

## Description of the materials of the Finnish Cancer Registry

The handling of any individual-level materials held by the Finnish Cancer Registry requires a research permit granted by the Finnish Institute for Health and Welfare (THL). Based on THL's research permit, we can disclose basic variables, permit-specific variables and, at our discretion, other variables that significantly benefit the research.

### Basic variables:

#### **sex (patient sex)**

| sex | Label  |
|-----|--------|
| 0   | Male   |
| 1   | Female |

#### **dg\_date (date of diagnosis)**

*Date of sampling of the sample leading to the diagnosis of cancer or the earliest date on which the cancer was clinically diagnosed*

#### **dg\_age (age at diagnosis)**

*Years, rounded to one decimal place*

#### **topo (the primary organ of the tumor)**

*Topographic code according to the ICD-O-3 classification*

#### **morpho (cytological or histological diagnosis of the tumor)**

*Morphological code according to the ICD-O-3 classification*

#### **beh (cancer malignancy)**

*behavior code according to the ICD-O-3 classification*

#### **later (cancer laterality)**

| later   | label          |
|---------|----------------|
| missing |                |
| 3       | Right          |
| 4       | Left           |
| 7       | Not applicable |
| 8       | Both           |
| 9       | Unknown        |

**basis (basis of diagnosis)**

| basis | label  |
|-------|--|
| 7     | Histology of a primary tumour                                      |
| 6     | Histology of a metastasis  |
| 5     | Cytology   |
| 4     | Specific tumour marker   |
| 14    | Morphology   |
| 13    | Immunophenotype  |
| 10    | Flow cytometry   |
| 12    | Molecular genetics   |
| 15    | Cytogenetics   |
| 8     | Autopsy, includes histological sample                              |
| 2     | Clinical investigation ( <i>confirmed by X-ray or equivalent</i> ) |
| 1     | Clinical ( <i>before death, not confirmed</i> )                    |
| 9     | Unknown (includes DCO 1953-2014)                                   |
| 0     | Death certificate only (2015-)                                     |

**stage (clinical spread of the tumor)**

*Finnish Cancer Registry's classification*

| stage | Label  |
|-------|--|
| 0     | Unknown  |
| 1     | Localised  |
| 2     | Non-localised, only regional lymph node metastases                                     |
| 3     | Metastasised farther than to regional lymph nodes or invades adjacent tissues (5 or 6) |
| 4     | Non-localised, no information on extent  |
| 5     | Locally advanced, tumour invades adjacent tissues                                      |
| 6     | Non-localised, also distant lymph node metastases                                      |

**cancertype (type of cancer)**

*The name of the cancer, Finnish Cancer Registry's classification*

**ex\_date (date of exit from follow-up)****exit\_status (follow-up/survival status at registry close date)**

*Is the person alive, dead, or living abroad at the end of follow-up*

| exit_status | label             |
|-------------|-------------------|
| 0           | Alive             |
| 2           | Dead              |
| 3           | Lost to follow-up |

**dg\_munic\_staty (home municipality on the year of finding \*)**

*Home municipality for the person who fell ill with cancer in the year of the finding according to the municipal division for the statistical year*

**dg\_hosp\_staty (hospital district on the year of finding\*)**

*Hospital district of diagnosis based on municipality code from statistical year*

| dg_hosp_staty | label                |
|---------------|----------------------|
| missing       |                      |
| 1             | Uusimaa              |
| 2             | Helsinki             |
| 3             | Southwest Finland    |
| 4             | Satakunta            |
| 5             | Kanta-Häme           |
| 6             | Pirkanmaa            |
| 7             | Päijät-Häme          |
| 8             | Kymenlaakso          |
| 9             | South Karelia        |
| 10            | South Savo           |
| 11            | East Savo            |
| 12            | North Karelia        |
| 13            | North Savo           |
| 14            | Central Finland      |
| 15            | South Ostrobothnia   |
| 16            | Vaasa                |
| 17            | Central Ostrobothnia |
| 18            | North Ostrobothnia   |
| 19            | Kainuu               |
| 20            | Länsi-Pohja          |
| 21            | Lapland              |
| 22            | Åland                |

**dg\_uni\_staty (university hospital district of diagnosis\*)**

*University hospital district of diagnosis based on municipality code from statistical year*

| dg_uni_staty | label    |
|--------------|----------|
| missing      |          |
| 1            | Helsinki |
| 2            | Turku    |
| 3            | Tampere  |
| 4            | Kuopio   |
| 5            | Oulu     |
| 6            | Åland    |

Permit specific variables:

**hetu (patient's social security number)**

*The THL permit should mention the retrieval of the social security number*

**bi\_date (patient's birthday)**

*The THL permit should mention the retrieval of the date of birth or social security number*

