

Unmet Needs in Global Neuroendocrine Tumour (NET) Care: Similarities and Differences in the Perspectives of Patients, Patient Advocates and NET Health Professionals

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INTRODUCTION

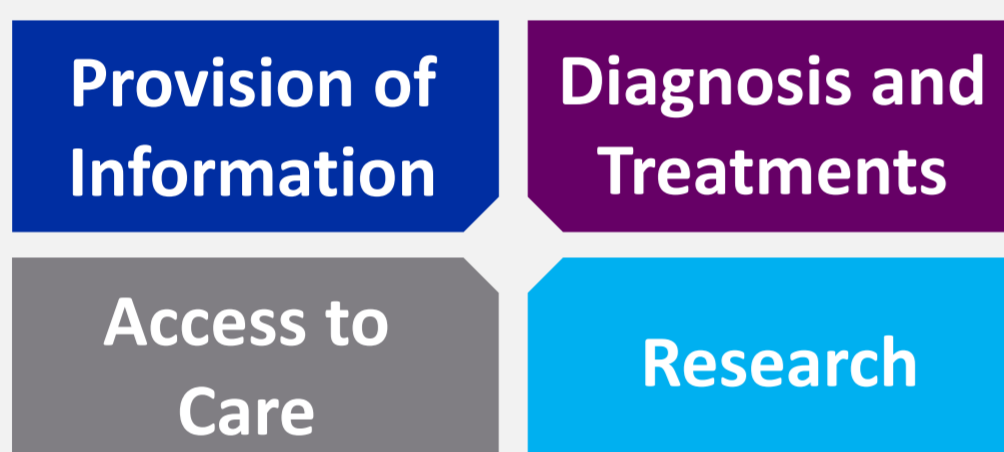
- Neuroendocrine tumours (NETs) are rare, although the incidence and prevalence have risen over the last 30 years¹
- Progress has been made in the understanding and diagnosis of NETs, but current management varies considerably and many patients still receive suboptimal care^{2,3}
- The International 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

OBJECTIVES

- INCA conducted a global survey to investigate potential unmet needs in quality care within the global NETs patient community

METHODS

- The survey was carried out in 2017 and consisted of 35 questions across four key areas:



- The survey was completed by three groups [patients/family members, advocates and healthcare professionals (HCPs)], with questions designed to be cross-comparable
- Questions were based on data from the first Global NETs Patient Survey conducted in 2014²
- Participants could skip questions; therefore, all answers were based on the total number of respondents for each question
- The survey was created using SurveyMonkey® and disseminated within the global NET community by INCA member organisations and advocates

PATIENT CHARACTERISTICS

- 443 participants from 26 countries responded: 338 patients/families; 35 advocates; 70 HCPs
- Most HCPs worked in oncology (39%), gastroenterology (29%) or nuclear medicine (13%); 10% were nurses
- Patients and advocates had broadly similar disease characteristics (Table 1)

