

**Chest Neuroendocrine Tumor**

**Registry**

User Manual

Version 1.0

[1 Introduction 4](#_gjdgxs)

[1.1 Preface 4](#_30j0zll)

[1.2 How to use this manual 4](#_1fob9te)

[2 Form A 5](#_3znysh7)

[2.1 Patients personal details 5](#_2et92p0)

[2.2 Details from the medical history 5](#_tyjcwt)

[2.3](#_3dy6vkm) Risk factors 5

[2.4 Complaints, symptoms 6](#_1t3h5sf)

[2.5 Admission details and state 6](#_4d34og8)

[2.6 Laboratory parameters on admission 6](#_2s8eyo1)

[2.7 Genetic testing 6](#_17dp8vu)

[2.8 Imaging examinations, diagnostic tests on admission, staging of chest neuroendocrine tumor and histology 6](#_3rdcrjn)

[2.9 Other complications 7](#_26in1rg)

[2.10 Therapy 7](#_lnxbz9)

[2.11 Quality of Life questionnaire 7](#_35nkun2)

[2.12 Outcome 7](#_1ksv4uv)

[2.13 Comments, notes 8](#_44sinio)

[3 Form B 9](#_2jxsxqh)

[3.1 Patient personal details 9](#_z337ya)

[3.2 Significant changes in the medical history since the last visit 9](#_3j2qqm3)

[3.3 Complaints, symptoms 9](#_1y810tw)

[3.4 Current details and state 9](#_4i7ojhp)

[3.5 Current laboratory parameters 10](#_2xcytpi)

[3.6 Genetic testing 10](#_1ci93xb)

[3.7 Any changes in imaging examinations, diagnostic tests, staging of chest neuroendocrine tumor and histology 10](#_3whwml4)

[3.8 Other complications 10](#_2bn6wsx)

[3.9 Any changes in the therapy 11](#_qsh70q)

[3.10 Quality of Life questionnaire 11](#_3as4poj)

[3.11 Outcome 11](#_1pxezwc)

[3.12 Comments, notes 12](#_49x2ik5)

[4 Other Forms 13](#_2p2csry)

[4.1 Form C 13](#_147n2zr)

[4.1.1 Patients personal details 13](#_3o7alnk)

[4.1.2 Chemotherapy 13](#_23ckvvd)

[4.2 Form D 13](#_32hioqz)

[4.2.1 Patients personal details 13](#_1hmsyys)

[4.2.2 Radiotherapy 13](#_41mghml)

[4.3 Form E 14](#_2grqrue)

[4.3.1 Patients personal details 14](#_vx1227)

[4.3.2 Immunological therapy 14](#_3fwokq0)

[4.4 Form F 14](#_1v1yuxt)

[4.4.1 Patients personal details 14](#_4f1mdlm)

[4.4.2 Surgery 14](#_2u6wntf)

[5 Appendix A 15](#_19c6y18)

[6 Appendix B 15](#_3tbugp1)

1. **Introduction**

## Preface

This document is the user manual for the Chest Neuroendocrine Tumor Registry (CNET). It was developed by the 1st Department of Internal Medicine, Division Endocrinology and Metabolism, University of Pécs, Medical School, Hungary.

CNET allows participants to collect data about chest neuroendocrine tumor screening procedures, including patients’ demographic information, medical history and risk factors, procedure indications, and follow-up information.

**Data security**
During upload, increased attention should be given to the security of personal data, with special regards to the covering and deletion of personal data (name, date of birth, social security number, etc.) found in the headers, footers, and other parts of attached documents, diagnostic reports, final reports, radiograms, and other images and documents. The filtering of incidental mistakes stemming from the abovementioned issue is also essential during monitoring (2nd, 3rd, and 4th check-marks).

## How to use this manual

We describe the procedure step by step.

All CNET data are captured in six CNET forms (you can see the details below):

* Form A – Admission form
* Form B – Visit form
* Form C – Chemotherapy form
* Form D – Radiotherapy form
* Form E – Immunological therapy form
* Form F – Surgery form

CNET Data Submission Methods:

1. An online data form is available for direct data entry.
2. A printable form is also available for download to assist you with your internal workflow. However, data collected on printable forms must be submitted to the CNET system.

**Register New Exam**

Register a new exam by clicking on **Forms** in the CNET folder.

A new exam should be created for either a baseline or annual screening. If a patient is receiving a screening exam for the first time, submit the exam as an A form, otherwise, if the patient is returning for a second or subsequent screening, submit the exam as a B form.

Any additional interim visits such as chemotherapy, radiotherapy, immunological therapy or surgery occurring during the screening should not be submitted as a new exam. Rather, the interim visit data should be registered on the C, D, E or F form.

