



# Perceptions of care and patient-reported outcomes in people living with neuroendocrine tumours

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## Abstract

**Background** Neuroendocrine tumours (NETs) are rare, and when metastatic NETs are incurable, the tumours are frequently slowly growing. Patients may be confronted with disease-specific problems and distinct issues when accessing health-care. We aimed to assess perceptions of care coordination, identify unmet needs, and examine if these varied by whether patients received specialist oncology care in a single hospital or shared between that and another hospital. We also quantified anxiety, depression, and NET-related physical symptoms.

**Methods** We conducted a cross-sectional survey of 111 NET patients managed at Royal Brisbane and Women's Hospital. Validated surveys measured care coordination (CCCQ), unmet needs (SCNS-SF34), anxiety and depression (HADS), and quality of life and symptoms (FACT).

**Results** Participants were between 2 months and 27 years after diagnosis. The worst-ranked items on the CCCQ related to health professionals having a full case history, providing information about financial entitlements and asking about how well patients and their families were coping. People with shared care were significantly less satisfied with some aspects of care. One in three participants reported a moderate-to-high unmet need for help with fatigue and one in four with psychological concerns about their cancer spreading, uncertainty about their future, and about the worries of those close to them. Overall, 30% of participants had anxiety and 20% had depression and they had significantly lower physical and emotional well-being compared to the general population.

**Conclusions** NETs are experienced as a chronic illness. In addition to ongoing psychological and physical symptom management, improvements to case history documentation and discussions about coping and finance are recommended.

**Keywords** Patient-reported outcomes · Neuroendocrine · Tumours · Care coordination · Supportive care needs · Quality of life

## Introduction

Neuroendocrine tumours (NETs) are a group of complex tumours that arise from specialised cells called neuroendocrine cells, originating from the intestine, pancreas, lung, and other

organs. Although there are many types of NETs, they have traditionally been treated as a group because of their common cellular characteristics and clinical behaviour. NETs are relatively rare, with an annual incidence of 2.5–5 cases per 100,000 [1, 2]. However, as the 5-year survival is greater than 60%, the prevalence of NETs is 35/100,000 and these patients are more likely to be encountered in practice than gastric, pancreatic, oesophageal, hepatobiliary adenocarcinomas, or any two of these cancers combined [3].

Some NETs secrete bioactive peptides that may cause a cluster of symptoms described as “carcinoid syndrome”, including flushing, diarrhoea, wheezing, and heart valve damage. These tumours are known as functional NETs. In addition, a very small number of functional NETs secrete specific hormones leading to other recognised clinical presentations, for example gastrinomas and insulinomas. However, most well-differentiated NETs are non-functioning (do not secrete

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hormones) and may cause nil or minimal symptoms until they become very large or metastatic.

Surgery for localised disease is the only curative treatment available. Many NETs, such as appendiceal and rectal NETs, are usually cured by surgery. However, some people with NETs present with metastatic disease or subsequently develop metastases after resection of localised disease. While metastatic NETs are not curable, the tumours are frequently slowly growing so patients may live for many years. Treatment options include systemic therapies such as somatostatin analogues and chemotherapy, targeted therapies such as everolimus and sunitinib, local therapies such as debulking surgery, hepatic artery embolization, or external beam radiotherapy and selectively available therapies such as peptide receptor radio-therapy (PRRT).

NETs are poorly understood, both by patients and their health-care providers. Due to the rarity, heterogeneity, non-specific symptoms, and unique biology of NETs, patients harbouring these tumours may be confronted with specific problems that are somewhat different from those of patients with more common epithelial cancers. The prognosis for patients with advanced NETs is often uncertain, both clinically and in relation to the ability to plan ahead practically and financially [4]. Qualitative interviews with 30 people living with NETs in Australia describe NETs as atypical, because they are often incurable and slowly progressing, and their treatment is not associated with common side effects, such as hair or weight loss [5]. As a consequence, people with NETs do not typify ‘normal’ cancer sufferers and are vulnerable to being overlooked in the provision of social support and counselling [5]. The carcinoid syndrome, when present, further decreases quality of life [6–8]. In addition, NET patients may encounter distinct issues when accessing the health-care system. Self-reported survey data from 1928 NET patients, mostly from North America and Europe, found that about half of patients desired better access to NET specialists (56%) and a better coordinated NET medical team (45%) [9].

