

# Experience of Australia and New Zealand (ANZ) Patients With Neuroendocrine Tumours (NET) Treated at a NET Specialist Centre: Results of a National Survey and the Royal North Shore Experience (29307)

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## BACKGROUND

- NETs are rare and heterogeneous malignancies
  - NET diagnosis can be challenging due to non-specific symptoms
  - Delays in diagnosis are common, and 50% of patients have either regional or distant metastases at diagnosis<sup>1</sup>
- Referral to a NET multidisciplinary meeting (MDM) has been recommended by international guidelines, especially for patients considered for complex procedures such as peptide receptor radionuclide therapy (eg, Lutate)<sup>2</sup>
  - Retrospective series have suggested that MDM referral may improve NET outcomes<sup>3</sup>
  - Collaborative discussion by multiple specialties (medical oncology, surgery, endocrinology, pathology, nuclear imaging, radiology) can lead to sharing of information, facilitate investigations, and optimise management plans<sup>4</sup>
- Despite the improvements made in diagnosis and management of NETs, the NET patient experience has not been well examined thus far
- The International Neuroendocrine Cancer Alliance (INCA) is a network of 18 independent charitable organizations and patient groups from 15 countries around the world. Novartis Pharmaceuticals Corporation collaborated with INCA on the first global survey to gather data about the NET patient experience from multiple countries, with the goals of:
  - Capturing individual patient experiences of a NET diagnosis to increase understanding of the NET journey and the needs of patients with NETs
  - Highlighting differences and similarities between countries and regions to help improve NET awareness and care
- We present ANZ data on referral to NET specialist centres and the impact of this on the patient experience
- We aimed to put the above survey findings into practical perspective by documenting the MDM experience at Royal North Shore Hospital, a tertiary referral centre with multi-specialty expertise in NETs

