Evaluating the impact of the Optimal Care Pathway for Neuroendocrine Tumours on patient care in Australia

An effort to prevent Australians from slipping through the NET

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Abstract

Purpose

This study aimed to assess the impact of the Optimal Care Pathway (OCP) on the care of patients with neuroendocrine tumours (NETs) in Australia after its publication in 2023, and to identify strategies to optimize its dissemination and effectiveness.

Methods

An observational mixed-methods study design was adopted, engaging NET patients through a questionnaire and interviews, with subsequent quantitative and qualitative analyses to evaluate experiences of NET patients and the impact of the OCP on patient care in Australia.
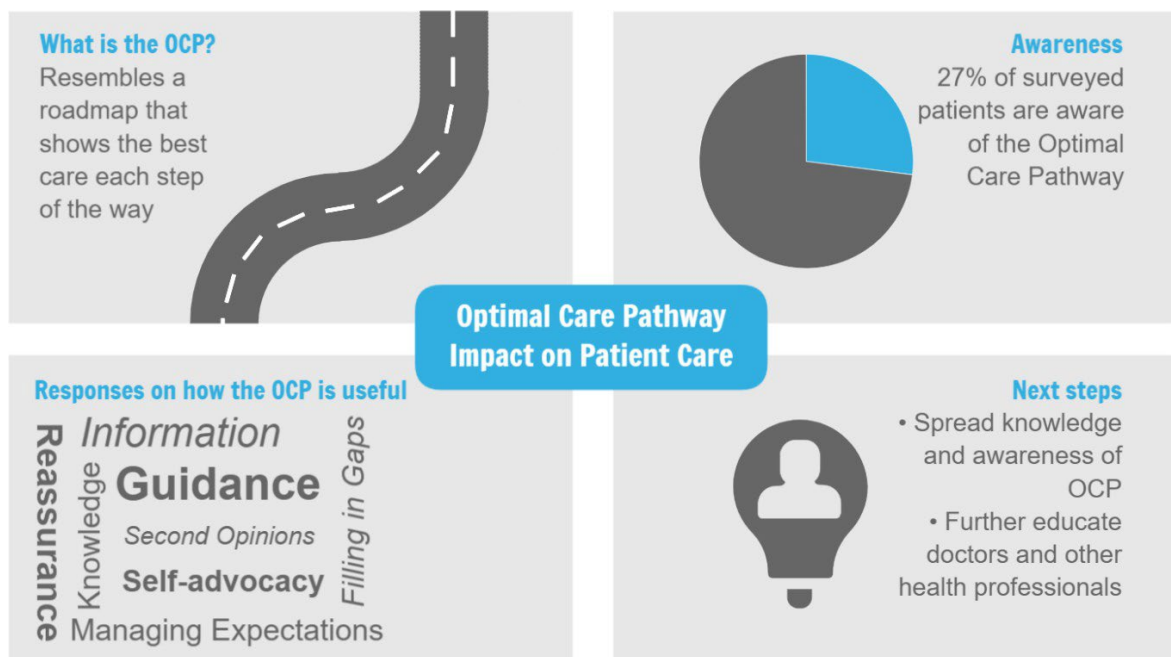
Results

Among 95 questionnaire respondents, a significant proportion reported misdiagnoses prior to NET identification. Time to diagnosis showed a decrease post-2021, highlighting the benefits of increased NET awareness. Most participants reported a lack of OCP awareness among themselves and their healthcare professionals (HCPs), despite its perceived benefits by those informed. Interviews highlighted the OCP's potential to aid in self-advocacy and care navigation, but also confirmed the prevalence of patient-HCP communication gaps.

Conclusion

The OCP is a valuable tool and has the potential to improve care for patients with NETs, but its impact is limited by current dissemination practices. Therefore, there is a need for targeted dissemination of the OCP to improve its utilization and efficacy. Strategic communication and education, in the form of enhanced patient education and training of HCPs are critical to ensuring that NET patients benefit from the standardized care the OCP intends to provide.

