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**Bundesamt für Gesundheit BAG**



Foundation  
National Institute  
for Cancer Epidemiology  
and Registration

# NATIONAL CANCER DATA DICTIONARY

V 1.0

**Part A**

**BASIC VARIABLES**

**for**

**Adults, Adolescents, and Children**

7.6.2019

# CONTENTS

<b>CONTENTS</b> .....	1
<b>ABBREVIATIONS</b> .....	7
<b>CASE DEFINITIONS</b> .....	8
<b>Person age at diagnosis</b> .....	8
<b>Person resident status</b> .....	8
<b>No veto from patient</b> .....	8
<b>Reportable diagnosed neoplasms</b> .....	8
<b>PATIENT DATA</b> .....	9
<b>Family Name(s)*</b> .....	10
<b>First Name(s)*</b> .....	11
<b>Sex</b> .....	12
<b>Date of Birth</b> .....	13
<b>Accuracy for date of birth</b> .....	14
<b>OASI number*</b> .....	15
<b>Street name*</b> .....	16
<b>Street number*</b> .....	17
<b>Extra address line*</b> .....	18
<b>Postcode*</b> .....	19
<b>City/Municipality name*</b> .....	20
<b>Canton number</b> .....	21
<b>FSO City/Municipality number</b> .....	22
<b>Place of birth</b> .....	23
<b>Nationality</b> .....	24
<b>Civil status</b> .....	25
<b>Vital status</b> .....	26
<b>Date for vital status</b> .....	27
<b>Accuracy for date of vital status</b> .....	28
<b>Cause of death (Registry based)*</b> .....	29

Principal cause of death .....	30
Underlying cause of death .....	31
Intermediate cause of death .....	32
First concomitant cause of death.....	33
Second concomitant cause of death.....	34
ICD-version for causes of death .....	35
<b>DIAGNOSIS .....</b>	<b>36</b>
Date of informing the patient* .....	37
Date of notification .....	38
Date of incidence .....	39
Accuracy for date of incidence.....	40
Age at incidence.....	41
DCN flag.....	42
Method of first detection.....	43
Most valid basis of diagnosis .....	44
Diagnostic method(s) used* .....	45
Diagnostic institution(s)* .....	47
Rank of diagnosis.....	48
Case number .....	49
<b>CLASSIFICATIONS (ICD, ICD-O) .....</b>	<b>50</b>
ICD version .....	51
ICD-O version .....	52
ICD code .....	53
ICD-O Topography .....	54
ICD-O Morphology.....	55
ICD-O Behaviour .....	56
Associated in situ tumour .....	57
ICD-O Histological grade.....	58
Laterality.....	59
ICCC-3 main group .....	60

ICCC-3 code*	61
ICCC-3 extended code*	62
<b>STAGE, GRADE</b>	<b>63</b>
UICC TNM version	64
y-Prefix of cTNM	65
cT	66
cN	67
cM	68
a-Prefix of pTNM	69
y-Prefix of pTNM	70
pT	71
m-Suffix of pT	72
pN	73
Number of involved regional lymph nodes	74
Number of examined regional lymph nodes	75
pM	76
Lymphatic invasion	77
Venous invasion	78
Perineural invasion	79
TNM stage group	80
Ann Arbor staging	81
COG staging	82
COG ALL staging	83
FIGO staging	84
INRGSS staging	85
IRSS staging	86
Lugano staging	87
PRETEXT staging	88
Rai staging	89
Binet staging	90

Rhabdomyosarcoma site staging .....	91
ISS staging .....	92
DSSplus.....	93
SIOP staging .....	94
St. Jude / Murphy staging .....	95
Toronto Tier II staging .....	96
Toronto Tier II (manual) staging .....	97
Creasman grading system .....	98
Elston/Ellis grading system .....	99
SalzerKuntschik grading system.....	100
Shimada grading system .....	101
WHO(CNS) grading system.....	102
Clinical tumour size .....	103
Pathological tumour size.....	104
Metastases at diagnosis indicator .....	105
Topography of metastases at diagnosis .....	106
<b>BREAST CANCER: tumour related prognostic factors .....</b>	<b>107</b>
Oestrogen receptor status .....	108
Progesterone receptor status .....	109
Her2 receptor status.....	110
Tumour proliferation labeling.....	111
<b>PROSTATE CANCER: tumour related prognostic factors.....</b>	<b>112</b>
Pretreatment Prostate Specific Antigen (PSA) .....	113
Gleason biopsy most common grade* .....	114
Gleason biopsy second most common or highest grade* .....	115
Gleason excision most common grade* .....	116
Gleason excision second most common or highest grade* .....	117
Gleason score.....	118
WHO grade group.....	119
<b>MELANOMA: tumour related prognostic factors.....</b>	<b>120</b>

Breslow thickness .....	121
<b>COLORECTAL CANCER: tumour related prognostic factors</b> .....	122
Circumferential resection margins.....	123
Microsatellite instability .....	124
<b>TESTICULAR CANCER: tumour related prognostic factors</b> .....	125
$\alpha$ -fetoprotein .....	126
hCG .....	127
LDH .....	128
Serum tumour markers .....	129
<b>HEAD/NECK CANCER: tumour related prognostic factors</b> .....	130
HPV/p16.....	131
EBV .....	132
<b>TREATMENT: prognostic factors related to treatment</b> .....	133
Residual invasive tumour.....	134
Residual in-situ tumour .....	135
Resection margin invasive tumour .....	136
Resection margin in-situ tumour .....	137
Sentinel lymph node assessment .....	138
Number of examined sentinel lymph nodes .....	139
Number of positive sentinel lymph nodes .....	140
<b>FIRST TREATMENT COMPLEX</b> .....	141
Basis of first treatment complex decision .....	142
Date of first treatment complex decision.....	143
Accuracy for date of 1 <sup>st</sup> treatment complex decision .....	144
First treatment complex goal(s).....	145
First treatment complex code(s).....	146
First treatment complex start date(s).....	147
Accuracy for date(s) of 1 <sup>st</sup> treatment complex start .....	148
First treatment complex institution(s)* .....	149
<b>COURSE OF DISEASE: Recurrences/Transformations</b> .....	150

<b>Type of event(s)</b> .....	151
<b>Date of event(s)</b> .....	152
<b>Accuracy for date of event(s)</b> .....	153
<b>Event ICD-O version</b> .....	154
<b>Morphology term before change of main diagnosis*</b> .....	155
<b>Morphology term after Transformation</b> .....	156
<b>Topography(s) of post-diagnosis metastases</b> .....	157
<b>END</b> .....	158

