The challenges of designing and implementing a structured, international multicentre audit on quality of life (QOL) and markers of response in patients with neuroendocrine neoplasms (NEN) treated with peptide receptor radionuclide therapy (PRRT)

Commonwealth Neuroendocrine Tumour Collaboration (CommNETS) PRRT Working Group

Aim

Audits of patient reported outcome measures (PROMs) are important for uncommon and heterogenous diseases, such as neuroendocrine neoplasms (NENs), in order to help optimise clinical and survivorship pathways for patients. Patients with NENs often have a reduced QOL due to tumour and hormone-related symptoms and potential treatment side-effects. Peptide Receptor Radionuclide Therapy (PRRT) is an effective treatment option, however QOL data is limited. This investigator-driven project was designed to undertake an international, multicentre, retrospective audit of PROMs and clinical data for patients with metastatic NEN treated with PRRT.

Method

The working group from 3 Australian and 2 Canadian centres with multidisciplinary experience in the uncommon tumour group, NENs and QOL, met in December 2016. The group convened remotely every 4-6 weeks for 12 months via teleconference to design and implement the project.

Results

Achievement to date: Project planning (12 months) involved several activities completed through strong collaboration between clinicians, data experts and researchers with QOL expertise (see figure). Implementation will commence in 2018. This will include data entry, analyses, and exploring new models of partnership to provide funding to secure ongoing collaborative effort at a national and international level.3

- Planning (2017)
  - Activities:
    - Protocol methodology and hypotheses developed
    - National ethics and site specific approval
    - Project governance
    - Data dictionary
    - Electronic data capture (EDC) system

- Implementation (2018)
  - >400 eligible patients completed PRRT from May 2009 – June 2017
  - EORTC QLQ-C30® and QLQ-GINET21® questionnaires and patient clinical data
  - Analysis including change in QOL during and following PRRT
  - Pursue additional funding avenues

- Reporting & Dissemination (2018-2019)
  - Publications and conferences for academic and clinical audiences
  - Consumer advisory group has been engaged to assist with interpretation of findings and dissemination to consumers

Conclusion

Solutions are required in order to advance knowledge of uncommon diseases. International multicentre audits of PROMs are feasible for uncommon cancers, yet resource intensive. A strong, coordinated effort from investigators with clinical and QOL expertise and engagement with patient organisations is crucial for success. With limited funding, considerable good-will and a high level of motivation is required from all team members.

References