**Supplemental Digital Content 1**

NET Patient Survey

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**Introduction**

**Please take a few moments to read the following:**

The aim of this survey is to gain the views and experiences of people living with a neuroendocrine tumor (NET) to provide a better understanding of NET patient needs and challenges. The data collected in this research may be used by the sponsoring pharmaceutical company or the patient group partners for disease awareness activities.

Any information that you disclose will be treated in the strictest confidence. No answers will be attributable to you as an individual.

You have the right to withdraw from the survey at any time and to withhold information as you see fit.

By answering ‘yes’ to the question below, you confirm that you have read, understood and accept the points above.

Are you happy to proceed on this basis?

|  |  |  |
| --- | --- | --- |
| 01 | Yes | **⭘** |
| 02 | No | **⭘** |

***If no, please stop the survey at this point*.**

S2 Have you been diagnosed with a neuroendocrine tumor(s) (NET)?

*Neuroendocrine tumor/NET: GI NET (Gastrointestinal neuroendocrine tumor),GEP NET (gastroenteropancreatic neuroendocrine tumor), pNET (pancreatic neuroendocrine tumor), lung NET, bronchial NET, carcinoid syndrome or carcinoid tumor, lung carcinoid, large cell neuroendocrine carcinoma, pheochromocytoma, paraganglioma, MEN (Multiple endocrine neoplasia), small cell lung cancer*

|  |  |  |
| --- | --- | --- |
| 01 | Yes | **⭘** |
| 02 | No | **⭘** |

***If no, please stop the survey at this point.***

S3. Approximately how many years ago were you first diagnosed with a neuroendocrine tumor(s) (NET)? If it was less than one year ago, please put 1.

|  |
| --- |
|  |

S4. What was the primary site/site of origin of your neuroendocrine tumor(s) (NET)? Please tick all options that apply.

|  |  |  |
| --- | --- | --- |
| 01 | I don’t know | **⭘** |
| 02 | Pancreas | **⭘** |
| 03 | Gastrointestinal tract (bowel, small intestine, duodenum, large intestine, stomach, colon, rectum, jejunum, ileum, appendix, cecum) | **⭘** |
| 04 | Thymus | **⭘** |
| 05 | Lung | **⭘** |
| 06 | Site unknown | **⭘** |
| 07 | Other | **⭘** |

S5. What has happened to your primary tumor since you were first diagnosed? Please tick only one option.

*Primary tumor: The primary tumor is where the cancer originated.*

|  |  |  |
| --- | --- | --- |
| 01 | I don’t know | **⭘** |
| 02 | It was surgically removed | **⭘** |
| 03 | It has grown or spread | **⭘** |
| 04 | It has stayed the same (stable disease) | **⭘** |
| 05 | It has gotten smaller | **⭘** |

S6. How, if at all, does your physician currently describe the **functional status** of your neuroendocrine tumor(s) (NET)? Please tick only one option.

|  |  |  |
| --- | --- | --- |
| 01 | I don’t remember | **⭘** |
| 02 | Physician does not describe or discuss | **⭘** |
| 03 | **Functional NET:** Produces symptoms caused by the secretion of hormones (eg, flushing, diarrhea, wheezing, cramping) | **⭘** |
| 04 | **Non-functional NET:** Does not secrete hormones; however they may cause symptoms caused by the tumors’ growth (eg, pain, intestinal blockage, bleeding) | **⭘** |
| 05 | **Asymptomatic** (experience no symptoms) | **⭘** |

S6a. Which of the following, if any, does your physician currently use to describe the **grade** of your neuroendocrine tumor(s) NET? Please tick only one option.

|  |  |  |
| --- | --- | --- |
| 01 | I don’t remember | **⭘** |
| 02 | Physician did not give my NET a grade | **⭘** |
| 03 | Physician did not describe or discuss | **⭘** |
| 04 | **Low (Grade 1):** NETs are relatively slow growing ; **Ki-67 index: ≤**2% | **⭘** |
| 05 | **Intermediate (Grade 2):** NETs have a less predictable, moderately aggressive course ; **Ki-67 index:** 3-20% | **⭘** |
| 06 | **High (Grade 3):** NETs can be highly aggressive ; **Ki-67 index:** >20% | **⭘** |

**Section A:** Current NET status

Thank you for agreeing to participate in this survey. It should take about **25 minutes** and **should be completed all at once**.

Please note that throughout the survey if there are any questions you **prefer not to answer**, you can select this option at the bottom of the question and move to the next question.

This survey is intended to capture **individual experiences of living with NET.** Please be aware that everyone’s experiences are different and some of the answers may not apply to you due to differing severities of disease**.**

Throughout the survey, we will be using some of the following terms:

|  |
| --- |
| “**Neuroendocrine tumor(s) or NET**”: *GI NET,GEP NET, pNET, Lung NET, bronchial NET, Carcinoid syndrome or Carcinoid tumor, lung carcinoid, neuroendocrine carcinoma, MEN, pheochromocytoma, paraganglioma, small cell lung cancer)* |
| “**Healthcare professionals (HCPs)**”: nurses, doctors and any other medical personnel |
| “**Your NET medical care providers**”: all healthcare professionals (HCPs) specifically involved in the management of your NET |

First, we would like to ask you a few questions about your current situation living with a neuroendocrine tumor(s) (NET).

A1. Which of the following best describes your current overall health? Please tick only one option.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | Very poor |  | **⭘** |
| 02 | Poor |  | **⭘** |
| 03 | Fair |  | **⭘** |
| 04 | Good |  | **⭘** |
| 05 | Very good |  | **⭘** |
| 06 | Prefer not to answer |  | **⭘** |

A2. How does having a neuroendocrine tumor (NET) make you feel? Please tick all options that apply.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | Stressed |  | **⭘** |
| 02 | Hopeless |  | **⭘** |
| 03 | Anxious/Worried |  | **⭘** |
| 04 | Isolated |  | **⭘** |
| 05 | Frustrated |  | **⭘** |
| 06 | Depressed |  | **⭘** |
| 07 | Angry |  | **⭘** |
| 08 | Scared |  | **⭘** |
| 09 | Uncertain |  | **⭘** |
| 10 | Shocked |  | **⭘** |
| 11 | Hopeful |  | **⭘** |
| 12 | Motivated |  | **⭘** |
| 13 | Brave |  | **⭘** |
| 14 | Confident |  | **⭘** |
| 15 | Optimistic |  | **⭘** |
| 16 | Concerned |  | **⭘** |
| 17 | Other |  | **⭘** |
| 18 | None of the above |  | **⭘** |
| 19 | Prefer not to answer |  | **⭘** |

A3a. Which of the following **symptoms**, if any, do you suffer from as a result of your neuroendocrine tumor(s) (NET)? Please tick all options that apply.

