

Study Title: Development of follow up recommendations for completely resected Gastroenteropancreatic Neuroendocrine Tumours (GEP-NETS): Practice Survey of Commonwealth Neuroendocrine Tumour Collaboration (CommNETS) in conjunction with North American Neuroendocrine Tumour Society (NANETS)

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Background: Published guidelines for follow up after R0 resection of GEP-NETS exist but are complex and emphasize closer surveillance in the first 3 years, extrapolating from guidelines for other GI malignancies. NETS have a different pattern and time scale of recurrence, hence may require more practical and tailored follow up. To test this, a broad ranging survey of real world practices across CommNETs and NANETS members was undertaken.

Aim: To examine current international real world practice compared to published guidelines to inform development of a new guideline document for follow up after R0 resection in patients with GEP-NETS.

Methods: A detailed electronic cross-sectional survey was developed to ascertain patterns of follow up and distributed to NET physicians, nurses and allied health professionals in the CommNETS Collaboration (Australia, New Zealand and Canada), and NANETS. Questions addressed demographics, knowledge and use of current guidelines and follow up practices relating to various prognostic factors. Descriptive statistics for all response options were stratified by country, patient volume and specialty.

Results: There were 163 respondents: Australia: 59; New Zealand: 25; Canada: 46; US: 33. 50% of respondents practiced Medical Oncology; 23% Surgery; 13% Nuclear Medicine; 14% other disciplines. 38% of respondents were “very familiar” with NCCN NET guidelines; 33% with ENETS and 17% with ESMO, however only 15%, 27% and 10% found them “very useful”, respectively. 63% reported not using guidelines at their institution. Ranking of prognostic factors was (top 5, in decreasing order): grade, Ki67/mitotic count, T stage, N stage and site of origin. Follow up in the first 2 years was most commonly every 6 months (62%); in years 3-5 every 12 months (59%) and after 5 years, 12 months (41%). Preferences for follow up did not differ significantly by patient volume. The commonest investigations ordered were CT scans (66%) and CgA (86%). When poor prognostic factors were introduced, increased visits and tests were recommended.

Conclusions: This large international survey yields rich and detailed information about current practices for follow up of fully resected GEP-NETS, highlighting variation in areas not well addressed by current guidelines. This forms a strong basis for the upcoming CommNETS/NANETS consensus meeting, which aims to produce user friendly and practical follow up guidelines tailored specifically to the expected pattern of recurrence in patients with NETs.