

# CommNETS: Formation of an International Commonwealth countries NET partnership

DRAFT

S. Singh<sup>1</sup>, B. Lawrence<sup>2</sup>, D.L. Chan<sup>3</sup>, N. Pavlakis<sup>3</sup>, E. Segelov<sup>4</sup>, for the CommNETS collaborators

<sup>1</sup>Sunnybrook Odette Cancer Centre, Toronto, Canada, <sup>2</sup>University of Auckland, Auckland, New Zealand

<sup>3</sup>Department of Medical Oncology, Royal North Shore Hospital, Australia, <sup>4</sup>St Vincent's Clinical School, University of New South Wales, Sydney, Australia



## Introduction/Background

- Neuroendocrine tumours (NETs) care in Canada, Australia and New Zealand is characterized by common challenges
  - Small populations in large geographical spaces
  - Limited drug funding
  - Lack of NET awareness
- All of the above factors are shared by the clinicians in each country, and can adversely impact the NET patient journey in ways that patients in other countries may not experience.
- There is a need for collaboration between these countries
  - To direct research
  - To improve care and outcomes for NET patients
  - To continue progressing towards patient-centred care
- We aimed to create an international partnership – Commonwealth Neuroendocrine Tumour Society (CommNETs) – in order to
  - Include patient voices from inception of the organization
  - Foster international ties and identify opportunities for research collaboration
  - Improve the NET patient journey

## Method

- A multidisciplinary group of NET clinicians, researchers and patient advocates from all three nations attended an inaugural meeting to create CommNETS in Nov 2015.
- Objectives for the meeting included the following:
  - To build and create a network of NET patients and health care providers to foster research
  - To establish Gaps in NET research
  - To establish working groups to build a foundation for collaboration
  - To review latest and newest development in NET care
- A modified Delphi process was undertaken to identify gaps for research
  - Both patients and clinicians were involved in this process
  - Two rounds of internet surveys were undertaken: Round 1 with 21 questions (and up to 14 sub-questions), Round 2 with 10 questions (ranking up to 17 research priorities)
  - The results were collated and workshopped at the meeting.
  - Priorities in research and improving patient care were discussed in a collaborative face-to-face meeting.

## Results

- The meeting was held in Honolulu, Hawaii on November 6-7, 2015 with significant participation from all three countries (Fig.1).
- Forty-eight participants including surgeons, medical oncologists, endocrinologists, scientists, nuclear medicine physicians/physicists, pathologists, and patients attended. (Fig 1, Tab 1)
- Day One consisted of review of recent NET developments and the final round of the Delphi process (two rounds were held prior to the meeting).
- Day Two consisted of establishing research collaborations and the development of working groups to further the CommNETS agenda.
  - Working groups were established in the following areas:
    - The formation of a common database – To facilitate collection of pertinent common data fields and enable future collaboration research; to minimize costs relating to database setup/data managers
    - Biomarkers – To utilize the above databases in combination with infrastructure available in each country to facilitate biomarker research
    - Functional imaging – addressing the disparities in provision of PET scans and undertaking innovative international research in functional imaging; need for standardized operating protocols with regard each modality; overcoming barriers of access to/transport of radiopharmaceuticals
    - Pathology – To aim for common synoptic reporting guidelines, and optimization of biobanking
    - Locoregional therapies – Feasibility of randomized trials; selection of optimal efficacy endpoints
    - Early diagnosis of NETs – To investigate a predictive model for early diagnosis of NETs, whether with classical biomarkers or in combination with constellations of symptoms
- The results of the Delphi process are presented in a separate poster.
  - The top three priorities as ranked by clinicians and patient advocates were: predictive biomarkers, prognostic biomarkers and the investigation of new drugs for advanced NETs. (Mean ranking 4.0 vs 9.6 on a 17 point scale – 1 being the most important, 17 the least important) (Table 2).
  - Significantly higher priority was given to early diagnosis of NETs by consumers compared to clinicians.

Fig 1: CommNETs attendance by countries (Can 18, Aus 15, NZ 15)



Table 1: CommNETs attendance by specialty

Medical Oncologist	24
Endocrinologist	5
Pathologist	4
Nuclear Medicine	4
Surgeon	2
Radiologist	2
Other (Patient advocates, NET nurses, Biochemists, bioinformaticians)	7

Table 2: Top three research priorities identified by Delphi process

	Total Mean	Std. Deviation
Biomarkers that tell us whether a particular treatment will be effective	4.4	3.6
Biomarkers that tell us about prognosis	5.7	4.3
New investigational drugs/trials for advanced NETs	6.3	3.9

## Discussion

- Whilst CommNETS is a new collaboration, concrete goals were set and achieved during the inaugural meeting.
- Participants noted commonalities amongst the three health systems
  - Limited research funding
  - Issues with equitable access to non-urban areas
  - Small populations arguing for novel trial designs in NET
- And also differences amongst the three
  - Availability of functional imaging (particularly 68Ga-based PET).
  - The progress towards integrative biobanking systems
  - Prior access to international phase III trials
  - Last but not least, differences in weather!
- Despite the above – the consensus at the meeting was that future collaboration is feasible and warranted.
  - CommNETs has planned for a second meeting in December 2016 with the preliminary topic set as “controversies in NET management”

## Conclusions

- Canada, Australia and New Zealand share a common health system and similar challenges in NET care.
- CommNETS provides a new, ongoing structure to further collaboration for NETs research, based on a robust process to define priorities and strengths of the group.
- As ongoing industry funding has been obtained, CommNETs is a promising forum to improve NETs care.