



Frequently Asked Questions

Radionuclide Therapy for Patients with Neuroendocrine Tumours (NETs)

What is the purpose of the Provincial Neuroendocrine Program?

The goal of the program is to ensure neuroendocrine tumour (NET) patients in Ontario receive safe, equitable and sustained access to high quality radionuclide therapy through a Health Canada-approved framework.

How many people are affected?

There are estimated to be 2,700 people in Ontario living with NETs, with 660 people newly diagnosed each year. However, only a small proportion of these patients will be appropriate candidates for radionuclide therapy.

How have people accessed treatment prior to the launch of the NETs Ontario Clinical Trial?

Until the NETs Ontario Clinical Trial, patients received radionuclide therapy at London Health Sciences Centre through the Health Canada [Special Access Programme \(SAP\)](#) or through a Health Canada approved interim clinical safety registry that follows a treatment protocol similar to one being conducted in Edmonton, Alberta.

Why is a Clinical Trial Agreement necessary?

The radiopharmaceuticals used for the treatment of NETs have not received a Notice of Compliance from Health Canada. Radionuclide therapy is not widely available in North America and between April 1, 2007 and October 2010, a number of Ontario patients were getting this care out of country. The [Ontario Neuroendocrine Expert Panel Report: Radionuclide Therapy for Patients with Neuroendocrine Tumours \(NETs\) in Ontario](#) makes recommendations for the organization and delivery of radionuclide therapy for NET patients and identified the clinical trial framework as the appropriate mechanism to provide access in Ontario at this time.

Which hospitals will be involved in the NETs Ontario Clinical Trial and how is it being organized?

In October 2011, Cancer Care Ontario issued a Request for Proposals looking for Ontario hospitals to participate in a provincial program to treat eligible NET patients with the radiopharmaceutical Lutetium 177 under the authority of a Health Canada Clinical Trial Agreement. In April 2012, a consortium of the following sites was selected to participate:

- University Health Network/Princess Margaret Cancer Centre,
- London Health Sciences Centre,
- Sunnybrook Health Sciences Centre/Odette Cancer Centre, and
- Hamilton Health Sciences Centre/ Juravinski Cancer Centre.



University Health Network/Princess Margaret Cancer Centre is leading the trial.

How can patients access the NETs Ontario Clinical Trial?

To determine if a patient is potentially a candidate for the NETs Ontario Clinical Trial, a patient's clinician may refer the patient's case to the provincial multidisciplinary cancer conference (MCC) for review.

Questions regarding the provincial MCC can be directed to Dr. Shereen Ezzat at shereen.ezzat@uhn.ca, or to submit a case for review, please email the MCC Coordinator, Antoinette Hyatt at antoinette.hyatt@sunnybrook.ca.

If the MCC decides that a patient may be a candidate for the Clinical Trial, their case will be referred to one of the Clinical Trial sites where the case will be assessed to ensure the patient meets the Clinical Trial eligibility criteria. Only patients meeting the eligibility criteria may receive treatment as part of the Clinical Trial. The provincial MCC may propose other treatment options for patients who are not candidates for the Clinical Trial.

What other treatment options are available for patients not eligible for NETs Ontario Clinical Trial?

Patients that do not meet eligibility criteria for the NETs Ontario Clinical Trial may have other treatment options proposed by members of the MCC or their health care provider(s).

Can patients from outside of Ontario enroll in the NETs Ontario Clinical Trial?

Cancer Care Ontario funding for out of province patients is not available. Out of province patients are defined as those who are not eligible for Ontario Health Insurance Plan (OHIP) coverage (i.e., individuals who do not have an OHIP card and number). An individual is not covered under their relatives' OHIP coverage since coverage is extended only to the one eligible person.

All patients enrolled in the Trial will be required to follow the approved Clinical Trial protocol. This includes standardized intake, treatment, monitoring and follow-up processes. Strict adherence is required as part of the study design and involves regular visits to the treating site.

Participating Ontario hospitals are open to sharing protocol details with other interested jurisdictions.

Who pays for these treatments?

Cancer Care Ontario funding will be provided for diagnostic scans, patient treatment and clinical trial administration for hospitals participating in the NETs Ontario Clinical Trial.



What is Cancer Care Ontario's oversight role?

Ongoing oversight is needed to support quality assurance, performance management and equitable access for all patients in Ontario. Cancer Care Ontario continues to closely oversee and support the development of the provincial oversight structure. Cancer Care Ontario's Neuroendocrine Tumours Steering Committee guides the development and implementation of the provincial oversight program to ensure equitable access to radionuclide therapy for patients with NETs. This includes the development of a performance management and communications strategy. Membership of the Steering Committee includes representation from patients, clinicians and administrators across the province. In addition, Cancer Care Ontario regularly meets with the Carcinoid Neuroendocrine Tumours Society of Canada (CNETs) to discuss issues of common concern.

What other quality measures are in place?

A provincial, multi-centre multidisciplinary cancer conference (MCC) is in place. The MCC is a forum for clinicians to bring cases for discussion when additional input is desired to inform treatment decisions for NET patients.

For questions regarding the NETs Ontario Clinical Trial, please contact Dr. Rebecca Wong at rebecca.wong@rmp.uhn.on.ca or SSOInfo@cancercare.on.ca or visit our website at www.cancercare.on.ca/specialized_services.