*Symptom: a direct experience as a result of the disease (eg, nausea, cramping)*

|  |  |  |  |
| --- | --- | --- | --- |
| **Symptoms** | | | |
| 01 | Abdominal pain or cramping |  | **⭘** |
| 02 | Diarrhea |  | **⭘** |
| 03 | Steatorrhea (increase in fat content in stools)~~;~~ |  | **⭘** |
| 04 | Heartburn/reflux |  | **⭘** |
| 05 | Skin reactions: Flushing; Skin rash; Redness and swelling of the mouth and tongue; Thinning of the skin |  | **⭘** |
| 06 | Breathlessness/Wheezing |  | **⭘** |
| 07 | Memory loss and/or confusion |  | **⭘** |
| 08 | Weight gain; Large, round face; Excessive torso fat |  | **⭘** |
| 09 | Weight loss |  | **⭘** |
| 10 | General fatigue; Muscle fatigue; Weakness |  | **⭘** |
| 11 | Osteoporosis |  | **⭘** |
| 12 | Vision problems |  | **⭘** |
| 13 | Sweating; Headaches/Dizziness; Nausea with or without vomiting |  | **⭘** |
| 14 | Jaundice |  | **⭘** |
| 15 | Rectal bleeding |  | **⭘** |
| 16 | Changes in blood pressure |  | **⭘** |
| 17 | Anxiety, palpitations |  | **⭘** |
| 18 | Other |  | **⭘** |
| 19 | None |  | **⭘** |
| 20 | Prefer not to answer |  | **⭘** |

A3b. Which of the following **conditions**, if any, do you suffer from as a result of your neuroendocrine tumor(s) (NET)? Please tick all options that apply.

*Condition: a state that causes an illness (eg, ulcers)*

|  |  |  |  |
| --- | --- | --- | --- |
| **Conditions** | | | |
| 01 | Poor or abnormal absorption of nutrients |  | **⭘** |
| 02 | Insulin resistance and/or glucose intolerance; diabetes - (Hyperglycemia) |  | **⭘** |
| 03 | Low blood potassium - (Hypokalemia) |  | **⭘** |
| 04 | Low stomach acid- (Hypochlorhydria) |  | **⭘** |
| 05 | Vitamin deficiency disease |  | **⭘** |
| 06 | Heart problems |  | **⭘** |
| 07 | Low blood sugar resulting in faintness and headache- (Hypoglycemia) |  | **⭘** |
| 08 | Ulcers |  | **⭘** |
| 09 | Other |  | **⭘** |
| 10 | None |  | **⭘** |
| 11 | Prefer not to answer |  | **⭘** |

A3c. How frequently do you suffer from each of the following symptoms as a result of your neuroendocrine tumor(s) (NET)?

You can indicate the frequency for each symptoms that apply using the following numbers; if not applicable, please leave blank:

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| 1 - Daily | 2 -Constantly | 3 - Couple of times a week | 4 - Weekly | 5 - Twice a month | 6 - Once a month | 7 - Less often than monthly |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | | **Symptoms Number** | | |
| 01 | Abdominal pain or cramping | |  |  |
| 02 | Diarrhea | |  |  |
| 03 | Steatorrhea (increase in fat content in stools)~~;~~ | |  |  |
| 04 | Heartburn/reflux | |  |  |
| 05 | Skin reactions: Flushing ; Skin rash; Redness and swelling of the mouth and tongue; Thinning of the skin | |  |  |
| 06 | Breathlessness/Wheezing | |  |  |
| 07 | Memory loss and/or confusion | |  |  |
| 08 | Weight gain; Large, round face; Excessive torso fat | |  |  |
| 09 | Weight loss | |  |  |
| 10 | General fatigue; Muscle fatigue; Weakness | |  |  |
| 11 | Osteoporosis | |  |  |
| 12 | Vision problems | |  |  |
| 13 | Sweating; Headaches/Dizziness; Nausea with or without vomiting | |  |  |
| 14 | Jaundice | |  |  |
| 15 | Rectal bleeding | |  |  |
| 16 | Changes in blood pressure | |  |  |
| 17 | Anxiety, palpitations | |  |  |
| 18 | Other | |  |  |
| 19 | None | |  |  |
| 20 | Prefer not to answer | |  |  |

A4. Do you have a caregiver (ie, close family member or friend) who helps you manage the day-to-day activities associated with caring for your neuroendocrine tumor(s) (NET) (ie, accompanies you to doctor visits; helps you make treatment decisions; helps you with daily household tasks; provides emotional support, etc.)?

|  |  |  |
| --- | --- | --- |
| 01 | Yes | **⭘** |
| 02 | No | **⭘** |
| 03 | Prefer not to answer | **⭘** |

A5. How would you describe your current employment status? Please tick only one option.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | Employed full time |  | **⭘** |
| 02 | Employed part time |  | **⭘** |
| 03 | Self-employed |  | **⭘** |
| 04 | Not employed, but looking for work |  | **⭘** |
| 05 | Not employed and not looking for work |  | **⭘** |
| 06 | Not able to work, on medical disability |  | **⭘** |
| 07 | Retired |  | **⭘** |
| 08 | Student |  | **⭘** |
| 09 | Homemaker |  | **⭘** |
| 10 | Prefer not to answer |  | **⭘** |

A5b. Which of the following healthcare professionals are involved in the ongoing management of your neuroendocrine tumor(s) (NET)? Please tick all options that apply.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | General Practitioner (GP)/Primary Care Physician (PCP)/Internist |  | **⭘** |
| 02 | Nurse Practitioner/Nurse |  | **⭘** |
| 03 | Gastrointestinal specialist (medical specialists who focus on disorders of the digestive system) |  | **⭘** |
| 04 | Endocrinologist (medical specialists who deal with the diseases and hormone secretions of the endocrine system) |  | **⭘** |
| 05 | Oncologist/Hematologist (medical specialists who deal with cancer) |  | **⭘** |
| 06 | Pulmonologist/Lung specialist (medical specialists who deal with diseases of the lungs and the respiratory tract) |  | **⭘** |
| 07 | Surgeon |  | **⭘** |
| 08 | Nutritionist |  | **⭘** |
| 09 | Nuclear medicine specialist (medical specialists who use tracers, usually radiopharmaceuticals, for diagnosis and therapy) |  | **⭘** |
| 10 | Physician Assistant |  | **⭘** |
| 11 | Other |  | **⭘** |
| 12 | Prefer not to answer |  | **⭘** |

Please note that we will refer to the list of professionals selected above as your ‘**NET medical care providers’** throughout the rest of the survey.