## METHODS

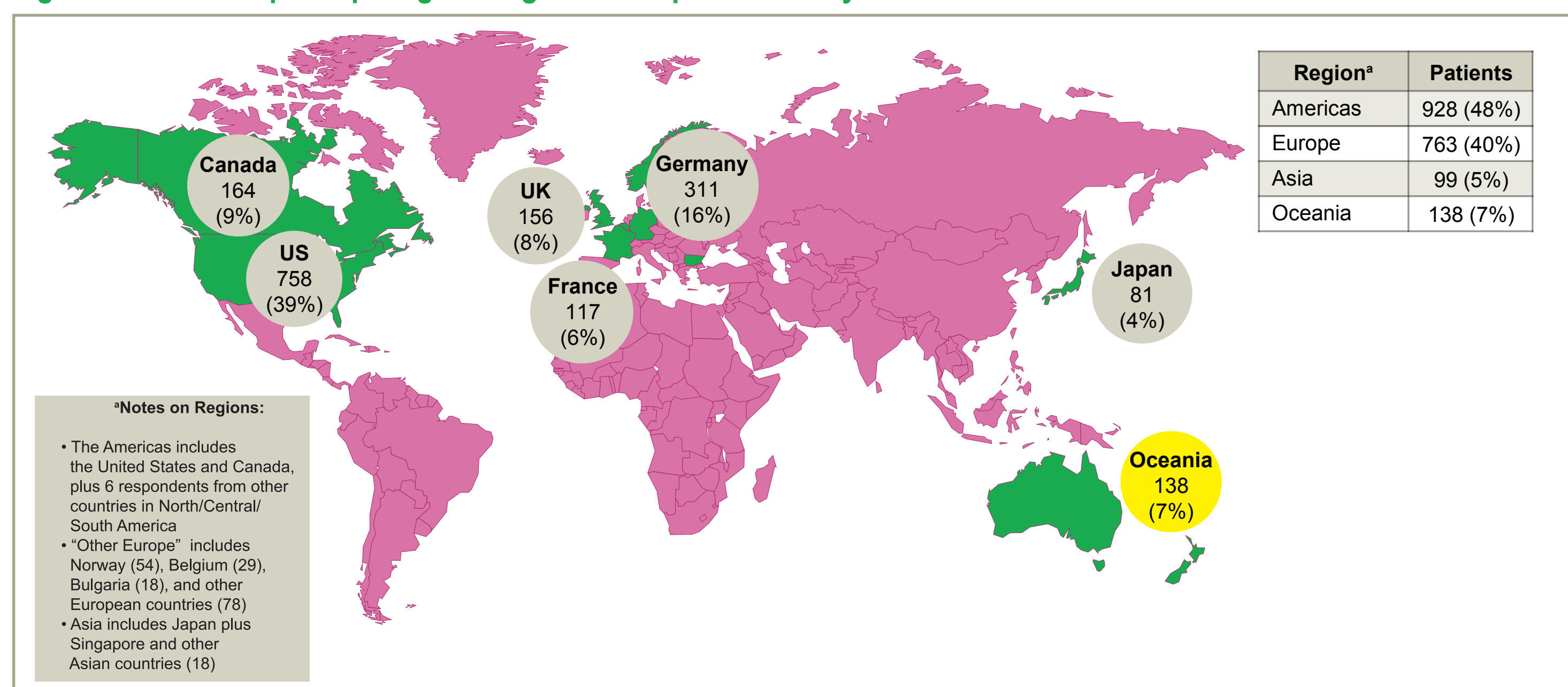
- From February through May 2014, patients with NETs participated in a 25-minute anonymous survey that captured the NET patient experience, including their diagnostic journey
  - With the exception of certain demographic information, survey questions were close-ended
- Patients were recruited via flyers, Web site postings, e-mails, and social media channels of the INCA member organizations/ patient advocacy groups (in 2014, INCA consisted of 17 organizations from 14 countries)
  - Extensive use of online social media sources through local/regional advocacy groups allowed recruitment of a large number of patients with this rare type of cancer
- This survey was primarily conducted online and was available in 8 languages: Bulgarian, Dutch, English, French, German, Japanese, Norwegian, and simplified Chinese
  - Paper surveys were developed in several languages and distributed by patient groups and health care professionals (HCPs) to reach patients without internet access
- Data were analyzed at global, regional, and country levels; here, we present results from the ANZ data
  - Statistical differences between comparisons were significant at the 95% confidence level ( $P < 0.05$ ) and are indicated by blue text
- This survey was conducted as an equal collaboration between INCA and Novartis, and was funded by Novartis. Hall & Partners, a research organization, fielded and analyzed the results

## RESULTS

### Demographics

- A total of 1928 patients with NETs were recruited from >12 countries in the Americas, Asia, Europe, and Oceania (Figure 1)
  - 138 respondents were recruited from ANZ, with the majority of participants coming from North America (n = 922) and Europe (n = 763)

Figure 1. Countries participating in the global NET patient survey.



