

## *Plain Language Summary*

An online survey was developed to identify the usefulness of information available for patients with neuroendocrine tumors, also called NETs. The survey had 12 questions with multiple-choice answers or free-text options. The survey aimed to:

- Understand the physical, informational, and emotional challenges that are faced before, at, and after diagnosis of NET.
- Identify key challenges that are faced by patients.
- Understand where patients obtain information and support, and whether they are able to find the information needed.

The survey was sent to patients with NETs by 3 patient or patient advocate organizations. There were 428 respondents in the United States, 240 in Germany, and 73 in France.

This plain language summary represents the opinions of the authors. This study was funded by Ipsen, Boulogne Billancourt, France. Medical writing assistance for this study was provided by Sarah Griffiths and Rebecca Crosby of Oxford PharmaGenesis and Richard Watt and Lindsay Queen of Sudler Medical Communications. For a full list of acknowledgments and disclosures for all authors of this article, please see the full text online. © The Author(s) 2019.

The survey found the most common emotion when people received their diagnosis was anxiety. The biggest physical challenges were fatigue and diarrhea. Findings about the best sources of information and the easiest way to understand information varied among the countries. Information sought and not found by NETs patients included:

- Information about treatments
- Causes of the tumors
- Prognosis
- Nutritional advice
- Psychological support
- The opportunity to discuss their experiences with other patients with NETs.

Key findings from this survey were:

- Patients living with NETs use a range of information sources, which vary between countries in their availability and popularity
- Respondents valued resources and support from other patients with NETs, such as direct contact and interaction, and “patients-like-me” case studies
- The variety of responses indicate that a tailored approach to symptom management, information, and support is needed, reflecting the diverse nature of the condition.