

Unmet needs in the global NETs patient community from the perspectives of patients, patient advocates and NET health professionals

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Kolarova, T; Hollander, R; Leyden, S; Bouvier, C; Caplin, M; Conroy, S; Davies, P; Dureja, S; Falconi, M; Ferolla, P; Fisher, G; Goldstein, G; Hicks, R; Lawrence, B; Majima, Y; Metz, D; O'Toole, D; Ruzniewski, P; Wiedenmann, B.

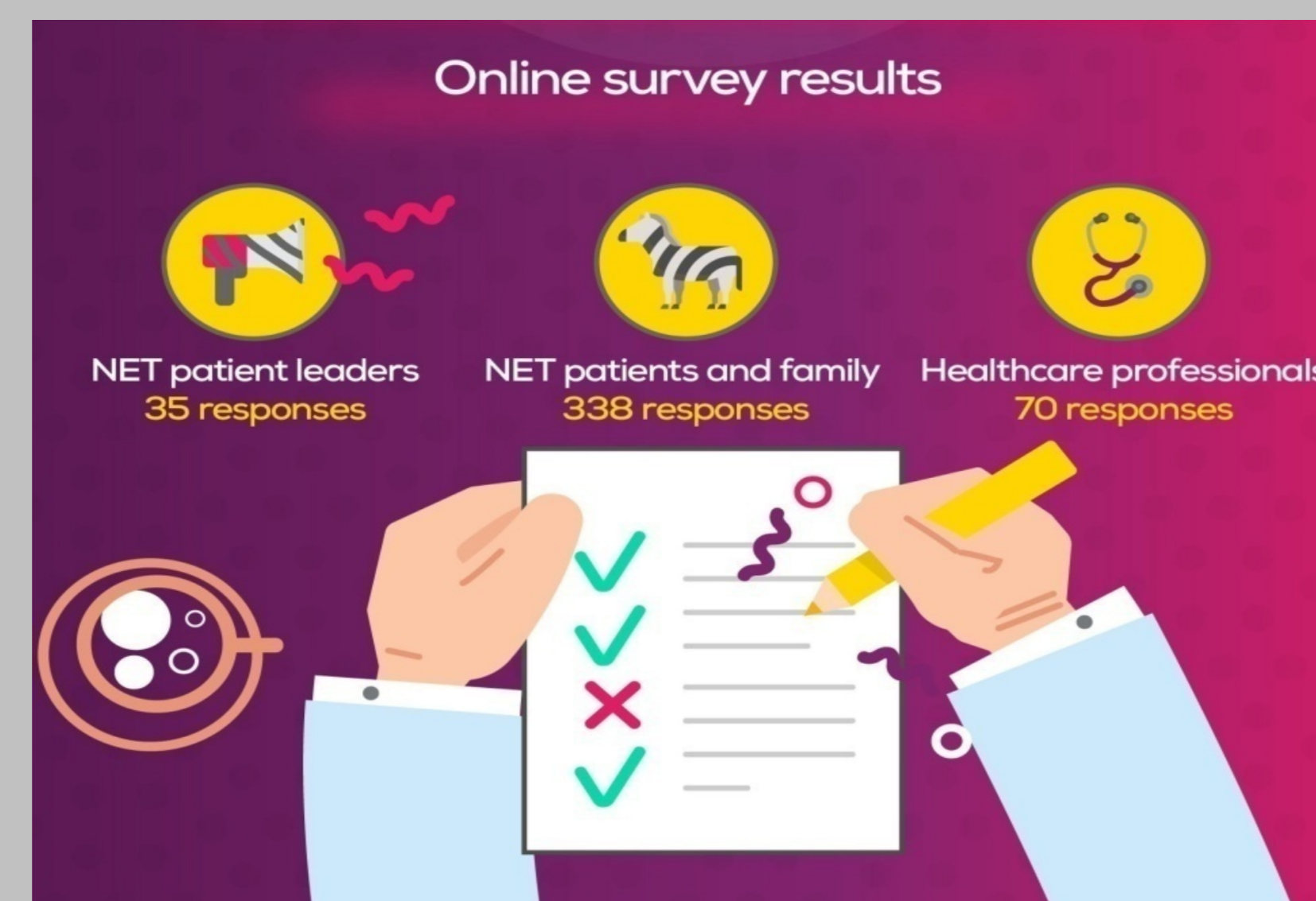
INCA , ENETS, NANETS, APNETS , CommNETs, JNETS