**Note:** Variables labelled with a star (\*) will not be submitted to the NKRS-ONEC-SNRT.

# ABBREVIATIONS

AHV	Alters- und Hinterlassenenversicherung
AIDS	Acquired immunodeficiency syndrome
AJCC	American Joint Committee on Cancer
AVS	Assurance vieillesse et survivants
BfS	Bundesamt für Statistik
CBC	Complete blood count
CHOP	Swiss Classification for Treatment Procedures
COG	Children's Oncology Group
CRM	Circumferential resection margins
CSF	Cerebrospinal fluid
DCO	Death Certificate Only
DSSplus	Durie-Salmon Plus staging system
EBV	Epstein Barr virus
ENCR	European Network of Cancer Registries
FDFA	Federal Department of Foreign Affairs
FIGO	International Federation of Gynecology and Obstetrics
FSO	Federal Statistical Office
hCG	Human chorionic gonadotropin
HPV	Human papillomavirus
IACR	International Association of Cancer Registries
IARC	International Agency for Research on Cancer – World Health Organization
ICCC	International Classification of Childhood Cancer
ICD	International Classification of Diseases
ICD-O	International Classification of Diseases for Oncology
INRGSS	International Neuroblastoma Risk Group Staging System
IRSS	International Retinoblastoma Staging System
ISS	International Staging System;
LDH	Lactate dehydrogenase
NKRS	Nationale Krebsregistrierungsstelle
OASI	Old-Age and Survivors' Insurance number
ONEC	Organe national d'enregistrement du cancer
PET/CT	Positron emission tomography and computed tomography
PRETEXT	PRE-Treatment EXTent of tumor
PSA	Prostate Specific Antigen
R-ISS	Revised International Staging System
SFSO	Swiss Federal Statistical Office
SIOP	International Society of Pediatric Oncology
SIOPEL	International Childhood Liver Tumor Strategy Group
SNRT	Servizio nazionale di registrazione dei tumori
SPECT	Single photon emission computed tomography
TNM	Classification of Malignant Tumours
UICC	Union for International Cancer Control
WHO	World Health Organization



# CASE DEFINITIONS

## Person age at diagnosis

Children (0-14.99 years), Adolescents (15-19.99 years), and Adults (20 and more years).

## Person resident status<sup>1</sup>

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-ID<sup>2</sup> [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 neoplasms<sup>3</sup>

	ICD-10	
All malignant neoplasms	C00 – C97	[except Basal cell skin carcinoma in Adults]
All carcinoma in-situ	D00 – D09	
Benign neoplasms	D32	(Meninges)
	D33	(Brain and other parts of central nervous system)
	D35	(Other and unspecified endocrine glands) [restricted to D35.2 Pituitary gland in Adults]
All Neoplasms of uncertain or unknown behaviour	D37 – D48	[except Monoclonal gammopathy D47.2]
	D61	(Other aplastic anaemias) [except in Adults]
	D76	(Certain diseases involving lymphoreticular tissue and reticulohistiocytic system) [except in Adults]

<sup>1</sup> Ordinance of 19.12.2008 on the Federal Population Census, Article 2 Letter d.

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

<sup>3</sup> Only verified diagnoses are reportable.

## PATIENT DATA

## Family Name(s)\*

---

**Variable number:** 1.1.1

Item length: 255

Item format: Text

### Definition

The data item records the family name (last name or surname) at the time of diagnosis.

### Rational

The information serves as personal identifier.

Code examples <sup>#</sup>
Müller
Müller-Rochat
Müller Rochat
...

<sup>#</sup>: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

>More than a single family name may optionally be registered per person (i.e. the person's family name history at different times, or name variants/spellings at the same time).

>If the patient has more than a single reportable diagnosis, the family name at diagnosis may be different in each case.

## First Name(s)\*

---

**Variable number:** 1.1.2

Item length: 255

Item format: Text

### Definition

The data item records the first name at the time of diagnosis. One or more names may be recorded.

### Rational

The data item is used to differentiate between persons with the same last name.

Code examples <sup>#</sup>
Daniel
Daniel Peter
Maria A. Ursula
...

<sup>#</sup>: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

>Official as well as unofficial (chosen) first names, i.e. the person's first name history at different times, or name variants/spellings at the same time, may optionally be registered to facilitate identification.

>If the patient has more than a single reportable diagnosis, the first name at diagnosis may be different in each case.

## Sex

---

**Variable number:** 1.2  
Item length: 1  
Item format: Numeric

### Definition

The data item records the person's sex at the time of diagnosis.

### Rational

The information is used to compare cancer rates and outcomes by sex.

Code	Label
1	Male
2	Female
3	Other (e.g. hermaphrodite; transsexual, born male; transsexual, born female; biological sex not same as self-assigned sex; genetic sex differs from sex assigned at birth; etc.)
9	Unknown (not stated in records)

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## Date of Birth

**Variable number:** 1.3.1  
Item length: 10  
Item format: Date (dd.mm.yyyy)

### Definition

The data item records the date of birth.

### Rational

The information is used for person identification and to compare cancer rates and outcomes by birth cohort.

Code examples <sup>#</sup>	Description
01.01.2005	Note: for single digit day or month, record with a leading 0.
15.01.2005	Note: if exact day unknown, set day as 15 <sup>th</sup> of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30 <sup>th</sup> of June of the respective year.
...	

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT in truncated form, with day set to unknown (i.e. 15) for all cases.

### References

-

### Notes

-

## Accuracy for date of birth

---

**Variable number:** 1.3.2

Item length: 1

Item format: Number

### Definition

The data item indicates the accuracy of the date of birth.

### Rational

The information is used to identify case groups where age or time period is not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

-

## OASI number\*

**Variable number:** 1.4

Item length: 13

Item format: Text

### Definition

The official 13-digit unique person identification number: OASI (Old-Age and Survivors' Insurance).

### Rational

The data item is used to uniquely identify the person.

<b>Code structure</b>	X <sub>n-12</sub> X <sub>n-11</sub> X <sub>n-10</sub>	X <sub>n-9</sub> X <sub>n-8</sub> X <sub>n-7</sub> X <sub>n-6</sub> X <sub>n-5</sub> X <sub>n-4</sub> X <sub>n-3</sub> X <sub>n-2</sub> X <sub>n-1</sub>	X <sub>n</sub>
<b>Description</b>	Country	Person	Control number

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT. The NKRS-ONEC-SNRT will use a pseudonymized number only.

### References

>Artikel 50c des Bundesgesetzes vom 20. Dezember 1946 (SR 831.10) über die Alters- und Hinterlassenenversicherung.

### Notes

>OASI in German/French, Italian: AHV/AVS.



## Street name\*

---

**Variable number:** 1.5.1

Item length: 255

Item format: Text

### Definition

The data item records the street name of the address at the time of diagnosis.

### Rational

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples <sup>#</sup>
Bahnhofstrasse
...

<sup>#</sup>: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

- >If more than a single diagnosis is registered per person, the address may be different for each case.
- >Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.
- >Addresses may be specified as a history including arrival, moving and last validated date of residence.

## Street number\*

---

**Variable number:** 1.5.2

Item length: 10

Item format: Alphanumeric

### Definition

The data item records the street number of the address at the time of diagnosis.

### Rational

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples#
10a
...

#: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

- >If more than a single diagnosis is registered per person, the address may be different for each case.
- >Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.
- >Addresses may be specified as a history including arrival, moving and last validated date of residence.