Qualitative research suggests that NET patients have unmet needs regarding disease-specific information, treatment centres, and support [10]. However, there have been no quantitative studies that have used validated instruments to assess unmet supportive care needs or perception of care coordination among the population of people living with NETs. Furthermore, while many studies have assessed quality of life outcomes of selected groups of NET patients receiving various treatments, many of these have not been population-based and have had a range of methodological shortcomings [11].

This study used validated assessment tools to assess perceptions of care coordination, identify unmet supportive care needs, and examine personal and clinical factors associated with these outcomes in a group of NET patients treated at a major tertiary hospital in Australia. Given the distinct access issues NET patients have reported facing in other global

regions [9], we investigated whether perception of care coordination among Australian NET patients varied by whether they were cared for at a single tertiary hospital with a specific NET management team versus shared care between the tertiary hospital and a specialist at another site. We also quantified the proportion of NET patients experiencing anxiety, depression, and NET-related physical symptoms, and the proportion that had quality of life scores below the general population average.

## Methods

### Participants and procedures

We conducted a cross-sectional mail survey of people with NETs who were being actively managed by the RBWH NET Multi-Disciplinary Team between August 2016 and February 2017. Patients with a histologically confirmed grade 1 or 2 NET [12], aged over 18 years, proficient in the English language, and able to give informed consent were eligible to participate. Patients with rapidly growing grade 3 NETs, such as small cell carcinoma, were excluded due to their significantly more aggressive clinical behaviour and worse survival [1].

Patients were mailed an information sheet, consent form, and questionnaire and asked to return them in an enclosed reply-paid envelope. If the questionnaire and consent form were not returned within approximately 3 weeks of the package being mailed, the study nurse telephoned the patient to ascertain their willingness to participate. Postcode was used to classify participants’ home location as major city versus regional/remote area using the Accessibility/Remoteness Index of Australia [13]. We obtained clinical data from medical records, including date of initial diagnosis, primary site, functional status, date diagnosed with metastatic disease if applicable, all treatments received, and whether RBWH was the only specialist provider or not.

### Patient-reported outcome measures

We administered four different instruments, the Cancer Care Co-ordination Questionnaire (CCCQ), the Supportive Care Needs Survey-Short Form (SCNS-SF34), the Functional Assessment of Cancer Therapy - General (FACT-G), and Hospital Anxiety and Depression Scale (HADS). These are described in detail below.

The CCCQ has 20 items which measure patients’ perception of cancer coordination on two subscales: communication (range 13–65) and navigation (range 7–35) [14]. Together, the subscales can be summed to a total score (range 20–100). These two components explained 91% of the variance. The instrument and its two subscales have high internal consistency (Cronbach’s alpha 0.88, 0.87, and 0.73 respectively). All

questions are answered on a 4-point Likert scale (1 to 5). A higher score indicates better care coordination.

The SCNS-SF34 assesses needs across five domains: psychological (10 items); physical/daily living (5 items); health system/information (11 items); patient care/support (5 items); and sexuality (3 items) [15]. This tool asks participants to rate their need for help with each item over the past month on a 5-point scale where 1 = not applicable (no need), 2 = satisfied (need was met), 3 = low unmet need, 4 = moderate unmet need, and 5 = high unmet need. Binary categories for any overall and domain-specific needs can be classified as follows: ‘no-to-low needs’ versus ‘at least one moderate-to-high need’. The SCNS-SF34 is a validated measure; its five domains collectively accounted for 73% of the variance, with Cronbach’s alpha for domains ranging from 0.86 to 0.96 [15].

The FACT-G is a 27-item scale which measures physical (range 0–28), social (range 0–28), emotional (range 0–24), and functional (range 0–28) well-being [16]. Together, the subscales add up to an overall quality of life score (range 0–108). A higher score indicates better quality of life. All scales have good-to-excellent reliability [16]. As there was no NET-specific subscale of the FACT instrument suite, we used 15 NET-specific physical symptom items from the European Organization for Research and Treatment Quality of Life Questionnaire GastroIntestinal NeuroEndocrine Tumours subscale (EORTC QLQ-GINET21) [17] to measure cancer-specific symptoms. For consistency, the FACT 5-point response scale was used for the 15 NET-specific symptoms.