Note: The forms cannot be submitted to the registry, using the **Finalize** button, unless all fields marked with an asterisk (\*) are filled. However, the form’s data can be retained and completed later using the **Save draft** button. There is an automatically saving method too (in every thirty seconds), if it’s needed you can select the previous states from a list. You can cancel the data entry with the **Cancel** button, but in this case all data will be lost.

# Form A

## Patients personal details

|  |  |
| --- | --- |
| Insurance number | In Hungary patient’s insurance number must be in the format NNN-NNN-NNN, where N is a digit; all 9 digits are required. Other countries can use their own format. |
| Name | First name, then last name. First and last names must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”.  |
| Date of birth | Enter the patient’s date of birth in yyyy/mm/dd format. |
| Gender | Select the patient’s gender. |
| Race | Select the patient’s race, as identified by the patient. |
| Date of diagnoses | Enter the patient’s date of diagnosis in yyyy/mm/dd format. |
| Age at diagnosis | Use only digits, years are required. |
| Last day of treatment | Enter the date in yyyy/mm/dd format. |
| Date of interview | Enter the date in yyyy/mm/dd format. |

## Details from the medical history

|  |  |
| --- | --- |
| Smoking | Select the appropriate response. Use only digits for the amount and years. |
| Drug abuse | Select the appropriate response. Use only digits for the years. Type must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |
| Alcohol consumption | Select the appropriate response. Use only digits for the amount and years. |
| Other comorbidities listed on patient record that may limit life expectancy | Select all that apply. |
| Cancer related history | Select all that apply. |
| Special diet | Select all that apply. |
| Malignant disease among first degree relative(s) | Select all that apply. Other cancer must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |

## Risk factors

Follow the additional instructions. In every case select the appropriate response.

|  |  |
| --- | --- |
| Other | Other must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |

## Complaints, symptoms

In every case select the appropriate response. Use the Appendix B for grading. If you can’t find the symptoms in the table, the physician has to decide the degree of the severity (G1: mild, G2: moderate, G3: severe, G4: life-threatening, G5: death). NG means not gradable. Other (NG), please, specify must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”.

|  |  |
| --- | --- |
| Weight loss | Select the appropriate response. Use only digits. |

## Admission details and state

|  |  |
| --- | --- |
| Blood pressure | Enter patient’s blood pressure in millimeter of mercury. |
| Heart rate | Enter patient’s heart rate. |
| Body weight | Enter patient’s weight in kilograms. |
| Body height | Enter patient’s height in centimeters. |
| Respiratory rate | Enter patient’s respiratory rate. |
| Body temperature | Enter patient’s axiliar temperature in C°. |
| Oxygen saturation | Enter patient’s oxygen saturation in %. |
| Previous O2 therapy | Select the appropriate response. |
| ECOG Performance Status | Use only one digit from the characters „0-5”. Use the attached table. |

## Laboratory parameters on admission

Enter the parameters’ amounts. Use only digits. Select the appropriate unit from the list.

|  |  |
| --- | --- |
| Measuring condition of blood gas parameters | Select the appropriate response. |
| Tumor marker or hormonal abnormalities | Select the appropriate response. In the following table select all that apply. Enter the parameters’ amounts. Use only digits. Select the appropriate unit from the list. |

## Genetic testing

Select the appropriate response. Description must be 2 to 200 characters. At least one character must be from the characters “A-Z”, “a-z”.

## Imaging examinations, diagnostic tests on admission, staging of chest neuroendocrine tumor and histology

For TNM staging use the Appendix A.

|  |  |
| --- | --- |
| T Status | Select the appropriate response. |
| N Status | Select the appropriate response. |
| M Status | Select the appropriate response. |
| Chest X-ray | Select the appropriate response. |
| Computed Tomography | Select the appropriate response. |
| Other investigations affecting TNM staging | Select the appropriate response. In the following list select all that apply. Other must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |
| Histology/Cytology | Select the appropriate response. Other must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. Enter the Ki67 index in %.If it’s needed you can add new Histology/Cytology line. |

## Other complications

Select the appropriate response.

|  |  |
| --- | --- |
| Pleural effusion | Select the appropriate response in all cases. |
| Bronchial obstruction | Select the appropriate response. |
| Vena Cava Superior obstruction | Select the appropriate response. |
| Paraneoplastic syndrome | Select the appropriate response. In the following list select all that apply. |

## Therapy

There are 4 forms that you can use.