A6a. How would you describe awareness of neuroendocrine tumor(s) (NET) among each of the following? Please select your level of awareness by ticking one option per row; if not applicable, please leave the row blank.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | Not at all aware | Somewhat aware | Very aware | Extremely aware | Prefer not to answer |
| 01 | Healthcare professionals in general | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 02 | Your caregiver(s) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 03 | Your work colleagues | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 04 | Other NET patients | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 05 | NET patient support groups | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 06 | Family | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 07 | Friends | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |

A8a. Which of the following best describes the **level of support** you receive from each of the following in helping you deal with your neuroendocrine tumor(s) NET? Please select the level of support by ticking one option per row; if not applicable, please leave the row blank.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | Not at all supportive | Somewhat supportive | Very supportive | Extremely supportive | Prefer not to answer |
| 01 | Healthcare professionals in general | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 02 | Your caregiver(s) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 03 | Your work colleagues | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 04 | Other NET patients | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 05 | NET patient support groups | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 06 | Family | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
|  |  | Not at all supportive | Somewhat supportive | Very supportive | Extremely supportive | Prefer not to answer |
| 07 | Friends | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 09 | General Practitioner (GP)/Primary Care Physician (PCP)/Internist | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 10 | Nurse Practitioner/Nurse | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 11 | Gastrointestinal specialist (medical specialists who focus on disorders of the digestive system) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 12 | Endocrinologist (medical specialists who deal with the diseases and hormone secretions of the endocrine system) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 13 | Oncologist/Hematologist (medical specialists who deal with cancer) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 14 | Pulmonologist/Lung specialist (medical specialists who deal with diseases of the lungs and the respiratory tract) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 15 | Surgeon | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 16 | Nutritionist | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 17 | Nuclear medicine specialist (medical specialists who use tracers, usually radiopharmaceuticals, for diagnosis and therapy) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 18 | Physician Assistant | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 19 | Other people in general | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |

A10a. To what extent do the following people understand how having a neuroendocrine tumor(s) NET affects your life? Please select the level of understanding by ticking one option per row; if not applicable, please leave the row blank.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | Not at all supportive | Somewhat supportive | Very supportive | Extremely supportive | Prefer not to answer |
| 01 | Healthcare professionals in general | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 02 | Your caregiver(s) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 03 | Your work colleagues | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 04 | Other NET patients | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 05 | NET patient support groups | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 06 | Family | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 07 | Friends | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 09 | General Practitioner (GP)/Primary Care Physician (PCP)/Internist | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 10 | Nurse Practitioner/Nurse | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 11 | Gastrointestinal specialist (medical specialists who focus on disorders of the digestive system) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 12 | Endocrinologist (medical specialists who deal with the diseases and hormone secretions of the endocrine system) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 13 | Oncologist/Hematologist (medical specialists who deal with cancer) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 14 | Pulmonologist/Lung specialist (medical specialists who deal with diseases of the lungs and the respiratory tract) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 15 | Surgeon | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 16 | Nutritionist | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 17 | Nuclear medicine specialist (medical specialists who use tracers, usually radiopharmaceuticals, for diagnosis and therapy) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 18 | Physician Assistant | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 19 | Other people in general | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |

**Section B:** Diagnosis

We would now like you to think back to when you were **diagnosed** with a neuroendocrine tumor(s) (NET).

B1a. At the moment when you were **initially diagnosed** with a neuroendocrine tumor(s) (NET), how did you feel? Please tick all options that apply.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | Hopeless |  | **⭘** |
| 02 | Isolated |  | **⭘** |
| 03 | Depressed/sad |  | **⭘** |
| 04 | Angry |  | **⭘** |
| 05 | Guilty |  | **⭘** |
| 06 | Scared |  | **⭘** |
| 07 | Uncertain |  | **⭘** |
| 08 | Shocked |  | **⭘** |
| 09 | Hopeful |  | **⭘** |
| 10 | Optimistic |  | **⭘** |
| 11 | Relieved |  | **⭘** |
| 12 | Frustrated |  | **⭘** |
| 13 | Bewildered |  | **⭘** |
| 14 | Other |  | **⭘** |
| 15 | None of the above |  | **⭘** |
| 16 | Prefer not to answer |  | **⭘** |

B2. What was the approximate length of time between your first symptom and your neuroendocrine tumor(s) (NET) diagnosis?

|  |  |  |  |
| --- | --- | --- | --- |
| Please entre the length of time in years and/or months | |  | **\_\_\_\_\_\_\_\_\_\_\_Years \_\_\_\_\_\_\_\_\_Months** |
| Prefer not to answer |  | | **⭘** |

B3. Which of the following best describes your experience of getting a neuroendocrine tumor(s) (NET) diagnosis? Please tick only one option.

|  |  |  |
| --- | --- | --- |
| 01 | I cannot remember/ I don’t know | **⭘** |
| 02 | I had no initial symptoms but was **diagnosed with NET during tests for another condition** | **⭘** |
| 03 | After my initial symptoms and the tests that followed, a neuroendocrine tumor(s) (NET) diagnosis was the **first diagnosis** I received | **⭘** |
| 04 | After my initial symptoms and the tests that followed, I was **diagnosed once with another condition** before eventually receiving a neuroendocrine tumor(s) (NET) diagnosis | **⭘** |
| 05 | After my initial symptoms and the tests that followed, I was **diagnosed more than once with other conditions** before eventually receiving a neuroendocrine tumor(s) (NET) diagnosis | **⭘** |
| 06 | Prefer not to answer | **⭘** |

**If you were diagnosed once with another condition before eventually receiving a neuroendocrine tumor(s) (NET) diagnosis OR you were diagnosed more than once with another condition before eventually receiving a neuroendocrine tumor(s) (NET) diagnosis, please answer the following question.**

B4. Which of the following conditions were you initially diagnosed with prior to receiving a neuroendocrine tumor(s) (NET) diagnosis? Please tick all options that apply.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | I don’t remember |  | **⭘** |
| 02 | Irritable Bowel Syndrome (IBS) |  | **⭘** |
| 03 | Inflammatory Bowel Diseases (Crohn’s disease, ulcerative colitis) |  | **⭘** |
| 04 | Ulcer |  | **⭘** |
| 05 | Menopause |  | **⭘** |
| 06 | Anxiety/Psychosomatic-type condition |  | **⭘** |
| 07 | Gastritis/other digestive disorder |  | **⭘** |
| 08 | Asthma |  | **⭘** |
| 09 | Pneumonia |  | **⭘** |
| 10 | Psychiatric disorder |  | **⭘** |
| 11 | Anorexia |  | **⭘** |
| 12 | Diabetes |  | **⭘** |
| 13 | Rosacea |  | **⭘** |
| 14 | Prefer not to answer |  | **⭘** |

B5a. Approximately **how many healthcare professionals** (including all doctors, specialists and nurses) were involved in your diagnosis of a neuroendocrine tumor(s) (NET)? Please consider all those you saw from the time you first experienced symptoms to the time you received the diagnosis of a neuroendocrine tumor(s) NET.

|  |  |  |
| --- | --- | --- |
| 01 | Enter number | **\_\_\_\_\_\_\_\_\_\_\_\_** |
| 02 | I don’t know/can’t remember | **⭘** |
| 03 | Prefer not to answer | **⭘** |

