# Unmet needs in the management of neuroendocrine tumours: A global survey involving patients, patient advocates and healthcare professionals



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### INTRODUCTION

- Neuroendocrine tumours (NETs) are neoplasms arising from the endocrine system which can form in various locations in the body<sup>1</sup>
- NETs are an uncommon disease with incidences varying from 1.51 to 6.98 per 100,000 annually<sup>2,3</sup>
- The incidence of NETs has been rising over the past 30 years which may be due to earlier and improved diagnosis<sup>2,4</sup>
- Receiving a NET diagnosis is often still a difficult and long-winded process characterised by misdiagnoses and delays<sup>5</sup>
- NETs survival rates depend on tumour location and range from 12 months to over 30 years, potentially giving rise to substantial morbidity<sup>2,6</sup>
- Due to several constraints including limited understanding of the disease and lack of funding, the current management of patients with NETs varies considerably, potentially leaving many with suboptimal care <sup>6</sup>
- The International Neuroendocrine Cancer Alliance (INCA) consists of 20 patient advocacy and research groups and supports NET patients (and their families) by advocating on their behalf to improve diagnosis, care and research

### OBJECTIVE

To capture perceived unmet needs, so that all healthcare professionals (HCPs), patients/families and patient leaders (advocates) can work together more effectively to enhance and improve patient access to information, quality care, and research

### METHODS

 The INCA survey was carried in 2017 and consisted of 35 questions covering:



 Questions were tailored towards three groups (patients, advocates and HCPs)

Research

- Data from the first Global NETs Patient Survey in 2014<sup>5</sup> was used to build the survey and participants were allowed to skip questions
- The survey was created with SurveyMonkey® and disseminated within the global NETs community by INCA member organisations and advocates

### RESULTS

### 1. Study population

- In total, 443 participants responded from 26 countries
- HCPs were most likely to work in oncology (39%) or gastroenterology (29%). Of all HCPs, 10% were nurses
- Patients and advocates had similar disease characteristics (Table 1)