Visual summary for patients

What is the OCP?
Resembles a roadmap that shows the best care each step of the way

Awareness
27% of surveyed patients are aware of the Optimal Care Pathway

Optimal Care Pathway Impact on Patient Care

Responses on how the OCP is useful
Reassurance
Knowledge
Information
Guidance
Second Opinions
Self-advocacy
Filling in Gaps
Managing Expectations

Next steps
• Spread knowledge and awareness of OCP
• Further educate doctors and other health professionals

Introduction

Neuroendocrine tumours (NETs) represent a complex and heterogeneous group of neoplasms that, despite their incidence rate of approximately 17 per 100.000 individuals annually, have exhibited a notable increase in diagnosis over recent decades.(1, 2) An estimated 5556 new patients were diagnosed with a NET in Australia in 2023, accounting for 3.36% of all diagnosed cancers.(1, 3) NETs can arise in various organs throughout the body, most frequently affecting the gastrointestinal tract and the lungs.(4, 5) Their varied clinical behaviours and diverse array of functional and non-functional characteristics pose significant challenges for timely diagnosis.(2, 5) The intricate nature of these tumours often leads to a convoluted path to diagnosis, with the majority of patients presenting with metastasized disease, experiencing significant delays in receiving appropriate care – a factor crucial to prognosis and quality of life for patients with NETs.(6, 7)

Aiming to address these challenges, enhance patient outcomes, and optimise the care for people affected by neuroendocrine tumours, the Optimal Care Pathway (OCP) for Neuroendocrine Tumours was introduced in Australia in 2023.(8) This pathway delineates a framework and standardized approach to diagnosis, treatment, and follow-up care of NETs, aiming to mitigate the inconsistencies in care delivery and to foster an evidence-based practice model.(8, 9)

The success of clinical pathways like the OCP relies heavily on their effective dissemination and implementation, requiring concerted efforts from healthcare professionals (HCPs).(10, 11) Research indicates that well-implemented care pathways can improve clinical outcomes, patient satisfaction, and healthcare resource utilization.(11, 12) Nonetheless, the practical application of these guidelines is frequently met with challenges, including gaps in awareness, education, and communication that hinder their integration into daily clinical practice.(12) However, beneath the clinical protocols and systematic approaches, the authentic experiences of patients navigating this pathway remain profoundly significant. Their stories, challenges, and triumphs provide a nuanced perspective, essential for shaping the pathway's efficacy in the real world.

This observational study delves into the experiences of Australian patients diagnosed with NETs, particularly focusing on their engagement with the OCP post-publication. It investigates the early impact of the OCP on patient care and seeks to identify strategies for improving its dissemination to maximise its utility. The findings from this study aim to illuminate the current state of NET care in Australia and offer insights into the practical implementation of the OCP, to facilitate early strategic adjustments in dissemination for a timely and meaningful impact. Ultimately, this study seeks to bridge the gap between clinical guidelines and patient experience, offering a critical evaluation of the OCP's role in shaping the trajectory of NET care and providing a foundation for strategic enhancements in patient-centred care delivery.

Methods

An observational mixed-methods design was used to investigate the experiences of NET patients in Australia with the Optimal Care Pathway for Neuroendocrine Tumours that was published in 2023. A cohort of patients that were diagnosed with a NET in Australia was selected through online information channels of NeuroEndocrine Cancer Australia (NECA). Eligible patients were aged 18 years or older and familiar with NECA.

Patients eligible for participation were asked to fill in an online, structured questionnaire. This questionnaire included a minimum of 21 and a maximum of 27 questions, depending on provided answers. Questions were related to patient demographics, onset of NET-related symptoms, differential diagnoses, their NET diagnosis, NET specialist referrals, received

treatment, experiences with supportive care, and the Optimal Care Pathway. Supportive care was defined as the care and support that aims to improve the quality of life of people living with cancer, cancer survivors, and their family and carers, while not directly treating the tumour itself. The questionnaire included multiple choice questions, Likert scale items and open-ended questions to capture both quantitative and qualitative data. Participants were provided with the option to provide additional comments for elaboration. Responses were collected between September 27th and November 13th, 2023. Due to the personal and sensitive nature, no questions were mandatory and responses where at least 17 questions were answered were considered complete and were used for analysis.

Participants from the questionnaire that were diagnosed in 2021 or later were invited for a voluntary in-depth qualitative interview. The cutoff year of 2021 was chosen to limit recall bias and ensure similar treatment guidelines for all interviewed patients. Semi-structured interviews were conducted online or over the phone to explore participants' experiences with their neuroendocrine tumour, communication with healthcare providers, their unmet needs, and the Optimal Care Pathway. Interviews were audio-recorded and transcribed verbatim for qualitative analysis.