## Extra address line\*

---

**Variable number:** 1.5.3

Item length: 255

Item format: Text

### Definition

The data item records additional lines of the patient's address at the time of diagnosis.

### Rational

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples <sup>#</sup>
Postlagernd
...

<sup>#</sup>: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

>.

### Notes

>If more than a single diagnosis is registered per person, the address may be different for each case.

>Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.

>Addresses may be specified as a history including arrival, moving and last validated date of residence.

## Postcode\*

**Variable number:** 1.6

Item length: 4

Item format: Number

### Definition

The data item records the four-digit postcode of the address at the time of diagnosis.

### Rational

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples <sup>#</sup>	Description
1000	Situated in Lausanne
1003	Situated in Lausanne
1004	Situated in Lausanne
1005	Situated in Lausanne
1006	Situated in Lausanne
1007	Situated in Lausanne
1008	Situated in Jouxens-Mézery
...	...
9657	Situated in Wildhaus-Alt St. Johann
9658	Situated in Gams
9658	Situated in Grabs
9658	Situated in Wildhaus-Alt St. Johann

#: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

><https://www.bfs.admin.ch/bfsstatic/dam/assets/4242620/master> [last access: 27.11.2018]

### Notes

- >If more than a single diagnosis is registered per person, the address may be different for each case.
- >Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.
- >Addresses may be specified as a history including arrival, moving and last validated date of residence.

## City/Municipality name\*

---

**Variable number:** 1.7

Item length: 255

Item format: Text

### Definition

The data item records the FSO City/Municipality name of the address at the time of diagnosis.

### Rational

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples <sup>#</sup>
Aeugst am Albis
Affoltern am Albis
Bonstetten
Hausen am Albis
...

#: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

><https://www.bfs.admin.ch/bfsstatic/dam/assets/4242620/master> [last access: 27.11.2018]

### Notes

- >If more than a single diagnosis is registered per person, the address may be different for each case.
- >Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.
- >Addresses may be specified as a history including arrival, moving and last validated date of residence.

## Canton number

---

**Variable number:** 1.8

Item length: 2

Item format: Number

### Definition

The data item records the FSO canton number of the address at the time of diagnosis.

### Rational

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples <sup>#</sup>	Label	Description
1	ZH	Zürich
2	BE	Bern / Berne
...	...	
25	GE	Genève
26	JU	Jura

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>FSO: <https://www.bfs.admin.ch/bfs/de/home/grundlagen/raumgliederungen.html> [last access: 4.2.19]

### Notes

- >If more than a single diagnosis is registered per person, the address may be different for each case.
- >Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.
- >Addresses may be specified as a history including arrival, moving and last validated date of residence.

## FSO City/Municipality number

**Variable number:** 1.9  
Item length: 4  
Item format: Number

### Definition

The data item records the FSO city/Municipality number of the address at the time of diagnosis.

### Rational

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples <sup>#</sup>	Label
1	Aeugst am Albis
2	Affoltern am Albis
...	...
6809	Haute-Ajoie
6810	La Baroche

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>FSO: <https://www.bfs.admin.ch/bfsstatic/dam/assets/4242620/master> [last access: 27.11.2018]

### Notes

- >If more than a single diagnosis is registered per person, the address may be different for each case.
- >Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.
- >Addresses may be specified as a history including arrival, moving and last validated date of residence.

## Place of birth

**Variable number:** 1.10  
**Item length:** 4  
**Item format:** Number

### Definition

The date item records the FSO city/municipality number of place of birth if the person was born in Switzerland, or the FSO country number of birth, if the country of birth is not Switzerland, or if the birth place in Switzerland is not stated.

### Rational

This data item is used to evaluate medical care delivery to special populations and to identify populations at special risk for certain cancers.

Code examples <sup>#</sup>	Label	Description
1	Aeugst am Albis	FSO city number (born in CH)
2	Affoltern am Albis	FSO city number (born in CH)
...	...	FSO city number (born in CH)
6809	Haute-Ajoie	FSO city number (born in CH)
6810	La Baroche	FSO city number (born in CH)
8100	Switzerland	FSO country code (born in CH), unspecified
8201	Albania	FSO country code (not born in CH)
...	...	FSO country code (not born in CH)
8703	French Southern and Antarctic Lands	FSO country code (not born in CH)
9999	Unknown (not stated in patient record)	FSO country code (not born in CH)

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

><https://www.bfs.admin.ch/bfsstatic/dam/assets/4242620/master> [last access: 27.11.2018].

### Notes

-



## Nationality

**Variable number:** 1.11

Item length: 4

Item format: Number

### Definition

The data item records the FSO country number of the person's nationality at time of diagnosis.

### Rational

This data item is used to evaluate medical care delivery to special populations and to identify populations at special risk for certain cancers.

Code examples <sup>#</sup>	Label
8100	Switzerland
8201	Albania
8202	Andorra
...	...
8701	Antarctica
8702	Bouvet Island
8703	French Southern and Antarctic Lands
9999	Unknown (not stated in patient record)

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

><https://www.bfs.admin.ch/bfsstatic/dam/assets/3644516/master> [last access: 27.11.2018]

### Notes

>If more than a single diagnosis is registered per person, the nationality may be different for each case.

## Civil status

**Variable number:** 1.12

Item length: 1

Item format: Number

### Definition

The data item records the civil status at the time of diagnosis using FSO Population and Households Statistics categories.

### Rational

Studies have shown that the civil status has significant impacts on the survival of various cancers. Civil status facilitates data linkage to the official Swiss Vital Statistics.

Code	Label	Description
1	Never Married	
2	Married	
3	Widowed	
4	Divorced	
5	Annulled marriage*	Der Zivilstand «Unverheiratet» kann als Folge einer Ungültigkeitsklärung der letzten Ehe oder als Folge einer Verschollenerklärung des letzten Ehepartners bzw. der letzten Ehepartnerin entstehen.
6	Registered partnership	
7	Dissolved partnership	
9	Unknown	Not stated / Not assessed.

\* German: "Unverheiratet"; French: "Non marié"; Italian: "Non coniugati"

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Amtlicher Katalog der Merkmale. Bundesamt für Statistik (BFS). Neuchâtel, 2014. ISBN: 978-3-303-00504-0.

><https://www.bfs.admin.ch/bfs/de/home/statistiken/bevoelkerung/erhebungen/statpop.html> [last access: 13.5.2019]

### Notes

>If more than a single diagnosis is registered per person, the civil status may be different for each case.

## Vital status

---

**Variable number:** 1.13

Item length: 1

Item format: Number

### Definition

The data item records the vital status at the date of reference.

### Rational

Essential information for prevalence statistics and survival studies.

Code	Label	Description
1	Alive	Person is alive at vital status update.
2	Dead	Person is dead at vital status update.
3	Lost to follow-up	Person has moved out of Switzerland. Date of reference is the last date when the person was known to be alive.
9	Unknown	Vital status could not be traced by any type of update procedure.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

>Vital status must be updated on a regular basis, at least annually.