BACKGROUND

- Recent studies show that 6.98 in every 100 000 people are diagnosed with NETs each year, while the incidence of NETs has increased almost seven fold between 1973 and 2012ⁱ.
- Almost half of the patients report making five or more visits to the doctor before receiving their NET diagnosisⁱⁱ.
- The International Neuroendocrine Cancer Alliance (INCA) carried out a survey to assess unmet needs in quality care for NET patients, which focused on the perspectives of a more well-informed sample of patients and NET clinicians, still points to major gaps in fulfilling the informational needs of patients, ensuring their access to highest standards of care and facilitating their involvement in research.

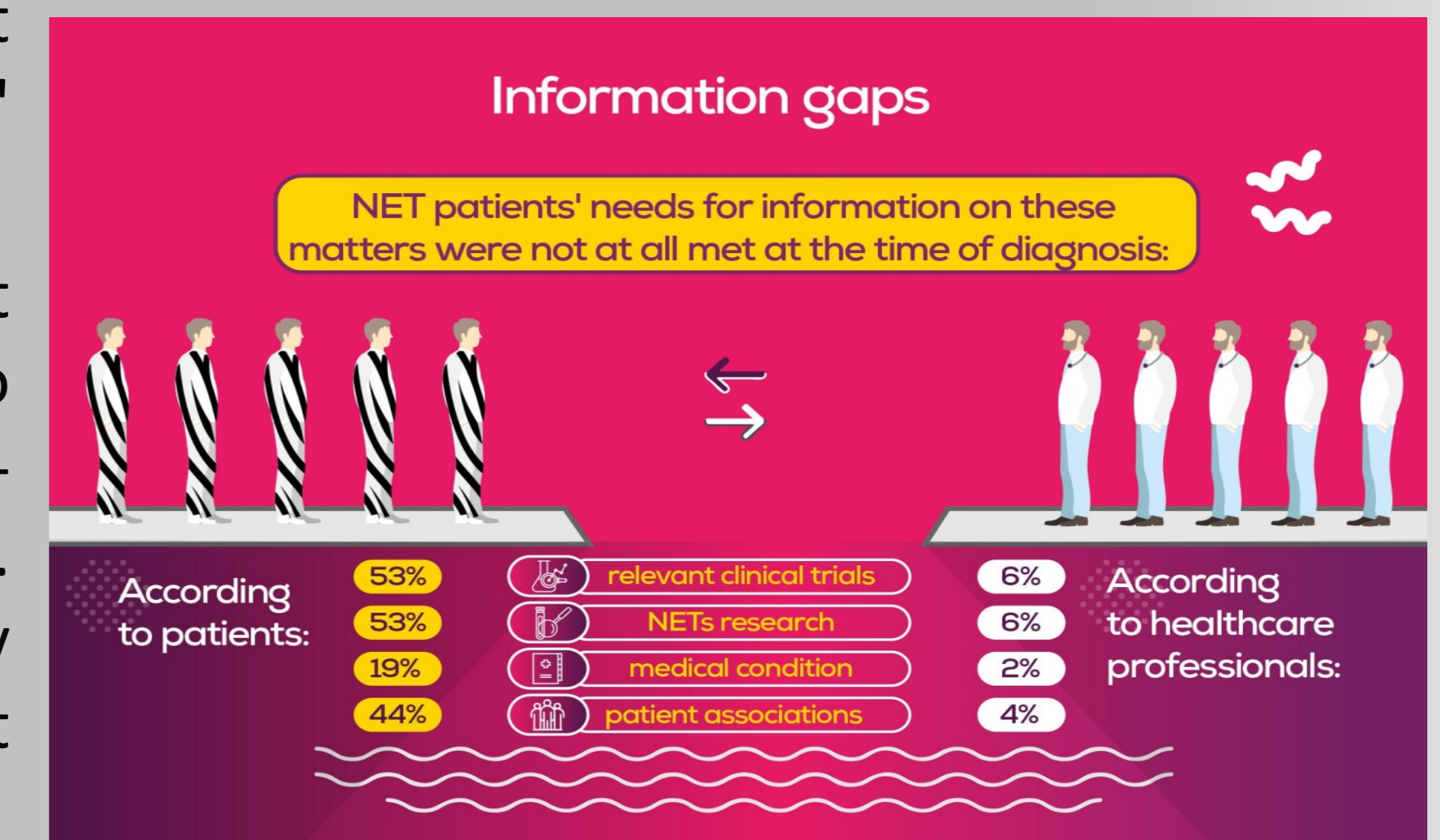
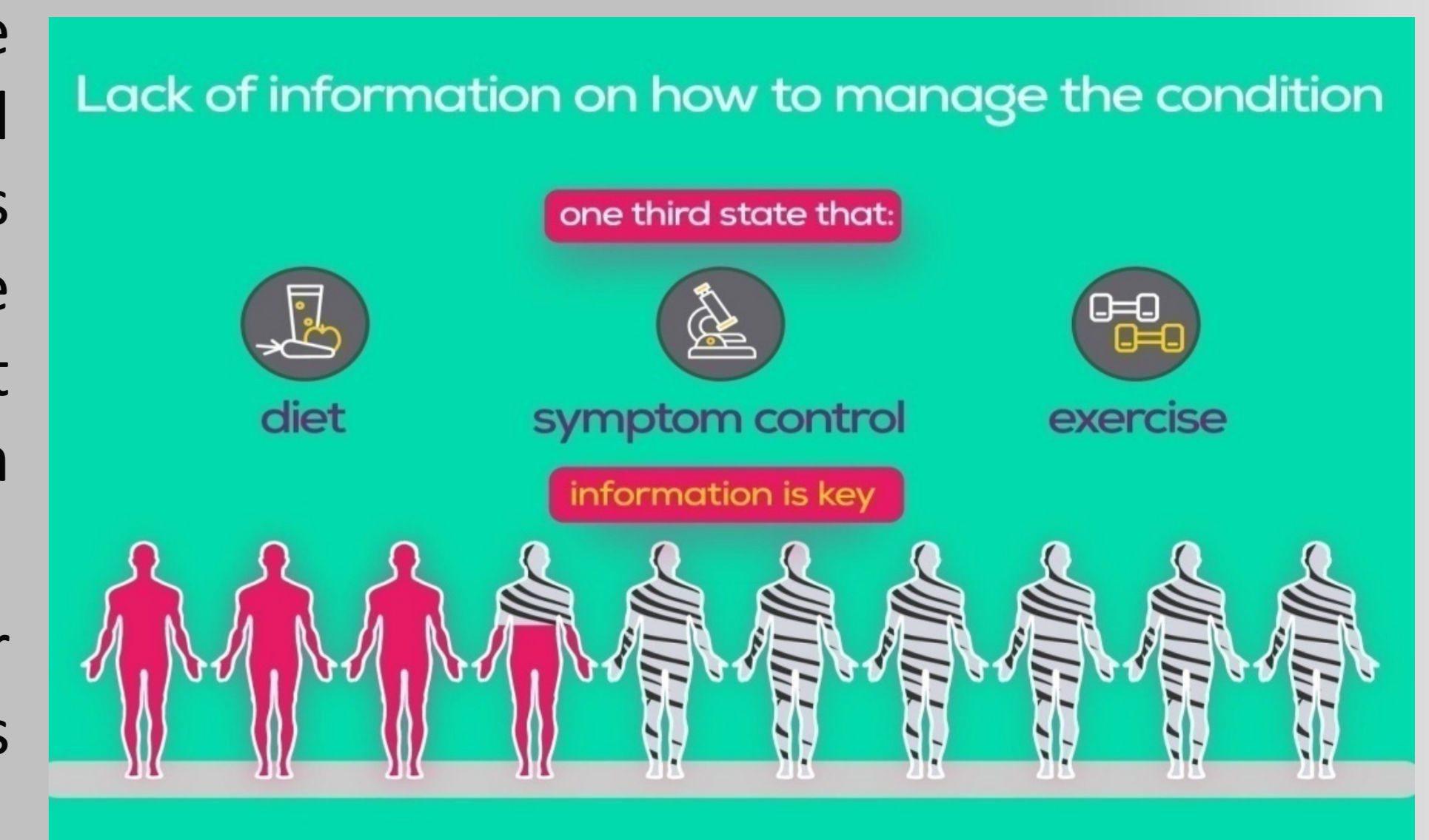
METHODS