Data analysis

To summarize questionnaire responses, descriptive statistics were calculated. Time between the onset of symptoms and NET diagnosis was calculated in years. Time between diagnosis and start of treatment, and time between diagnosis and referral to NeuroEndocrine Cancer Australia were calculated in days. Australian postcodes were used to determine participants' state of residence. The Modified Monash Model (MMM) was used to classify whether participants reside in a metropolitan, regional, rural, or remote zone.(13) A Chi-square test was used to compare the population spread over the Australian states and territories in the

analysed cohort and the general Australian population. Data for the Australian population spread was obtained from the Australian Bureau of Statistics 2021 population census.(14) T-tests and Chi-square tests were used to determine baseline differences between patients diagnosed before 2021 and patients diagnosed in 2021 or later, as well as to compare time to diagnosis, time to treatment start, and time to NECA referral. The 2021 cutoff point was chosen to match the cutoff point for interview participation. Kruskal-Wallis tests were used to compare baseline differences and differences in time to diagnosis, time to treatment start, and time to NECA referral between metropolitan, rural, and remote patients. All statistical analyses were conducted using R v. 4.2.2, with a significance level set at $p < 0.05$.

Qualitative data collected through interviews were analysed thematically. Transcripts were coded to identify recurring themes and patterns related to NET experiences, communication with healthcare providers, unmet needs, and the Optimal Care Pathway. Codes were grouped into broader themes, which were summarised to provide insights into patients' experiences and perceptions.

Results

Baseline Characteristics

A total of 95 patients that were diagnosed with a neuroendocrine tumour in Australia was included in this study after completing the online questionnaire. The median age of this cohort was 58.8 years, ranging from 24 to 78 years of age (Table 1). The majority (77.9%) of participants was female, and 82.1% were born in Australia (Table 1). None of the participants recorded being of Aboriginal or Torres Strait origin. Participants predominantly resided in New South Wales and Western Australia (Table 1), with a significantly different distribution across the states and territories than the Australian population (P < 0.001). Urban residency was common (60.1%), with smaller

proportions from regional (10.5%), rural (24.2%), and remote areas (3.2%) (Table 1).

The most frequently reported tumour site was the small bowel (38.9%), and the majority of participants was diagnosed at an advanced stage, with 41.0% of patients presenting with metastatic disease (Table 1). The most common malignancy grade was Grade 1 (33.7%), with 28 participants (29.5%) being unaware of the grade of their tumour (Table 1). Surgery was the initial treatment for 62.1% of patients, with 18.9% of patients having somatostatin analogue injections as a first treatment, and 9.5% of patients starting with active surveillance. Comparative analyses showed no statistical differences in age, sex, tumour stage, and tumour grade between the 46 participants that received their NET diagnosis in 2021 or later and the 48 participants that received their diagnosis prior to 2021. The absence of statistical differences in these baseline characteristics continued when comparing metropolitan, regional, rural, and remote participants.

Misdiagnoses

The majority (58.9%) of participants reported receiving at least one prior misdiagnosis before their NET diagnosis (Table 1). In total, 92 misdiagnoses were reported by 56 of the questionnaire participants. The most common misdiagnosis was related to gastrointestinal issues, with mental health issues also frequently being misattributed, comprising 16 cases (Table 2). Hormonal and endocrine disorders, including 6 cases of misdiagnosed menopause and a case of misdiagnosed pre-diabetes, were noted in 7 instances (Table 2). Other serious conditions, including heart problems, other cancers, and an aortic aneurysm were diagnosed in 6 cases (Table 2). Musculoskeletal and respiratory conditions were less frequently reported, with 3 misdiagnoses in both categories (Table 2). A diverse range of other misdiagnoses comprised the remaining 15 cases, including among others a spider bite, an unidentified virus, and medication side effects (Table 2).

Table 1: Baseline characteristics of the cohort of 95 NET patients that filled in the online questionnaire distributed through NeuroEndocrine Cancer Australia online channels.

