

Neuroendocrine Tumor Patient Experience and Disease Burden: Results From the First Global NET Patient Survey—A Collaboration Between the International Neuroendocrine Cancer Alliance (INCA) and Novartis Pharmaceuticals

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BACKGROUND

- Neuroendocrine tumors (NET) are rare neoplasms arising from neuroendocrine cells throughout the body... Despite a continuously increasing incidence, NETs remain poorly understood among the general public...

AIM

- To raise awareness of the burden of NETs on patients' daily lives by tumor location

METHODS

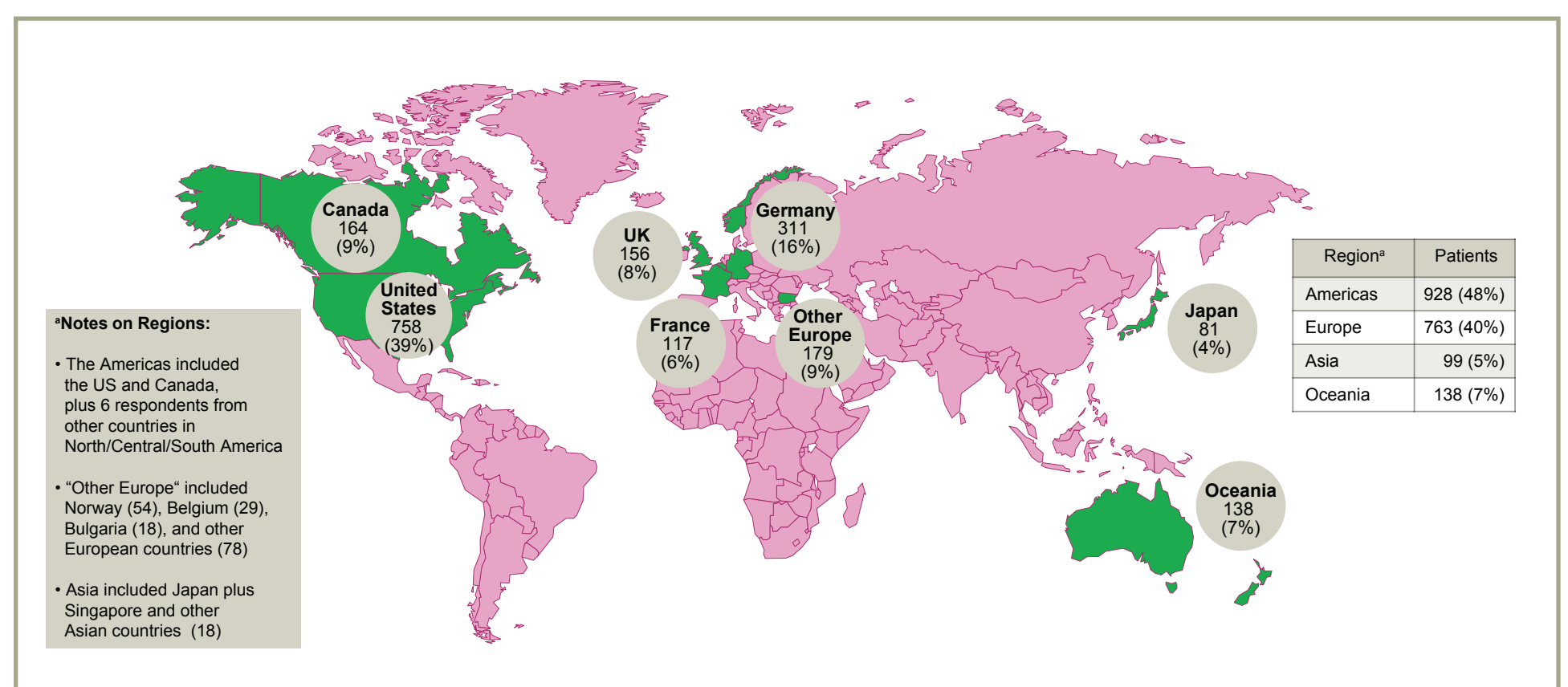
- From February through May 2014, patients with NETs participated in a 25-minute anonymous survey that captured the NET patient experience, including disease burden by NET type

RESULTS

Demographics

- A total of 1928 patients with NETs were recruited from >12 countries in the Americas, Asia, Europe, and Oceania (Figure 1)

Figure 1. Countries participating in the global NET patient survey.