The HADS assesses psychological distress [18]. It has been validated against clinical interview, and its sensitivity and specificity for depression and anxiety in cancer patients is good-to-excellent [19, 20]. All questions are answered on a 4-point Likert scale (0 to 3). Seven items form a depression scale and seven an anxiety scale (both scales range from 0 to 21). A score of 8–10 in each subscale indicates borderline depression or anxiety, while a score of 11 or greater indicates a likely state of depression or anxiety.

## Statistical methods

To rank the 20 care coordination items in order of how they were rated by participants, we calculated the mean score for each item. We assessed associations between personal and clinical factors with the overall care coordination score using the two-sample *t* test and analysis of variance. We also used the Mann-Whitney tests to assess differences in each care coordination item according to whether RBWH was the only specialist provider or not. We considered differences with  $p < 0.05$  to be statistically significant.

We calculated the proportion of participants who reported a moderate-to-high level need for each supportive care need item and each domain and the proportion of participants classified as having normal, borderline, and clinical anxiety and depression. Mean scores for anxiety, depression, quality of life, and well-being subscales were also calculated. The well-being subscale scores and overall quality of life were compared to Australian norms [21]. Finally, we classified each of the NET-specific symptoms as not at all to somewhat versus quite a bit to very much and calculated the proportion in the latter category.

## Results

### Participant response and characteristics

In total, 170 eligible patients were invited to participate in the study and 111 responded (65% response proportion). Of the non-responders, 6 (4%) could not be contacted, 7 (4%) died shortly after receiving the questionnaire, and 46 (27%) did not return the questionnaire. The demographic and clinical characteristics of participants are shown in Table 1. Most (61%) were 60 years or older, 56% were male, 76% were married or living with their partner, 67% had completed further education after high school, 55% lived in a major city, and 45% were treated solely at RBWH. Two-thirds (66%) of participants had metastatic disease at the time of initial NET diagnosis, and 93% had metastatic disease at the time of survey completion. The time since initial diagnosis ranged from 2 months to 27 years with the majority of primary tumours originating from the small bowel (42%) and pancreas (27%). Approximately half (56%) the tumours were functional. Participants were mostly treated with surgery of the primary tumour (70%), hormone therapy (72%), and PRRT (46%). Live non-responders had similar age (54%; 28/52 aged 60 and over) and sex (54%; 28/52 male) distributions to participants in the study.

### Care coordination scores

Overall, the mean total cancer care coordination score was 73.7 (11.5 SD), and mean scores for the communication and navigation domains were 47.8 (8.4 SD) and 25.9 (3.9 SD) respectively. The lowest-ranked care items related to health professionals being fully informed about patient history and progress, communication about financial entitlements, and doctors asking about how well the family and patient were coping (Table 2). The number of specialist providers, age, sex, remoteness of home location, time post-diagnosis, tumour functional status, and treatment with PRRT were not significantly associated with total cancer care coordination score (data not shown). However, compared to patients treated

**Table 1** Participant characteristics (*n* = 111)

	<i>N</i>	Percent
Age (years)		
< 60	43	39
60+	68	61
Sex <sup>a</sup>		
Male	62	56
Female	49	44
Marital status		
Married/partner	82	76
Single/divorce/separated/widowed	26	23
Education		
High school or lower	36	33
Diploma/trade	41	38
University	32	29
Place of residence		
Major city	61	55
Inner regional	30	27
Outer regional	17	15
Remote/very remote	3	3
Care provider <sup>a</sup>		
RBWH sole provider	45	41
RBWH and other providers	66	59
Metastatic at diagnosis <sup>a</sup>		
Yes	73	66
No	38	34
Time since first diagnosed with a NET <sup>a</sup>		
2 months to < 2 years	24	22
2 to < 5 years	39	35
5 to < 10 years	28	25
10 to 27 years	20	18
Time since diagnosed with metastatic disease <sup>a</sup>		
N/A—non-metastatic disease	8	7
2 months to < 2 years	27	24
2 to < 5 years	40	36
5 to < 10 years	26	23
10 to 17 years	10	9
Site of primary tumour <sup>a</sup>		
Small bowel	47	42
Colon	4	4
Rectum	2	2
Stomach	2	2
Pancreas	30	27
Other gastrointestinal	3	3
Lungs	8	7
Unknown	12	11
Other	3	3
Type of NET <sup>a</sup>		
Non-functional	49	44
Functional	62	56