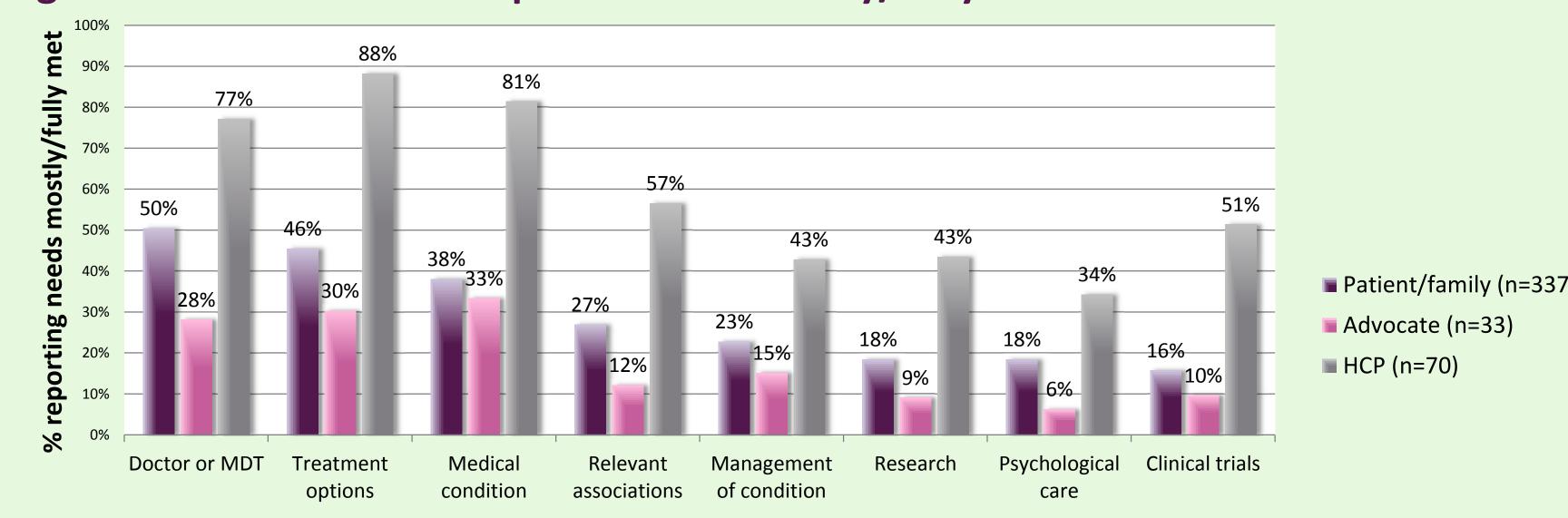
### Table 1: Baseline characteristics

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	(total responses=338)	(total responses=35)		
Patient	88% (296/336)	69% (24/35)		
Current age				
<18 years	1% (3/334)	0% (0/35)		
>49 years	69% (231/334)	63% (22/35)		
Age at diagnosis				
<18 years	4% (12/336)	0% (0/24)		
>49 years	56% (187/336)	29% (7/24)		
Most common type of tumour				
Pancreatic	28% (91/329)	33% (8/24)		
Small intestine	23% (76/329)	38% (9/24)		

### 2. Informational needs

- 84% of HCPs felt they were able to provide sufficient information to patients/ families
- However, a much smaller amount of patients/families and advocates thought that the patient's needs were mostly/fully met (Fig. 1)

Fig. 1: Informational needs perceived as mostly/fully met

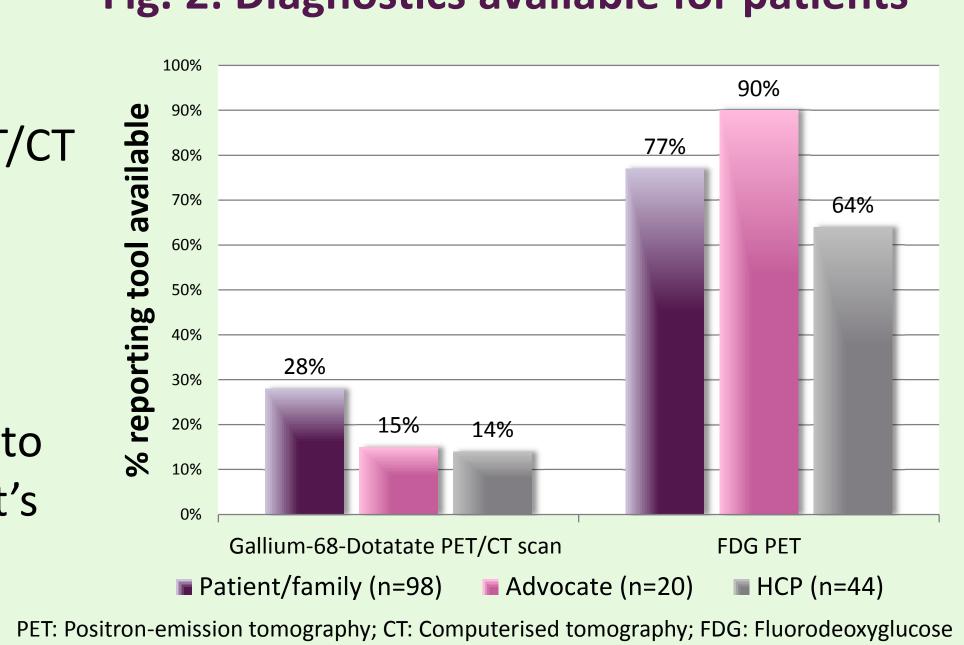


- After diagnosis, 91% of patients requested more information
- Patient associations were more successful than HCPs at meeting the patient's informational needs online (61% vs. 44%) and printed (49% vs. 28%)