## Date for vital status

**Variable number:** 1.14.1

Item length: 10

Item format: Date (dd.mm.yyyy)

### Definition

The data item records the date of last vital status update or the date of death.

### Rational

The information is required for prevalence statistics and survival time analyses.

Code examples <sup>#</sup>	Description
01.01.2005	Note: for single digit day or month, record with a leading 0.
15.01.2005	Note: if exact day unknown, set day as 15 <sup>th</sup> of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30 <sup>th</sup> of June of the respective year.
...	

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT in truncated form, with day set to unknown (i.e. 15) for all cases. In addition, the accompanying age in days will be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

>Vital status must be updated on a regular basis, at least annually.

## Accuracy for date of vital status

---

**Variable number:** 1.14.2

Item length: 1

Item format: Number

### Definition

Indicates the accuracy of the date of reference for the given vital status of the patient.

### Rational

The data item is used to identify groups of patients where ages or time periods are not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

-

## Cause of death (Registry based)\*

**Variable number:** 1.15

Item length: 5

Item format: Alphanumeric

### Definition

The data item indicates the International Classification of Diseases (ICD) code for the primary cause of death, according to the cancer registry. To code with three digits is sufficient (exception see Notes). To code only cases with cancer as cause of death is sufficient. The item is entered without decimal point.

### Rational

The cancer registry may have more accurate information on the cause of death than is provided on the death certificate. It opens the possibility to collaborate with the FSO in correcting the official vital statistics.

Code examples <sup>#</sup>	Label
B17	Other acute viral hepatitis
B24	Unspecified human immunodeficiency virus [HIV] disease
C342	Malignant neoplasm of middle lobe, bronchus or lung.
...	...
Z99	Dependence on enabling machines and devices, not elsewhere classified

#: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

>ICD: <https://icd.who.int/browse10/2016/en> [last accessed: 27.12.2018].

### Notes

>Mesothelioma of pleura (C450) and malignant neoplasm of pleura (C384) must be recorded with four digits.

## Principal cause of death

**Variable number:** 1.16

Item length: 5

Item format: Alphanumeric

### Definition

The data item records the International Classification of Diseases (ICD) principal cause of death according to Swiss Federal Statistical Office (SFSO). This is the underlying disease that caused all other ailments within a logical chain and is considered as the mono-causal cause of death. The official name in German is “endgültige Todesursache”, and in French “la cause finale de décès”, and in Italian “causa finale di morte”. The data item is entered without decimal point.

### Rational

The principal cause of death, determined from cause of death certificate information using international guidelines, forms the basis of the official cancer mortality statistics.

Code examples <sup>#</sup>	Label
A000	Cholera due to <i>Vibrio cholerae</i> 01, biovar cholerae
A001	Cholera due to <i>Vibrio cholerae</i> 01, biovar el tor
...	...
Z998	Dependence on other enabling machines and devices
Z999	Dependence on unspecified enabling machine and device

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

> <https://icd.who.int/browse10/2016/en> [last accessed: 27.12.2018].

>Richtlinien für die ärztliche Bescheinigung der Todesursachen. Bundesamt für Statistik (BFS). Reihe: Statistik der Schweiz. Fachbereich: 14 Gesundheit. Bern 1996. ISBN: 3-303-14025-1.

>Richtlinien zur Kodierung der Todesursachen nach der ICD-10-Klassifikation. Bundesamt für Statistik (BFS). Stand der Überarbeitung: 5.7.2011.

### Notes

>It is required that the official vital statistics issued annually by the SFSO is linked to the registry dataset.

## Underlying cause of death

**Variable number:** 1.17.1

Item length: 5

Item format: Alphanumeric

### Definition

The data item records the International Classification of Diseases (ICD) primary cause of death from the cause of death certificate according to Swiss Federal Office of Statistics. The official name in German is “Grundkrankheit, Grundursache”, and in French “Maladie initiale, cause primaire”, and in Italian “Malattia iniziale, causa primaria”. The item is entered without decimal point.

### Rational

This information is required to identify missed cancer diagnoses. It is also used to estimate the number of existing cancer diagnoses that were not captured by registration.

Code examples <sup>#</sup>	Label
A000	Cholera due to <i>Vibrio cholerae</i> 01, biovar cholerae
A001	Cholera due to <i>Vibrio cholerae</i> 01, biovar el tor
...	...
Z998	Dependence on other enabling machines and devices
Z999	Dependence on unspecified enabling machine and device

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

><https://icd.who.int/browse10/2016/en> [last accessed: 27.12.2018].

>Richtlinien für die ärztliche Bescheinigung der Todesursachen. Bundesamt für Statistik (BFS). Reihe: Statistik der Schweiz. Fachbereich: 14 Gesundheit. Bern 1996. ISBN: 3-303-14025-1.

>Richtlinien zur Kodierung der Todesursachen nach der ICD-10-Klassifikation. Bundesamt für Statistik (BFS). Stand der Überarbeitung: 5.7.2011.

### Notes

>It is required that the official vital statistics issued annually by the SFSO is linked to the registry dataset.



## Intermediate cause of death

**Variable number:** 1.17.2

Item length: 5

Item format: Alphanumeric

### Definition

The data item records the International Classification of Diseases (ICD) secondary cause of death from the cause of death certificate according to Swiss Federal Office of Statistics. The official name in German is "Folgekrankheit, unmittelbare Ursache des Todesfalles", and in French "Maladie secondaire, cause directe du décès", and in Italian "Malattia secondaria, causa di morte diretta". The item is entered without decimal point.

### Rational

This information is required to identify missed cancer diagnoses. It is also used to estimate the number of existing cancer diagnoses that were not captured by registration.

Code examples <sup>#</sup>	Label
A000	Cholera due to <i>Vibrio cholerae</i> 01, biovar cholerae
A001	Cholera due to <i>Vibrio cholerae</i> 01, biovar el tor
...	...
Z998	Dependence on other enabling machines and devices
Z999	Dependence on unspecified enabling machine and device

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

><https://icd.who.int/browse10/2016/en> [last accessed: 27.12.2018].

>Richtlinien für die ärztliche Bescheinigung der Todesursachen. Bundesamt für Statistik (BFS). Reihe: Statistik der Schweiz. Fachbereich: 14 Gesundheit. Bern 1996. ISBN: 3-303-14025-1.

>Richtlinien zur Kodierung der Todesursachen nach der ICD-10-Klassifikation. Bundesamt für Statistik (BFS). Stand der Überarbeitung: 5.7.2011.

### Notes

>It is required that the official cause of death statistics issued annually by the SFSO is linked to the registry dataset.

## First concomitant cause of death

**Variable number:** 1.17.3

Item length: 5

Item format: Alphanumeric

### Definition

The data item records the International Classification of Diseases (ICD) first tertiary cause of death from the cause of death certificate according to Swiss Federal Office of Statistics. The official name in German is “Begleitkrankheiten”, and in French “Maladie concomitantes”, and in Italian “Malattie concomitanti”. The item is entered without decimal point.