**Table 1** (continued)

	<i>N</i>	Percent
Surgery of the primary tumour attempted <sup>a</sup>		
No	31	28
Yes	78	70
Not stated	2	2
Had non-surgical local procedure <sup>a</sup>		
None	104	94
Radio frequency ablation (RFA)	2	2
Trans-arterial chemo-embolisation (TACE)	1	1
Selective internal radiation therapy (SIRT)	1	1
Procedure not stated	3	3
Had palliative radiotherapy <sup>a</sup>		
No	104	94
Yes	5	5
Not stated	2	2
Had hormone therapy <sup>a</sup>		
No/not stated	31	28
Yes (octreotide and/or lanreotide)	80	72
Had targeted oral therapy <sup>a</sup>		
No/not stated	106	96
Yes (everolimus and/or sunitinib)	5	5
Had peptide receptor radionuclide therapy (PRRT) <sup>a</sup>		
No/not stated	60	54
Yes	51	46
Had chemotherapy <sup>a</sup>		
No/not stated	102	92
Yes (dacarbazine/temozolomide, streptozocin, oxaliplatin, and/or other chemotherapy)	9	8

Not all frequencies sum to 111 due to some missing data

<sup>a</sup>Data from medical record

solely at RBWH, patients with multiple specialist providers had significantly poorer scores related to health professionals being fully informed about their history and progress and meeting health-care costs (Table 2). Specialist provider type (single/multiple) was not significantly associated with home location (city/regional-remote); thus, these associations were independent of the remoteness of participants' home location.

### Supportive care needs

Sixty-three percent (95% CI 54–72%) of participants reported having at least one moderate-to-high level unmet need. Moderate-to-high level needs were reported by 44% (95% CI 35–54%) of participants for psychological needs, 38% (95% CI 29–47%) for physical/daily living needs, 28% (95% CI 20–37%) for health system/information needs, 17% (95% CI 10–24%) for sexuality needs, and 11% (95% CI 5–

**Table 2** Care coordination items – ranked from worst (1) to best (20) – reported by people living with neuroendocrine tumours

