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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Background: Australia, Canada and New Zealand share similar challenges in NET research and care provision. We aimed to identify gaps in NET research and develop research priorities to underpin collaborations across the newly formed CommNETS group using the robust Delphi methodology with broad stakeholder engagement.

Methods: A 3 round Delphi: 2 online surveys plus final round at the Inaugural CommNETS meeting; was performed with wide participation from stakeholders including subject experts (medical, nursing, scientific) and consumers (patients, families, advocates). Round 1 identified gaps in NET research and CommNETS’ strengths compared to USA & Europe; Round 2 identified research priorities; Round 3 ranked priorities after extensive workshops and established project groups.

Results: Round 1 had 203 participants (64% experts; 36% consumers; 52% Canadians, 32% Australians, 17% New Zealanders); of which 132 undertook Round 2. Rankings from experts and consumers were similar except for early diagnosis (mean rank of 17 priorities for experts 9.6, SD=5.8; consumers=4.0, SD=5.2, p=0.000003). Final priorities (from 147 votes) were: biomarkers (33%); PRRT (16%); new drugs/trials in advanced NET (12%); functional imaging (10%); sequencing therapies for metastatic NET including validated surrogate endpoints (10%); pathological classification (9%); early diagnosis (7%); interventional therapeutics (3%). 6 working groups were founded.

Conclusion: A robust set of CommNETS research priorities was developed by consensus through the Delphi process. Collaborations have commenced to address the research questions.

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