### Rational

This information is required to identify missed cancer diagnoses. It is also used to estimate the number of existing cancer diagnoses that were not captured by registration.

Code examples#	Label
A000	Cholera due to <i>Vibrio cholerae</i> 01, biovar cholerae
A001	Cholera due to <i>Vibrio cholerae</i> 01, biovar el tor
...	...
Z998	Dependence on other enabling machines and devices
Z999	Dependence on unspecified enabling machine and device

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

><https://icd.who.int/browse10/2016/en> [last accessed: 27.12.2018].

>Richtlinien für die ärztliche Bescheinigung der Todesursachen. Bundesamt für Statistik (BFS). Reihe: Statistik der Schweiz. Fachbereich: 14 Gesundheit. Bern 1996. ISBN: 3-303-14025-1.

>Richtlinien zur Kodierung der Todesursachen nach der ICD-10-Klassifikation. Bundesamt für Statistik (BFS). Stand der Überarbeitung: 5.7.2011.

### Notes

>It is required that the official vital statistics issued annually by the SFSO is linked to the registry dataset.

## Second concomitant cause of death

**Variable number:** 1.17.4

Item length: 5

Item format: Alphanumeric

### Definition

The data item records the International Classification of Diseases (ICD) second tertiary cause of death from the cause of death certificate according to Swiss Federal Office of Statistics. The official name in German is “Begleitkrankheiten”, and in French “Maladie concomitantes”, and in Italian “Malattie concomitanti”. The item is entered without decimal point.

### Rational

This information is required to identify missed cancer diagnoses. It is also used to estimate the number of existing cancer diagnoses that were not captured by registration.

Code examples#	Label
A000	Cholera due to <i>Vibrio cholerae</i> 01, biovar cholerae
A001	Cholera due to <i>Vibrio cholerae</i> 01, biovar el tor
...	...
Z998	Dependence on other enabling machines and devices
Z999	Dependence on unspecified enabling machine and device

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

><https://icd.who.int/browse10/2016/en> [last accessed: 27.12.2018].

>Richtlinien für die ärztliche Bescheinigung der Todesursachen. Bundesamt für Statistik (BFS). Reihe: Statistik der Schweiz. Fachbereich: 14 Gesundheit. Bern 1996. ISBN: 3-303-14025-1.

>Richtlinien zur Kodierung der Todesursachen nach der ICD-10-Klassifikation. Bundesamt für Statistik (BFS). Stand der Überarbeitung: 5.7.2011.

### Notes

>It is required that the official vital statistics issued annually by the SFSO is linked to the registry dataset.

## ICD-version for causes of death

**Variable number:** 1.18  
Item length: 2  
Item format: Number

### Definition

The data item records the version of the International Classification of diseases published by the World Health Organization (WHO).

### Rational

The development of the medical diagnoses over time requires regular adaptations of the International Classification of diseases. Switzerland used the ICD-8 for the coding of causes of death until 1994. Since 1995, the classification of causes of death in Switzerland is based on the World Health Organisation's (WHO) international statistical classification of diseases and related health problems, 10th revision (ICD-10).

Code	Label
8	ICD-8 Swiss version
10	ICD-10 WHO
11	ICD-11 WHO

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- ><https://www.who.int/classifications/icd/en/> [last accessed: 27.12.2018].
- ><https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/erhebungen/ecod.html> [last accessed: 29.12.2018].

### Notes

- >An adapted version of the ICD-8 WHO was used in Switzerland.
- >Version ICD-9 was not used in Switzerland to code the cause of death.
- >The date of death is the date of reference for the relevant ICD-version.

# DIAGNOSIS

## Date of informing the patient\*

**Variable number:** 2.1

Item length: 10

Item format: Date (dd.mm.yyyy)

### Definition

The data item records the date when the patient was informed according to KRG Art. 5 and KRV Art. 13. This date is a mandatory part of the patient's medical records. The physician responsible to inform the patient about the diagnosis is also responsible to inform about patient-relevant aspects of the cancer registration law, and to ensure documentation of the date.

### Rational

The information defines the start of the waiting period for a potential patient veto to registration.

Code examples <sup>#</sup>	Description
01.01.2005	Note: for single digit day or month, record with a leading zero.
...	

#: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

>Partially known dates are not accepted. Day, month and year has to be decided. If the exact day is not known, the last day in the respective month has to be coded.

>Not mandatory if the patient has died before he or she could be informed.

## Date of notification

---

**Variable number:** 2.2

Item length: 10

Item format: Date (dd.mm.yyyy)

### Definition

The data item records the date when the case was first notified to the registry.

### Rational

The time between incidence and registry notification is an important indicator for the timeliness of the registration process. It is also required for assessment of completeness of case ascertainment.

Code examples <sup>#</sup>	Description
01.01.2005	Note: for single digit day or month, record with a leading zero.
...	

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT in truncated form, with day set to unknown (i.e. 15) for all cases. In addition, the accompanying age in days will be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

>The date of notification may be before the date when the waiting period for potential patient veto to registration ends.

>Partially known dates are not accepted. Day, month and year has to be decided on.

## Date of incidence

**Variable number:** 2.3.1

Item length: 10

Item format: Date (dd.mm.yyyy)

### Definition

The data item records the definite date of diagnosis. It is the date of the first event (of the six listed below) to occur chronologically. If an event of higher priority occurs within three months of the date initially chosen, the date of the higher priority event should take precedence. Order of declining priority:

1. Date of first histological or cytological confirmation of this malignancy (with the exception of histology or cytology at autopsy). This date should be, in the following order:
  - a) date when the specimen was taken (biopsy)
  - b) date of receipt by the pathologist
  - c) date of the pathology report.
2. Date of admission to the hospital because of this malignancy.
3. When evaluated at an outpatient clinic only: date of first consultation at the outpatient clinic because of this malignancy.
4. Date of diagnosis, other than 1, 2 or 3.
5. Date of death, if no information is available other than the fact that the patient has died because of a malignancy.
6. Date of death, if the malignancy is discovered at autopsy.

### Rational

The timing for staging and treatment begins with the date of incidence. Date of incidence is the starting point to calculate survival time.

Code examples <sup>#</sup>	Description
01.01.2005	Note: for single digit day or month, record with a leading 0.
15.01.2005	Note: if exact day unknown, set day as 15 <sup>th</sup> of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30 <sup>th</sup> of June of the respective year.
...	

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT in truncated form, with day set to unknown (i.e. 15) for all cases.

### References

>Recommendation issued by ENCR. <https://encr.eu/working-groups-and-recommendations> .

### Notes

>There are cases where "in situ" or "highly suspicious" is reported first and later on this changes to invasive cancer (e.g. if invasive parts are found during the operation). Only the date of invasive diagnosis is the valid date of diagnosis.



## Accuracy for date of incidence

---

**Variable number:** 2.3.2

Item length: 1

Item format: Number

### Definition

The data item indicates the accuracy of the date of incidence.

