TM CNET REGISTRY
ENDOCRINOLOGY STUDY GROUP

Institute number:

Physician number:

Blood sample code:

Date of blood sampling:

*1. Patient personal details

Insurance number:……
Name: ……
Date of birth:.……
Gender: female / male
Race: Asian-Indian / Caucasian / Black / N/A
Date of diagnosis: ……
Age at diagnosis: …….
Last day of treatment: ……
Date of interview: ……

2. Details from the medical history

Smoking: yes / no
if yes: amount (cigarettes/day):……
for how many years? ……

if not: Did he/she smoke earlier? yes/no/ N/A
if yes: amount (cigarettes/day):……
for how many years?……
Number of years since quit: …….
Did the physician provide smoking cessation guidance to patient? yes/no/ N/A

Does the patient suffer from secondhand smoke? yes/no/ N/A

Drug abuse: yes / no *Prescribed medication should not be included here.*
if yes: type of drug:…….
amount: heavy moderate mild
for how many years:……

Alcohol consumption: yes / no
Guide for estimation of the amount:
1 dl beer (4.5 vol. %) = ~3.5 g alcohol
1 dl wine (12.5 vol. %) = ~10 g alcohol
1 dl hard drink (50 vol. %) = ~40 g alcohol

If yes: frequency: occasionally/monthly/weekly/daily/N/A
amount (g/occasion):……
for how many years: ……

If not: Did he/she drink alcohol earlier? yes/no/ N/A
If yes: frequency: occasionally/monthly/weekly/daily/N/A
amount (g/occasion):……
for how many years?……
Number of years since quit:……

Other comorbidities listed on patient record that may limit life expectancy:

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Select all that apply:

□ COPD □ Pulmonary fibrosis □ Emphysema □ Coronary artery disease □ Congestive heart failure □ Peripheral vascular disease □ Atypical mycobacterial infection □ Other type of lung cancer □ Cancer other than lung cancer □ Other, please specify:

Cancer related history:

Select all that apply:

□ Prior history of lung cancer □ Lymphoma □ H&N cancer □ Bladder cancer □ Esophageal cancer □ Pulmonary fibrosis □ Other interstitial pulmonary diseases □ Other cancer, please specify: □ Other:

Special diet: yes / no

if yes:

Diet form: vegetarian / vegan / gluten free / lactose free / other, please specify:

Malignant disease among first degree relative(s) yes / no

if yes: lung cancer (if yes: type: SCLC /Adeno/Squamosa/Other) / other cancer: ….. (if yes: organ: …)

3. Risk factors

The answer is "yes" if the etiological factor is proven, the answer is "no" if the etiological factor can be ruled out, the answer is "N/A" if the etiological factor was not examined. Please answer "yes" to" Idiopathic" if etiological factor was not identified.

Tobacco smoking	yes	no	N/A
Secondhand smoke	yes	no	N/A
Air pollution	yes	no	N/A
Asbestos	yes	no	N/A
Diesel exhaust	yes	no	N/A
Inert gas	yes	no	N/A
Uranium miner	yes	no	N/A
if yes: How many years?	5 yrs>	5-10 yrs	10 yrs<
Genetic	yes	no	has not been tested yet
Idiopathic	yes	no	
Other	yes	no	

if yes: please describe:……

4. Complaints, symptoms

		Severity:
Cough:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Coughing up blood:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:

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Shortness of breath/Dyspnea:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Chest pain worsened by deep breathing:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Hoarse voice:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Difficulty swallowing/Dysphagia:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Swelling of the face and hands:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Fatigue:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Severe muscle weakness/ Generalized muscle weakness:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Trouble with balance or walking:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Changes in mental status:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Changes in skin color:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Headache:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Blurred vision:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Nausea:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Vomiting:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Seizures:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Paralysis:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Loss of bowel/bladder function:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Bone pain:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:
Pain in the right upper part of the abdomen/Abdominal pain:	yes / no	Grade 1 / 2 / 3 / 4 / 5 / Other (NG), please, specify:

Appetite: good / retained / bad

***Weight loss:** yes / no

If yes: How long did it take? (weeks):……

How much (kg):……

Weight loss in percentage (%=100*(original total body weight - current total body weight)/original total body weight): ……%