B5b. Approximately **how many different visits** to healthcare professionals (including all doctors, specialists and nurses) did you have to make? Please consider all those you saw from the time you first experienced symptoms to the time you received the diagnosis of a neuroendocrine tumor(s) (NET).

|  |  |  |
| --- | --- | --- |
| 01 | Enter number | **\_\_\_\_\_\_\_\_\_\_\_\_** |
| 02 | I don’t know/can’t remember | **⭘** |
| 03 | Prefer not to answer | **⭘** |

B5c. Did you receive your NET diagnosis at a medical center that specializes in NET? Please tick only one option.

|  |  |  |
| --- | --- | --- |
| 01 | Yes | **⭘** |
| 02 | No | **⭘** |
| 03 | Prefer not to answer | **⭘** |

B6. Which of the following best describes your neuroendocrine tumor(s) (NET) at the time of diagnosis? Please tick only one option

|  |  |  |
| --- | --- | --- |
| 01 | I cannot remember | **⭘** |
| 02 | I don’t know | **⭘** |
| 03 | It was confined to one organ/site of origin | **⭘** |
| 04 | It had spread/metastasized to other organs | **⭘** |
| 05 | Prefer not to answer | **⭘** |

B7. Which of the following impressions did you get from your NET medical care providers about your neuroendocrine tumor(s) (NET) at the time of diagnosis? Please tick all options that apply.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | Uncommon |  | **⭘** |
| 02 | Malignant |  | **⭘** |
| 03 | Poorly understood |  | **⭘** |
| 04 | Benign |  | **⭘** |
| 05 | Unusual type of cancer |  | **⭘** |
| 06 | Cancer in slow motion |  | **⭘** |
| 07 | Hard to predict |  | **⭘** |
| 08 | Curable |  | **⭘** |
| 09 | Controllable |  | **⭘** |
| 10 | Life threatening |  | **⭘** |
| 11 | Not something to worry about too much |  | **⭘** |
| 12 | Curable with surgery |  | **⭘** |
| 13 | Cancer-like |  | **⭘** |
| 14 | Other |  | **⭘** |
| 15 | None of the above |  | **⭘** |
| 16 | Prefer not to answer |  | **⭘** |

B8. Prior to diagnosis, did you ever think that the symptoms you were experiencing could be the result of a cancer? Please tick only one option.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | Yes |  | **⭘** |
| 02 | No |  | **⭘** |
| 03 | Don’t know |  | **⭘** |
| 04 | Can’t remember |  | **⭘** |
| 05 | Prefer not to answer |  | **⭘** |

B9. To what extent do you agree or disagree with the following statements? Please indicate how strongly you agree or disagree with each statement by placing a tick in each row.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | Strongly disagree | Somewhat disagree | Somewhat agree | Strongly agree | Prefer not to answer |
| 01 | I think there is a lot of room for improvement in the process of diagnosing neuroendocrine tumor(s) (NET) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 02 | I received comprehensive medical care after I was diagnosed | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 03 | When/after I was diagnosed, I had sufficient information to educate me about neuroendocrine tumor(s) (NET) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 04 | I was able to get answers to the questions I had about NET | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |

B10. Which of the following, if any, would have helped you have a better experience with your neuroendocrine tumor(s) (NET) diagnosis? Please tick all options that apply.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | Everything went to my satisfaction |  | **⭘** |
| 02 | More knowledgeable healthcare professionals |  | **⭘** |
| 03 | A better aligned/coordinated medical team |  | **⭘** |
| 04 | Immediate access to NET patient support groups |  | **⭘** |
| 05 | Immediate access to healthcare professionals to help me deal with the emotional effect of the diagnosis |  | **⭘** |
| 06 | A clearer idea of treatment options available |  | **⭘** |
| 07 | Better direction on where to find useful information about neuroendocrine tumor(s) (NET) |  | **⭘** |
| 08 | Less travel to numerous different healthcare professionals |  | **⭘** |
| 09 | Clearer information on the diagnostic tests given |  | **⭘** |
| 10 | A better understanding of test results and how they influence the best treatments for me |  | **⭘** |
| 11 | Clearer information about the longer term impact of the disease |  | **⭘** |
| 12 | More immediate access to the correct healthcare professionals who have NET expertise |  | **⭘** |
| 13 | A more positive future outlook from the healthcare professionals involved in diagnosis |  | **⭘** |
| 14 | Other |  | **⭘** |
| 15 | Prefer not to answer |  | **⭘** |

**Section C: Quality of Life**

Now we would like to focus on the impact of NET on your daily life.

C1. How much of a **negative impact**, if any, has your neuroendocrine tumor(s) (NET) had on your overall quality of life? Please tick only one option.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | None |  | **⭘** |
| 02 | A little |  | **⭘** |
| 03 | A moderate amount |  | **⭘** |
| 04 | A lot |  | **⭘** |
| 05 | Prefer not answer |  | **⭘** |

C2. How much has each of the following areas of your life been **negatively affected**, if at all, by your neuroendocrine tumor(s) (NET)? Please indicate the level of negative affect your neuroendocrine tumor(s) (NET) has had on each area by placing a tick in each row.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | None | A little | A moderate amount | A lot | Not Applicable | Prefer not to answer |
| 01 | My relationship with my spouse/partner | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 02 | My relationships with my family (other than a spouse/partner) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 03 | My relationships with my friends | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 04 | My ability to perform my job | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 05 | My ability to participate in leisure activities | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 06 | My ability to travel | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 07 | My ability to perform everyday household chores | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 08 | My ability to care for my family | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 09 | My finances | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 10 | My emotional health | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 11 | My attitude towards daily life | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 12 | The emotional health of those close to me (family, friends, etc.) | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 13 | My overall energy levels | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 14 | My social life | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |

C3. Which feelings, if any, do you experience, as a **direct consequence** of having a neuroendocrine tumor(s) (NET)? Please tick all options that apply.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | Depression |  | **⭘** |
| 02 | Anxiety/stress |  | **⭘** |
| 03 | Lack of interest in activities that used to interest me |  | **⭘** |
| 04 | Inability to participate in activities that I used to enjoy |  | **⭘** |
| 05 | Confusion about the management of my disease |  | **⭘** |
| 06 | Feeling isolated from friends and family |  | **⭘** |
| 07 | Less interest in interacting with friends and family |  | **⭘** |
| 08 | Worry a lot about the uncertainty of the future |  | **⭘** |
| 09 | Feel like no one understands what I am going through |  | **⭘** |
| 10 | Other |  | **⭘** |
| 11 | None of the above |  | **⭘** |
| 12 | Prefer not to answer |  | **⭘** |