### Rational

The information is used to identify case groups where ages or time periods are not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

-

## Age at incidence

---

**Variable number:** 2.4

Item length: 5

Item format: Number

### Definition

The data item indicates the age at the date of incidence, exact to the number of days.

### Rational

The information is used to compare cancer rates and outcomes by age.

Code examples <sup>#</sup>	Description
0	Diagnosed <i>in utero</i> or at day of birth
...	
99999	Unknown (Not stated / Not assessed).

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

>If more than a single diagnosis is registered per person, then the age at incidence may be different in each case.

## DCN flag

**Variable number:** 2.5

Item length: 1

Item format: Number

### Definition

The data item identifies cases that first come to attention of the registries from death certificates (Death Certificate Notification).

### Rational

Unexpected high proportions of cases that first come to attention of the registries from death certificates are a potential problem for completeness of case ascertainment. DCN cases have to be traced back in order to find better information on this diagnosis (e.g. the incidence date). Cases with unsuccessful trace back are defined as DCO (Death Certificate Only), which serve as a quality measure for cancer registration.

Code	Label	Description
0	No	Not a DCN case.
1	Yes	DCN case.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Bray, F and Parkin, DM. Evaluation of data quality in the cancer registry: Principles and methods. Part I: Comparability, validity and timeliness. *Eur J Cancer* 2008; 45: 747-755.
- >Parkin, DM and Bray, F. Evaluation of data quality in the cancer registry: Principles and methods. Part II: Completeness. *Eur J Cancer* 2008; 45: 756-764.

### Notes

-

## Method of first detection

**Variable number:** 2.6  
 Item length: 1  
 Item format: Number

### Definition

The data item records the method or circumstance by which the case came to medical attention and the cancer was first diagnosed.

### Rational

The information facilitates the interpretation of cancer incidence trends and the evaluation and monitoring of organized cancer screening programmes.

Code	Label	Description
1	Clinical symptoms	Clinical symptoms related to the tumour.
2	Incidental discovery	Diagnosis on the occasion of surveillance/treatment for another disease, incl. tumour aftercare for a previous primary tumour, routine medical consultation/routine check-up, surgery.
3	Organised screening program	Screening programmes organized at national or regional level, with an explicit policy, that includes several essential elements from target population to treatment. Screening refers to a targeted examination/search for an asymptomatic tumour.
4	Opportunistic screening	Screening outside an organized or population-based screening programme, as a result of, for example, a recommendation made during a routine medical consultation/check-up for the woman, on the basis of a possibly increased risk for developing cervical cancer or by self-referral. Screening refers to a targeted examination/search for an asymptomatic tumour.
5	Self-examination	Use this code if it is known that the chain of events leading to a diagnosis of cancer was a self-exam by the patient (e.g. a lump in the breasts, or a skin lesion).
6	Death with autopsy	Cancer diagnosed after death.
7	Death without autopsy	Cancer diagnosed after death.
8	Other	
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >IARC Handbooks of Cancer Prevention, Vol 7, 10, 17 etc. Lyon, <http://publications.iarc.fr/Book-And-Report-Series/Iarc-Handbooks-Of-Cancer-Prevention>.
- >Erläuterungen zur KRV (11.4.2018). EDI, BAG.

### Notes

- >Registration of specific screening methods (i.e. occult blood test, colonoscopy, mammography, PSA test, etc.) has been postponed to future revisions of the KRG/KRV.

## Most valid basis of diagnosis

**Variable number:** 2.7

Item length: 2

Item format: Number

### Definition

The data item records the most valid diagnostic procedure by which the tumour was confirmed. Validity increases from codes 0 to 7.

### Rational

The information indicates the precision and reliability of the diagnosis.

Code	Label	Description
0	Death Certificate Only	The only information to the registry is from a death certificate.
1	Clinical	Diagnosis made before death without diagnostic methods 2 to 7.
2	Clinical investigation	Clinical methods such as endoscopy, exploratory surgery and autopsy, without tissue diagnosis.
3	Imaging	Radiology and other imaging techniques without microscopic confirmation. Code 3 is not part of the ENCR recommendation or ICD-O. The quality of diagnostic imaging in some cases makes detailed differential diagnosis possible with a clinical impact equal to that of microscopic examination.
4	Specific tumour markers	Positive laboratory tests/marker studies.
5	Cytology	Positive cytology (fluid cells microscopically examined).
6	Histology of metastasis	Positive histology from a metastasis (tissue microscopically examined).
7	Histology of primary tumour	Positive histology from the primary tumour (tissue microscopically examined).
9	Unknown	Basis of diagnosis not stated.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- > Recommendation issued by ENCR (1999) <https://encr.eu/working-groups-and-recommendations> .
- > International classification of diseases for oncology (ICD-O) – 3rd edition, 1st revision (2011) (Section 4.5).

### Notes

>Code 3 for Imaging does not imply higher validity as compared with code 2 for Clinical Investigation. In reporting the most valid basis of diagnosis, code 3 cases might have to be combined with code 2 cases.

## Diagnostic method(s) used\*

**Variable number:** 2.8

Item length: 2

Item format: Number

### Definition

The optional data item records all diagnostic methods used.

### Rational

The information is the basis for decision-making on the most valid diagnostic procedure.

Code	Label
0	Death certificate notification
1	Clinical examination undefined
2	Clinical examination defined
3	Tumour clinically palpable
4	Radiodiagnostic of tumour (Xray)
5	Echography of tumour (ultrasound, sonography)
6	Scintigraphy of tumour (e.g. MIBG)
7	CT scan of tumour
8	MRI scan of tumour
9	Specific imaging of tumour (e.g. PET/CT, SPECT, fluorescent optical imaging)
10	Imaging to determine spread of disease (metastases)
11	Endoscopy
12	Imaging NOS
13	Specific markers ( biochemical or immunological)
14	Cytogenetic analysis (karyotype)
15	Molecular markers (FISH, SNP, MLPA, PCR, DNA sequence etc.)
16	Cytology NOS / Blood smear / peripheral blood
17	Cytology of tumour (e.g. fine needle aspirate/ PAP)
18	Bone marrow aspirate
19	Bone marrow biopsy
20	Biopsy unspecified
21	Biopsy locoregional
22	Biopsy of metastasis
23	Biopsy of primary tumour
24	Biopsy and resection (z.B. melanoma)
25	Surgical tissue from operation (e.g. neuroendocrine tumours)

26	Autopsy with histological confirmation
99	Unknown

**National usage**

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

**References**

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**Notes**

>This variable is optional.

>For this data item, address of the reporting institution(s) as well as report availability, report date, and report results may be registered.

>Negative diagnostic tests before date of incidence are not registered.

## Diagnostic institution(s)\*

---

**Variable number:** 2.9

Item length: 255

Item format: Text

### Definition

The data item records the name and address of the responsible person and institution and submitting diagnostic information to the cancer registry.

