



Nationale Krebsregistrierungsstelle
Organe national d'enregistrement du cancer
Servizio nazionale di registrazione dei tumori
National Agency for Cancer Registration



Kinderkrebsregister
Registre du cancer de l'enfant
Registro dei tumori pediatrici
Childhood Cancer Registry

NATIONAL CANCER DATA DICTIONARY

V 1.1

Part B1

SUPPLEMENTARY VARIABLES

Adults

15.10.2019

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CASE DEFINITIONS

Person age at diagnosis

Adults (20.0 and more years of age).

Person resident status¹

The person diagnosed is part of the permanent resident population (i.e. the dominator for calculation of event rates):

- >Swiss citizens with main place of residency in Switzerland.
- >Foreign citizens with an annual or a permanent residence permit for at least twelve months (Permit B or C or FDFA-ID² [international civil servants, diplomats and their family members]).
- >Foreign citizens with a short-term residence permit (Permit L) for a cumulative length of stay of at least twelve months.
- >Foreign citizens seeking asylum (Permit F or N) with a total length of stay of at least twelve months.

No veto from patient

The diagnosed person did not veto registration of his or her data before the end of the three months waiting period after the date of patient information.

Reportable diagnosed neoplasms³

	ICD-10
Colon-rectum	C18 – C20
Breast	C50
Prostate	C61

¹ Ordinance 431.112.1 (19.12.2008) on the Federal Population Census, Article 2 Letter d.

² International civil servants, diplomats and their family members with undefined regional responsibility of the registry are excluded.

³ Only verified diagnoses are reportable. Verification refers to medically accepted diagnostic procedures (clinical, cytological, histological, laboratory test).

PREDISPOSITIONS

Inherited Predisposition(s)

Variable number: 9.1

Item length: 2

Item format: Number

Definition

The data item records the patient's inherited medical conditions.

Rationale

Pre-existing medical conditions which increase the risk of developing colorectal, breast or prostate cancer.

Code	Label	Description/ clinical manifestation	Assignment#
1	Familial ovarian cancer	ICD10 Z80.4	B
2	Familial prostate cancer	ICD10 Z80.4	P
3	Hereditary breast and ovarian cancer syndrome (HBOC)	ICD10 Z80	B
4	Hereditary breast cancer	ICD10 Z80.3	B
5	Li-Fraumeni syndrome	TP53 mutation; ICD10 D48.9	B,P,C
6	Nijmegen breakage syndrome	Microcephaly, other malformations; mutations NBS1 gene; incr. risk for breast and other cancer; ICD10 Q87.8	B,P
7	Saethre-Chotzen syndrome	Craniosynostosis, other malformations; TWIST1; ICD10 Q87.0	B
8	Familial adenomatous polyposis	Hundreds to thousands of adenomas in the rectum and colon; mutation in the APC gene; ICD10 D12.6	C
9	Juvenile gastrointestinal polyposis	Hamartomatous polyps in the gastrointestinal tract; ICD10 D12.6	C,P
10	Peutz-Jeghers syndrome	Hamartomatous polyps, mucocutaneous pigmentation in the gastrointestinal tract; ICD10 Q85.8	B,C
11	Hyperplastic polyposis syndrome	Pancolonic multiple hyperplastic serrated polyps; ICD10 D12.6	C
12	Hereditary mixed polyposis syndrome	Higher numbers of polyps at younger ages. risk for colon cancer; ICD10 D12.6	C
13	Familial or hereditary nonpolyposis colorectal	DNA mismatch repair (MMR) genes mutation. ICD10 C18.9	B,P,C

	cancer (HNPCC), Lynch syndrome		
14	McCune-Albright syndrome	Fibrous dysplasia, café au lait, mutation GNAS gene; ICD10 Q78.1	B
15	Bannayan-Riley-Ruvalcaba syndrome	PTEN mutation; ICD10 Q87.8	B
16	Cowden syndrome	Multiple hamartomas; PTEN mutation; ICD10 Q85.8	B
17	Bloom syndrome	BLM mutation; ICD10 Q82.2	C
99	Unknown	Inherited medical conditions not stated/not assessed.	

B: Breast cancer, P: prostate cancer, C: colorectal cancer

National usage

The variable is to be submitted to the NACR.