**If you are employed full time, part time, or self-employed, please answer the following:**

C4a. Has your neuroendocrine tumor(s) (NET) impacted you at work in any of the following ways? Please tick all options that apply.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | I have had to take days off from work |  | **⭘** |
| 02 | I have had to take a less demanding job within the company |  | **⭘** |
| 03 | I have had to work reduced hours |  | **⭘** |
| 04 | I have had to stop working altogether for a period of time |  | **⭘** |
| 05 | I have had to switch to a new job |  | **⭘** |
| 06 | I have had to ask my employer to make accommodations (eg, flexible work schedule, work from home, adaptive devices, opportunities for rest, etc.) |  | **⭘** |
| 07 | Colleagues have looked at me differently |  | **⭘** |
| 08 | The healthcare professionals who treat my cancer have advised me to stop working |  | **⭘** |
| 09 | Seek disability |  | **⭘** |
| 10 | Other |  | **⭘** |
| 11 | None of the above |  | **⭘** |
| 12 | Prefer not to answer |  | **⭘** |

**If you fall into any of these categories, please answer the following question:**

**● Not employed and looking for work**

**● Not employed but not looking for work**

**● Not able to work and on medical disability**

C4b. Have you had to stop working as a direct result of your neuroendocrine tumor (NET)?

|  |  |  |
| --- | --- | --- |
| 01 | Yes | **⭘** |
| 02 | No | **⭘** |
| 03 | Prefer not to answer | **⭘** |

**If you are retired, please answer the following:**

C4c. When you were working, did your neuroendocrine tumor(s) (NET) impact you in any of the following ways? Please tick all options that apply.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | It did not affect my work |  | **⭘** |
| 02 | I had to retire earlier than I planned to |  | **⭘** |
| 03 | I had to take days off from work |  | **⭘** |
| 04 | I had to take a less demanding job within the company |  | **⭘** |
| 05 | I had to work reduced hours |  | **⭘** |
| 06 | I had to stop working altogether for a period of time |  | **⭘** |
| 07 | I had to switch to a new job |  | **⭘** |
| 08 | I had to ask my employer to make accommodations (eg, flexible work schedule, work from home, adaptive devices, opportunities for rest, etc.) |  | **⭘** |
| 09 | My colleagues looked at me differently |  | **⭘** |
| 10 | The healthcare professionals who treat my cancer advised me to stop working |  | **⭘** |
| 11 | I had to seek disability |  | **⭘** |
| 12 | Other |  | **⭘** |
| 13 | None of the above |  | **⭘** |
| 14 | Prefer not to answer |  | **⭘** |

C5. Since you were diagnosed with your neuroendocrine tumor(s) (NET), have you had to make any of the following changes? Please tick all options that apply.

|  |  |  |  |
| --- | --- | --- | --- |
| 01 | Stop or cut back on my social life |  | **⭘** |
| 02 | Stop or cut back on childcare (either for children or grandchildren) |  | **⭘** |
| 03 | Increase spending on nutritional products |  | **⭘** |
| 04 | Cut back on leisure purchases (ie, entertainment, vacations, etc.) |  | **⭘** |
| 05 | Increase spending on travel to and from medical appointments |  | **⭘** |
| 06 | Stop or cut back on caregiving for a family member or close friend |  | **⭘** |
| 07 | See a therapist to help with the emotional aspect of my disease |  | **⭘** |
| 08 | Spend a lot of time on travel to and from medical appointments |  | **⭘** |
| 09 | Stop or cut back on physical activities |  | **⭘** |
| 10 | Make dietary changes |  | **⭘** |
| 11 | Make exercise changes |  | **⭘** |
| 12 | Other |  | **⭘** |
| 13 | I have not had to make any changes since being diagnosed with my neuroendocrine tumor(s) (NET) |  | **⭘** |
| 14 | Prefer not to answer |  | **⭘** |

C6. Are the following people aware that you have a neuroendocrine tumor(s) (NET)? Please tick one option per row.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  |  | Yes | No | Not Applicable | Prefer not to answer |
| 01 | Spouse/partner | **⭘** | **⭘** | **⭘** | **⭘** |
| 02 | Children | **⭘** | **⭘** | **⭘** | **⭘** |
| 03 | Other relative(s) | **⭘** | **⭘** | **⭘** | **⭘** |
| 04 | Close friend(s) | **⭘** | **⭘** | **⭘** | **⭘** |
| 05 | Neighbor(s) | **⭘** | **⭘** | **⭘** | **⭘** |
| 06 | Your boss/supervisors | **⭘** | **⭘** | **⭘** | **⭘** |
| 07 | Co-worker(s) | **⭘** | **⭘** | **⭘** | **⭘** |
| 08 | Acquaintances | **⭘** | **⭘** | **⭘** | **⭘** |

C6b. Why have you not told the following people about your NET? Please indicate why the following people are not aware that you have a neuroendocrine tumor (NET) by ticking one option per row.

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | I am embarrassed | Because I don’t know where to start | I am very private | I don’t want them to view me differently | | Because they know little about NET, it can be hard to explain | Other | Prefer not to answer | Not applicable |
| 01 | Spouse/  partner | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 02 | Children | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 03 | Other relative(s) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 04 | Close friend(s) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 05 | Neighbor(s) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 06 | Your boss/ supervisors | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 07 | Co-worker(s) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 08 | Acquaintances | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |

C7. Which of the following, if any, would help you with living with a neuroendocrine tumor(s) (NET)? Please tick all options that apply.

|  |  |  |
| --- | --- | --- |
| 01 | Materials that would help me better explain my condition to family and friends | **⭘** |
| 02 | Better understanding of steps I can take to help manage my disease-related symptoms | **⭘** |
| 03 | Better understanding of steps I can take to help manage my treatment-related symptoms | **⭘** |
| 04 | Greater support to help me deal with the mental health consequences associated with the disease | **⭘** |
| 05 | Greater understanding from my employer about the impact my neuroendocrine tumor(s) (NET) has on me | **⭘** |
| 06 | More awareness of the condition in general to make it easier for me to be more open about it with other people | **⭘** |
| 07 | Better access to NET specific medical treatments | **⭘** |
| 08 | More knowledgeable health team | **⭘** |
| 09 | Access to a NET medical team | **⭘** |
| 10 | Other | **⭘** |
| 11 | None of the above | **⭘** |
| 12 | Prefer not to answer | **⭘** |

**Section D:** NET management

Now we would like to focus on the interactions you have with your **NET medical care providers**, those individuals involved in the ongoing management of your neuroendocrine tumor (NET).

