

What Matters Most? An Exploration of Decision Criteria Considered by Patients with GEP-NET and Physicians Using Holistic Multi-Criteria Decision Analysis

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Background: Patient-centered care implies identifying what matters most to patients and physicians through shared decision making on disease management. EVIDEM provides a generic holistic MCDA platform to explore decision criteria and trade-offs. The study aimed to develop a comprehensive decision framework and identify preferences of patients and physicians in the management of unresectable, well- or moderately differentiated non-functioning GEP-NET.

Methods: A decision support framework was designed based on EVIDEM structure, literature review and insights from a Chatham-house panel of US physicians and patients, representative of different management approaches for GEP-NET. During a second extended panel session (5 patients, 6 physicians), participants provided criteria weights using Hierarchical Point Allocation and Direct Rating Scale (DRS, sensitivity analyses). Insights were collected in writing and through discussions.

Results: The decision support framework included 6 domains pertaining to Outcomes of the intervention (Effectiveness, Patient-Reported Outcomes, autonomy, dignity & convenience, Safety); Type of benefit; Need (Disease severity; Unmet needs; Population size); Costs & constraints (Intervention; Medical and Non-medical [to patients or the healthcare system]); Knowledge (Quality of evidence, Expert consensus) and Feasibility (System capacity). Of the 30 criteria and subcriteria, 26 were considered by more than 90% of participants. Criteria weights were widely distributed reflecting variability in individual perspectives on what matters most. At the group level, highest weights were attributed to Effectiveness ($0.18 \pm \text{SD } 0.12$ on a total of 1) and Disease severity (0.12 ± 0.08), followed by Safety (0.10 ± 0.09), Type of therapeutic benefit (0.10 ± 0.08) and Quality of evidence (0.09 ± 0.06). Most important Effectiveness subcriteria were Overall survival (33% of effectiveness criteria), followed by Progression-free survival (30%). DRS showed similar overall results.

Conclusion: Many aspects are considered by patients and physicians in their decision making processes. Holistic MCDA reveals and structures the complexity and variability of what matters most to patients.