Base population: All respondents (N = 1928). Question: In which country do you live? Question: In which region do you live?

- The average age of patients was 56.8 years; 64% were female. Gastrointestinal NET was the most common NET type (54%), followed by pancreas (22%), lung (12%), thymus (1%), other (8%), and unknown site (5%).

Table. Patient-Reported Functional Status and Grade of NETs*

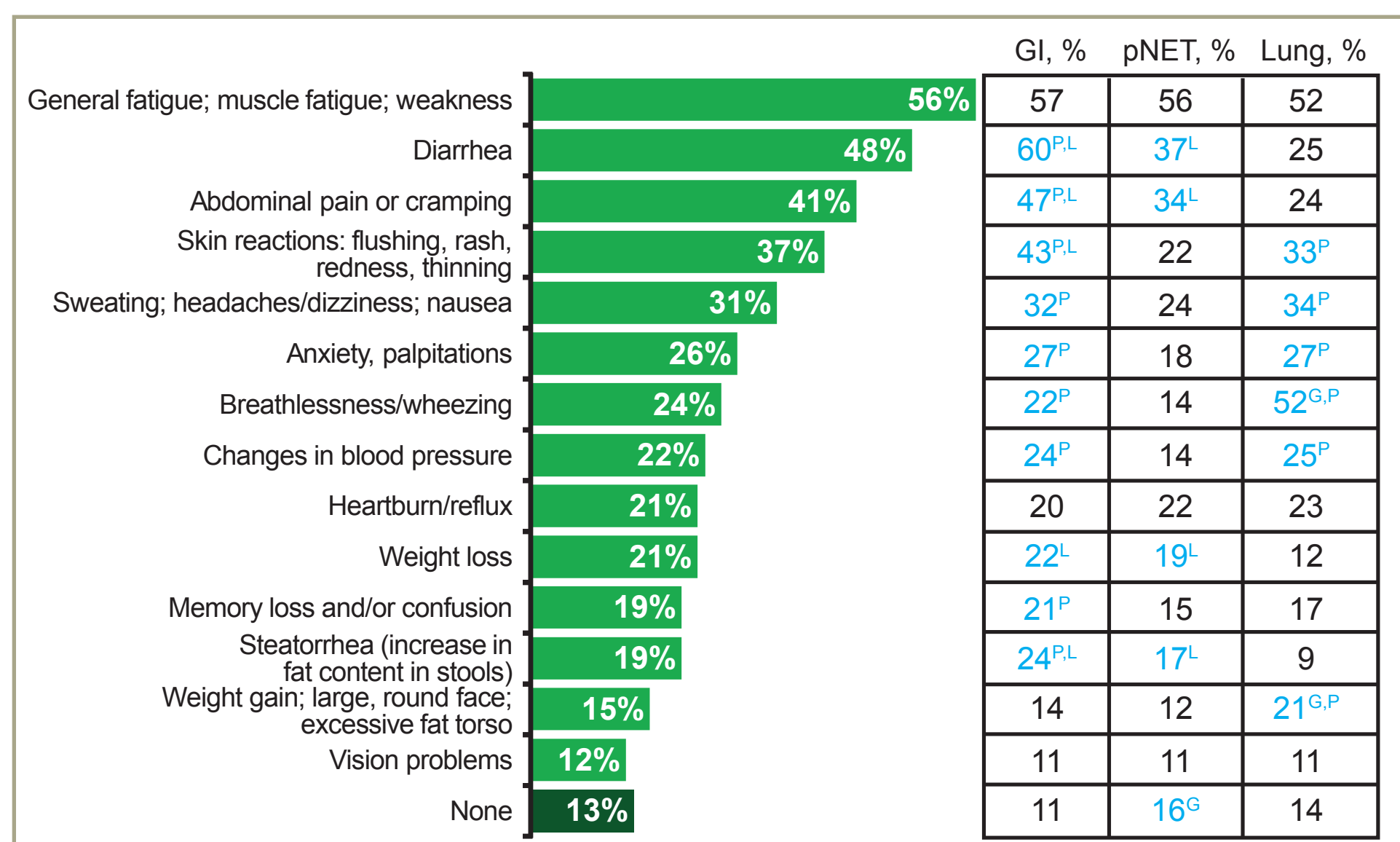
Table with columns for Tumor Type (GI NET, pNET, Lung NET), Functional Status (Functional, Nonfunctional/Asymptomatic, Unknown), and Grade (G1/G2, G3, Unknown).