Form C: Chemotherapy Form

Form D: Radiotherapy Form

Form E: Immunological therapy Form

Form F: Surgery Form

Jump to the section 4 OTHER FORMS.

|  |  |
| --- | --- |
| Intensive care | Select the appropriate response. In the following list select all that apply. Other must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |

## Quality of Life questionnaire

Select the appropriate response.

Fill out the form following the additional instructions. In every case choose the most appropriate answer.

|  |  |
| --- | --- |
| 43. Did you take any pain relief medication | Select the appropriate response. |
| How much did it help | Choose the most appropriate answer. |
| Active substance | Enter the name. The name must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |
| Highest/lowest dose | Enter the amount, use only digits. Select the appropriate unit from the list. |
| If fluid, concentration | Enter the amount and the unit. |
| How many times per day | Enter the amount, use only digits. |
| Method of administration | Select the appropriate response. |

If it’s needed you can add new line of pain relief medication.

## Outcome

Select the appropriate response.

|  |  |
| --- | --- |
| The exact time of death | Enter the patient’s date of death in yyyy/mm/dd; and the time in hh/mm format. |

## Comments, notes

A short summary, if necessary of how the patient got to medical care, diagnosis, most important facts and events of the hospitalization, what happened with the patient after the hospitalization, any recommended control examinations, surgery etc.

# Form B

## Patient personal details

|  |  |
| --- | --- |
| Insurance number | Patient’s insurance number must be in the format NNN-NNN-NNN, where N is a digit; all 9 digits are required. |
| Name | First name, then last name. First and last names must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”.  |
| Date of birth | Enter the patient’s date of birth in yyyy/mm/dd format. |

## Significant changes in the medical history since the last visit

Select the appropriate response.

|  |  |
| --- | --- |
| Previous comorbidities that may limit life expectancy | Select the appropriate response, then select the degree from the list. |
| New comorbidities that may limit life expectancy | Select the appropriate response, then select all that apply. Other, please specify must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |
| Special diet | Select the appropriate response, then select all that apply. Other, please specify must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |
| Malignant disease among first degree relative(s) | Select the appropriate response, then select all that apply. Other cancer and organ must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”.  |

## Complaints, symptoms

Select the appropriate response.

|  |  |
| --- | --- |
| Previous complaints, symptoms | Select the appropriate response, then select the degree from the list. |
| New complaints, symptoms | In every case select the appropriate response. |
| Weight loss | Select the appropriate response. Use only digits. |

## Current details and state

|  |  |
| --- | --- |
| Blood pressure | Enter patient’s blood pressure in millimeter of mercury. |
| Heart rate | Enter patient’s heart rate. |
| Body weight | Enter patient’s weight in kilograms. |
| Body height | Enter patient’s height in centimeters. |
| Respiratory rate | Enter patient’s respiratory rate. |
| Body temperature | Enter patient’s axiliar temperature in C°. |
| Oxygen saturation | Enter patient’s oxygen saturation in %. |
| Previous O2 therapy | Select the appropriate response. |
| ECOG Performance Status | Use only one digit from the characters „0-5”. Use the attached table. |

## Current laboratory parameters

Enter the parameters’ amounts. Use only digits. Select the appropriate unit from the list. If it wasn’t measured then type zero to the amount.

|  |  |
| --- | --- |
| Measuring condition of blood gas parameters | Select the appropriate response. |
| Tumor marker or hormonal abnormalities | Select the appropriate response. In the following table select all that apply. Enter the parameters’ amounts. Use only digits. Select the appropriate unit from the list. |

## Genetic testing

Select the appropriate response. Description must be 2 to 200 characters. At least one character must be from the characters “A-Z”, “a-z”.

## Any changes in imaging examinations, diagnostic tests, staging of chest neuroendocrine tumor and histology

Select the appropriate response. For TNM staging use the Appendix A.

|  |  |
| --- | --- |
| T Status | Select the appropriate response. |
| N Status | Select the appropriate response. |
| M Status | Select the appropriate response. |
| Chest X-ray | Select the appropriate response. |
| Computed Tomography | Select the appropriate response. |
| Other investigations affecting TNM staging | Select the appropriate response. In the following list select all that apply. Other must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |
| Histology/Cytology | Select the appropriate response. Other must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. Enter the Ki67 index in %.If it’s needed you can add new Histology/Cytology line. |

## Other complications

Select the appropriate response.

|  |  |
| --- | --- |
| Previous complications | Select the appropriate response, then select the degree from the list. |
| New complications | Select the appropriate response. |
| Pleural effusion | Select the appropriate response in all cases. |
| Bronchial obstruction | Select the appropriate response. |
| Vena Cava Superior obstruction | Select the appropriate response. |
| Paraneoplastic syndrome | Select the appropriate response. In the following list select all that apply. |

## Any changes in the therapy

Select the appropriate response.