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5. Admission details and state

Blood pressure: …… / …… Hgmm
Body weight:…… kg
Respiratory rate:…… / min
Oxygen saturation: …… %

Heart rate:…… /minute
Body height: …… cm
Body temperature (axiliar): ……°C
Previous O2 therapy: yes / no / N/A

***ECOG Performance Status**……..

GRADE	ECOG PERFORMANCE STATUS
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair
5	Dead

6. Laboratory parameters on admission

*White blood cell (WBC): ……(szám) unit: (legördülő) G/l
*Hemoglobin: …… unit: mmol/l / umol/l / g/l
*Thrombocyte: …… unit: G/l
Glucose: …… unit: mg/dl / mmol/l / umol/l
Creatinine: …… unit: mg/dl / umol/l / mmol/l
eGFR: …… unit: ml/min/1.73 m²
CRP: …… unit: mg/l / nmol/l
ASAT/GOT: …… unit: U/l
LDH: …… unit: U/l
*Calcium: ……. unit: mmol/l / umol/l
*Sodium: …… unit: mmol/l
Potassium: …… unit: mmol/l
Total protein: …… unit: g/l
Albumin: …… unit: g/l / mmol/l / umol/l
ALAT/GPT: …… unit: U/l
Gamma GT: …… unit: U/l

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ALP: …… unit: U/l

Measuring condition of blood gas parameters): N/A / room air / 100% O_2

PaO2: …… unit: Hgmm
HCO3: …… unit: mmol/l / umol/l
sO2: …… unit: %
pCO2: ……. unit: Hgmm

*Tumor markers or hormonal abnormalities:: yes / no
If yes:
Type:
chromogranin A (CgA): …… unit: pmol/ml
5-Hydroxi-indol-acetate: …… unit: g/mol
pro-gastrin releasing peptide (ProGRP): …… unit: pg/ml
neuron-specific enolase (NSE): …… unit: ng/ml
Procalcitonin (PCT): …… unit: ug/l / ng/l
Co-Peptin: …… unit: pmol/l
PTHrP: …… unit: pmol/l
ACTH: …… unit: pmol/l
Cortisol: ……. unit: nmol/l
TSH: …… unit: mIU/l

7. Genetic testing yes/no

If yes: Description: ……..

*8. Imaging examinations, diagnostic tests on admission, staging of chest neuroendocrine tumor and histology

TNM stage:

T Status (select one):	O TX	O T1a	O T1b	O T2a	O T2b	O T3	O T4	O Unknown
N Status (select one):	O NX	O N0	O N1	O N2	O N3			
M Status (select one):	O MX	O M0	O M1a	O M1b				

***Chest X-ray:** yes / no

***Computed Tomography:** yes / no
If yes: Did it specify the TNM stage? yes / no

***Other investigations affecting TNM staging:** yes / no
Magnetic Resonance Imaging (if yes: Region: head / adrenal gland) / Positron Emission Tomography / CT head scan / Bone scan / Bronchoscopy / Bone marrow aspiration / Ultrasound / Peptide receptor radionuclide scintigraphy / Other: ...

***Histology/Cytology:** yes / no

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If yes: Place of sampling: Pleural effusion / Lung / Lymph node / Other:
If yes: Ki67 index: …… %

#add new line (Histology/Cytology blokk)

9. Other complications yes / no

If yes:
Details:

Pleural effusion: yes / no
if yes: exsudative ? yes / no
if yes: carcinosis? yes / no

Bronchial obstruction: yes / no

Vena Cava Superior obstruction: yes / no

Paraneoplastic syndrome: yes / no
If yes:
Type: SIADH / humoral hypercalcemia of malignancy / Cushing's syndrome / Hypoglycemia / Acromegaly / Carcinoid syndrome / Gynecomastia / Hyperthyroidism / Other:

*10. Therapy:

(fill out the Forms)
C form: Chemotherapy Form
D form: Radiotherapy Form
E form: Immunological therapy Form
F form: Surgery Form

Intensive care: yes / no
if yes: Type: ventilation / vasopressor therapy / kidney treatment / other:…

11. Quality of Life questionnaire (EORTC QLQ-C30, EORTC QLQ - LC13)

yes / no / ND
If yes:
Patients sometimes report that they have the following symptoms or complaints. Please indicate the extent to which the patient has experienced these symptoms or complaints.