Base population: All respondents (N = 1928). Question: How, if at all, does your physician describe the functional status of your NET? Question: Which of the following, if any, does your physician currently use to describe the grade of your NET?

Impact of NETs on patients' lives

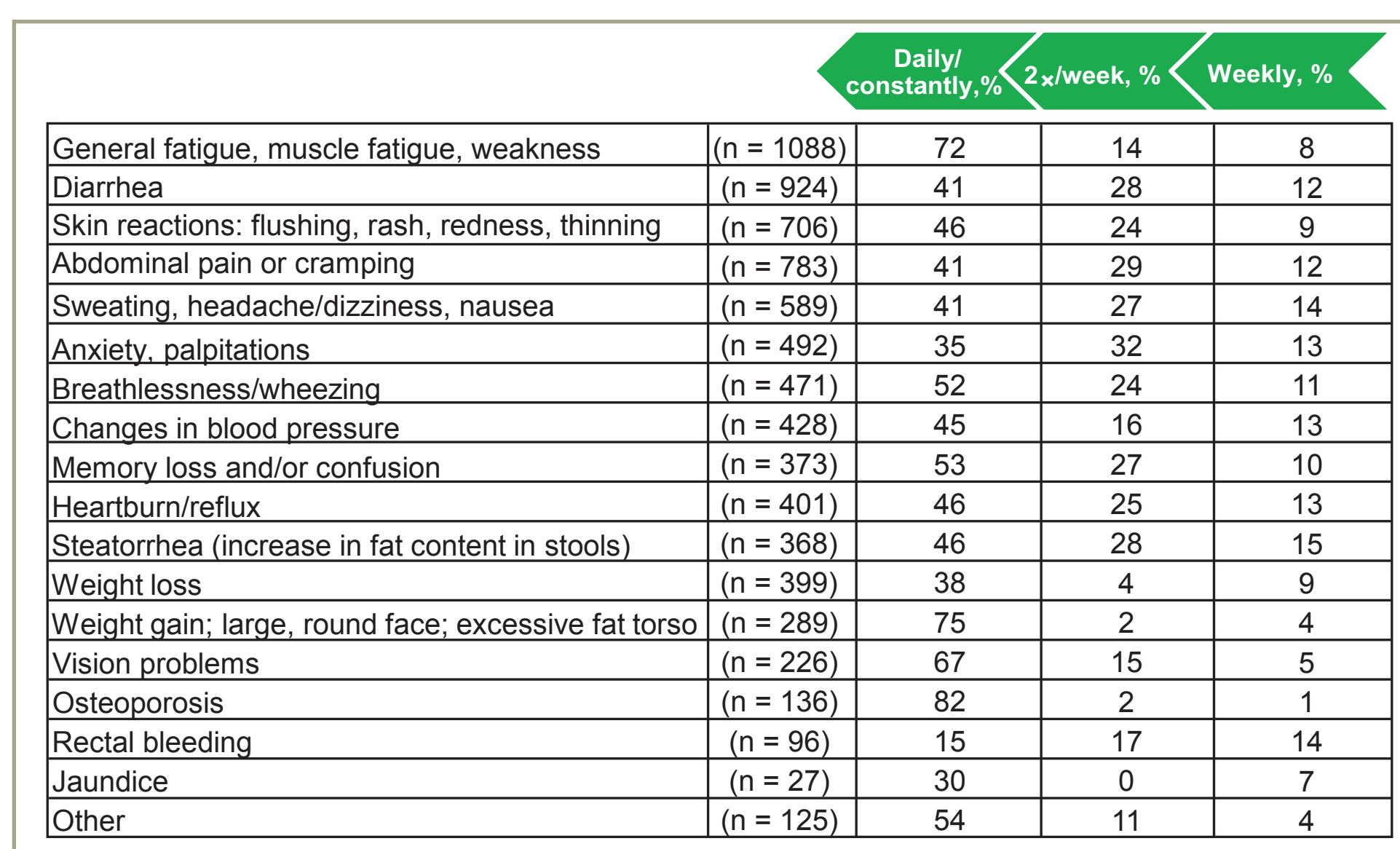
- Patients with GI NETs (73%) were significantly more likely than those with lung NETs (66%) but not pNETs (70%) to report experiencing a large/moderate negative impact on daily life