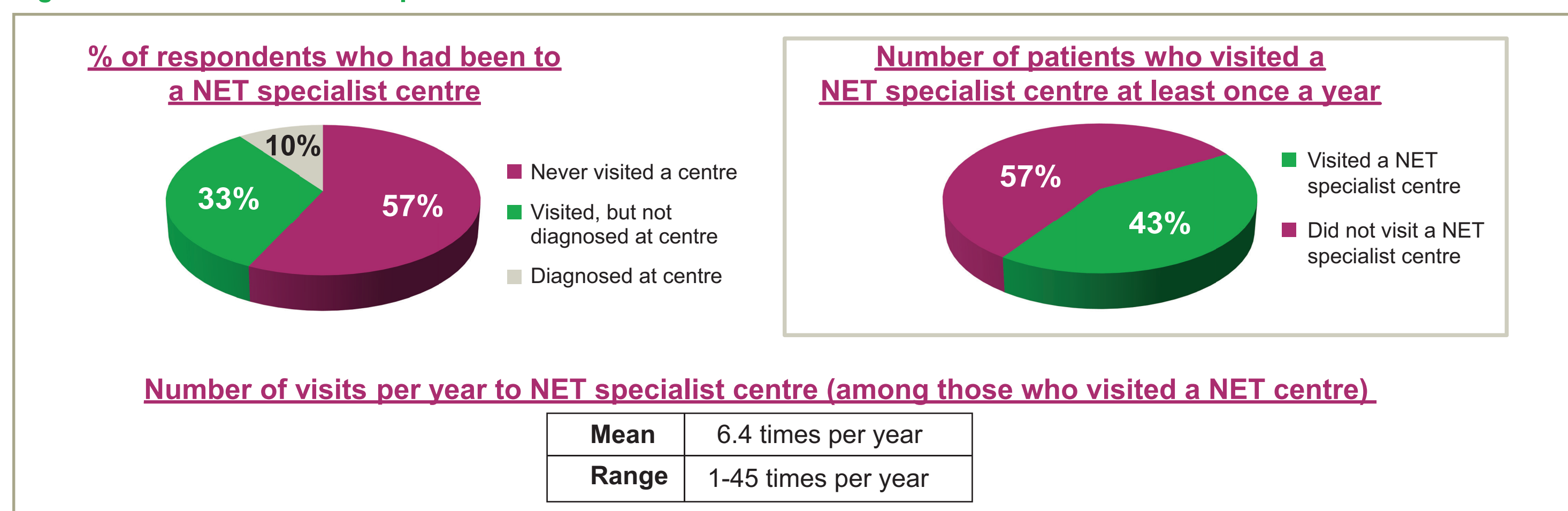
Base population: All respondents (N = 1928).  
 Questions: In which country do you live? In which region do you live?

- The average age of ANZ patients was 54 years, with 68% being female
- Nearly half of the respondents reported a primary site in the gastrointestinal tract (GI NET, 49%), with other commonly reported primary sites being the pancreas (pNET, 21%) and lung (9%)
- 54% of patients reported locally advanced or metastatic tumour at time of diagnosis

### Attendance at NET Specialist Centre

- 43% of patients had visited a NET centre previously (Figure 2)
- Only 10% were diagnosed at the NET specialist centre
- However, all of these patients continued to attend the specialist centre at least once a year (average, 6.4 times; range, 1-45)

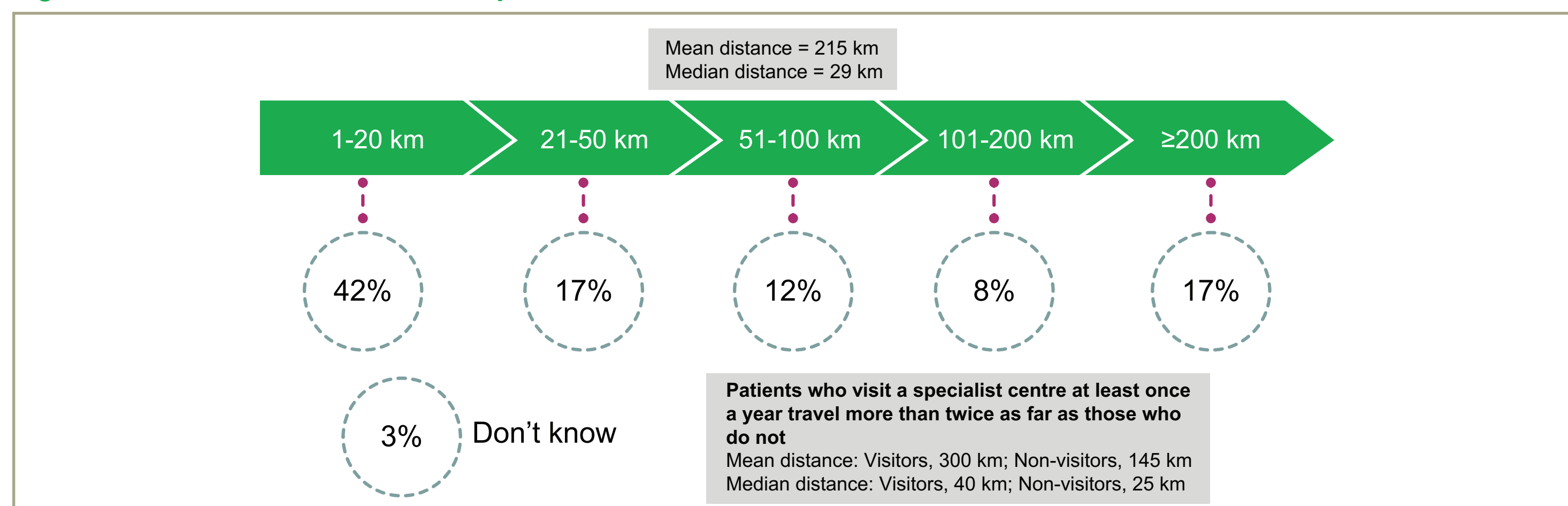
Figure 2. Attendance at NET specialist centre.