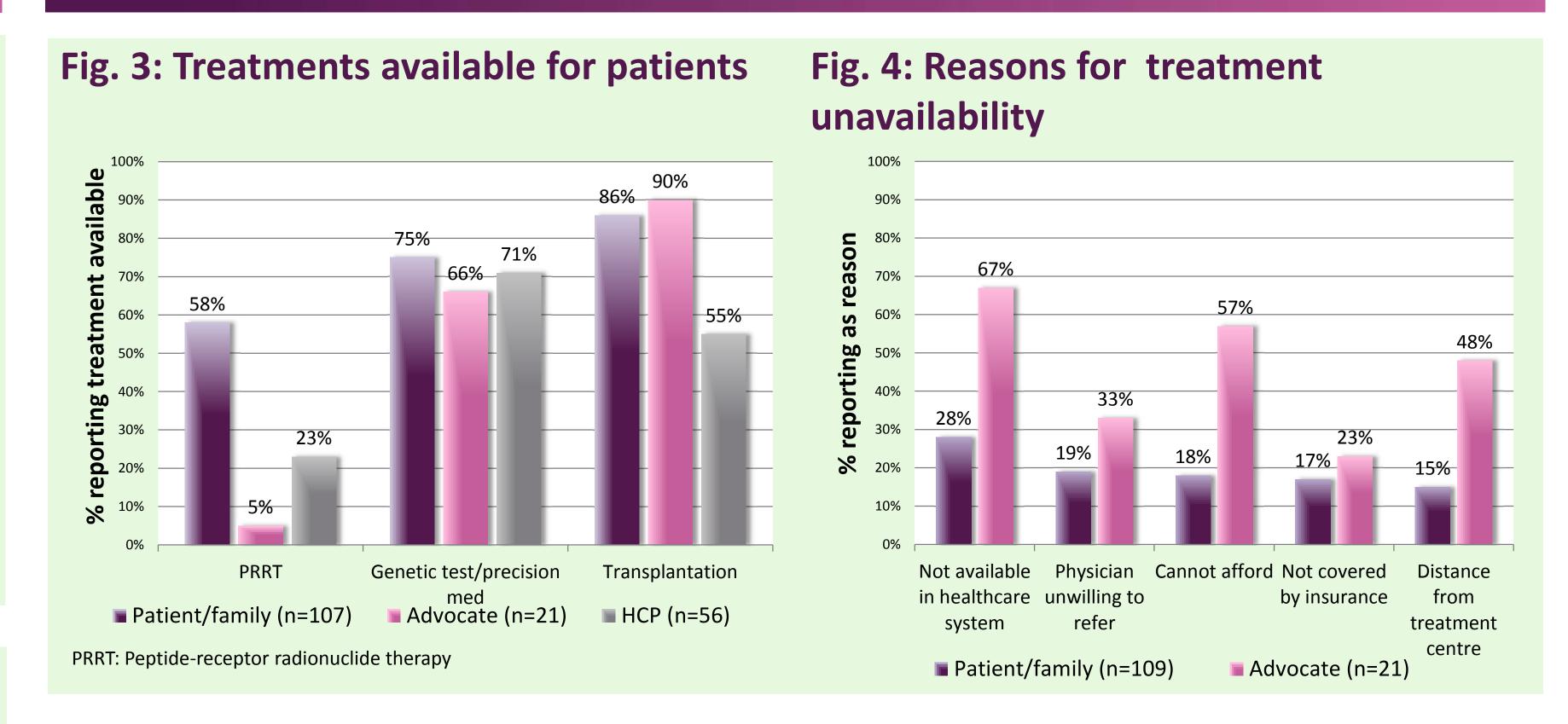
### 3. Diagnosis and treatment needs

- Gallium-68-DOTATATE/DOTATOC PET/CT and PRRT were, reportedly, only available for a limited number of patients (Fig. 2 and 3)
- The most common reason for unavailability of treatment was due to the healthcare system of the patient's country (Fig. 4)