References

- >Familial ovarian cancer, Familial prostate cancer, Hereditary breast and ovarian cancer syndrome, Hereditary breast cancer, Li-Fraumeni syndrome: Hereditary Cancer Predisposition Syndromes, J Clin Oncol 23:276-292. 2005 by American Society of Clinical Oncology.
- >Nijmegen breakage syndrome: Int J Cancer. 2008 Feb 15;122(4):802-6. Nijmegen Breakage Syndrome mutations and risk of breast cancer. Bogdanova N(1), Feshchenko S, Schürmann P, Waltes R, Wieland B, Hillemanns P, Rogov YI, Dammann O, Bremer M, Karstens JH, Sohn C, Varon R, Dörk T.
- >Saethre-Chotzen syndrome breast cancer: Genes Chromosomes Cancer. 2007 Jul;46(7):656-60. Women with Saethre-Chotzen syndrome are at increased risk of breast cancer. Sahlin P(1), Windh P, Lauritzen C, Emanuelsson M, Grönberg H, Stenman G.
- >Familial adenomatous polyposis colon : Hereditary Cancer Predisposition Syndromes, J Clin Oncol 23:276-292. 2005 by American Society of Clinical Oncology
- >Juvenile gastrointestinal polyposis colon cancer : Hereditary Cancer Predisposition Syndromes, J Clin Oncol 23:276-292. 2005 by American Society of Clinical Oncology
- >Peutz-Jeghers syndrome: Hereditary Cancer Predisposition Syndromes, J Clin Oncol 23:276-292. 2005 by American Society of Clinical Oncology
- >Hyperplastic polyposis syndrome : Evidenced-based Guideline for Colorectal Cancer, long version 1.0, AWMF registration number: 021-007OL, <http://leitlinienprogrammonkologie.de/Leitlinien.7.0.html>
- >Hereditary mixed polyposis syndrome: Evidenced-based Guideline for Colorectal Cancer, long version 1.0, AWMF registration number: 021-007OL, <http://leitlinienprogrammonkologie.de/Leitlinien.7.0.html>
- >Familial nonpolyposis colorectal cancer : Hereditary Cancer Predisposition Syndromes, J Clin Oncol 23:276-292. 2005 by American Society of Clinical Oncology
- >McCune-Albright syndrome: Increased Risk of Breast Cancer at a Young Age in Women with Fibrous Dysplasia. Majoor BC, Boyce AM, Bovée JV, Smit VT, Collins MT, Cleton-Jansen AM, Dekkers OM, Hamdy NA, Dijkstra PS, Appelman-Dijkstra NM. J Bone Miner Res. 2018 Jan;33(1):84-90. doi: 10.1002/jbmr.3286. Epub 2017 Sep 20. PMID:28856726
- >Bannayan-Riley-Ruvalcaba syndrome: Hereditary Cancer Predisposition Syndromes, J Clin Oncol 23:276-292. 2005 by American Society of Clinical Oncology
- >Cowden syndrome: Hereditary Cancer Predisposition Syndromes, J Clin Oncol 23:276-292. 2005 by American Society of Clinical Oncology
- >Bloom syndrome: Hereditary Cancer Predisposition Syndromes, J Clin Oncol 23:276-292. 2005 by American Society of Clinical Oncology

> ICD-11 <https://icd.who.int/dev11/l-m/en>

Notes

> Multiple predispositions may be registered for each diagnosis.

> It is not required to generate this information for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

COMORBIDITIES

Rationale

All variables in this section are required to calculate the **Charlson Comorbidity Index**, a widely used measure of comorbidity. The information is used to adjust outcome statistics when evaluating patient survival and other outcomes.

References

- >Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis* 1987; 40(5):373-383.
- >Website for Charlson Comorbidity Index (CCI): www.mdcalc.com/charlson-comorbidity-index

Note

- >The Charlson index components “Person age” (as 5-level score⁴) and “Malignancy” (as 2-level score⁵) are lacking from this list because they are created from basic data variables (see document “National Basic Data Variables Part A”).
- >It is not required to generate this information for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.
- >If no information has been provided on a specific Charlson index component, absence of this respective comorbidity will be assumed.

⁴ Score 0: age <50, score 1: 50-59, score 2: 60-69, score 3: 70-79, score 4: ≥80

⁵ Score 2: localized solid tumour, score 6: metastatic solid tumour.