HCP = health care professional.  
 Base population: All ANZ respondents (n = 138).  
 Questions: Have you ever been to a medical centre that specialises in NET and has a team of different HCPs to help manage your NET? Did you receive your NET diagnosis at a medical centre that specialises in NET?  
 Base population: All ANZ respondents who had been to a NET medical centre (n = 59).  
 Questions: How often do you visit a medical centre that specialises in NET and has a team of different HCPs to help manage your NET care in a 1-year period?

- Patients had to travel further to attend a NET specialist centre (Figure 3)
- Median distance travelled was 40 km (visitor) versus 25 km (non-visitor)

Figure 3. Distance from NET medical provider.

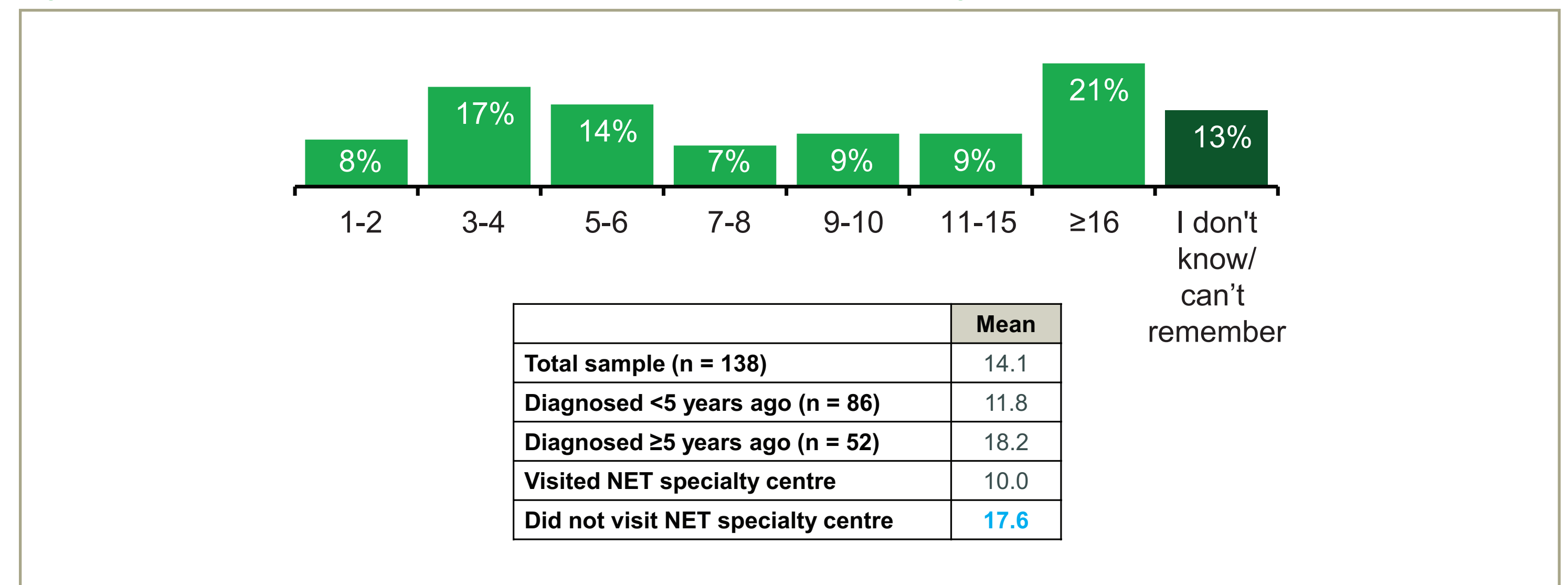


Base population: All ANZ respondents (n = 138).  
 Question: How far do you live from your main NET medical care provider?  