### Rational

This information allows providing quality feedback to those institutions requesting it. It also allows regional and national statistical reports on the relative contribution of different types of institutions to diagnosing cancer.

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

>Medical practices: GLN (Global Location Number) aus refdata - [https://www.refdata.ch/content/partner\\_d.aspx](https://www.refdata.ch/content/partner_d.aspx).  
Updates via <https://refdatabase.refdata.ch/Service/Partner.aspx>.

>Hospitals: official hospital lists [https://www.bag.admin.ch/bag/de/home/zahlen-und-statistiken/zahlen-fakten-zu-spitaelern/spital-suchen.exturl.html/aHR0cDovL3d3dy5iYWctYW53LmFkbWluLmNoLzlwMTZfdGFnbG/FiLzlwMTZfc3BpdGFsc3RhdGlzdGlrL3BvcnRhbF9kZS5waHA\\_/cD1tYXBrdCZsYW5nPWRI.html](https://www.bag.admin.ch/bag/de/home/zahlen-und-statistiken/zahlen-fakten-zu-spitaelern/spital-suchen.exturl.html/aHR0cDovL3d3dy5iYWctYW53LmFkbWluLmNoLzlwMTZfdGFnbG/FiLzlwMTZfc3BpdGFsc3RhdGlzdGlrL3BvcnRhbF9kZS5waHA_/cD1tYXBrdCZsYW5nPWRI.html).

### Notes

>Addresses will be taken from national uniform lists of health service providers.

>Metadata for the institution responsible for diagnostics can also be registered to facilitate the exchange of information.

>The cancer registries define, and update on a regular basis, the official address of all responsible persons and hospital units submitting cancer information.

>Multiple persons or institutions may optionally be registered per diagnosis.



## Rank of diagnosis

**Variable number:** 2.10  
Item length: 2  
Item format: Number

### Definition

The data item records whether the diagnosis is the 1<sup>st</sup>, 2<sup>nd</sup>, etc. reportable primary neoplasms in the patient's lifetime.

### Rational

The type and existence of previously diagnosed reportable primary neoplasms has etiologic significance.

Code examples <sup>#</sup>	Label	Description
1	1st	The 1st cancer diagnosis in the patient's lifetime.
2	2nd	The 2nd cancer diagnosis in the patient's lifetime.
...	...	
99	Unknown	Rank of diagnosis not known.

#: only examples are shown to reduce table size

### National usage

The variable will be generated by the NKRS-ONEC-SNRT and then reported back to the cancer registries.

### References

>[http://www.iacr.com.fr/images/doc/MPrules\\_july2004.pdf](http://www.iacr.com.fr/images/doc/MPrules_july2004.pdf)

### Notes

- >Only primary diagnoses will be counted chronologically. Primary diagnoses are defined according to the International Rules for Multiple Primary Cancers (as issued by IACR, IARC, and ENCR).
- >If several primary diagnoses occur at the same time, the most malignant has the lowest rank.

## Case number

**Variable number:** 2.11  
Item length: 11  
Item format: Number

### Definition

The data item allocates a unique case number to the diagnosis. The number also indicates the FSO canton number of the patient address at the time of diagnosis by using the first two digits (e.g. "01" for canton ZH, "26" for canton JU). The federal Swiss Childhood Cancer Registry assigns "99" as first two digits.

### Rational

The case number serves as nation-wide unique identifier of the diagnosis.

Code examples <sup>#</sup>	Description
09123456789	Hypothetical case number in the Cancer Registry responsible for patients diagnosed while living in the canton of ZG.
99123456789	Hypothetical case number in the Swiss Childhood Cancer Registry who is responsible for all diagnoses in Switzerland in patients below 20 years of age at diagnosis.
...	

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## CLASSIFICATIONS (ICD, ICD-O)

> It is not required to generate information solely 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.

## ICD version

**Variable number:** 3.1

Item length: 2

Item format: Number

### Definition

This data item records the version of the International Classification of diseases published by the World Health Organization (WHO) used to code the diagnosis.

### Rational

The International Classification of diseases (ICD) is the most important classification of morbidities worldwide. It is uniaxial and forms the basis for most types of cancer reporting to inform cancer control, research activity, treatment planning and health economics. It is regularly updated to include the progress in medical knowledge.

Code	Label	Description
10	ICD-10 WHO	English WHO version; or the official (SFSO) translation of the WHO version into German (ICD-10-GM), French and Italian.
11	ICD-11 WHO	

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

><https://www.who.int/classifications/icd/en/> [last accessed: 27.12.2018].

><https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/nomenklaturen/medkk/instrumente-medizinische-kodierung.html> [last accessed: 29.12.2018].

### Notes

>The German modification of ICD-10 (ICD-10-GM) is used in Switzerland. ICD-10-GM is based on ICD-10 (WHO) and is issued by the “Deutsches Institut für Medizinische Dokumentation und Information” (DIMDI). DIMDI issues yearly updates, which are implemented in Switzerland every two years.

### Notes

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## ICD-O version

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**Variable number:** 3.2

Item length: 2

Item format: Number

### Definition

The data item records the version of the International Classification of Diseases for Oncology (ICD-O).

### Rational

The International Classification of Diseases for Oncology (ICD-O) is a multiaxial classification coding separately for the site (topography) and the histology (morphology) of neoplasms. The ICD-O is internationally recognized as the definitive classification of neoplasms and is used by cancer registries throughout the world. Regularly updates incorporate the progress in medical knowledge.

Code	Label	Description
10	Version 1	
20	Version 2	
30	Version 3.0	WHO 2000
31	Version 3.1	Update 2011
32	Version 3.2	Update 2019

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S , editors. International Classification of Diseases for Oncology, third edition. Geneva, World Health Organization, 2000.
- >Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, Third edition, first revision. Geneva, World Health Organization, 2011.

### Notes

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## ICD code

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**Variable number:** 3.3  
Item length: 5  
Item format: Alphanumeric

### Definition

Disease code of the International Classification of diseases published by the World Health Organization (WHO). The item is entered without decimal point.

### Rational

The purpose of the ICD is to allow the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries or areas and at different times.

Code examples <sup>#</sup>	Label
C000	Malignant neoplasm of lip, external upper lip
...	

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- ><https://icd.who.int/browse10/2016/en> [last accessed: 27.12.2018].
- ><https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/nomenklaturen/medkk/instrumente-medizinische-kodierung.html> [last accessed: 29.12.2018].

### Notes

>The German modification of ICD-10 (ICD-10-GM) is used in Switzerland. ICD-10-GM is based on ICD-10 (WHO) and is issued by the "Deutschen Institut für Medizinische Dokumentation und Information" (DIMDI). DIMDI issues yearly updates, which are implemented in Switzerland every two years.

### Notes

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## ICD-O Topography

**Variable number:** 3.4

Item length: 255

Item format: Text

### Definition

Identifies the primary site, or topography, of the neoplasm according to ICD-O. It is based on the most valid source of information. The item is entered without decimal point.