Diabetes mellitus

Variable number: 10.1

Item length: 1

Item format: Number

Definition

The data item records the presence and severity of diabetes mellitus at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	Inclusive: - Diabetes during pregnancy alone. ICD-10: O24.0-9 - Diabetes treated with diet alone. -Other endocrines like hypopituitarism, adrenal insufficiency, and recurrent acidosis. ICD-10: E20-E35
1	Uncomplicated (score 1)	Inclusive all patients - diagnosed with diabetes AND - treated with insulin or oral hypoglycaemic, but not diet alone. ICD-10: E10.0, E10.1, E10.6, E10.8, E10.9, E11.0, E11.1, E11.6, E11.8, E11.9, E12.0, E12.1, E12.6, E12.8, E12.9, E13.0, E13.1, E13.6, E13.8, E13.9, E14.0, E14.1, E14.6, E14.8, E14.9.
2	End-organ damage (score 2)	End organ damage can include retinopathy AND/OR neuropathy AND/OR nephropathy attributable to diabetes. ICD-10: E10.2–E10.5, E10.7, E11.2–E11.5, E11.7, E12.2–E12.5, E12.7, E13.2–E13.5, E13.7, E14.2–E14.5, E14.7.

National usage

The variable is to be submitted to the NACR.

Liver Disease

Variable number: 10.2

Item length: 1

Item format: Number

Definition

The data item records the presence and severity of liver disease at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	
1	Mild (score 1)	Inclusive: - cirrhosis without portal hypertension. Child-Pugh-Score A; CLIF-SOFA Score 0. ICD-10:; K70.0–K70.3, K70.9, K71.3–K71.5, K71.7, K73, K74, K76.0, K76.2–K76.4, K76.8, K76.9, Z94.4.
2	Moderate to severe (score 3)	> Moderate liver disease - cirrhosis with portal hypertension, but without bleeding OR - Child-Pugh-Score B OR - CLIF-SOFA Score 1-2. > Severe liver disease - Child-Pugh-Score C OR - CLIF-SOFA Score 3-4, OR - coagulation disorder AND portal hypertension, - I85.0, I85.9, I86.4, I98.2, K70.4, K71.1, K72.1, K72.9, K76.5–K76.7.

National usage

The variable is to be submitted to the NACR.

References

>Vicente Arroyo, Rajiv Jalan. Acute-on-Chronic Liver Failure: Definition, Diagnosis, and Clinical Characteristics. *Semin Liver Dis* 2016;36:109–116.

HIV/AIDS

Variable number: 10.3

Item length: 1

Item format: Number

Definition

The data item records the presence of HIV/AIDS at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	
1	Yes (score 6)	Acquired immune deficiency syndrome includes with definite or probable AIDS, i.e. AIDS related complex, ICD-10: B20–B22, B24.

National usage

The variable is to be submitted to the NACR.

Moderate to Severe Chronic Kidney Disease

Variable number: 10.4

Item length: 1

Item format: Number

Definition

The data item records the presence of moderate to severe chronic kidney disease at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	Inclusive mild renal insufficiency. GFR (Glomerular Filtration Rate) 60-90 ml/min/1.73qm.
1	Yes (score 2)	Inclusive Patients with moderate (GFR 30-59 ml/min/1.73qm) and severe renal insufficiency (GFR <30 ml/min/1.73qm (kidney failure <15 ml/min/1.73qm); OR patients on dialysis; OR patient has a transplant; OR patient with uremia). ICD-10: I12.0, I13.1, N03.2–N03.7, N052–N05.7, N18, N19, N25.0, Z49.0–Z49.2, Z94.0, Z99.2.

National usage

The variable is to be submitted to the NACR.

References

- >Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease.
- >Kidney International Supplements volume 3 | issue 1 | JANUARY 2013
- >www.kidney-international.org.

Congestive Heart Failure

Variable number: 10.5

Item length: 1

Item format: Number

Definition

The data item records the presence of congestive heart failure at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	Exclusive: It does not include patients who are on one of the medications below but who have had no response and no evidence of improvement of physical signs with treatment.
1	Yes (score 1)	Inclusive: Congestive Heart Failure includes patients who have had - exertional or paroxysmal nocturnal dyspnea AND - who have responded symptomatically (or on physical examination) to digitalis, diuretics, or afterload reducing agents (like ACE-inhibitor and Angiotensin1-Receptorantagonists). ICD-10: I09.9, I11.0, I13.0, I13.2, I25.5, I42.0, I42.5-I42.9, I43, I50, P29.0.

National usage

The variable is to be submitted to the NACR.