	N 95	(%) (100.0)
Mean age in years	58.8	± 12.0
Sex*		
Female	74	(77.9)
Male	20	(21.1)
Country of birth		
Australia	78	(82.1)
England	8	(8.4)
New Zealand	3	(3.2)
Other	6	(6.3)
State of residence*		
Australian Capital Territory	5	(5.3)
New South Wales	26	(27.4)
Northern Territory	0	(0.0)
Queensland	15	(15.8)
South Australia	10	(10.5)
Tasmania	4	(4.2)
Victoria	14	(14.7)
Western Australia	20	(21.1)
MMM classification*		
Metropolitan	58	(60.1)
Regional	10	(10.5)
Rural	23	(24.2)
Remote	3	(3.2)
Tumour site		
Large bowel	8	(8.4)
Lung	3	(3.2)
Pancreas	15	(15.8)
Small bowel	37	(38.9)
Stomach	9	(9.5)
Other	23	(24.2)
Stage		
Stage I	18	(19.0)
Stage II	13	(13.7)
Stage III	10	(10.5)
Stage IV	39	(41.0)
Unknown	15	(15.8)
Malignancy grade		
Grade 1	32	(33.7)
Grade 2	25	(26.3)
Grade 3	10	(10.5)
Unknown	28	(29.5)
First treatment*		
Active surveillance	9	(9.5)
Somatostatin analogue	18	(18.9)
Surgery	59	(62.1)
Treatment not discussed	3	(3.2)
Other	5	(5.4)
Mean time to diagnosis in years	4.2	± 5.4
Misdiagnosis*		
No	37	(38.9)
Yes	56	(58.9)

* Not all participants supplied their sex, postcode, first received treatment, and whether they received a misdiagnosis prior to their NET diagnosis

Table 2: Overview of the categories of misdiagnoses reported by NET patients.

Misdiagnosis Category	Count
Gastrointestinal issues	42
Hormonal/endocrine disorders	7
Mental health issues	16
Misdiagnosed serious issues	6
Musculoskeletal issues	3
Respiratory conditions	3
Other/miscellaneous	15

Prior to Diagnosis

Before diagnosis, 28 participants consulted one healthcare professional, and 65 patients consulted multiple healthcare professionals. The most reported healthcare professionals that were consulted before diagnoses were general practitioners, as reported by 78 participants (Table 3). Furthermore, 40 patients consulted with a gastroenterologist and 29 with a surgeon. Cardiologists, dietitians, and gynaecologists were the most reported other healthcare professionals, with 12, 10, and 9 participants consulting them before diagnosis, respectively.

Table 3: Overview of the healthcare professionals a cohort of 95 NET patients consulted with before their NET diagnosis.

Healthcare professional	Count
Cardiologist	12
Dietitian	10
Emergency department staff	2
Endocrinologist	6
Functional doctor	1
Gastroenterologist	40
Geneticist	1
GP	78
Gynaecologist	9
Haematologist	1
Lung physician	4
Medical oncologist	6
NET nurse	2
Other cancer nurse	1
Pathologist	2
Physiotherapist	7
Psychiatrist	2
Psychologist	5
Rheumatologist	2
Skin cancer specialist	1
Surgeon	29

Time to Diagnosis, Treatment Start and NECA Referral

The time from the onset of symptoms to a NET diagnosis could be calculated for 85 patients, with a mean time to diagnosis of 4.2 years (SD ± 5.4). Median time to diagnosis for all patients was 2.2 years, with 90% getting a NET diagnosis within 10 years after the first onset of symptoms (Figure 1A). When splitting the cohort based on diagnosis date, the patients that were diagnosed in 2021 or later, the median time to diagnosis after symptom onset was 1.34 years, while the group of patients diagnosed before 2021 had a median time to diagnosis of 3.84 years (Figure 1B). A comparative analysis showed that the mean time to diagnosis differed significantly between the two groups ($P < 0.05$). No statistical significance was obtained when comparing patients from metropolitan, regional, rural, and remote areas. More than half of the 83 patients for whom the time from diagnosis to the start of treatment could be determined, started their treatment within 50 days of diagnosis, with 22 patients (26.5%) starting their treatment within a week of diagnosis (Figure 1C). 56 out of 93 patients (60.2%) reported finding out about NECA within the first month after their diagnosis (Figure 1D). Patients diagnosed prior to 2021 had a significantly longer time to NECA referral than patients diagnosed in 2021 or later ($P < 0.05$). Almost half of the patients found NECA by themselves on the internet (48.4%), with the majority of the other patients getting referred by one of their treating healthcare professionals (37.9%) (Table 4).

Table 4: Overview of the methods through which a cohort of NET patients learned about NeuroEndocrine Cancer Australia.