Rank <sup>a</sup>	Items	Overall ( <i>n</i> = 111) Mean (SD)	Single specialist provider ( <i>n</i> = 45) Mean (SD)	Multiple specialist providers ( <i>n</i> = 66) Mean (SD)	<i>p</i> value	Domain
1	The health professionals looking after me were not always fully informed about my history and progress	3.2 (1.1)	3.5 (1.1)	3.0 (1.1)	0.026	Navigation
2	I was fully informed by health professionals about my financial entitlements (e.g. Medicare and health fund claims, travel allowances)	3.3 (1.0)	3.3 (1.1)	3.3 (1.0)	0.950	Communication
3	My Doctors always asked how well my family and I were coping	3.3 (1.0)	3.3 (1.1)	3.3 (1.0)	0.735	Communication
4	I always knew who to call out of business hours if I had a problem	3.4 (1.0)	3.4 (1.1)	3.3 (1.0)	0.725	Navigation
5	I had sufficient help from health professionals with dealing with the emotional impact of my cancer	3.4 (1.1)	3.4 (1.2)	3.4 (1.1)	0.847	Communication
6	The health professionals looking after me always picked up on whether I was feeling anxious or down	3.4 (0.9)	3.3 (1.1)	3.5 (0.7)	0.402	Communication
7	It was difficult to meet the financial costs associated with my health care	3.4 (1.0)	3.7 (1.1)	3.2 (0.9)	0.020	Navigation
8	I knew the warning signs and symptoms I should watch for to monitor my health	3.4 (1.1)	3.6 (1.0)	3.3 (1.1)	0.121	Communication
9	My Doctors always asked how my visits with other health professionals were going	3.5 (1.0)	3.4 (1.0)	3.5 (1.0)	0.674	Communication
10	I had sufficient help from health professionals with practical arrangements such as organising transport, accommodation and appointments	3.6 (1.0)	3.6 (1.0)	3.6 (1.0)	0.640	Communication
11	I had access to all the additional services that I needed (e.g. physiotherapy, counselling, cancer support groups, social worker support, pain management, palliative care, nutritional advice, stoma therapy)	3.6 (1.0)	3.8 (0.9)	3.5 (1.1)	0.255	Communication
12	I was confused about the roles of the different health professionals involved in my care	3.7 (0.9)	3.8 (1.0)	3.7 (0.8)	0.743	Navigation
13	I had a good understanding of what I was responsible for to help my treatment plan run smoothly	3.9 (0.9)	4.0 (0.9)	3.9 (0.9)	0.277	Communication
14	I knew which therapies were suitable for me (e.g. surgery, chemotherapy, radiotherapy)	4.0 (0.9)	3.9 (1.1)	4.0 (0.7)	0.590	Communication
15	I never had to wait too long to get the first available appointment for a test or treatment	4.0 (0.9)	3.9 (0.9)	4.0 (0.9)	0.675	Navigation
16	I always knew what tests, treatments and follow up were planned for me	4.0 (0.9)	4.1 (0.9)	3.9 (0.9)	0.084	Communication
17	I always knew who to contact if I had concerns about my health or treatment plan	4.0 (0.8)	4.0 (0.9)	4.0 (0.7)	0.763	Navigation
18	I never had any difficulty getting an appointment with my GP	4.2 (0.8)	4.2 (0.6)	4.1 (0.9)	0.947	Navigation
19	I was fully informed about the benefits and harms of any treatments	4.2 (0.8)	4.2 (1.0)	4.2 (0.6)	0.282	Communication
20	I always knew the reason why I was having a test or treatment	4.3 (0.7)	4.4 (0.6)	4.2 (0.7)	0.079	Communication

<sup>a</sup> Ranking based on overall position

17%) for patient care/support needs. The top 10 moderate-to-high unmet need items all came from the physical and psychological domains and are shown in Table 3. Specifically, having a moderate-to-high need for help with lack of energy/tiredness was reported by one in three participants, while about a quarter of participants had a moderate-to-high need for help with their fears about the cancer spreading, their concerns about the worries of those close to them, their uncertainty about the future, and with not being able to do the things they used to do.

### Anxiety, depression, quality of life, and cancer-specific symptoms

Overall, 14% (95% CI 8–20%) of participants were classified by the HADS as having clinical anxiety, with an additional 16% (95% CI 9–23%) classified as having borderline anxiety. Nine percent (95% CI 4–14%) of participants were classified as having clinical depression and 11% (95% CI 5–17%) were borderline. Mean scores for anxiety, depression, individual well-being scales, and overall quality of life are shown in



**Table 3** Top 10 moderate-to-high unmet supportive care needs in 111 people living with neuroendocrine tumours

Rank	Items participants needed help with	% (95% confidence interval)	Domain
1	Lack of energy/tiredness	33 (24–41)	Physical
2	Fears about the cancer spreading	26 (18–34)	Psychological
2	Concerns about the worries of those close to you	26 (18–34)	Psychological
4	Uncertainty about the future	25 (17–33)	Psychological
5	Not being able to do the things you used to do	24 (16–32)	Physical
6	Feeling down or depressed	19 (12–26)	Psychological
7	Work around the home	17 (10–25)	Physical
7	Anxiety	17 (10–25)	Psychological
7	Feeling of sadness	17 (10–25)	Psychological
7	Worry that the results of treatment are beyond your control	17 (10–25)	Psychological

Table 4. Compared with the general population average, the majority of people living with NETs reported having lower physical (72%;  $n = 78$ ) and emotional (72%;  $n = 79$ ) well-being. The most prevalent symptoms included diarrhoea (29%; 95% CI 21–38%), a bloated feeling in the abdomen (29%; 95% CI 20–38%), abdominal discomfort (27%; 95% CI 18–35%), hot flushes (22%; 95% CI 14–30%), and flatulence (20%; 95% CI 13–28%) (Table 5).