### Rational

Primary site determines the staging and treatment options. It also affects the prognosis and course of the disease. The data item is used to compare cancer rates and outcomes by site.

Code examples#	Label
C000	External upper lip
C809	Unknown primary site
...	

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S , editors. International Classification of Diseases for Oncology, third edition. Geneva, World Health Organization, 2000.

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, Third edition, first revision. Geneva, World Health Organization, 2011.

### Notes

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## ICD-O Morphology

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**Variable number:** 3.5

Item length: 255

Item format: Text

### Definition

This data item records the microscopic anatomy or morphology of cells at time of diagnosis according to ICD-O.

### Rational

Morphology determines the staging and treatment options. It also affects the prognosis and course of the disease. The data item is used to compare cancer rates and outcomes by morphology.

Code examples <sup>#</sup>	Label	Description
8000	Neoplasm	Unclassified tumour
9992	Refractory thrombocytopenia	
...		

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S , editors. International Classification of Diseases for Oncology, third edition. Geneva, World Health Organization, 2000.

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, Third edition, first revision. Geneva, World Health Organization, 2011.

### Notes

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## ICD-O Behaviour

**Variable number:** 3.6.1

Item length: 1

Item format: Number

### Definition

This data item records the behaviour of the neoplasm at time of diagnosis according to ICD-O.

### Rational

Behaviour determines the treatment options. It also affects the prognosis and course of the disease. The data item is used to compare cancer rates and outcomes by behaviour.

Code	Label	Description
0	Benign	Benign tumours do not metastasize or locally invade tissues.
1	Borderline	Uncertain whether benign or malignant. Low, borderline, or uncertain malignant potential.
2	In situ	Carcinoma in situ; intraepithelial; non-infiltrating; non-invasive.
3	Malignant	Invasive behaviour.
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S , editors. International Classification of Diseases for Oncology, third edition. Geneva, World Health Organization, 2000.
- >Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, Third edition, first revision. Geneva, World Health Organization, 2011.

### Notes

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## Associated in situ tumour

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**Variable number:** 3.6.2

Item length: 1

Item format: Number

### Definition

This data item records the simultaneous presence of in situ and invasive tumour components.

### Rational

This information serves as prognostic factor, especially for breast cancer.

Code	Label	Description
0	No	
1	Yes	
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

> Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.0, 2017 AWMF Registernummer: 032-045OL, <http://www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom/> (4.5.2.7).

### Notes

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## ICD-O Histological grade

**Variable number:** 3.7

Item length: 1

Item format: Number

### Definition

The data item describes the neoplasm's resemblance to normal (parent) tissue according to ICD-O. Well differentiated (grade 1) is the most like normal tissue, and undifferentiated (grade 4) is the least like normal tissue. Codes 5 to 8 define particular cell lines for lymphoma and leukaemia.

### Rational

The information is useful for prognosis.

Code	Label	Description
1	Grade I	Well differentiated; Differentiated, NOS; Low grade
2	Grade II	Moderately (well) differentiated; Intermediate differentiation.
3	Grade III	Poorly differentiated; Dedifferentiated; High grade.
4	Grade IV	Undifferentiated; Anaplastic.
5	T-cell	T-cell; T-precursor.
6	B-cell	B-cell; Pre-B; B-precursor.
7	Null cell	Null cell; Non-T-non-B.
8	NK cell	NK cell; Natural killer cell.
9	Unknown	Grade or differentiation not determined, not stated, or not applicable. Unknown primary.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S , editors. International Classification of Diseases for Oncology, third edition. Geneva, World Health Organization, 2000.

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, Third edition, first revision. Geneva, World Health Organization, 2011.

### Notes

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## Laterality

**Variable number:** 3.8

Item length: 1

Item format: Number

### Definition

Laterality describes the side of a paired organ or side of the body on which the reportable cancer originated. A paired organ is one in which there are two separate organs of the same kind, one on either side of the body (e.g. kidney, breast, ovary, testis and lung).

Laterality should be coded for those paired organs for which such information may be relevant for clinical or epidemiological reasons: ICD-O-3 C07 (parotid gland), C09 (tonsil), C30.0 (nasal cavity), C34 (bronchus and lung with the exception C34.2), C38.4 (pleura), C40.0-40.3 (long/short bones), C41.3 (rib, clavicle), C41.4 (pelvic bones), C44.1 (skin of eyelid), C44.2 (skin of external ear), C44.6 (skin of arm and shoulder), C44.7 (skin of leg and hip), C50 (breast), C56 (ovary), C57.0 (fallopian tube), C62 (testis), C63.0 (epididymis), C64 (kidney), C65 (renal pelvis), C66 (ureter), C69 (eye), C74 (adrenal gland).

### Rational

Laterality information is required to determine the number of primaries involved.

Code	Label	Description
0	Not applicable	Midline tumour; unpaired organ.
1	Right	
2	Left	
3	Unilateral, NOS	Unilateral, but unknown whether right or left.
4	Bilateral	Origin of primary tumour is on both sides of a paired organ (when tumours of the same morphology are diagnosed simultaneously in both sides of a paired organ). Bilateral cancers are very rare, e.g. bilateral retinoblastoma, bilateral Wilms tumour of the kidney, or both ovaries involved simultaneously.
9	Unknown	It is unknown whether, for a paired organ, the origin of the cancer was on the left or right side of the body.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>JRC Technical Report (version 1.1), 2018. A proposal on cancer data quality checks: one common procedure for European cancer registries. <https://ec.europa.eu/jrc/en/publication/proposal-cancer-data-quality-checks-one-common-procedure-european-cancer-registries-version-11> [last access: 4.2.19].

### Notes

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## ICCC-3 main group

**Variable number:** 3.9.1

Item length: 2

Item format: Alphanumeric

### Definition

This data item records the main diagnostic group according to the third revision (2005) of the 1996 International Classification of Childhood Cancer (ICCC-3).

### Rational

ICCC-3 classifies tumours coded according to ICD-O-3 into 12 main groups, which allow standardised comparisons of the broad categories of childhood neoplasms. ICCC-3 was designed for use in international, population-based, epidemiological studies and cancer registries. In paediatric oncology the low frequency of cases requires the use of an international classification system to ensure data comparability between countries.

Code examples <sup>#</sup>	Label	Description
I	Leukaemia, myeloproliferative diseases, and myelodysplastic diseases.	ICD-O-3 codes: 9800, 9801, 9805, 9820, 9823, 9826, 9827, 9831-9837, 9840, 9860, 9861, 9863, 9866, 9867, 9870-9876, 9891, 9895-9897, 9910, 9920, 9930, 9931, 9940, 9945, 9946, 9948, 9950, 9960-9964, 9975, 9980, 9982-9987, 9989.
...		

#: only examples are shown to reduce table size

### National usage

(\*) The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Steliarova-Foucher E et al. 2005. International Classification of Childhood Cancer, Third Edition. *Cancer* 2005; **103**:1457–67.

### Notes

>There has been no update in ICCC-3 since 2005. