

Range of Current Services for NET Patients

1. Range of Current Services for NET Patients

Thank you for taking the time to fill out this survey.

This questionnaire asks for personal information, which is your right to withhold. If you can complete and submit the form, we will respect your privacy and take care to use the information provided in a confidential manner that will not identify you or allow others to do so.

Questions with asterisks are required answers. It helps with our research if you can answer all the questions in the survey. However, if the question is not relevant to you, then you may leave it blank. There is a question on the last page that allows you to add additional information, if you need to.

If you know someone with a NET diagnosis who is not attending our current conference, please send them a link to this survey so we can capture the greatest number of responses.

To start the survey, click next.

2. About you

While only questions with an * asterisk need to be answered, all responses are important information

* 1. Of what country are you a citizen?

Country:

* 2. If Canadian, what Province/Territory?

* 3. How old are you?

under 21

between 41 and 65

between 22 and 40

66 and older

* 4. What is your gender?

Male

Female

3. Your diagnosis - part 1

While only questions with an * asterisk need to be answered, all responses are important information

* 1. How many years from onset of symptoms to your present cancer diagnosis? (please write zero if less than one year)

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* 2. What year were you diagnosed?

* 3. What was your initial diagnosis? Please specify.

4. First location of any metastases and location(s) of any subsequent metastases. Please leave blank if no known metastases.

5. How many years did it take from biochemical diagnosis (i.e. specialized bloodwork and 24-hour 5-HIAA urine testing) to locate the primary tumour site? (please leave blank if the primary has never been located)

4. Your diagnosis - part 2

While only questions with an * asterisk need to be answered, all responses are important information

* 1. Were you diagnosed without localizing the primary site?

yes

no

* 2. Which diagnostic studies did you initially undergo to establish the diagnosis: (click all that apply);

CT

MRI

Octreotide

MIBG

PET

Other - If other please elaborate (eg. tissue pathology, specific markers, etc.)

* 3. What is your current cancer diagnosis; please specify

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4. Do you have any other medical condition(s) requiring active treatment/monitoring?

yes

no

If yes, please specify

5. Which diagnostic studies have since been used to follow your responses to subsequent treatment(s): (click all that apply)

CT

MRI

Octreotide

MIBG

PET

Other (please elaborate)

5. Treatments

While only questions with an * asterisk need to be answered, all responses are important information

* 1. Which treatments have you received to date? (Click all that apply)

Surgery

Long-acting Somatostatin (LAR)

Chemotherapies

External Beam Radiation therapy

None so far

Other (please specify)

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2. For any of the treatments selected in the above question, please give details below:

Surgery (please describe and give date)	<input type="text"/>
Long-acting Somatostatin (LAR) how many years on LAR - and at what dosage(s)?	<input type="text"/>
Chemotherapies: Which protocols (eg. Xeloda/Epirubicin/Carboplatin etc.)?	<input type="text"/>
External Beam Radiation therapy: How many courses?	<input type="text"/>
Other (please give details)	<input type="text"/>

6. Radio-isotope therapies

While only questions with an * asterisk need to be answered, all responses are important information

* 1. What Radio-isotope Therapies have you undergone? (choose any that apply)

- 131 I-MIBG
- 111 In-Octreotide
- 90 Y-Octreotide analogues
- 177 Lu-Octreotide analogues
- No Radio-isotope Therapies

Other (please describe)

2. How many radio-isotope therapies mentioned above were combined with chemotherapy?

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3. If you did have radio-isotope therapy combined with chemotherapy, which of the therapies was it combined with?

- I-MIBG
- In-Octreotide
- Y-Octreotide analogues
- Lu-Octreotide analogues
- Other (please specify)

7. Healthcare

While only questions with an * asterisk need to be answered, all responses are important information

1. Where did you receive your treatments? (check all that apply)

- In my home city
- In Canada outside my home province/territory
- In my home province/territory
- Outside Canada

for all the answers above, please specify exactly where you received treatment in each/any case.

2. Are you confident that your healthcare team will continue to be available to you?

yes

no

Please elaborate

8. Your health and treatment

While only questions with an * asterisk need to be answered, all responses are important information

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* 1. What is your current health status?

No evidence of cancer

Stable cancer

Progressing cancer

How long have you had this status?

* 2. What current treatment plan do you and your oncologist have in place?
(Click all that apply)

No active treatment

Chemotherapy

Other

Long-acting Somatostatin only

Radiation therapy

Pain and symptom control only

Radio-isotope therapy

Please specify for each treatment

9. Additional Information

* 1. In simple numbers, no dollar signs or decimal points, please estimate your personal annual out-of-pocket financial costs for:

Drugs

Professional Care (e.g. home care, physiotherapy etc.)

Travel to treatment centres

Indirect costs through diversion of your family members
from other financially productive activities

Other

2. What other additional information do you feel we should collect to improve the level of diagnosis, patient care, specific treatments and continuity of follow up?

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3. What specific recommendations to improve health care for our NET community would you like us to take to our elected policy/decision makers? Please provide supporting rationale for your recommendations.