D1. How often do you see each of these healthcare professionals with respect to your neuroendocrine tumor (NET)? Please insert time in number of months between visits for each care provider. If a row is not applicable, please leave the row blank.

|  |  |
| --- | --- |
|  | Insert time in months between visits |
| General Practitioner (GP)/Primary Care Physician (PCP)/Internist |  |
| Nurse Practitioner/Nurse |  |
| Gastrointestinal specialist (medical specialists who focus on disorders of the digestive system) |  |
| Endocrinologist (medical specialists who deal with the diseases and hormone secretions of the endocrine system) |  |
| Oncologist/Hematologist (medical specialists who deal with cancer) |  |
| Pulmonologist/Lung specialist (medical specialists who deal with diseases of the lungs and the respiratory tract) |  |
| Surgeon |  |
| Nutritionist |  |
| Nuclear medicine specialist (medical specialists who use tracers, usually radiopharmaceuticals, for diagnosis and therapy) |  |
| Physician Assistant |  |
| Other |  |
| Prefer not to answer |  |

D1b. How far do you live from your main NET medical care provider?

|  |  |  |
| --- | --- | --- |
| 01 | Insert distance in kilometers/miles | **\_\_\_\_\_\_\_\_\_\_\_** |
| 02 | I don’t know | **⭘** |
| 03 | Prefer not to answer | **⭘** |

**If you did not receive your NET diagnosis at a medical center that specializes in NET, please answer the following:**

D1d. Have you **ever** been to a medical center that specializes in NET and has a team of different healthcare professionals to help manage your NET care?

|  |  |  |
| --- | --- | --- |
| 01 | Yes | **⭘** |
| 02 | No | **⭘** |
| 03 | I don’t know | **⭘** |
| 04 | Prefer not to answer | **⭘** |

**If you received your NET diagnosis AND/OR attended a medical center that specializes in NET please answer the following:**

D1e. How often do you visit a medical center that specializes in NET and has a team of different healthcare professionals to help manage your NET care in a one-year period?

|  |
| --- |
|  |

*Per one-year period*

*Prefer not to answer* **⭘**

D2. Which of the following best describes the approach taken by your NET medical care providers in the management of your neuroendocrine tumor(s) (NET)? Please tick only one option.

I feel the NET medical care providers involved in my NET management…

|  |  |  |
| --- | --- | --- |
| 01 | …**always** function as a **well-coordinated team that is aligned** on how best to manage my condition | **⭘** |
| 02 | …**sometimes** function as a **well-coordinated team that is aligned** on how best to manage my condition and **at other times** function as a **group of individuals** who are not well coordinated and I am passed around a lot | **⭘** |
| 03 | …function as a **group of individuals who are not well coordinated** and I am passed around a lot | **⭘** |
| 04 | Prefer not to answer | **⭘** |

D5b. Which of the following, if any, do you discuss at these meetings with your NET medical care providers? Please tick all options that apply.

|  |  |  |
| --- | --- | --- |
| 01 | The results of ongoing tests | **⭘** |
| 02 | New research developments in the NET field | **⭘** |
| 03 | New treatment options for you | **⭘** |
| 04 | Your emotional/mental health | **⭘** |
| 05 | Your overall well-being | **⭘** |
| 06 | Patient advocacy groups | **⭘** |
| 07 | Changes in symptoms | **⭘** |
| 08 | Changes in physical health | **⭘** |
| 09 | Other | **⭘** |
| 10 | None of the above | **⭘** |
| 11 | Prefer not to answer | **⭘** |

D6a. Which of the following best describes your approach to the management of your neuroendocrine tumor(s) (NET)? Please tick only one option

|  |  |  |
| --- | --- | --- |
| 01 | **I like to drive the decisions** about my care with input from my NET medical care providers | **⭘** |
| 02 | I like to **work in partnership** with my NET medical care providers to make decisions about my care | **⭘** |
| 03 | I **look to my** NET medical care providers **to guide me** in making decisions about my care | **⭘** |
| 03 | Prefer not to answer | **⭘** |

**Section G:** NET management: Treatment

Now we would like to focus on your experience of NET treatments and tests.

G1. How would you rate the **overall quality** of NET treatments available today? Please tick only one option.

|  |  |  |
| --- | --- | --- |
| 01 | Very poor | **⭘** |
| 02 | Poor | **⭘** |
| 03 | Good | **⭘** |
| 04 | Very Good | **⭘** |
| 05 | Prefer not to answer | **⭘** |

G2a/b/c. This is a list of available neuroendocrine tumor(s) (NET) treatments. Please select those you have **heard of**, those you have **access to** (meaning they are available to you) and those you **have received/are currently receiving** for the treatment of your neuroendocrine tumor(s) (NET).

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | G2a  Treatments I have **heard of** | G2b  Treatments I have **access to** | G2c Treatments I have **received/am currently receiving** |
| 01 | Surgery | **⭘** | **⭘** | **⭘** |
| 02 | Chemotherapy | **⭘** | **⭘** | **⭘** |
| 03 | Drug therapy other than chemotherapy | **⭘** | **⭘** | **⭘** |
| 04 | PRRT (peptide receptor radionuclide therapy or targeted radiation therapy) | **⭘** | **⭘** | **⭘** |
| 05 | Interventional radiology | **⭘** | **⭘** | **⭘** |
| 06 | Observation (eg, watch and wait) | **⭘** | **⭘** | **⭘** |
| 07 | Other | **⭘** | **⭘** | **⭘** |
| 08 | Prefer not to answer | **⭘** | **⭘** | **⭘** |

G4a. Have you ever been asked to participate in a NET clinical trial?

|  |  |  |
| --- | --- | --- |
| 01 | Yes | **⭘** |
| 02 | No | **⭘** |
| 03 | Prefer not to answer | **⭘** |

G4b. Have you ever approached your medical team to participate in a NET clinical trial?

|  |  |  |
| --- | --- | --- |
| 01 | Yes | **⭘** |
| 02 | No | **⭘** |
| 03 | Prefer not to answer | **⭘** |

**If you have ever been asked to participate in a NET clinical trial OR you have ever approached your medical team to participate in a NET clinical trial, please answer the following:**

G4c. Have you ever participated in a NET treatment clinical trial?

|  |  |  |
| --- | --- | --- |
| 01 | Yes | **⭘** |
| 02 | No | **⭘** |
| 03 | Prefer not to answer | **⭘** |

G6a. Which of the following tests, if any, have you received for the ongoing management of your neuroendocrine tumor(s) (NET)? Please tick all options that apply.

|  |  |  |
| --- | --- | --- |
| 01 | I am not sure which tests I had | **⭘** |
| 02 | Imaging  or enhanced imaging (examples include computed tomography [CT]; magnetic resonance imaging [MRI]; positron emission tomography [PET]; somatostatin-receptor scintigraphy [Octreoscan™];  PET/CT with Ga68; F-DOPA scan; FDG PET/CT; MIBG scan) | **⭘** |
| 03 | Endoscopic procedures (examples include gastroscopy, colonoscopy, capsule endoscopy) | **⭘** |
| 04 | 5-Hydroxyindoleacetic acid in serum (5-HIAA) | **⭘** |
| 05 | Other blood tests (examples include fasting serum glucose; fasting gastrin;  glucagon; vasoactive intestinal peptide (VIP); somatostatin) | **⭘** |
| 06 | 5-hydroxyindoleacetic acid  in urine (5-HIAA) | **⭘** |
| 07 | Chromogranin A (CgA) | **⭘** |
| 08 | Other | **⭘** |
| 09 | None of the above | **⭘** |
| 03 | Prefer not to answer | **⭘** |