## Discussion

People with slow-growing metastatic NETs are different to patients with the more common epithelial metastatic cancers. Many of them live with metastatic disease for a long time, yet

because NETs are rare, there is little knowledge available about how patients perceive their encounters with the health system and how well their supportive care needs are being met. We found that people with NETs who were seen at a NET specialist centre were satisfied with their knowledge about suitable treatments, the treatments and follow-up planned for them, why they were having treatment, the benefits and harms of treatment, waiting times, who to contact if they had concerns, and access to their general practitioner. In contrast, they were less satisfied with aspects of their care such as health professionals having a full case history, providing information about financial entitlements, and asking about how well they and their family were coping. People who were being managed by multiple specialist providers were significantly less satisfied with health professionals being fully informed about their

**Table 4** Mean anxiety, depression and quality of life scores among 111 people living with neuroendocrine tumours

	Mean (SD)
Psychological distress <sup>a</sup>	
Anxiety	5.6 (4.2)
Depression	4.4 (4.0)
Overall distress	10.0 (7.5)
Quality of life	
Physical well-being <sup>b</sup>	21.0 (6.2)*
Social/family well-being <sup>b</sup>	21.0 (6.1)
Emotional well-being <sup>b</sup>	18.0 (4.6)*
Functional well-being <sup>b</sup>	20.1 (6.2)
Cancer-specific symptoms <sup>c</sup>	45.7 (10.7)
Quality of life (FACT-G) <sup>b</sup>	80.2 (19.0)

<sup>a</sup>HADS measure

<sup>b</sup>FACT-G measure

<sup>c</sup>EORCT-modified NET subscale—not comparable to general population

\* FACT score significantly lower than Queensland general population norms [21]

**Table 5** Gastrointestinal symptoms among 111 people living with neuroendocrine tumours

Symptoms in the past week	Experienced symptom quite a bit to very much % (95% confidence interval)
Diarrhoea	29 (21–38)
Bloated feeling in abdomen	29 (20–38)
Abdominal discomfort	27 (18–35)
Hot flushes	22 (14–30)
Problem with passing wind/gas/flatulence	20 (13–28)
Looked flushed/red	17 (10–25)
Night sweats	15 (8–21)
Headaches	15 (8–21)
Weight loss been a problem	12 (6–18)
Difficulty with eating	11 (5–17)
Acid indigestion/heartburn	10 (4–16)
Weight gain been a problem	10 (4–16)
Cold sweats	6 (1–10)
Problem from repeated injections	4 (0–7)
Vomiting	2 (0–4)

history and about being able to meet their health-care costs than those solely being managed by specialists at the RBWH. We also found that about one in three people living with NETs reported a moderate-to-high level unmet need for help with fatigue and one in four with psychological concerns about the cancer spreading, uncertainty about the future, and about the worries of those close to them. As the aim of treatment in patients who present with metastatic disease is to improve quality of life rather than achieve a cure [22] and perception of care coordination and unmet supportive care needs are associated with quality of life [23, 24], these are important findings which can be used to guide improvements in practice.

There are few studies of peoples' cancer care coordination experiences with which to compare our results; most did not use the same instrument or did not report on individual care coordination items [25–28]. However, one key issue was less satisfaction with health professional asking about how well they and their family were coping [23]. This finding alongside the prevalent concerns of NET patients about the worries of those close to them points to the requirement for more focused awareness of health professional on emotional care of both the patient and their families, especially as these patients often look well and therefore may not be offered support in these areas as often as other patients who look less well [5]. Additionally, our study suggests continuity of care with knowledge of case history could be improved, particularly for patients being cared for by multiple specialist providers. Provision of care plans to patients and all of their providers may be particularly helpful in models of shared care for NET patients.

