence in their HTA submissions, 35% received positive feedback from ≥1 HTA body on their submitted PRO evidence. Attention to PRO data collection is key to demonstrate the value of AML products to HTA bodies. Without these data, a clear gap in the understanding of patients' experience is evident.

OP31 HTA And Patients' Preferences: Starting A Discrete Choice Experiment

Thomas Poder (thomas.poder@usherbrooke.ca), Marion Beffarat, Maria Benkhalti, Pierre Dagenais and Ginette Ladouceur

Introduction. Hospital-based health technology assessment (HB-HTA) needs to consider all relevant data to help decision-making, including patients' preferences. In this study, we comprehensively describe the process of identification, refinement and selection of attributes and levels for a discrete choice experiment (DCE).

Methods. A mixed-methods design was used to identify attributes and levels explaining low back pain (LBP) patients' choice for a non-surgical treatment. This design combined a systematic literature review with a patients' focus group, one-on-one interactions with experts and patients, and discussions with stakeholder committee members. Following the patient's focus group, ranking exercises were conducted. A consensus about the attributes and levels was researched during discussions with committee members.

Results. The literature review yielded 40 attributes to consider in patients' treatment choice. During the focus group, one additional attribute emerged. The ranking exercises allowed selecting eight attributes for the DCE. These eight attributes and their levels

https://doi.org/10.1017/S0266462319001004 Published online by Cambridge University Press