	N 95	(%) (100.0)
Cancer Council	3	(3.2)
Family or friends	2	(2.1)
Internet	46	(48.4)
Medical specialist	29	(30.5)
Other healthcare professional	7	(7.4)
Support group	4	(4.2)
Other	4	(4.2)

(A) Cumulative Incidence for Time from Symptom Onset to Diagnosis

(B) Cumulative Incidence for Time to Diagnosis by Diagnosis Period

(C) Cumulative Incidence for Time from Diagnosis to Treatment Start

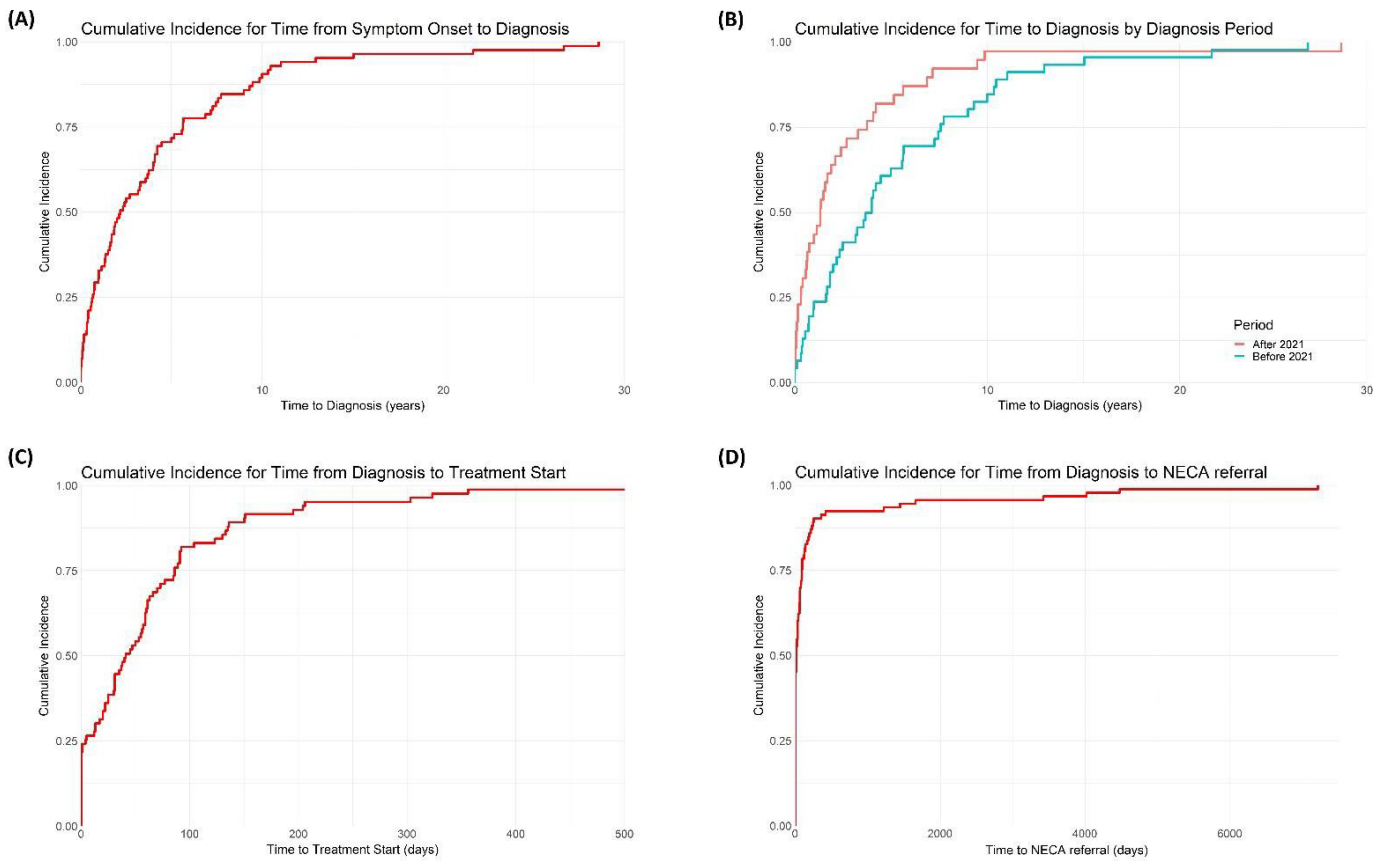**(D)** Cumulative Incidence for Time from Diagnosis to NECA referral

Figure 1: Cumulative incidence functions for the time from symptom onset to NET diagnosis for the entire cohort of patients (A) and for the cohort of patients split on diagnosis period (B), for the time from diagnosis to the start of first treatment (C), and for the time between diagnosis and referral to NeuroEndocrine Cancer Australia (D).