There are 4 forms that you can use.

Form C: Chemotherapy Form

Form D: Radiotherapy Form

Form E: Immunological therapy Form

Form F: Surgery Form

Jump to the section 4 OTHER FORMS.

|  |  |
| --- | --- |
| Intensive care | Select the appropriate response. In the following list select all that apply. Other must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |

## Quality of Life questionnaire

Select the appropriate response.

Fill out the form following the additional instructions. In every case choose the most appropriate answer.

|  |  |
| --- | --- |
| 43. Did you take any pain relief medication | Select the appropriate response. |
| How much did it help | Choose the most appropriate answer. |
| Active substance | Enter the name. The name must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |
| Highest/lowest dose | Enter the amount, use only digits. Select the appropriate unit from the list. |
| If fluid, concentration | Enter the amount and the unit. |
| How many times per day | Enter the amount, use only digits. |
| Method of administration | Select the appropriate response. |

If it’s needed you can add new line of pain relief medication.

## Outcome

Select the appropriate response.

|  |  |
| --- | --- |
| The exact time of death | Enter the patient’s date of death in yyyy/mm/dd; and the time in hh/mm format. |

## Comments, notes

A short summary, if necessary of how the patient got to medical care, diagnosis, most important facts and events of the hospitalization, what happened with the patient after the hospitalization, any recommended control examinations, surgery etc.

# Other Forms

## Form C

### Patients personal details

|  |  |
| --- | --- |
| Insurance number | Patient’s insurance number must be in the format NNN-NNN-NNN, where N is a digit; all 9 digits are required. |
| Name | First name, then last name. First and last names must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”.  |
| Date of birth | Enter the patient’s date of birth in yyyy/mm/dd format. |

### Chemotherapy

|  |  |
| --- | --- |
| Onset date | Enter the date in yyyy/mm/dd format. |
| Protocol | Select the appropriate response. |
| Change in or addition to the Protocol above | Select the appropriate response.  |
| Active substance | Select all that apply. Enter dose in mg/m2 or other and enter the unit. |
| Side effects | Select all that apply. Use the Appendix B for grading. NG means not gradable. Other (NG), please, specify must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |
| Concomitant radiotherapy | Select the appropriate response. If the answer is yes fill out the Form D. |

## Form D

### Patients personal details

|  |  |
| --- | --- |
| Insurance number | Patient’s insurance number must be in the format NNN-NNN-NNN, where N is a digit; all 9 digits are required. |
| Name | First name, then last name. First and last names must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”.  |
| Date of birth | Enter the patient’s date of birth in yyyy/mm/dd format. |

### Radiotherapy

Select all that apply. In the following questions select the appropriate response.

|  |  |
| --- | --- |
| Date | Enter the date in yyyy/mm/dd format. |
| Dose | Enter the amount, then select the unit from the list. |
| Concomitant chemotherapy | Select the appropriate response. If the answer is yes fill out the Form C. |

## Form E

### Patients personal details

|  |  |
| --- | --- |
| Insurance number | Patient’s insurance number must be in the format NNN-NNN-NNN, where N is a digit; all 9 digits are required. |
| Name | First name, then last name. First and last names must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”.  |
| Date of birth | Enter the patient’s date of birth in yyyy/mm/dd format. |

### Immunological therapy

|  |  |
| --- | --- |
| Date | Enter the date in yyyy/mm/dd format. |
| Cycle | Select the number of cycle from the list. |
| Type | Select the appropriate response. Other must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |
| Side effects | Select all that apply. In the following questions select the appropriate response. In the case of skin symptoms other must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. Use the Appendix B for grading. NG means not gradable. Other (NG), please, specify must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”. |

## Form F

### Patients personal details

|  |  |
| --- | --- |
| Insurance number | Patient’s insurance number must be in the format NNN-NNN-NNN, where N is a digit; all 9 digits are required. |
| Name | First name, then last name. First and last names must be 2 to 45 characters. At least one character must be from the characters “A-Z”, “a-z”.  |
| Date of birth | Enter the patient’s date of birth in yyyy/mm/dd format. |

### Surgery

Select the appropriate response.

# Appendix A

For the TNM staging please download the file Appendix A from the CNET Supplementary material folder.

<https://tm-centre.org/en/registries/supplementary-material/>

The staging system described above is the most recent version of the AJCC system, effective as of January 2018.

# Appendix B

For symptom and side effect severity grading please download the file Appendix B from the CNET Supplementary material folder.

<https://tm-centre.org/en/registries/supplementary-material/>