

Identifying and prioritising Gaps in Neuroendocrine Tumour Research - results of the Delphi consensus project of the Commonwealth Neuroendocrine Tumour Research Collaboration (CommNETS)

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Introduction/background

The newly formed CommNETS group of collaborators from Canada, Australia and New Zealand specifically sought to set its research priorities using a robust methodology rather than the ad hoc and opportunistic process which too often dictates research agendas. Engagement of a large and diverse group of multidisciplinary clinicians and patients/ advocates as an integral part of the CommNETS membership was sought.

Aim

To identify gaps in NET research and develop research priorities and activities to underpin collaborations using the robust Delphi methodology with broad stakeholder engagement. Understanding the importance of the methodology on the process of reaching an agreed agenda for the new collaboration was emphasized.

Methods

Round 1 consisted of a 30 minute internet survey, disseminated widely through patient and professional groups, comprising 21 questions each with up to 14 sub-questions. Agreement for the Delphi process was set at > 80% of participants. Priorities were then discussed by e-survey (Round 2) comprising 10 questions, ranking up to 17 individual research priorities. The top 10 priorities were workshoped at the Inaugural CommNETS meeting considering importance, feasibility, relevance for CommNETS and the consumer/patient perspective before final voting (Round 3). Research opportunities aligned to the top priorities were then defined considering key research questions, goals, funding sources and collaborative models. Satisfaction with the Delphi process was evaluated.

Results

Process: Participation in the 3 rounds was proportionally similar by country: approximately 50% Canadian, 33% Australian and 17% New Zealand. Rounds 1 (n=203) and 2 (n=100) were answered by approximately 66% health professionals and 33% patients/consumers whereas for Round 3 (n=48) this was 94% and 6%. Research priorities after Round 2 are shown (Table 1) 93% of participants were satisfied or very satisfied with the process.

Outcomes: The final research topics were allocated priorities:

Standardizing NET trials:

1. Trial endpoint selection (DFS v OS)
2. Nuclear scan assessment criteria
3. Pathology assessment
4. Biochemical assessment parameters
5. Radiological assessment criteria

Trials not involving therapy:

1. Biomarkers with integration into clinical treatment pathways
2. National/international tissue banking
3. Standardizing QOL indices
4. Utility of preoperative investigations and optimal followup
5. Standardizing staging and nomenclature

Trials of systemic therapy:

1. Novel agents in metastatic NET
2. Further trials of PRRT v systemic drug therapy
3. Targeted drugs based on tumour molecular profiling
4. Control of refractory functional symptoms
5. Radiosensitizing chemotherapy
6. Adjuvant therapies
7. Sequencing of current therapies
8. Optimal PRRT scheduling
9. Chemotherapy regimens in G3/NEC
10. Novel non-chemotherapy systemic treatment including antiangiogenics, anti-PD1 etc

Trials of local therapy:

1. Comparing different LDT
2. Role of debulking in metastatic NET
3. Surgical trials based on primary NET site



Table 1: Research priorities after Round 2

	Health professional	Patient/consumer	Total
Biomarkers that tell us whether a particular treatment will be effective	4.4	4.4	4.4
Biomarkers that tell us about prognosis	5.1	7.0	5.7
New investigational drugs/trials for advanced NETs	6.1	6.8	6.3
Sequencing of therapies for metastatic disease	6.3	8.9	7.1
Peptide receptor radionuclide therapy	6.6	8.8	7.3
Early diagnosis of NETs	9.6	4.0	8.0
Functional imaging	7.8	10.0	8.4
Curative surgery for NETs	9.9	7.2	9.1
Interventional radiology/Liver-directed therapy	9.1	9.5	9.2
Pathological classification of NETs	9.4	9.9	9.6
Coordination of care pathways for NET patients	9.8	10.4	10.0
Managing physical symptoms of NETs patients	10.2	9.9	10.2
Palliative surgery for advanced NETs	10.6	10.8	10.6
Use of somatostatin analogues (SSAs)	10.9	11.3	11.0
Cross-sectional imaging (CT, MRI)	12.4	10.3	11.8
Managing psychological needs of NETs patients	12.1	12.2	12.2
Management of rural patients (living >2 hours away from major NET centre)	12.5	11.6	12.2

Discussion

The CommNETS process differed from many Delphi processes because of the very large number of participants and significant representation of patient/consumer perspectives. The disparately higher ranking of early diagnosis of NETs and curative surgery by consumers prompted reconsideration to include these in the final list.

Conclusion

The Delphi process allowed CommNETS to develop a consensus about research priorities using a robust, defensible and inclusive process. Seven working groups with streamlined goals have begun working on identified projects. The process was widely endorsed as inclusive, informative and novel, challenging usual paradigms for setting research agendas.

Collaborators

Australia:

Dale Bailey – Nuclear Medicine
Philip Beale – Medical Oncologist
David Chan – Medical Oncology
Lorraine Chantrill – Medical Oncology
Yu Jo Chua – Medical Oncology
Jon Gani – Surgeon
Grace Kong – Nuclear Medicine
Diana Learoyd – Endocrinologist
Michael Michael – Medical Oncologist
Nick Pavlakis – Medical Oncologist
Aravind Kumar – Nuclear Medicine
Paul Roach – Nuclear Medicine
Eva Segelov – Medical Oncology
Katrin Sjoquist – Medical Oncology
K. Wakelin – NET Patient Support Nurse
David Wyld – Medical Oncology

Canada:

Sylvia Asa – Pathologist
Tim Asmis – Medical Oncology
Bryan Chan – Medical Oncology
Chris Dey – Interventional Radiologist
Shereen Ezzat – Endocrinologist
Rachel Goodwin – Medical Oncologist
Vallerie Gordon – Medical Oncologist
Hagen Kennecke – Medical Oncologist
Walter Kocha – Medical Oncologist
David Laidly – Nuclear Medicine
Calvin Law – Surgeon
E. Mandino – Patient Coordinator
Janice Pasioka – Surgeon
Daniel Rayson – Medical Oncologist
Juan Rivera – Endocrinologist
Simron Singh – Medical Oncologist
Anna Spreafico – Medical Oncologist
Ralph Wong – Medical Oncologist

New Zealand:

Cherie Blenkiron – Medical Scientist
Richard Carroll – Endocrinologist
Ruelllyn Cockcroft – Paediatric Oncologist
Siobhan Conroy – Unicorn Foundation
Marianne Elston – Endocrinologist
Dean Harris – Medical Oncologist
Kimiora Henare – Biomedical Researcher
Avril Hull – Clinical Nurse Specialist, NET
Christopher Jackson – Medical Oncologist
Nicole Kramer – Anatomical Pathologist
Ben Lawrence – Medical Oncologist
Lucy Modahl – Consultant Radiologist
Kate Parker – Research Program Manager
Cristin Print – Medical Scientist
Reena Ramsaroop – Pathologist