Supportive Care

Out of all patients, 83 patients (87.4%) reported receiving some form of supportive care, with 57 patients (60.0%) reporting consulting with more than one type of healthcare professional for supportive care. Mean satisfaction with the received supportive care was a 6.8 on a scale from 0 to 10, with no correlation found between the number of healthcare professionals visited and supportive care satisfaction (P = 0.31). General practitioners were reported the most, with 50 patients (52.6%) indicating they visited their general practitioner for supportive care (Table 5). This was followed by NECA, as reported by 45 patients (47.4%). 34 participants (35.8%) reported seeing a dietitian, and 18 participants (18.9%) saw a psychologist (Table 5).

Table 5: Overview of the healthcare professionals a cohort of NET patients consulted with for their supportive care.

Healthcare professional	Count
Alternative medicine	3
Cancer Council	3
Diabetes educator	1
Dietitian	34
Emergency department staff	1
Endocrinologist	1
Exercise physiologist	11
General practitioner	50
NECA	45
Occupational therapist	1
Oncologist	5
Other cancer nurse	14
Palliative and supportive care team	10
Physiotherapist	9
Psychiatrist	4
Psychologist	18
Rheumatologist	1
Social worker	4

(A)

Patient awareness of the Optimal Care Pathway

(B)

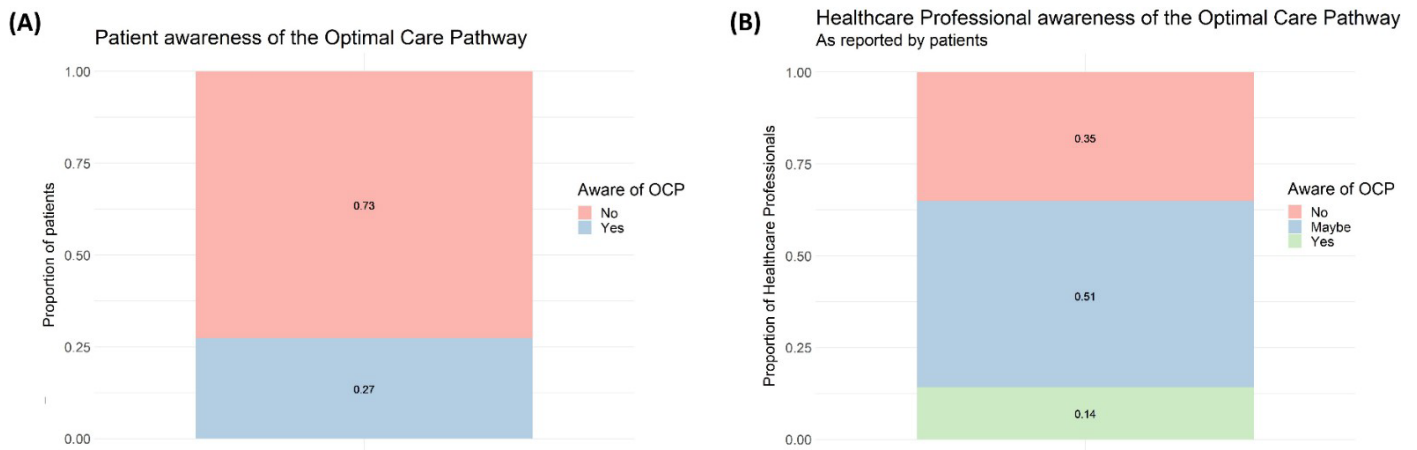Healthcare Professional awareness of the Optimal Care Pathway
As reported by patients

Figure 2: Awareness of the Optimal Care Pathway as indicated by patients about themselves (A), and their treating healthcare professionals (B).

Optimal Care Pathway

Most patients reported that they were not aware of the Optimal Care Pathway. Only 26 patients (27.3%) reported that they knew about the existence of the OCP (Figure 2A). Of these patients, 2 reported that they used a digital copy of the OCP in a visit with their healthcare professionals, and 7 indicated that they had not used it yet but intended to do so in the future. Patients reported that the main ways in which the OCP has improved their care is through acting as guidance, and reassurance that they are on the correct path. Some patients also report that the OCP has helped them advocate for themselves and seek out NET specialists for their treatment. When asked about OCP awareness in their treating healthcare professionals, only 11 out of 77 patients that answered the question (14.3%) indicated that their HCPs are aware of the OCP, with the other 66 patients either not being sure, or indicating that their healthcare professionals are not aware of it (Figure 2B).