Table 1: Baseline characteristics

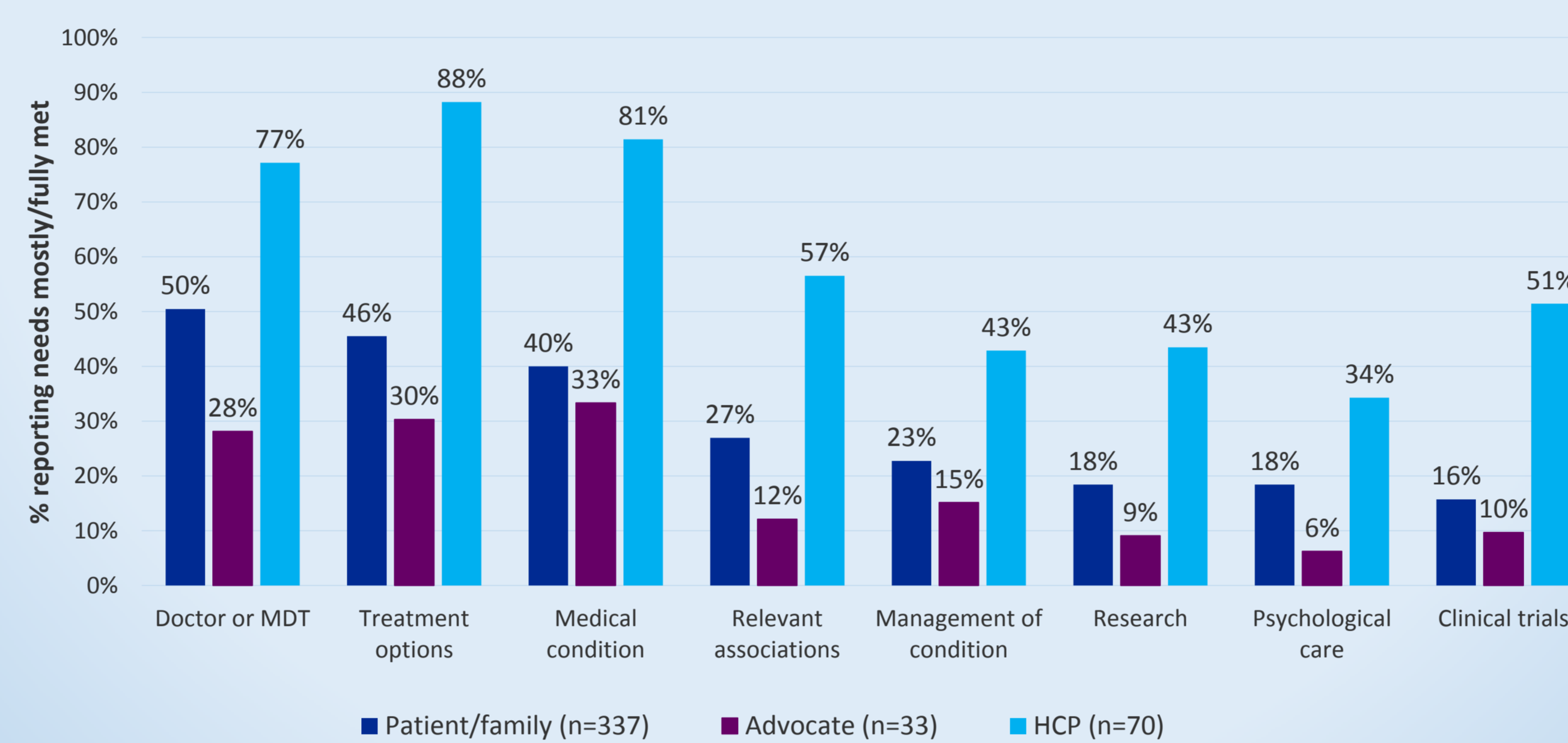
	Patient/family (total responses=338)	Advocate (total responses=35)
Patient	88% (296/336)	69% (24/35)
Current age		
<18 years	1% (3/334)	0% (0/35)
>49 years	69% (231/334)	63% (22/35)
Age at diagnosis		
<18 years	4% (12/336)	0% (0/24)
>49 years	56% (187/336)	29% (7/24)
Most common type of tumour		
Pancreatic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

RESULTS

1. Informational Needs

- Perceived unmet needs regarding the provision of information differed between groups (Fig. 1)
- For patients, the primary source of information were HCPs (68%)
- In the majority of cases, patients had to search for further information themselves following diagnosis (patients: 91%; advocates: 97%), yet 84% of HCPs thought they provided sufficient information regarding NETs to patients and their families
- Those patients who searched for additional information mostly consulted patient association websites (69%)
- The information requested or found on patient association or HCP websites mostly (61%) or fully (48%) met patients' needs