**If you have ever had any of the tests listed in G6a, please answer the following:**

G6b. Have you ever had to go to another country for a treatment or test?

|  |  |  |
| --- | --- | --- |
| 01 | Yes | **⭘** |
| 02 | No | **⭘** |
| 03 | Prefer not to answer | **⭘** |

**If you have ever had any tests other than the ones listed in G6a, please answer the following:**

G6c. Thinking about all of the tests you have for the ongoing management of your neuroendocrine tumor(s) (NET), approximately how many times do you go in for each of these tests in a one-year period? If a row is not applicable, please leave the row blank.

|  |  |
| --- | --- |
|  | Number of times you go in for each of these tests in a one-year period |
| Imaging  or enhanced imaging (examples include computed tomography [CT]; magnetic resonance imaging [MRI]; positron emission tomography [PET]; somatostatin-receptor scintigraphy [Octreoscan™];  PET/CT with Ga68; F-DOPA scan; FDG PET/CT; MIBG scan) |  |
| Endoscopic procedures (examples include gastroscopy, colonoscopy, capsule endoscopy) |  |
| 5-hydroxyindoleacetic acid in serum (5-HIAA) |  |
| Other blood tests (examples include fasting serum glucose; fasting gastrin;  glucagon; vasoactive intestinal peptide (VIP); somatostatin) |  |
| 5-hydroxyindoleacetic acid  in urine (5-HIAA) |  |
| Chromogranin A (CgA) |  |
| Other |  |
| Prefer not to answer |  |

G7. To what extent do you agree or disagree with the following statements? Please indicate how strongly you agree or disagree with each statement by placing a tick in each row.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | Strongly disagree | Somewhat disagree | Somewhat agree | Strongly agree | Prefer not to answer |
| 01 | I have a very close relationship with my NET medical care providers | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 02 | I have full confidence in my NET medical care providers | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 03 | Given resources available I receive the best possible cares for my NET | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 04 | I believe that my NET medical care providers are experts in the field of neuroendocrine tumors | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 05 | I believe that the healthcare providers involved in my NET management have a lot more knowledge now than they did at the time of my diagnosis | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 06 | I believe there is still a lot of room for improvement in the management of my NETs | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 07 | My NET medical care providers provide the emotional support I need | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 08 | I often feel left with a lot of questions after a meeting with my NET medical care providers | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 09 | I believe that more treatment options are needed for the treatment of NET | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |
| 10 | I am very knowledgeable about the NET treatment options available | **⭘** | **⭘** | **⭘** | **⭘** | **⭘** |

G8. Which of the following would help with the ongoing management of your neuroendocrine tumor(s) (NET)? Please tick all options that apply.

|  |  |  |
| --- | --- | --- |
| 01 | Better access to NET experts/medical centers that specialize in NET | **⭘** |
| 02 | A better coordinated/aligned team of NET medical care providers | **⭘** |
| 03 | More information brochures from my NET medical care providers | **⭘** |
| 04 | More knowledgeable NET medical care providers | **⭘** |
| 05 | More information about/more opportunity to participate in NET clinical trials | **⭘** |
| 06 | A wider range of NET treatment options | **⭘** |
| 07 | More treatments available in my country that I see in other countries | **⭘** |
| 08 | Other | **⭘** |
| 09 | None of the above | **⭘** |
| 10 | Prefer not to answer | **⭘** |

**Section E:** NET education

Now we would like to focus on information sources you have used to learn about neuroendocrine tumor(s) (NET)

E1. How knowledgeable do you feel you are about neuroendocrine tumor(s) (NET)? Please tick only one option.

|  |  |  |
| --- | --- | --- |
| 01 | Not at all knowledgeable | **⭘** |
| 02 | Somewhat knowledgeable | **⭘** |
| 03 | Very knowledgeable | **⭘** |
| 04 | Extremely knowledgeable | **⭘** |
| 05 | Prefer not to answer | **⭘** |

E2. Beyond your medical team, which of the following information sources, if any, do you use to learn about neuroendocrine tumor(s) (NET)? Please tick all options that apply.

|  |  |  |
| --- | --- | --- |
| 01 | In person patient meetings/patient advocacy groups | **⭘** |
| 02 | Online patient meetings/patient advocacy groups | **⭘** |
| 03 | Brochures provided by healthcare professionals | **⭘** |
| 04 | World NET Cancer Awareness Day | **⭘** |
| 05 | Your national support group/charity | **⭘** |
| 06 | Brochures provided by patient advocacy groups | **⭘** |
| 07 | NET websites | **⭘** |
| 08 | Mobile phone apps | **⭘** |
| 09 | Social media related to NET (ie, Facebook groups; YouTube videos; Twitter accounts; blogs) | **⭘** |
| 10 | NET conferences and events | **⭘** |
| 11 | Other | **⭘** |
| 12 | None of the above | **⭘** |
| 13 | Prefer not to answer | **⭘** |

E2b. And how useful do you find each of these information sources? For each one that you have used, please indicate how useful each one was by ticking one box per row.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | Not at all useful | Somewhat useful | Very useful | Extremely useful | | Not applicable | Prefer not to answer |
| 01 | In person patient meetings/patient advocacy groups | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 02 | Online patient meetings/patient advocacy groups | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 03 | Brochures provided by healthcare professionals | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 04 | World NET Cancer Awareness Day | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 05 | Your national support group/charity | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 06 | Brochures provided by patient advocacy groups | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 07 | NET websites | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 08 | Mobile phone apps | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 09 | Social media related to NET (ie, Facebook groups; YouTube videos; Twitter accounts; blogs) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 10 | NET conferences and events | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 11 | Other | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |

E2a. Which of the following websites, if any, did you use to learn about neuroendocrine tumor(s) (NET)? Please tick all options that apply.

