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Unmet Needs in the Global NETs Patient Community from the Perspectives of Patients, Patient Advocates and NET Health Professionals

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BACKGROUND: The International Neuroendocrine Cancer Alliance (INCA) carried out a survey to assess unmet needs in quality care for NET patients.

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.

RESULTS: 443 respondents from 26 countries (338 patient/family; 70 HCPs; 35 patient advocates) took the survey. 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 having to specifically seek information about their disease, on patient associations' (69.41%) or HCP websites (48.03%). 94% of advocates reported 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. Patient involvement in research was considered paramount by all 3 groups (patients 53%; HCPs 57%; advocates 82%), while research priorities differed with patients and advocates interested in earlier diagnosis and HCPs in clinical drug trials.

CONCLUSION: The INCA survey showed major gaps in addressing the information needs of patients, providing access to gold-standard care, and involving patients in research.