Figure 2. NET-related symptoms reported by patients.



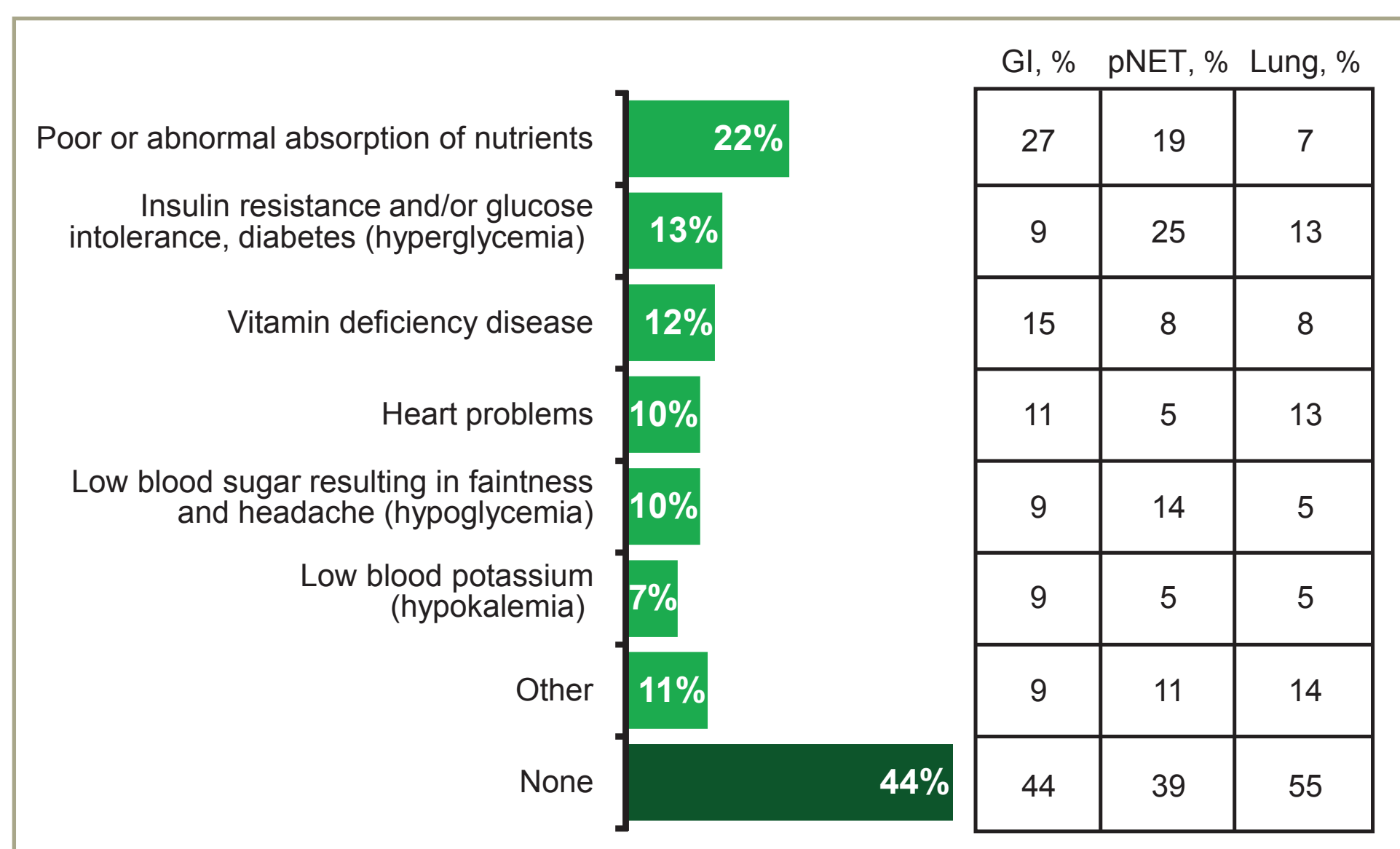
Base population: All respondents (N = 1928). Question: Which of the following symptoms, if any, do you suffer from as a result of your NET? Select all that apply.