**status\_close (follow-up/survival status at registry close date, unmodified)**

*alive, dead of this cancer, dead of causes other than this cancer, living abroad*

*A permit from Statistics Finland for cause of death data*

| status_close | label                   |
|--------------|-------------------------|
| 0            | Alive                   |
| 1            | Dead due to cancer      |
| 2            | Dead due to other cause |
| 3            | Lost to follow-up       |

**de\_cause (patient's cause of death)**

*Reported according to ICD-10 codes*

*Requires a permit from Statistics Finland to access cause of death data and a note that the cause of death data have been obtained from the Finnish Cancer Registry.*

**lab\_sample\_id (pathology laboratory sample identifier)**

*Laboratory-specific designation that identifies the sample*

*The THL permit should mention the pathology laboratory sample number*

## Special variables:

Special variables in the Finnish Cancer Registry are separately produced data obtained from the material reported in the registry. The data contain more specific information about e.g. individual pathological samples. The disclosure of special variables is always considered on a case-to-case basis. Compared with basic variables, processing and compiling special variables is more laborious.

### **gradus (tumour grade)**

*The coverage of the tumour grade variable varies, and this variable is available from recent years only*

### **Clinical stage classifications**

#### **TNM**

*TNM classification given in the clinical notification submitted to the Finnish Cancer Registry. Definitions are disease-specific. Incomplete coverage*

#### **Ann Arbor -stage**

*The stage given in the clinical notification submitted to the Finnish Cancer Registry. Definitions are disease-specific. Incomplete coverage.*

#### **Verbal staging**

*Verbal description of the stage given in the clinical notification. Incomplete coverage.*

### **met\_syre (clinical spread of the tumor (FCR))**

| met_syre | label  |
|----------|--|
| 0        | Unknown  |
| 1        | Localised  |
| 2        | Non-localised, only regional lymph node metastases                                     |
| 3        | Metastasised farther than to regional lymph nodes or invades adjacent tissues (5 or 6) |
| 4        | Non-localised, no information on extent  |
| 5        | Locally advanced, tumour invades adjacent tissues                                      |
| 6        | Non-localised, also distant lymph node metastases                                      |

### **met\_def\_type (spread category basis)**

| met_def_type | label           |
|--------------|-----------------|
| missing      |                 |
| 0            | TNM             |
| 1            | Verbal          |
| 2            | Stage           |
| 3            | Ann Arbor stage |

### **met\_tumor (spread category, tumor)**

*See met\_def\_type, what information the variable includes*

| Column class | Number of levels | First level | Last level |
|--------------|------------------|-------------|------------|
| "character"  | 72               | 0           | X          |

**met\_lymph\_node (spread category, lymph node)**

See *met\_def\_type*, what information the variable includes

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| met_lymph_node |
|----------------|
| 0              |
| 1              |
| 9              |
| N0             |
| N0 (i+)        |
| N0 (i-)        |
| N1             |
| N1a            |
| N1b            |
| N1c            |
| N2             |
| N2a            |
| N2b            |
| N2c            |
| N3             |
| N3a            |
| N3b            |
| N3c            |
| NX             |

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**met\_metastases (spread category, metastasis)**

See *met\_def\_type*, what information the variable includes

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| met_metastases |
|----------------|
| 0              |
| 1              |
| 9              |
| M0             |
| M1             |
| M1a            |
| M1b            |
| M1c            |
| MX             |

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**org\_name (pathology laboratory organization identifier\*)****pad, morpho\_text, topo\_text (diagnosis of pathology sample)**

*Sample-specific, one cancer diagnosis may be associated with multiple pathological diagnoses.*

**multi (multiple primary rank)**

*Will be supplied upon request, definition to be agreed separately*

**iccc3 (childhood cancer classification)**

*Intern. Class. of Childhood Cancer, 3rd ed.*

*Will be disclosed if specifically requested*

**iarccrgtools\_icd10 (ICD-10 code from IARC CRG Tools)**

*ICD-10 code produced by the ICD-O-3 -> ICD-10 programme of IARC CRG Tools.*

*Automatically generated ICD-10 classes may be illogical due to changes in registration practices*

**ex\_munic\_staty (municipality at exit from follow-up\*)**

*Same definitions as in dg\_munic\_staty*

**ex\_hosp\_staty (hospital district at exit from follow-up\*)**

*Same definitions as in dg\_hosp\_staty*

**ex\_uni\_staty (university hospital district at exit from follow-up\*)**

*Same definitions as in dg\_uni\_staty*

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**\*Will not be disclosed if the person has prohibited the disclosure of his/her data.**

More detailed information about variables is available by e-mail at [kirjaamo@cancer.fi](mailto:kirjaamo@cancer.fi)