

Identifying and Prioritizing Gaps in Neuroendocrine Tumor Research: A Modified Delphi Process with Patients and Health Care Providers to Set the Research Action Plan for the Newly Formed Commonwealth Neuroendocrine Tumor Collaboration

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For which topic were research priorities identified?

neuroendocrine tumor

In which location was the research priority setting conducted?

Australia - Australia; Australia - New Zealand; North America - Canada

Why was it conducted at all?

Neuroendocrine tumors (NETs) are a diverse group of malignancies that pose challenges common to all rare tumors. The Commonwealth Neuroendocrine Tumor Collaboration (CommNETS) was established in 2015 to enhance outcomes for patients with NETs in Canada, Australia, and New Zealand. The Commonwealth Neuroendocrine Tumor Group (CommNETS) is a new collaboration among patients with NETs, clinicians, and researchers in Canada, Australia, and New Zealand. The group formed in 2015, with the mission of improving outcomes for patients with NETs, recognizing similarities of care provision in the three countries.

What was the objective?

to identify gaps in neuroendocrine tumor research to produce a comprehensive and defensible research action plan

What was the outcome?

a ranking list of 9 research areas

How long did the research prioritization take?

6 months

Which methods were used to identify research priorities?

Delphi

How were the priorities for research identified exactly?

Step 1: systematic literature review undertaken to identify areas. Step 2: Delphi with patient/advocate and health care provider/researcher expert panel. Delphi round 1: 70-question survey designed, participants were asked to rate 17 research areas and asked to rate agreement with 52 specific research topics, lists of areas and topics then reduced to 10 areas and 26 topics for round 2. Step 3: Delphi round 2: participants were asked to rank areas and topics. Step 4: Delphi round 3: workshop: discussion on the top ten research areas and topics, participants were asked to vote

Which stakeholders took part?

Patients, caregivers, patient advocates, support societies, and healthcare consumer representatives, multidisciplinary healthcare professionals: medical, nursing, and allied health practitioners and basic and translational researchers. Delphi round 1: 203 participants. Delphi round 2: 132 participants. Delphi round 3: 49 participants.

How were stakeholders recruited?

The panel participants were recruited through e-mail invitations circulated through NET patient advocacy groups and support societies and clinical and research groups and networks in Canada, Australia, and New Zealand.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a multi-disciplinary project steering group. The members designed the survey.