Figure 3. Frequency of NET-related symptoms reported by patients.



Base population: All respondents (N = varies). Question: How frequently do you suffer from each of the following symptoms as a result of your NET?

Figure 4. Conditions occurring as a result of NETs.

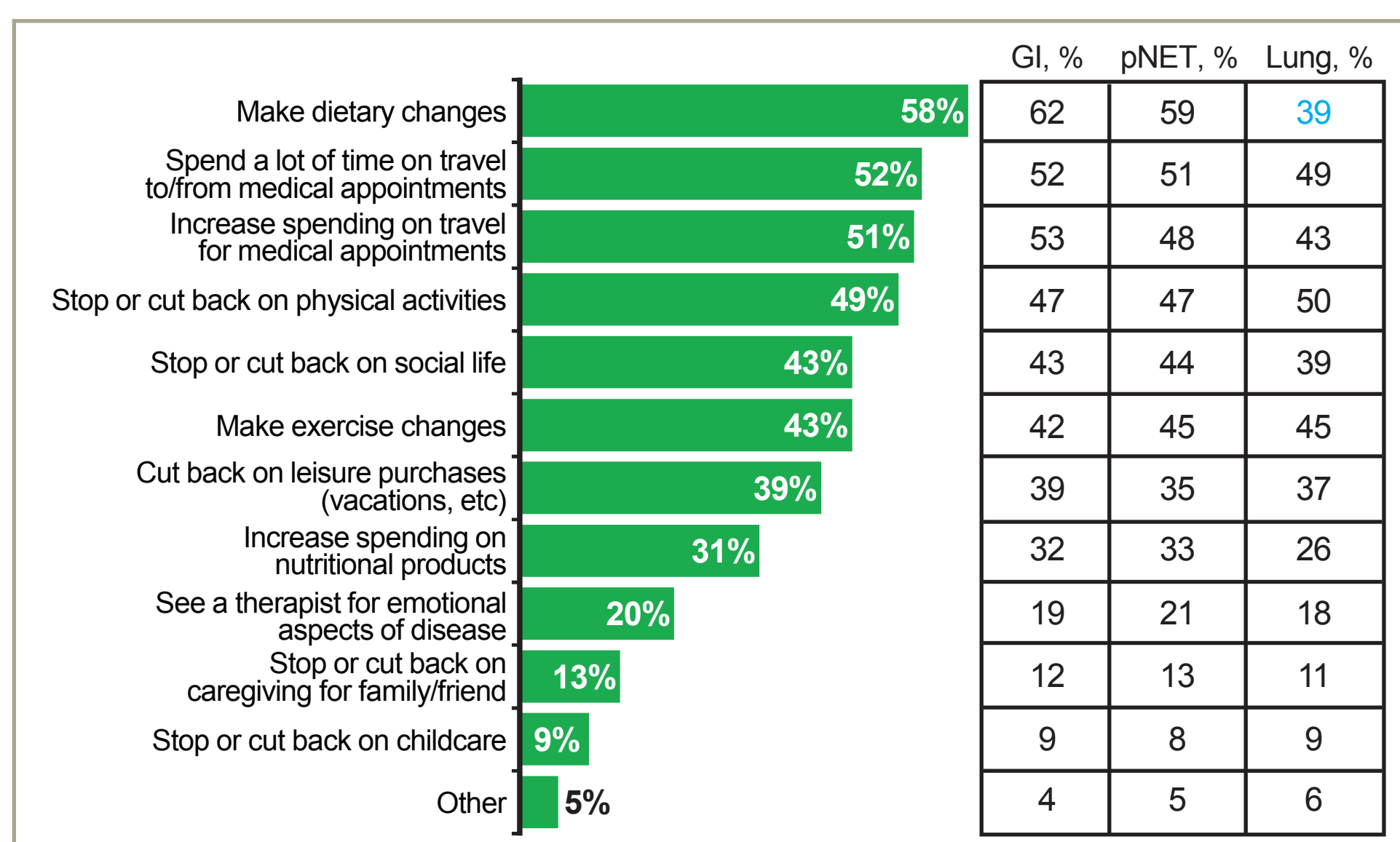


Base population: All respondents (N = 1928). Question: Which of the following conditions, if any, do you suffer from as a result of your NET? Select all that apply.