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

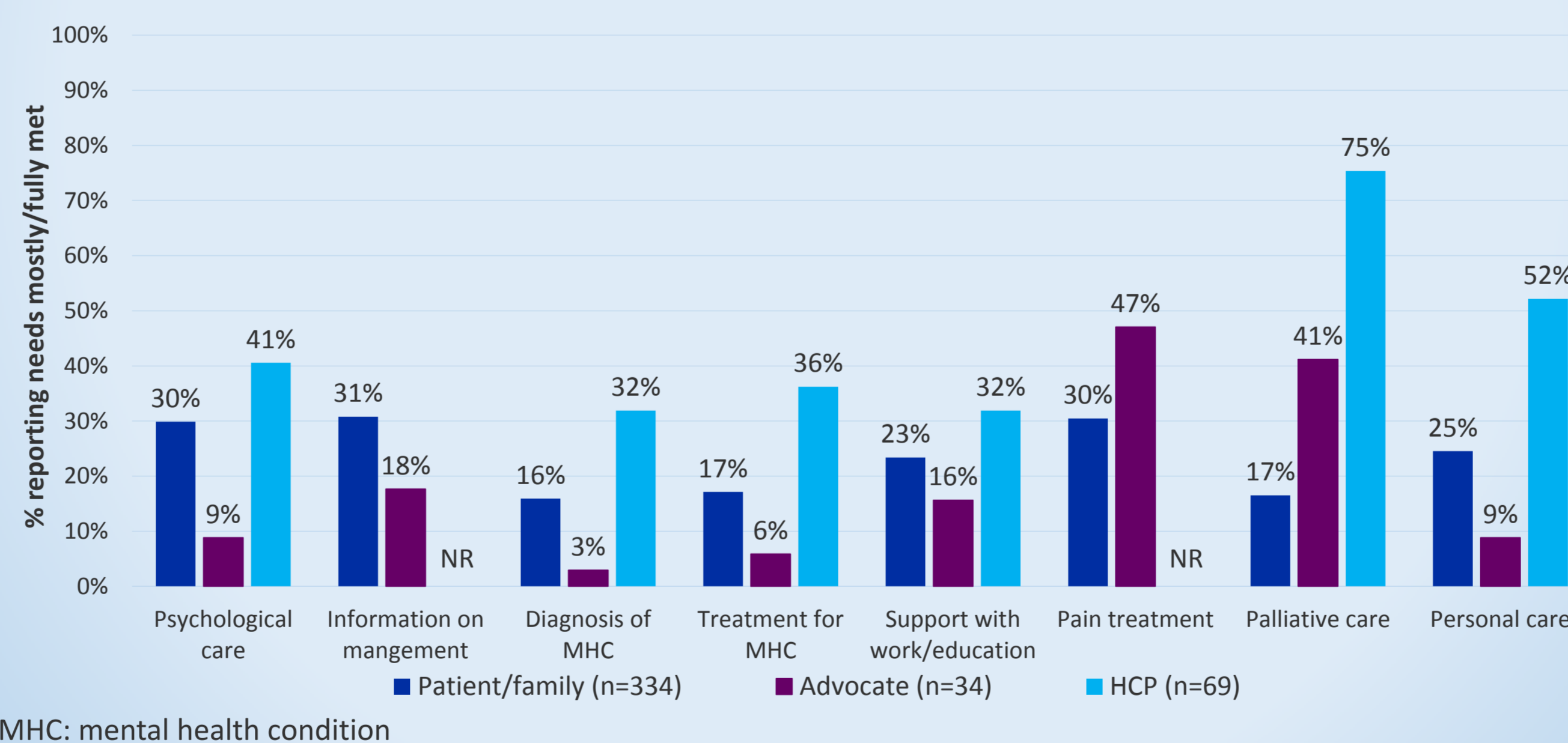


MDT: multidisciplinary team

2. Care Needs

- All groups felt that many standards of care, including psychological care and diagnosis of mental health conditions, were not fully met (Fig. 2)
- Most patients' care was managed by multidisciplinary teams (MDTs) (patients: 66%; advocates: 94%; HCPs: 70%); however, patient needs were not fully/mostly met by 34% of MDTs and around 14% of patients felt they did not receive enough contact

Fig. 2: Care needs mostly/fully met



MHC: mental health condition

3. Diagnosis and Treatment Needs

- Access to key diagnostic tools and treatments patients had heard about was perceived to be limited by all three groups
- A higher proportion of patients felt that the highest global standard of care – including access to Gallium-68-Dotate PET/CT scans (28%) and peptide receptor radionuclide therapy (PRRT) (58%) – was available to them than HCPs (14% and 23%) and advocates (15% and 5%) considered being available to patients (Fig. 3 and Fig. 4)
- For patients, limited availability of treatments was perceived to be due to their healthcare system (28%), followed by lack of referral (19%), financial reasons [treatment not covered by insurance (17%) or patients' inability to afford treatment (18%)]
- A higher proportion of advocates attributed the unavailability of treatment on the healthcare system (67%) and inability to afford treatment (57%)

