

Medical Professionals on the Range of Services for NET Patients

1. Welcome to CNETS Canada's Survey of Current Services.

Thank you for taking the time to complete this survey.

Carcinoid NeuroEndocrine Tumour Society Canada (CNETS) seeks to ensure that persons diagnosed with NeuroEndocrine tumours will be assured of ready access to "state of the art" facilities and treatments under the guarantees afforded by the Canada Health Act wherever they happen to reside within Canada. This is not the case at this time. So the CNETS leadership team intend to take the matter forward to Canada's leaders.

The CNETS appreciates that the management of patients with NETS requires specialized diagnostics, imaging and novel systemic and targeted therapeutics including pharmaceuticals. A strategic and collaborative approach by all, those medical and non-medical, to these rare and complex neoplasms can help guide best practice in their diagnosis and management and optimize service delivery.

We need information about your experience with this disease and the varied management resources available to you. This will help us move forward from what is to what might be.

We thank you in advance for your professional response to our shared concern. Together we can make a difference.

If you can complete and submit the survey, 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.

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 space on the last page that allows you to add additional information, if you need to.

To start the survey, click next.

2. About Your Practice

1. What is your clinical area?

Primary Care

Endocrinology

Surgery

Medical Oncology

Radiation Oncology

Nuclear Medicine

Pathology

Other (please specify)

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2. What is the Geographical area of your practice?

Ontario

Other province in Canada

Other (please specify)

3. What type of practice do you work in?

Academic medical centre

Large community medical centre

Small community centre

Rural area

3. Patients with NETS in Your Practice

1. How many patients with NETs have you seen in your clinical practice?

0 - 10

11 - 20

> 20

2. Have you noticed any change in incidence of this disease?

Yes

No

If yes, please specify

3. In your experience, what is the average number of years from onset of symptoms to correct diagnosis? (number only)

4. Comments on the reason for delay(s) if any?

4. Patient Diagnosis

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1. What were the types and distribution of the primaries? Please specify

Lung	<input type="text"/>
Pancreas	<input type="text"/>
GI	<input type="text"/>
Unknown	<input type="text"/>
Other	<input type="text"/>

2. What percentage of your patients have known metastases?

3. What were the locations of metastases? Please specify.

4. What was the average time in years from biochemical diagnosis to localization of the primary site?

5. Your Diagnostic Tools (Part 1)

1. Which diagnostic studies do you have access to for diagnosis? (Click all that apply)

CT

Octreotide

PET

MRI

MIBG

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

What treatments do you have access to for your patients in the following categories?

2. Surgical Treatments: (mark all that apply)

In my home city	<input type="text"/>
In my home province/territory	<input type="text"/>
In Canada outside my home province/territory, please specify	<input type="text"/>
Outside Canada, please specify	<input type="text"/>

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3. Long-acting Somatostatin (LAR) (mark all that apply)

In my home city

In my home

province/territory;
please specify

Outside Canada:

please specify

4. Chemotherapy: How many different protocols do you have access to?

5. Chemotherapies: (mark all that apply)

In my home

province/territory

In Canada outside my

home

province/territory,
please specify

Outside Canada,

please specify

6. Your Diagnostic Tools (Part 2)

1. Do you have access to External beam radiation therapies?

yes

no

2. Do you have Liver Metastasis Embolization Procedures available?

yes

no

If yes, please elaborate

In the category of Radio-isotope therapies, where are each of these types available (mark all that apply)?

3. ¹³¹I-MIBG (mark all that apply)

In my home city

In my home

province/territory

In Canada outside my

home province/territory

Outside Canada:

please specify

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4. 111 In-Octreotide

In my home city

In my home province/territory

In Canada outside my home province/territory

Outside Canada: please specify

5. 90 Y-Octreotide analogues

In my home city

In my home province/territory

In Canada outside my home province/territory

Outside Canada: please specify

6. 177 Lu-Octreotide analogues

In my home city

In my home province/territory

In Canada outside my home province/territory

Outside Canada: please specify

7. Other treatments (please describe)

In my home city

In my home province/territory

In Canada outside my home province/territory

Outside Canada: please specify

7. Health Care

1. Are you confident that your health care team can handle these patients at standard of care?

yes

no

Please elaborate

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2. Is there any additional information we should collect to improve the level of diagnosis, patient care, specific treatments and continuity of follow up?

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.

8. Thank you

CNETS Canada Carcinoid NeuroEndocrine Tumour Society thanks you for your time in completing this survey.