Impact of NETs on daily life and work life

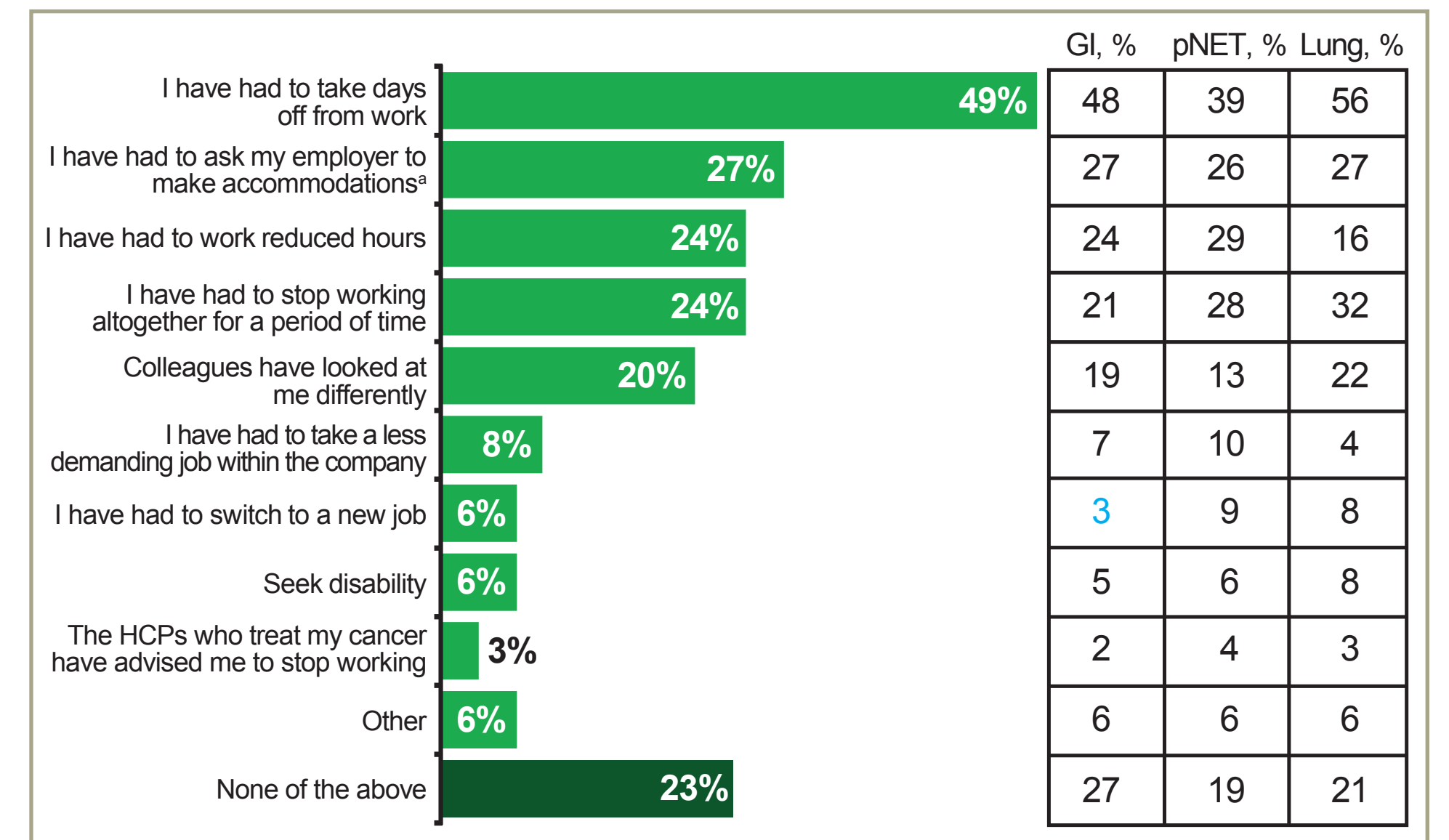
- NETs impacted various aspects of patients' daily lives (Figure 5). Patients with GI NETs (62%) or pNETs (59%) more often made dietary changes than those with lung NETs (39%).

Figure 5. Impact of NETs on patients' daily lives.



Base population: All respondents (N = 1928). Question: Since you were diagnosed with your NET, have you had to make any of the following changes? Please select all that apply.

Figure 6. Impact of NETs on patients' work.