|  |  |  |
| --- | --- | --- |
| 01 | [www.carcinoid.org](http://www.carcinoid.org)  (Carcinoid Cancer Foundation) | **⭘** |
| 02 | [www.caringforcarcinoid.org](http://www.caringforcarcinoid.org)   (Caring for Carcinoid Foundation) | **⭘** |
| 03 | [www.netcancerday.org](http://nyintranet/clients/Novartis%20Pharmaceuticals%20Corporation/Projects/NET%20patient%20research/Documents/2_Project/2_Questionnaire/Qre/Master/www.netcancerday.org) (NET Cancer Day) | **⭘** |
| 04 | [www.thenetalliance.com](http://www.thenetalliance.com)  (The NET Community) | **⭘** |
| 05 | [www.pannetconnections.com](http://www.pannetconnections.com) (Pancreatic NET Connections) | **⭘** |
| 06 | [www.carcinoidinfo.info](http://www.carcinoidinfo.info) (Susan Anderson’s website) | **⭘** |
| 07 | [carcinoidawareness.org](http://www.carcinoidawareness.org) (Carcinoid Cancer Awareness Network) | **⭘** |
| 08 | [www.norcalcarcinet.org](http://www.norcalcarcinet.org) (Northern California CarciNET Community) | **⭘** |
| 09 | [www.cancer.org](http://www.cancer.org)  (American Cancer Society) | **⭘** |
| 10 | [www.cancer.gov](http://www.cancer.gov) (National Cancer Institute) | **⭘** |
| 11 | [www.acor.org](http://www.acor.org) (ACOR listserv – Association of Cancer Online Resources) | **⭘** |
| 12 | [www.corp.inspire.com](http://nyintranet/clients/Novartis%20Pharmaceuticals%20Corporation/Projects/NET%20patient%20research/Documents/2_Project/2_Questionnaire/Qre/Master/www.corp.inspire.com) (Inspire online community) | **⭘** |
| 13 | [www.clinicaltrials.gov](http://nyintranet/clients/Novartis%20Pharmaceuticals%20Corporation/Projects/NET%20patient%20research/Documents/2_Project/2_Questionnaire/Qre/Master/www.clinicaltrials.gov) (Clinical Trials, US National Institutes of Health) | **⭘** |
| 14 | [www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed) (Pub Med, US National Library of Medicine) | **⭘** |
| 15 | Other | **⭘** |
| 16 | None of the above | **⭘** |
| 17 | Prefer not to answer | **⭘** |

E3. And how useful do you find each of these resources? For each one that you have used, please indicate how useful each one was by ticking one box per row.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | Not at all useful | Somewhat useful | Very useful | Extremely useful | | Not applicable | Prefer not to answer |
| 01 | [www.carcinoid.org](http://www.carcinoid.org) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 02 | [www.caringforcarcinoid.org](http://www.caringforcarcinoid.org) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 03 | [www.netcancerday.org](http://nyintranet/clients/Novartis%20Pharmaceuticals%20Corporation/Projects/NET%20patient%20research/Documents/2_Project/2_Questionnaire/Qre/Master/www.netcancerday.org) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 04 | [www.thenetalliance.com](http://www.thenetalliance.com) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 05 | [www.pannetconnections.com](http://www.pannetconnections.com) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 06 | [www.carcinoidinfo.info](http://www.carcinoidinfo.info) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 07 | [carcinoidawareness.org](http://www.carcinoidawareness.org) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 08 | [www.norcalcarcinet.org](http://www.norcalcarcinet.org) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 09 | [www.cancer.org](http://www.cancer.org) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 10 | [www.cancer.gov](http://www.cancer.gov) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 11 | [www.acor.org](http://www.acor.org) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 12 | [www.corp.inspire.com](http://nyintranet/clients/Novartis%20Pharmaceuticals%20Corporation/Projects/NET%20patient%20research/Documents/2_Project/2_Questionnaire/Qre/Master/www.corp.inspire.com) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 13 | [www.clinicaltrials.gov](http://nyintranet/clients/Novartis%20Pharmaceuticals%20Corporation/Projects/NET%20patient%20research/Documents/2_Project/2_Questionnaire/Qre/Master/www.clinicaltrials.gov) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |
| 14 | [www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed) | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** | **⭘** |

E7. To what extent do you agree or disagree with the following statements? Please indicate how strongly you agree or disagree with each statement by placing a tick in each row.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | Strongly disagree | Somewhat disagree | Somewhat agree | Strongly agree | | Don’t know | Prefer not to answer |
| 01 | There are reliable and easy to understand websites available about neuroendocrine tumor(s) (NET) | **⭘** | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** |
| 02 | There is enough information available for people with neuroendocrine tumor(s) (NET) | **⭘** | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** |
| 03 | I receive wonderful support from patient support groups | **⭘** | **⭘** | **⭘** | **⭘** |  | **⭘** | **⭘** |

E8b. Which of the following best describes your access to and impressions of each of the following today? Please indicate your access to and impressions with each statement by placing a tick in each row.

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | **Not available/would notbe useful** | **Not available/would be useful** | **Available**, **not at all useful** | **Available**, **somewhat useful** | | | **Available, very useful** | **Prefer not to answer** |
| 01 | Tools to help maintain medication schedules | **⭘** | **⭘** | **⭘** | **⭘** |  | **⭘** | | **⭘** |
| 02 | Resources to help my friends and family cope with and understand my neuroendocrine tumor(s) (NET) | **⭘** | **⭘** | **⭘** | **⭘** |  | **⭘** | | **⭘** |
| 03 | Resources for talking with healthcare professionals | **⭘** | **⭘** | **⭘** | **⭘** |  | **⭘** | | **⭘** |
| 04 | Information about side effects of treatment | **⭘** | **⭘** | **⭘** | **⭘** |  | **⭘** | | **⭘** |
| 05 | Information on how to manage the side effects of treatment | **⭘** | **⭘** | **⭘** | **⭘** |  | **⭘** | | **⭘** |
| 06 | Information about clinical trials | **⭘** | **⭘** | **⭘** | **⭘** |  | **⭘** | | **⭘** |

**Section F:** Demographics

F1. How old are you?

|  |
| --- |
|  |

*years old*

*Prefer not to answer* **⭘**

F2. And are you?

|  |  |  |
| --- | --- | --- |
| 01 | Male | **⭘** |
| 02 | Female | **⭘** |
| 03 | Prefer not to answer | **⭘** |

F2a. What is the region where you are located?

|  |  |  |
| --- | --- | --- |
| 01 | List of regions/provinces were customized for each market | **⭘** |
| 08 | Prefer not to answer | **⭘** |

F3. What is the highest level of education you have completed or the highest degree you have received? Please tick only one option.

|  |  |  |
| --- | --- | --- |
| 01 | Less than high school | **⭘** |
| 02 | Completed high school | **⭘** |
| 03 | Job-specific training program(s) after high school | **⭘** |
| 04 | Some college, but no degree | **⭘** |
| 05 | Associate degree | **⭘** |
| 06 | College (such as BA, BS) | **⭘** |
| 07 | Some graduate school, but no degree | **⭘** |
| 08 | Graduate degree (such as MBA, MS, MD, PhD) | **⭘** |
| 09 | Prefer not to answer | **⭘** |

F4. How did you hear about participating in this study? Please tick all options that apply.

|  |  |  |
| --- | --- | --- |
| 01 | Patient advocacy group | **⭘** |
| 02 | Read about it in a brochure | **⭘** |
| 03 | Nurse | **⭘** |
| 04 | Website | **⭘** |
| 05 | Social media | **⭘** |
| 06 | Others | **⭘** |
| 07 | Prefer not to answer | **⭘** |