Myocardial infarction

Variable number: 10.6

Item length: 1

Item format: Number

Definition

The data item records the presence of myocardial infarction at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	<p>Inclusive:</p> <ul style="list-style-type: none"> - Patients with electrocardiographic changes alone who have no clinical history are not designated as having had an infarction. - Chronic exertional Angina Pectoris (Stenocardia), those who had coronary artery bypass and those initially admitted with stable or unstable angina. ICD-10: I20, I25.0, I25.1 - Arrhythmia (chronical atrial fibrillation or flutter ICD-10 I48, sick sinus syndrome ICD-10 I49.5, or ventricular arrhythmias ICD-10 I49 requiring chronic treatment). - Valvular disease (hemodynamically significant aortic stenosis and /or insufficiency, those with prosthetic aortic or mitral valves, asymmetric septal hypertrophy requiring treatment, or tricuspid insufficiency. ICD-10 I39
1	Yes (score 1)	<p>Inclusive:</p> <p>Patients with one or more definite or probable MI.</p> <ul style="list-style-type: none"> - The patients should have been hospitalized for chest pain or an equivalent clinical event AND - Have had electrocardiographic and/or enzyme changes. <p>ICD-10: I21, I22, I25.2</p>

National usage

The variable is to be submitted to the NACR.

Chronic Pulmonary Disease

Variable number: 10.7

Item length: 1

Item format: Number

Definition

The data item records the presence of chronic pulmonary disease at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	Inclusive: - Conditions that had completely resolved (e.g. pneumonia)
1	Yes (score 1)	Inclusive: CPD includes patients with - asthma, - chronic bronchitis, - emphysema, - and other chronic lung disease who have ongoing symptoms such as dyspnea or cough, with mild or moderate activity. This includes patients who are dyspneic with slight activity, with or without treatment and those who are dyspneic with moderate activity despite treatment, as well as patients who are dyspneic at rest., despite treatment, those who require constant oxygen, those with CO2 retention and those with baseline pO2 below 50 torr. ICD-10: I27.8, I27.9, J40–J47, J60–J67 J68.4, J70.1, J70.3.

National usage

The variable is to be submitted to the NACR.

Peripheral Vascular Disease

Variable number: 10.8

Item length: 1

Item format: Number

Definition

The data item records the presence of peripheral vascular disease at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	Inclusive: <ul style="list-style-type: none"> - coronary arteriosclerosis - pulmonary arteriosclerosis - cerebral arteriosclerosis - mesenterial arteriosclerosis - Raynaud-syndrom - other aneurism and dissection (I72) - arteriitis, arterionecrosis, erosion and ulcera of artery
1	Yes (score 1)	Inclusive: Peripheral Vascular Disease includes <ul style="list-style-type: none"> - patients with intermittent claudication OR - those who had a bypass for arterial insufficiency, OR - those with gangrene or acute arterial insufficiency, OR - those with a treated and untreated thoracic or abdominal aneurism and dissection (6 cm or more). ICD-10: I70, I71, I73.1, I73.8, I73.9, I77.1, I79.0, I79.2, K55.1, K55.8, K55.9, Z95.8, Z95.9.

National usage

The variable is to be submitted to the NACR.

Cerebrovascular Accident or Transient Ischemic Attack

Variable number: 10.9

Item length: 1

Item format: Number

Definition

The data item records the presence of cerebrovascular accident or transient ischemic attack at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	Inclusive: - Parkinson disease ICD-10: G20-26 - uncontrolled seizures ICD-10: G40-43 - syncope without an identified cause or treatment.
1	Yes (score 1)	Inclusive: Cerebrovascular Disease includes patients with a history of a Cerebrovascular accident - with minor or no residua, OR - patients who have had transient ischemic attacks (incl. Transient retinal artery occlusion) . ICD-10: G45, G46, H34.0, I60-I69.

National usage

The variable is to be submitted to the NACR.

Notes

>If the CVA (cerebrovascular accident) resulted in hemiplegia, code only hemiplegia.

Dementia

Variable number: 10.10

Item length: 1

Item format: Number

Definition

The data item records the presence of dementia at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	Inclusive: - Mild cognitive deficit (F06.7, see Notes) - Parkinson disease without dementia G20-26 - Alcohol withdrawal delirium without dementia
1	Yes (score 1)	Inclusive: Dementia includes patients with moderate to severe chronic cognitive deficit resulting in impaired function from any cause. ICD-10: F00–F03, F05.1, G30, G31.1.