- In 2017, patients and family, healthcare professionals (HCPs) and patient advocates completed an online survey to identify gaps in NET information, standards of care, diagnostics/treatment and research.
- 443 respondents from 26 countries (338 patient/family; 70 HCPs; 35 patient advocates) took the survey on SurveyMonkey®.
- The larger percentage of HCPs were in oncology (39%) or gastroenterology (29%), and 10% were specialized nurses.



RESULTS

- Patients identified a number of information gaps at diagnosis that were not perceived by HCPs: relevant clinical trials (53% vs. 6%, respectively); NETs research (53% vs. 6%); psychological care (48% vs. 13%); signposting to patient associations (44% vs. 4%); symptom management (34% vs. 1%).
- Only 16% of patients felt their needs for information about treatment options were fully met (vs. 41% of HCPs).
- 91.07% (306/336) of patients reported specifically seeking information about their disease, on patient associations' (69.41%) or HCP websites (48.03%).
- The survey found that one of the biggest perceived challenges in access to diagnostics is Gallium-68-DOTATATE/DOTATOC PET/CT scanning. Peptide Receptor Radionuclide Therapy (PRRT) was by far seen as the most common unmet treatment need.



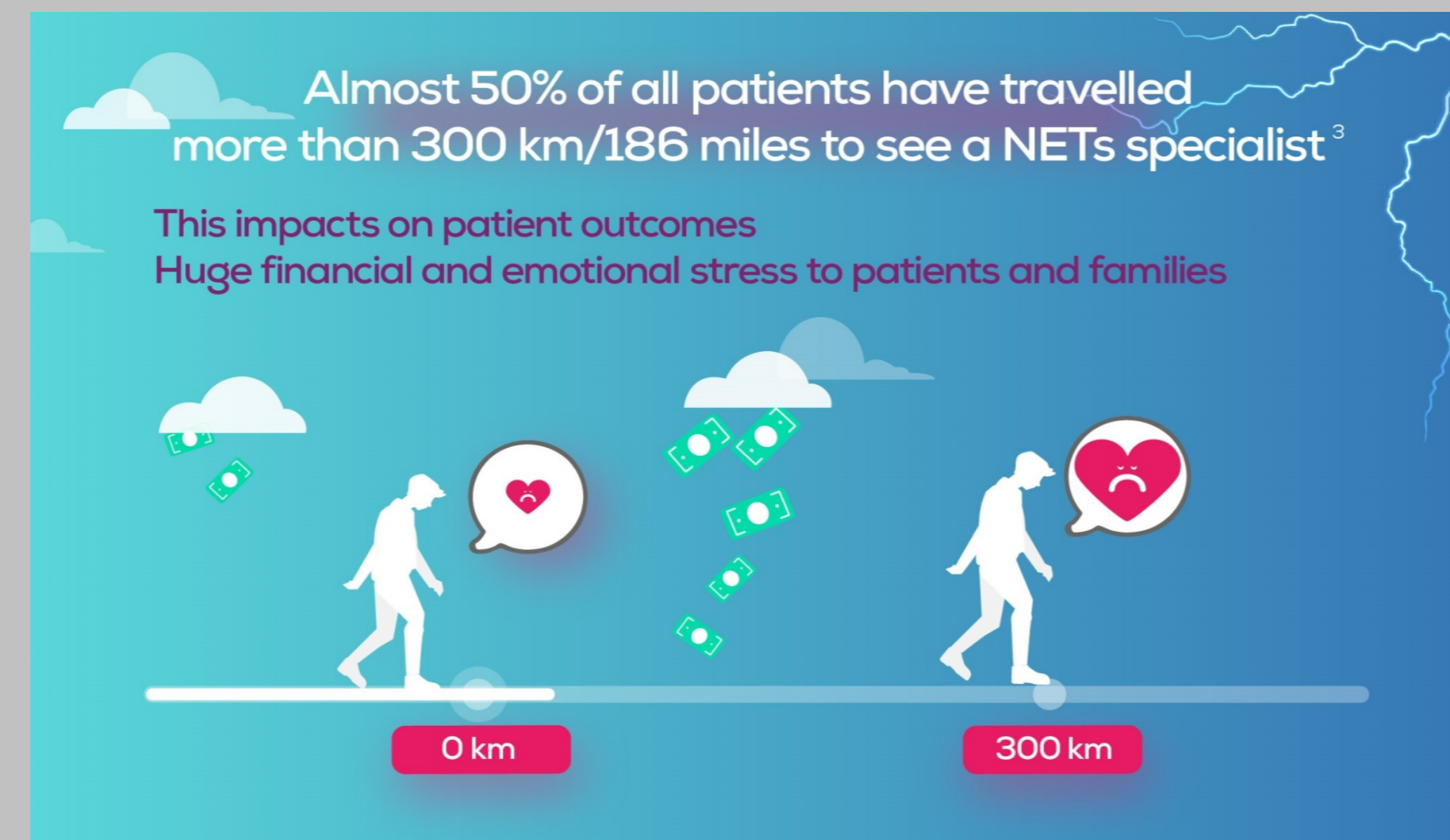
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RESULTS CONTINUED