 Note: "Mean" indicates the average distance, while "median" shows the distance traveled by the 50th percentile, eg, half of patients traveled this distance or less, while the other half travelled further.

### Impact of Attending NET Specialist Centre

- Patients who attended a NET specialist centre at least once a year felt more likely to be "able to get answers to questions about NET" (66% vs 53% for non-visitors) and "had sufficient information to educate me about NET" (54% vs 43% for non-visitors)
- Patients who attended NET specialist centres were less likely to receive ≥2 alternate diagnoses prior to diagnosis of NET (27% vs 44%,  $P = 0.043$ )
- Patients required fewer visits overall for NET diagnosis (10 vs 17.6 visits,  $P < 0.05$ ; Figure 4)
  - Only 25% of patients required ≤4 visits for diagnosis of NET

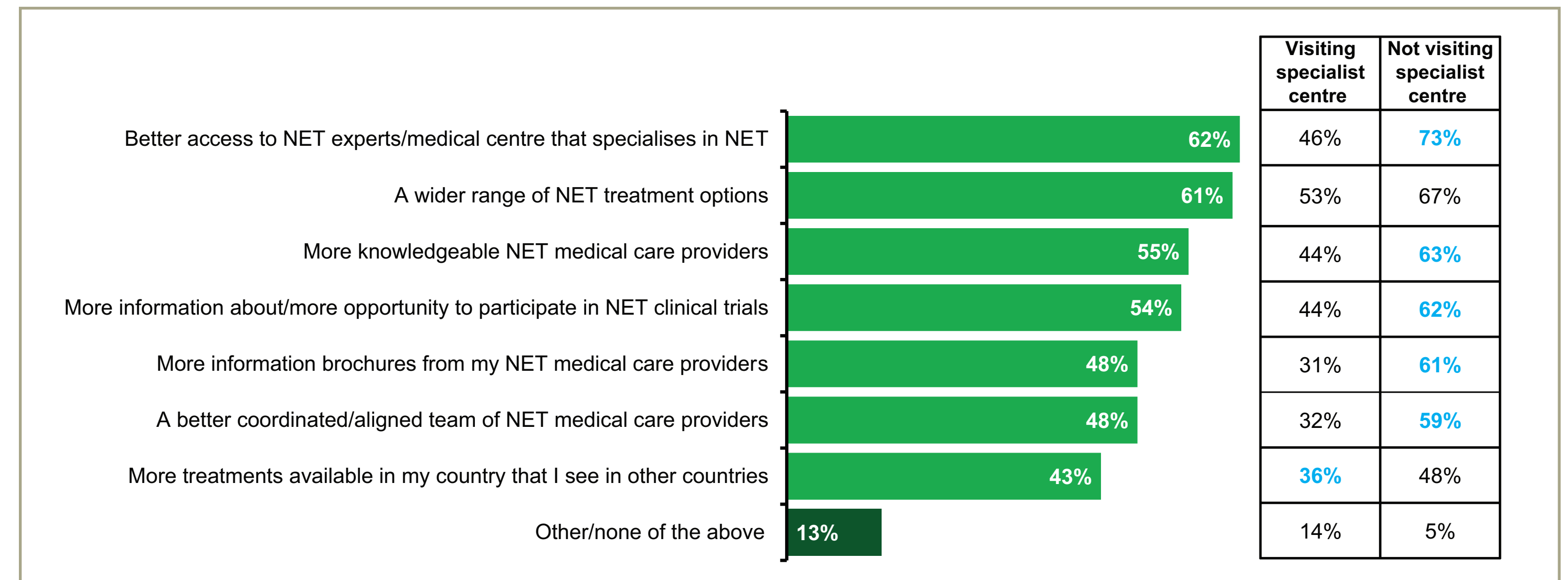
Figure 4. Number of visits to health care professionals to receive NET diagnosis.