## Fig. 2: Diagnostics available for patients

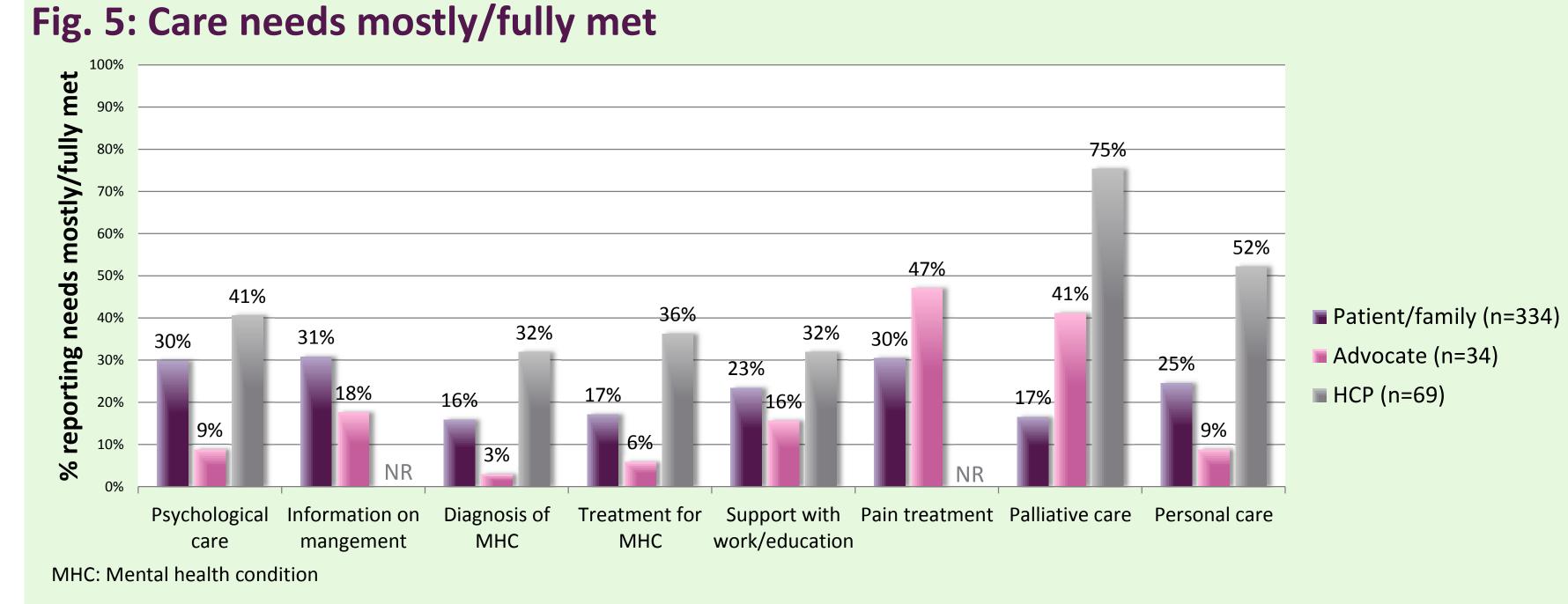


### RESULTS continued



### 4. Care needs

Less than 18% of patients reported their care needs to be mostly/fully met (Fig. 5)



- Only 66% of patients reported having access to a multidisciplinary team, which was overestimated by advocates (94%) and HCPs (70%)
- For 66% of patients contact needs with their multidisciplinary team were mostly/fully met
- 62%; HCPs: 46%) (Table 2)
- However; in practice, most patients (84%) had never participated in a clinical trial and if they had, their single trial (76%)

CONCLUSIONS

- The INCA survey revealed several unmet patients needs which appear to be underestimated by HCPs, specifically in the provision of information, access to quality care and involvement in research
- There is an urgent need for further research and improved collaboration between patients, advocates and HCPs to tighten these gaps and improve the lives and prospects of the increasing numbers of NET patients worldwide

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### ACKNOWLEDGEMENTS

INCA would like to thank Board members of the key international medical societies ENETS (European Neuroendocrine Tumor Society), NANETS (North American Neuroendocrine Tumor Society), APNETS (Asia-Pacific Neuroendocrine Society), CommNETs (Commonwealth Neuroendocrine Tumor Group) and JNETS (Japan Neuroendocrine Tumor Society) who kindly contributed their time and expertise. Strategen Ltd, Basingstoke, UK provided editorial support to the authors.

### FUNDING AND DISCLOSURE

- This study was sponsored by the Neuroendocrine Tumor Research Foundation, a nonprofit, charitable foundation dedicated to NET research and support of NET patients
- The authors have nothing to declare

ESMO 2018 Congress, 19<sup>th</sup>-23<sup>rd</sup> October Munich, Germany

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### 5. Research needs

- The majority of participants felt that patient involvement in research was important (patients: 68%; advocates:
- experience was mostly limited to a

### Table 2: Top 3 research priorities

5		Patient/family (n=329)	Advocate (n=34)	HCP (n=66)
•	Improving diagnoses	1	1	3
	Basic science	2	-	-
	Research to improve QoL and symptoms	3	3	2
	Improving treatments	-	2	1
	QoL: Quality of Life			