Patients also expressed a desire for their health professionals to initiate conversations about out-of-pocket expenses and information about financial benefits available, with this being particularly prevalent in patients not being treated solely at the RBWH. This is likely due to RBWH being a public hospital so those treated solely at RBWH have fewer out-of-pocket health-care costs. Some of those treated at multiple institutions likely have a mix of care in the public and private systems, with contingent out-of-pocket costs. Financial uncertainty is likely to be more prevalent in NET patients than in other cancer patient groups given the advanced slow-growing nature of most of these tumours. A German study found that 78% of NET patients reported high out-of-pocket costs, mostly in terms of travel expenses and co-payments for medication and 29% of participants in the study reported a loss of income; 62% of these said this could not be compensated by their savings or credits [29]. Furthermore, higher cancer-related out-of-pocket costs per month were associated with significantly lower quality of life, self-reported health status, and a more severe perception of disease burden [29] indicating the importance of considering targeted measures that could prevent financial problems and reduce emotional burden.

Similarly to many other cancer populations, the top unmet supportive care needs in this study related to fatigue and fear

of cancer spreading [30, 31]. The proportion of NET patients reporting these top two needs at moderate-to-high levels was generally similar to or higher than patients with other types of advanced or metastatic cancers. For example, having an unmet need for help with fatigue was reported by 33% of NET patients compared with 28% of people with pancreatic cancer [32], 16–19% of women with ovarian cancer [33], 13% of people with advanced or metastatic prostate cancer [34], < 25% with metastatic breast cancer [35], and 26–30% among people with a mix of different cancer types [36, 37]. Having an unmet need for help with fear of cancer spreading was reported by 26% of NET patients compared with 26% of people with pancreatic cancer [32], 16–25% of women with ovarian cancer [33], 16% of people with advanced or metastatic prostate cancer [34], 33% with metastatic breast cancer [35], and 19% among people with a mix of different cancer types [37]. It is not surprising that we also found people living with NETs to have clinically lower physical and emotional well-being than the general populations. In particular, the proportion with clinical depression (9%) was three times higher than is observed in the general population (3%) [38] and 1.5-fold higher than observed across cancer populations (6%) [39]. In addition to facing one's own mortality and experiencing existential distress (i.e. concerns about the cancer spreading, uncertainty about the future), depression in this population may be compounded by the high symptom burden and potential social isolation related to one in four participants experiencing frequent to constant diarrhoea, abdominal symptoms, and flushing. These findings emphasise the importance of careful management of physical and psychological symptoms in patients with NETs.

This study adds valuable information to our understanding of patient-reported outcomes in people with NET. It does, however, have several limitations. Participants were recruited from a single treatment centre. While this centre is a specialist centre for NETs and the only treatment centre in Queensland, Australia, to offer PRRT, not all NET patients from Queensland are referred to the RBWH. The sample over-represents patients with metastatic disease, particularly those who are progressing on initial therapy, as well as those receiving PRRT. Furthermore, due to the rarity of the disease, the sample size was relatively small and therefore confidence intervals around point estimates are wide. For practical purposes, the study design was cross-sectional and does not have a sample size that allows for consideration of outcomes during particular events, for example immediately after treatment or during follow-up treatments where supportive care needs are often at their highest. Thus, it is likely that unmet needs may be even higher than reported here at certain times across the care continuum.

Management of people with NETs is complex. With two-thirds of patients in our sample presenting with metastatic disease and one-third living with metastatic disease for more

than 5 years, NETs are experienced as a chronic illness, with consequent demands for ongoing coordinated care and high levels of supportive care needs. Internationally, there has been a move toward development of better models of person-centred cancer care to optimise survival times and quality of life [40]. This study identifies key aspects of care that could be improved, including the need for communication of case history between professionals, for health professionals to ask patients and their families about how they are coping, and initiating financial discussions. Enhancing these aspects of care, along with ongoing psychological and physical symptom management, is likely to help with improved perceptions of care provision and patient outcomes for people living with this rare, chronic, and advanced disease.

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### Compliance with ethical standards

This study was approved by the Royal Brisbane and Women's Hospital (RBWH) Human Research Ethics Committee. Informed consent from participating patients was obtained.

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