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Understanding Neuroendocrine Tumour Patient Preferences for Medical Management of Midgut NETs Using Discrete Choice Experiments: a DIRECT NETs Study

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BACKGROUND: Neuroendocrine tumours (NETs) are heterogenous in terms of prognosis, symptom burden, and quality of life impact. Understanding the heterogeneity in NET patient preferences, perspectives and values is therefore essential for providing patient centered care. The DIRECT NETs (DIrect Experience with Choice of Therapy for NeuroEndocrine Tumours) studies, conducted by CommNETs, are discrete choice experiment (DCE) surveys that model clinical scenarios where advanced NET patients have several treatment options. We present results from a DCE modelling treatment options for advanced midgut NETs following progression on first line somatostatin analogues (SSA).

METHODS: Peptide receptor radionuclide therapy (PRRT), SSA dose escalation, and everolimus were the treatments modeled. Attributes included progression free survival (PFS), method of treatment administration, and key differentiating adverse event rates reported in randomized control trials. The DCEs employ the 'potentially all pairwise rankings of all possible alternatives' (PAPRIKA) method as implemented by the 1000minds platform. Participants self-enrolled to complete an online, self-reported, anonymous survey, which was disseminated by CommNETs and NET patient advocacy groups. Key outputs included part-worth utilities for individual attribute levels, ranking of attributes, and ranking of

attribute profiles matching specific treatments.

RESULTS: 110 NET patients completed the survey. Attribute importance in descending order was as follows: PFS, mucositis, diarrhea, secondary malignancy, and method of treatment. 64.5% of participants placed the greatest importance on longer PFS. Amongst treatment profiles, 60.9% preferred attribute levels matching PRRT, 30.0% SSA dose escalation, 7.3% everolimus. Patients reporting non-functional tumours were more likely to prioritize PFS than those with functional tumours (78.1% vs 57.9%; Chi-square $P = 0.046$).

CONCLUSION: Most NET patients may prefer treatments that maximize PFS, however more than a third place more importance on other treatment attributes such as adverse event rates. Discussion of treatment options with NET patients should balance quality of life impacts with achieving disease control.

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