Thematic analysis interviews

The qualitative thematic analysis of 8 patient interviews revealed a multifaceted impact of NETs on the lives of patients, spanning psychological, emotional, financial, and healthcare navigation domains. Several recurring themes were identified:

Initial Reactions and Awareness: Patients commonly recounted an initial reaction of shock and fear upon receiving their NET diagnosis, often stemming from a profound lack of awareness about their condition. This experience was not isolated to patients; it was mirrored by a notable deficit in awareness among healthcare professionals, compounding the initial distress and confusion. A participant said the following when talking about lack of awareness: 'So if I had breast cancer or cervical cancer, everyone would just know about it straight away and they would go, this is where you go, this is what you do. But with this it's not like that at all.'

Information Seeking and Self-Advocacy: Navigating the healthcare landscape and lack of NET awareness among HCPs post-diagnosis required patients to become proactive in seeking out information. The analysis underscored a need for patients to engage in self-advocacy to secure appropriate information, care, and treatment. One participant said about advocating for themselves, that 'I've now got a new oncologist because the old one was hopeless, and I knew that. The only difference between the old oncologist and my cat is that my cat doesn't have hands. So, I wanted to switch to the NET expert oncologist in my area and had my first appointment with him last month. And he's been amazing and has really taken an interest

in me.' This experience shows that there is a need for NET experts and for self-advocacy by patients to feel validated and have faith in the healthcare systems. It also shows that there are gaps in communication between patients and HCPs.

Communication between Patient and Healthcare Professional: The majority of participants reported positive communication with their healthcare providers, which was instrumental in managing their condition. However, this was juxtaposed with accounts of negative interactions with certain HCPs or elements of the healthcare system, highlighting inconsistencies in the quality of communication and the challenges this results in for patients.

Impact on Daily Living: The pervasiveness of NETs was evident, with patients articulating significant disruptions to daily life and overall well-being due to both the disease and its treatment. Despite these challenges, most patients endeavoured to maintain a positive outlook on life and expressed feeling fortunate, as their overall life and well-being could be a lot worse. A participant mentioned: 'I can hardly eat any food now; I've lost nearly 40 kilos in weight. I can't work full time like I used to. But in saying that, though, I'm still lucky in that I can still work part time and I can still eat small amounts of food. And I don't have a feeding tube.' This suggests that resilience as an important aspect of the experiences of NET patients.

Psychological and Emotional Well-Being: Many patients expressed a high emotional toll of their disease, as they had to confront their own mortality and the consequences of their tumours. The imperative for emotional support was clear, both from healthcare professionals and support systems in the form of family and friends. One participant that spoke to several HCPs for emotional support noted, 'Nobody recommended or suggested to me that I speak to a psychologist, psychiatrist or have counselling. But I would recommend it to any person who has NETs, at least for a number of weeks to get their head around their emotional set up and understanding where other people might be coming from.' Several other participants echoed this sentiment, stating that counselling was beneficial for their psychological and emotional well-being.

Financial Strain: Several patients indicated financial repercussions because of their disease. Their financial strain was multi-faceted, including both increased costs due to treatment-related expenses and the loss of income due to an inability to sustain employment.

Optimal Care Pathway Awareness: The OCP was largely unknown among the patient cohort. Yet, recognition of its potential benefits was recognised by many patients, as they believed that knowledge about the OCP could have significantly ameliorated their diagnostic journey. One participant noted, 'It's interesting how things have changed from when I was first diagnosed, which wasn't that long ago. Everyone wanted to do an invasive procedure, whereas now they're looking at the size of the tumour, so now there's no push to have the procedure since the Optimal Care Pathway says to watch and wait. So yeah, I'm happy with the Optimal Care Pathway.' There was a consensus that increased OCP familiarity among HCPs could enhance care delivery, with some patients expressing a desire that their HCPs had introduced them to the OCP at the onset of their care pathway.

Discussion

This study aimed to assess the changes that occurred in the care for patients with neuroendocrine tumours in Australia as a consequence of the publication of the Optimal Care Pathway for neuroendocrine tumours. The study highlighted that the experienced of NET patients are complex and vary wildly for each individual. The majority of patients were unaware of the existence of the OCP, with the patients that were aware indicating in both the questionnaire and the interviews that the OCP provided them with reassurance, guidance, and a possibility to improve their care and route to diagnosis. It is, therefore, crucial to ensure that communicative strategies are used to educate patients about the OCP, to maximise the effects on care for NET patients.

