Introduction

• Published guidelines for follow up after R0 resection of GEP-NETS are complex.
  - Closer surveillance in the first 3 years is emphasized, as per other GI malignancies.
  - Knowledge of, and compliance with guidelines may vary widely.
• NETs are heterogeneous, and the pattern and timescale of recurrence is poorly documented.
• Follow up schedules impact on patient experience and health resource utilization. Practical and tailored follow up would be more appropriate than broad guidelines which may overinvestigate.
• As part of a larger project to define optimal follow up for fully resected NETs, we performed a detailed survey of real world practices amongst CommNETs and NANETS members to assess current practice.

Aim

To examine real world follow up practices for patients with resected GEP-NETS.

Methods

• A detailed electronic survey was developed and distributed during a 2-week period to the member database of the CommNETs Collaboration and NANETS.
  - Australia, New Zealand, Canada, United States
  - NET physicians, nurses and allied health professionals
• Questions addressed the following areas:
  - Demographics of respondent
  - Knowledge and use of current guidelines
  - Follow up practices (frequency and modality) according to various prognostic factors
  - Descriptive statistics were reported.
  - Stratified by country, patient volume and specialty.
  - For stratified analyses, follow up patient care volume was categorized as “low” (0-10 patients per year), “medium” (11-50) and “high” (>50).

Results

Demographics:

• 163 respondents contributed to the survey
  - Australia (59), New Zealand (25), Canada (46), US (33)
  - 50% Medical Oncology, 23% Surgery, 13% Nuclear Medicine, 14% Others
  - NET patient volumes varied widely (Table 1)
• Interpretation of various terminology eg “complete resection” was highlighted as a potentially confounding issue when discussing optimal follow up

Familiarisation with NET follow up guidelines:

• 38% were “very familiar” with NCCN NET guidelines, 33% with ENETs, and 17% with ESMO (Fig 1)
• However, only 15%, 27% and 10% respectively found them “very useful” (Fig 2)
• 63% reported that their institution did not have guidelines regarding NET follow up; there were various reasons for not developing or following guidelines (Fig 3)

Familiarity with existing guidelines

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Usefulness of existing guidelines

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Prognostic factors influencing follow up patterns:

• Grade and Ki-67/mitotic count were considered the most important prognostic factors when deciding follow up protocols for individual patients (Table 2).

Patterns of follow up

• Follow up in the first 2 years was most commonly every 6 months (62%); in years 3-5 every 12 months (59%) and > 5 years, 12 months (41%).
• In general, patients were discharged from NET-specific follow up after 5 years (28%), 6-10 years (26%) or > 10 years (23%) of follow up.
• Follow up patterns did not differ significantly by patient volume
• Histology affected follow up recommendations significantly,
  - Respondents were likely to increase follow up (frequency of tests and/or clinic visits) for:
    - G2 NET compared to G1 (51% of respondents)
    - G3 NET compared to G1 (90%)
    - Lymph node positivity (53%)
    - Pancreatic primary compared to small bowel (40%)
  - Follow up varied for the following scenarios:
    - Appendiceal primary: Less frequent follow up (40%), no change (40%)
    - Rectal primary with local excision: No change (44%), increased follow up (21%)
    - Colorectal primary with surgical resection including lymph nodes:
      - No change (59%), increased follow up (21%)
• The commonest investigations ordered were CT scans (66%) and CgA (86%).
  - Follow up investigations did not differ significantly according to country, patient volume or specialty of respondent.

Discussion

• Follow up patterns vary widely amongst different specialists and countries but appear uninfluenced by patient volume
• Current guidelines do not appear to be widely adopted
• Various prognostic factors affect follow up frequency and investigations, particularly grade and Ki-67

Conclusions

• This large international survey yields detailed information about variation in current follow up practices and raises questions about the applicability of current guidelines.
• More data regarding patterns and timelines of NET recurrences is needed. Detailed examination of recurrences in a large population database is currently underway as part of the CommNETS follow up project.
• This survey information was used in combination with the aforementioned data as the foundation of a CommNETS/NANETS Expert Consensus meeting on Optimal follow up of fully resected GJ-NETS held in December 2016 which produced scenario-based, practical guidelines.