- 94% of advocates reported multi-disciplinary teams (MDTs) were available in their region and 70% of HCPs said care was by MDT; while only 66% of patients reported access to MDT.
- 48% of patients reported travelling >300km/186 miles to see a NET specialist.
- Evidence shows that remoteness has an adverse impact on overall survival of NET patientsⁱⁱⁱ.



- There is a shared view among all 3 groups (patients 53%; HCPs 57%; advocates 82%) that patients are not involved enough in research design.
- Research priorities differed with patients and advocates most interested in earlier diagnosis and HCPs ranking clinical trials to improve current treatments and test new ones with the highest priority.



CONCLUSIONS

- The INCA survey showed major gaps in addressing the information needs of patients, providing access to gold-standard care, and involving patients in research .
- There are clear differences in the perceptions of patient advocates, patients and healthcare professionals about provision of information.
- Patient group leaders and healthcare professionals need to work together to close the information gap and improve the quality of communication, to empower patients to be active partners in the treatment process.
- Patient and medical leaders would advocate together for a global standard of access to care including the latest technologies and diagnostic/treatment tools for NET patients in countries around the globe.
- Collaboration between patient and clinical leaders to get patients more involved in the process of setting research priorities, and advocating for more research funding is crucial.



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ⁱ Dasari A, Shen C, Halperin D, et al. Trends in the incidence, prevalence, and survival outcome in patients with neuroendocrine tumors in the United States. *JAMA Oncol* 2017;3:1335-42.

ⁱⁱ Singh S, Granberg D, Wolin E, et al. Patient-reported burden of a neuroendocrine tumor (NET) diagnosis: Results from the first global survey of patients with NETs. *J Glob Oncol* 2017;3:43-53.

ⁱⁱⁱ Hafeez, Umbreen, Joshi, Abhishek, Bhatt, Manoj, Kelly, Jenny, Sabesan, Sabe and Vangaveti, Venkat (2017). *Clinical profile and treatment outcomes of advanced neuroendocrine tumours in rural and regional patients: a retrospective study from a regional cancer centre in North Queensland, Australia : neuroendocrine tumours in rural patients. Internal Medicine Journal* 47 (3) 284-290.