Base population: All ANZ respondents (n = 138).  
 Question: Approximately how many different visits to health care professionals (including all doctors, specialists and nurses) did you have to make? Please consider all those you saw from the time you first experienced symptoms to the time you received the diagnosis of a NET.

- 62% of patients believed that better access to NET experts/NET specialty centres would help with their ongoing NET management (Figure 5)
  - NET specialty centre visitors reported increased satisfaction with coordination of NET medical providers (59% of non-visitors desired a better coordinated team vs 32% of visitors,  $P = 0.018$ ) and were less likely to feel a reduced interest in activities (20% vs 38%,  $P = 0.019$ )

Figure 5. Patient priorities for improving NET management.



Base population: All ANZ respondents (n = 138).  
 Question: Which of the following would help with the ongoing management of your NET?

### The Royal North Shore MDM Experience

- The Royal North Shore Hospital NET MDM commenced in April 2014 with input from medical oncology, nuclear medicine, surgery, radiology, and other departments
  - 118 patients (median age, 60 years; 48% female) have been discussed over 21 meetings (Table 1)

Table 1. Distribution of Primary Site – Patients Discussed at RNSH NET MDM

Site	Number of Patients
Midgut	43
Pancreas	40
Lung	7
Hindgut	5
Foregut	3
Other	20

MDM, multidisciplinary meeting; RNSH, Royal North Shore Hospital.

- A prospective database, based on research electronic data capture (REDCAP),<sup>5</sup> has been established
  - Real-time MDM documentation is feasible
  - Secure online access
  - Facilitates later data mining/research
- The management plan was altered in 96/213 (45%) of discussions (Table 2)
  - Many patients had multiple discussions over the course of the MDM, with 213 presentations of 118 unique patients

Table 2. RNSH NET MDM Discussions – Summary of Recommendations

Treatment Options	Number of Recommendations
Commence SSA	11
Targeted liver-directed therapy – SIRT, TACE, or MWA	17
Continue on current treatment plan, observations, repeat imaging, or repeat consultation, with a view to representation at MDT	117
Lutate	14
Surgery	21
Other – chemotherapy, clinical trials, biopsy, radiotherapy	33

MDM, multidisciplinary meeting; MWA, microwave ablation; RNSH, Royal North Shore Hospital; SIRT, selective internal radiation therapy; SSA, somatostatin analogue; TACE, transarterial chemoembolization.

## LIMITATIONS

- This global NET patient survey had several important limitations that may have impacted results:
  - A patient-reported design was employed without independent verification, leading to potential recall bias
  - This survey did not use standardized, validated quality-of-life assessments
  - ANZ patients were primarily recruited through patient advocacy groups (38%) and online sources (54%), which may have resulted in a potentially biased sample not fully representative of the heterogeneous NET patient population
  - Respondents were more likely to be highly engaged and motivated care seekers, including female patients and/or those with a poorer prognosis
- While the data used to analyse the RNSH MDM were entered prospectively, each discussion and recommendation was considered individually, resulting in a large number of "continue current treatment" recommendations
  - Given that all patients in this analysis were referred to the MDM, it is not possible to comment on the role of MDM referral on patient outcomes

## CONCLUSIONS

- Treatment at a NET specialist centre is associated with earlier diagnosis, increased patient satisfaction, and less negative impact on quality of life
- Despite the issues of increased travel distance and low rates of referral, patients with NETs should ideally be managed at a NET specialist centre with MDM input

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- RNSH NET MDM Study data were collected and managed using REDCap electronic data capture tools hosted at Sydney University.<sup>5</sup> REDCap (Research Electronic Data Capture) is a secure, Web-based application designed to support data capture for research studies, providing (1) an intuitive interface for validated data entry; (2) audit trails for tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for importing data from external sources
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