The majority of NET patients still get misdiagnosed prior to their NET diagnosis, most notably with a gastrointestinal issue or a mental health related issue. This underscores the complexity and varied presentation of NET symptoms, highlighting the diagnostic challenge posed by NETs and the need for heightened clinical awareness to prevent delays in accurate diagnosis. In the questionnaire, one patient noted that 'If I had not researched symptoms myself and changed gastroenterologists, then demanded more investigation, I would still be undiagnosed' Over time, the time to diagnosis has decreased, with patients that received a NET diagnosis in 2021 or later having a significantly shorter time to diagnosis than patients that were diagnosed before 2021. This implies that recent efforts to educate about NETs are effective and improve the care for NET patients. Nonetheless, half of the recently diagnosed patients still waited over 1.34 years to receive their NET diagnosis.

Patients indicated that they want their healthcare professionals to supply them with the OCP at diagnosis. However, only 11 patients were sure that their treating healthcare professionals are aware of the Optimal Care Pathway. In the questionnaire, a participant indicated the following: 'This appears to be an excellent document, a direction that addresses our unmet needs and to be promoted to all HCPs, specialists and patients.' As this sentiment was shared by multiple participants in both the questionnaire and the interview, this highlights a dire need to educate HCPs on the OCP.

This study has several strong aspects, including the direct engagement with patients through interviews, providing rich, qualitative insights into their healthcare journeys and experiences. These narratives offer a depth of context that cannot be achieved through quantitative data alone. Another significant strength is the evaluation of the OCP from the perspective of those it is intended to serve, underscoring the importance of communication with patients and highlighting opportunities for improving educational and support mechanisms. Moreover, the study's methodological approach, combining both quantitative and qualitative data, with an even split between recently diagnosed patients and patients that received their diagnosis before 2021, enriches the evidence base. This mixed-methods strategy allows for a more comprehensive analysis of the factors that affect time to diagnosis, treatment initiation, and patient satisfaction with care, as well as an assessment of these factors over different time periods.

However, this study also has some limitations. Most notably, due to the limited sample size and the relatively short time to diagnosis reported by the interviewed patients, there is a possibility that this group of patients is not representative for the broader NET patient population, impacting generalizability of the results. This sampling bias is inherent to cancer care studies, where those that experience more favourable outcomes may be more inclined to participate.(15) Given that participation was voluntary, the sample might be biased towards more stable patients, which could result in an overestimation of the perceived quality of care

and an underrepresentation of the challenges faced by NET patients. Furthermore, the questionnaire respondents were predominantly female, despite the incidence of NETs being approximately equal between genders. While this gender imbalance is a common issue in survey-based research, it is particularly pertinent here given the known differences in health-seeking behaviour between males and females, potentially skewing perceptions of healthcare satisfaction. (16, 17) Additionally, only patients familiar with NeuroEndocrine Cancer Australia were included in the study. It is a possibility that patients involved with patient organizations may have greater access to information and support, influencing their healthcare experiences and satisfaction levels.

Based on this study, several recommendations can be made. Due to the limited sample size of this study, the results could be solidified by repeating this study with a larger sample size that is representative of the entire population of NET patients. To increase the effects of the OCP on patient care, dissemination and communication to both patients and HCPs are crucial. Dissemination strategies focused on healthcare professionals include the implementation of training programs that emphasize the importance of the OCP and instruct on how to integrate it into standard care practices. A collaborative awareness campaign to highlight the OCP, involving several stakeholders and national peak bodies, could improve dissemination among both patients and HCPs. Increased dissemination of the Optimal Care Pathway would lead to better communication between patients and healthcare professionals, eventually leading to better patient outcomes and improved care. The OCP can achieve this in several ways. First of all, it generates a shared understanding that makes it easier to discuss care options. It also empowers patients and helps them advocate for themselves, and helps to set realistic expectations for both patients and HCPs, which can reduce misunderstandings and improve healthcare satisfaction. Lastly, the OCP encourages proactive conversations and shared decision-making, leading to better care for patients.

In conclusion, even though the experiences of NET patients differ wildly between individuals, and many still get misdiagnosed, the OCP is a valuable tool that can ameliorate their path to diagnosis. To improve care for NET patients, efforts should be made to disseminate the Optimal Care Pathway for neuroendocrine tumours to both patients and healthcare professionals. Increased awareness and education about the OCP will improve patient outcomes and lead to better communication between healthcare professionals and patients. The findings of this study serve as a call to action to enhance the reach and effectiveness of the OCP, driving improvements in care and support for those affected by NETs.

Acknowledgements

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