RESULTS continued

Fig. 3: Diagnostics available for patients

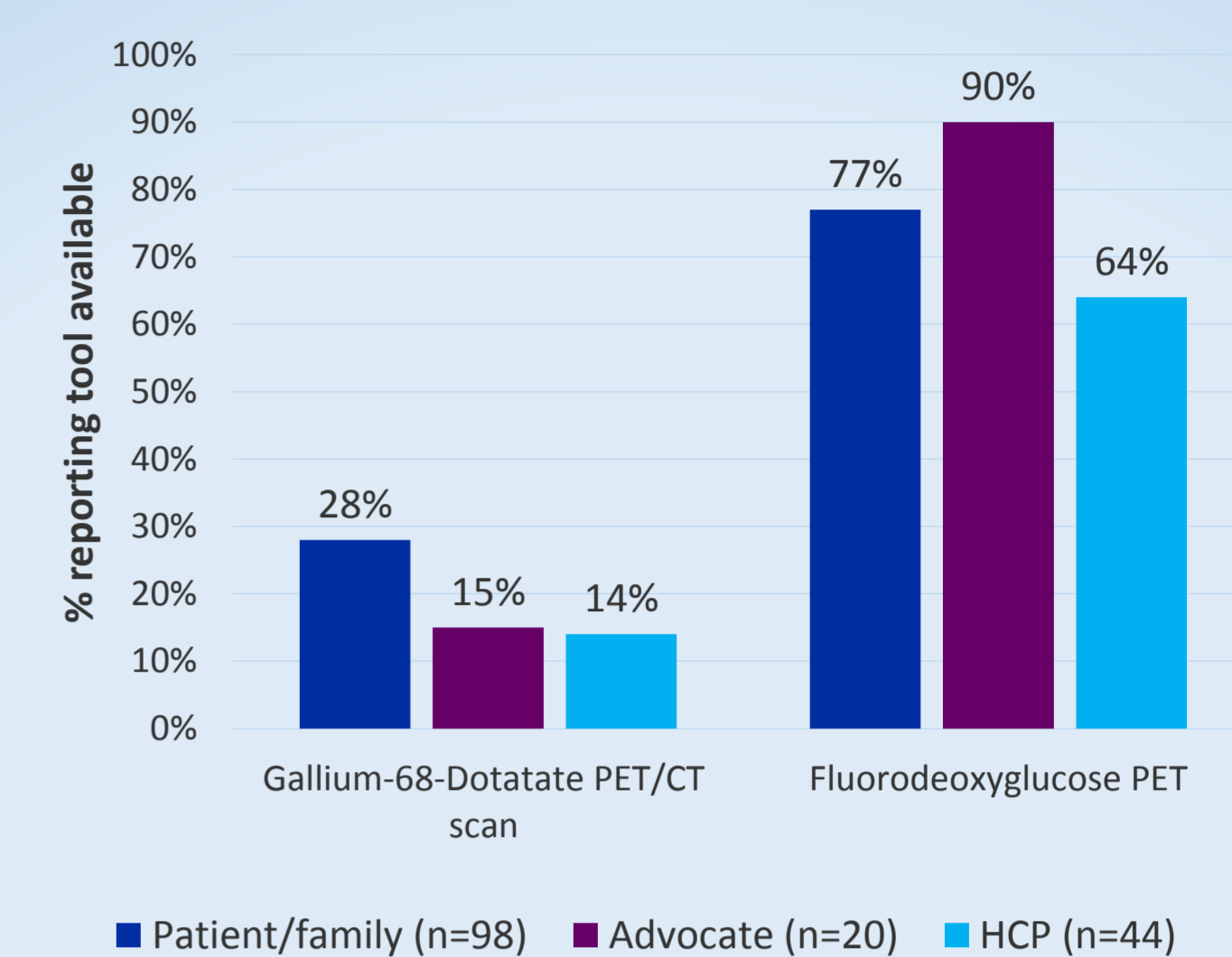
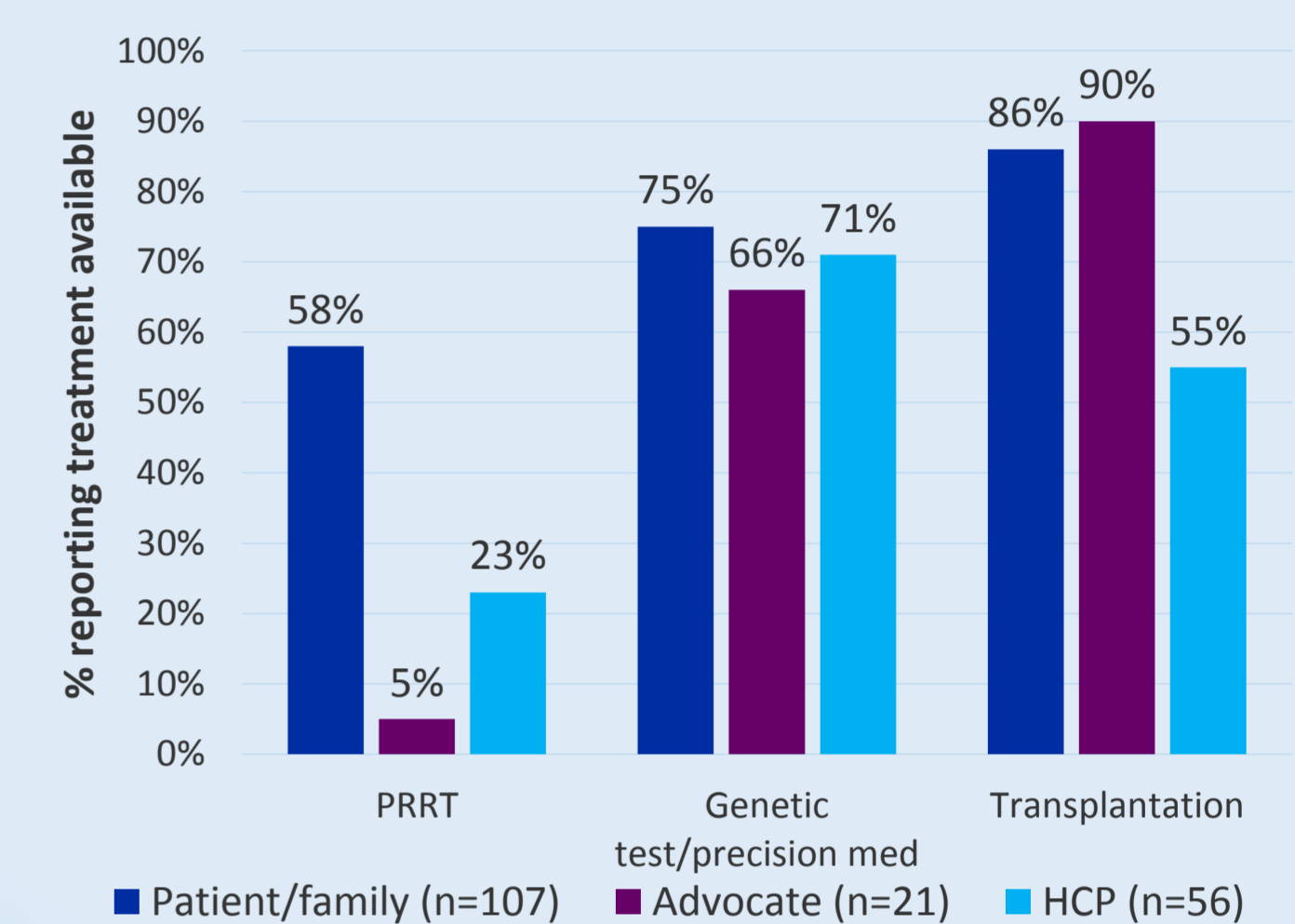


Fig. 4: Treatments available for patients



- All three groups reported that many patients had to travel long distances or abroad for treatment or consultation with a NET specialist

CONCLUSION

- This survey found significant unmet needs in the integrated, 'wrap-around' care that supports treatment of NETs
- There is a clear need to increase awareness and education in NETs amongst HCPs in both primary and secondary care
- This may help to facilitate not only more prompt diagnosis and referral for patients, but also provision of improved 'wrap-around' care

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