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Understanding the Treatment Preferences of Neuroendocrine Tumour Patients Using Discrete Choice Experiments

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BACKGROUND: Neuroendocrine tumours (NETs) are a diverse group of rare malignancies, with significant heterogeneity in terms of prognosis, symptom burden, and impact on quality of life. There is little published information on NET patient preferences and priorities in regards to medical management. Improved understanding of the perspectives and values of the NET patient population in regards to available treatments would facilitate patient-centered care.

METHODS: We designed three discrete choice experiments (DCE) which model clinical scenarios where advanced NET patients have several treatment options. The DCEs employ the 'potentially all pairwise rankings of all possible alternatives' (PAPRIKA) method as implemented in the 1000minds platform. Data from the randomized clinical trials that support the use of different medical treatments was used to generate the content for the DCE attributes. The online DCEs surveys were trialled in a pilot study as a test of technical issues and face validity, which were assessed through semi-structured interviews.

RESULTS: Based on semi-structured interviews, the DCEs achieved face validity, as they included treatment attributes identified as important by the participants. Participants expressed concern with the length of the DCEs, and on apparent redundancy of the choices between the clinical scenarios. The participant-level partial worth utility data revealed variable willingness to trade off factors like progression free survival (PFS) for side effects rates and method of treatment

administration, and variable preference for attribute profiles matching specific treatments for advanced NETs.

CONCLUSION: We developed and piloted a series of DCEs that model preferences for NET treatment. Preliminary results indicate that patients place variable importance on factors like PFS, and preference for profile matching specific treatments. The DCEs are currently being refined based on feedback from the pilot study, with plans to begin participant recruitment at sites in Canada, Australia, and New Zealand.