National usage

The variable is to be submitted to the NACR.

Notes

>Mild cognitive disorder: A disorder characterized by impairment of memory, learning difficulties, and reduced ability to concentrate on a task for more than brief periods. There is often a marked feeling of mental fatigue when mental tasks are attempted, and new learning is found to be subjectively difficult even when objectively successful. None of these symptoms is so severe that a diagnosis of either dementia (F00-F03) or delirium (F05.-) can be made.

Hemiplegia / Paraplegia

Variable number: 10.11

Item length: 1

Item format: Number

Definition

The data item records the presence of hemiplegia/paraplegia at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	Inclusive: - Muscular atrophy (e.g. Amyotrophic lateral sclerosis) ICD-10: G12 - Parkinson disease G20-26 - Poliomyelitis sequelae B91
1	Yes (score 2)	Inclusive: Hemiplegia from any cause: - hemiplegia/hemiparesis OR - paraplegia/paraparesis, whether it occurred as a result of a cerebrovascular accident or other condition. ICD-10: G04.1, G11.4, G80.1, G80.2, G81, G82, G83.0–G83.4, G83.9.

National usage

The variable is to be submitted to the NACR.

Connective Tissue Disease - Rheumatic disease

Variable number: 10.12

Item length: 1

Item format: Number

Definition

The data item records the presence of connective tissue disease or rheumatic disease at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	Inclusive: - mild rheumatoid arthritis (Disease Activity Score 28 (DAS 28) <3.2).
1	Yes (score 1)	Inclusive: - systemic lupus erythematosus, - polymyositis, - mixed connective tissue disease, - moderate (Disease Activity Score 28 (DAS 28) >3.1 and <5.2) and severe rheumatoid arthritis (Disease Activity Score 28 (DAS 28) >5.1.), - polymyalgia rheumatic ICD-10: M05, M06, M31.5, M32–M34, M35.1, M35.3, M36.0.

National usage

The variable is to be submitted to the NACR.

References

>Rheumatoid Arthritis Measures. Arthritis & Rheumatism (Arthritis Care & Research). Vol. 49, No. 5S, October 15, 2003, pp S214–S224. DOI 10.1002/art.11407. © 2003, American College of Rheumatology.

Peptic Ulcer Disease

Variable number: 10.13

Item length: 1

Item format: Number

Definition

The data item records the presence of peptic ulcer disease at the time of diagnosis as pre-existing medical condition. Scores weight the estimated effect on patient survival.

Code	Label	Description
0	No (score 0)	Inclusive: - Inflammatory bowel disease (Colitis Ulcerosa/ulcerative colitis or Morbus Crohn/regional enteritis). - Bleeding requiring transfusion due to other reason than ulcer disease - Coagulopathy including patients with a circulating anticoagulant, or other coagulopathy.
1	Yes (score 1)	Inclusive: - Gastric or Peptic Ulcer disease includes patients who have required treatment for ulcer disease, including those who have bled from ulcer. ICD-10: K25–K28

National usage

The variable is to be submitted to the NACR.

Charlson Index

Variable number: 10.14

Item length: 2

Item format: Number

Definition

The data item records the summed scores of all components of the Charlson Index. It estimates the combined effect of the Charlson Index components on patient survival.

Code examples	Label	Description
2	Charlson Index 2	Minimum value for persons <50 years of age without any Charlson Index comorbidity, except a cancer diagnosis where supplementary data is reportable.
...		
33	Charlson Index 33	Maximum value for persons ≥80 years of age with severe levels of Charlson Index comorbidities, including a cancer diagnosis where supplementary data is reportable.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

Note:

>The value of the Charlson index has to be submitted only if it is available as part of the diagnosis and treatment of the patient.

APPENDIX

List of changes between version 1.0 and 1.1

Item / No / Page	Changes as of 15.10.2019
Titelpage	New logos for NACR and SCCR has been created and replaces the old logos.
Case definitions /p2	Added text in Footnote 1: "431.112.1" after Ordinance. Added text in Footnote 3: "Verification refers to medically accepted diagnostic procedures (clinical, cytological, histological, laboratory test)."
Congestive Heart Failure / 10.5 / p12	Text in description for code 0: "Inclusive" replaced with: "Exclusive", and "...those medications..." replaced with: "...the medications below...".

END