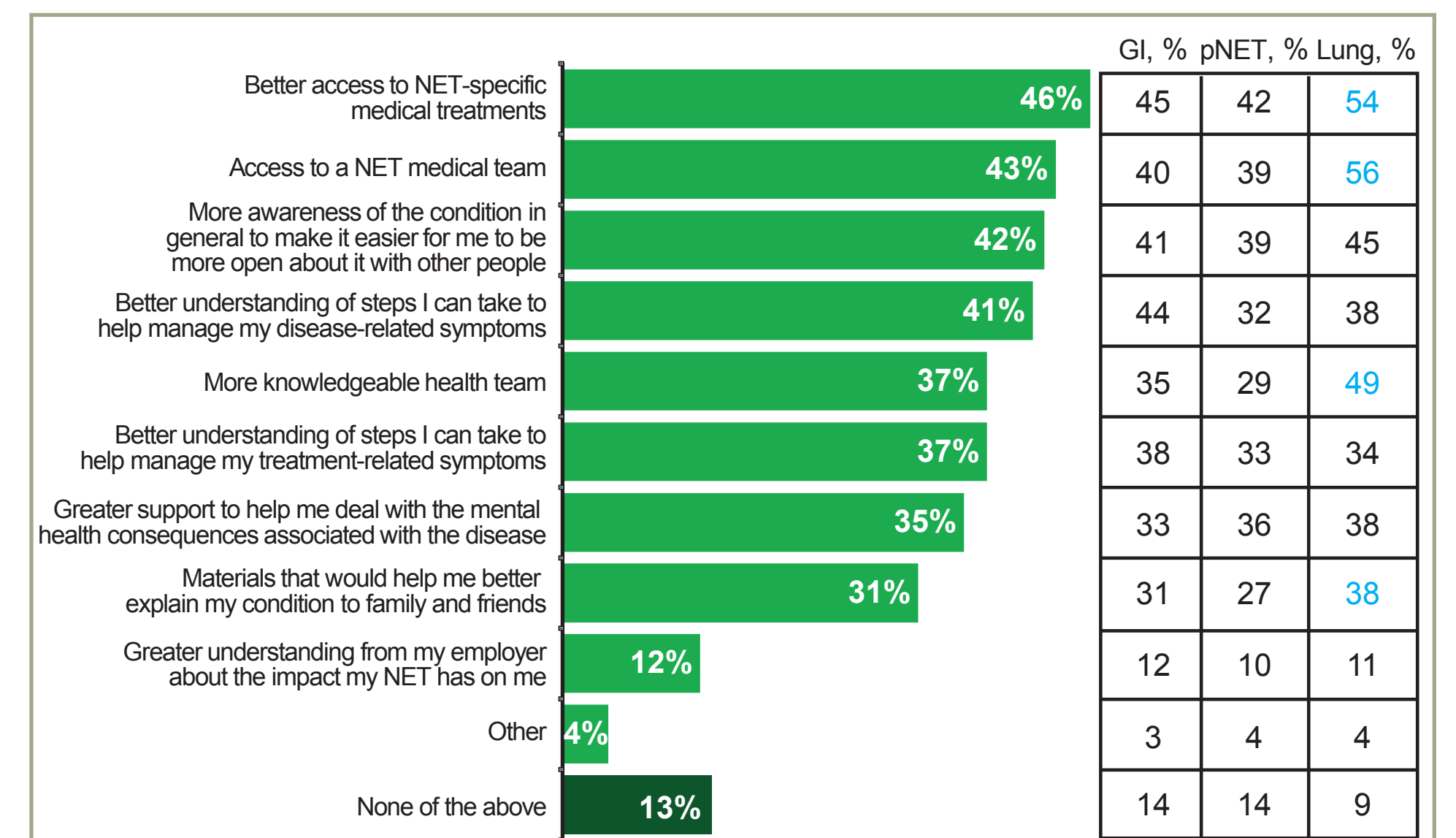


Base population: Respondents who are working full time/part time or self-employed (n = 741). Question: Has your NET impacted you at work in any of the following ways? Please select all that apply.

Key improvements patients believe would help them live better with NETs

- Patients suggested various improvements they felt would help them live better with NETs (Figure 7). Patients with lung NETs were more likely to desire better access to NET-specific treatments, a NET medical team, a more knowledgeable medical team, and materials that help explain NETs to family and friends...

Figure 7. Improvements patients believed would help them live better with NETs.



Base population: All respondents (N = 1928). Question: Which of the following, if any, would help you living with a NET? Blue text indicates significant differences between comparison groups, P < 0.05.

LIMITATIONS

- This global NET patient survey had several important limitations that may have impacted results: A patient-reported design was employed without independent verification, leading to potential recall bias.

CONCLUSIONS

- This first large global NET patient survey demonstrated the considerable impact NETs have on patients' daily lives and work-related activities, and identified select differences among tumor types.

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1. Oberg KE. Ann Oncol. 2010;21(suppl 7):vii72-vii80. 2. Vinik AI, et al. Pancreas. 2010;39(6):713-734. 3. Yao JC, et al. J Clin Oncol. 2008;26(18):3063-3072.

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