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		No	Mild / Rarely	Moderate / Often	Severe / All the time
1.	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	□	□	□	□
2.	Do you have any trouble taking a long walk?	□	□	□	□
3.	Do you have any trouble taking a short walk outside of the house?	□	□	□	□
4.	Do you need to stay in bed or a chair during the day?	□	□	□	□
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	□	□	□	□

During the past week:	No	Mild / Rarely	Moderate / Often	Severe / All the time
6. Were you limited in doing either your work or other daily activities?	□	□	□	□
7. Were you limited in pursuing your hobbies or other leisure time activities?	□	□	□	□
8. Did you experience shortness of breath?	□	□	□	□
9. Have you had pain?	□	□	□	□
10. Did you need to rest after doing any activity?	□	□	□	□
11. Have you had trouble sleeping?	□	□	□	□
12. Have you felt weak?	□	□	□	□
13. Did you have a lack of appetite?	□	□	□	□

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14.	Have you felt nauseated?	□	□	□	□
15.	Did you vomit?	□	□	□	□
16.	Have you been constipated?	□	□	□	□
17.	Did you have diarrhea?	□	□	□	□
18.	Did you feel tired?	□	□	□	□
19.	Did pain interfere with your daily activities?	□	□	□	□
20.	Have you had any difficulty in concentrating on things, like reading a newspaper or watching television?	□ □	□ □	□ □	□ □
21.	Did you feel tense?	□	□	□	□
22.	Did you worry?	□	□	□	□
23.	Did you feel irritable?	□	□	□	□
24.	Did you feel depressed?	□	□	□	□
25.	Have you had any difficulty remembering things?	□	□	□	□
26.	Has your physical condition or medical treatment interfered with your <u>family</u> life?	□ □	□ □	□ □	□ □
27.	Has your physical condition or medical treatment interfered with your <u>social</u> activities?	□ □	□ □	□ □	□ □

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28.	Has your physical condition or medical treatment caused any financial difficulties?	□ □	□ □	□ □	□ □

For the following questions please select the number between 1 and 7 that best applies to the patient

29. How would you rate your overall <u>health</u> during the past week?

□1	□2	□3	□4	□5	□6	□7
Very poor						Excellent

30. How would you rate your overall <u>quality of life</u> during the past week?

□1	□2	□3	□4	□5	□6	□7
Very poor						Excellent

During the past week :		**No**	**Mild / Rarely**	**Moderate / Often**	**Severe / All the time**
31.	How much did you cough?	□	□	□	□
32.	Did you cough up any blood?	□	□	□	□
33.	Did you have any shortness of breath while resting?	□	□	□	□
34.	Did you have any shortness of breath while walking?	□	□	□	□
35.	Did you have any shortness of breath while climbing stairs?	□	□	□	□
36.	Was your mouth or tongue sore?	□	□	□	□
37.	Did you have trouble swallowing?	□	□	□	□
38.	Did you have any tingling in your hands of feet?	□	□	□	□
39.	Did you experience hair loss?	□	□	□	□

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40.	Did you suffer from chest pain?	□	□	□	□
41.	Did you have any pain in your arm or shoulder?	□	□	□	□
42.	Did you have any pain anywhere else? If yes, where: _____	□	□	□	□

43. Did you take any pain relief medication?

□ **No** □ **Yes**

If yes, how much did it help? □ □ □ □

If yes:

Details: (informális szöveg)
Active substance:……
Highest/lowest dose: …… unit: g / mg / IU
If fluid, concentration (e.g. 10%, 1g/2ml, etc.)……
How many times per day: ……
Method of administration: N/A / intravenious / oral / enteral / subcutan

#add new line (Details-től Method of administration-ig)

*12. Outcome

- **Not available for care/ Regular follow-up / Death#**

#The exact time of death: …….

13. Comments, notes

(E.g. 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.).

Description

……
……

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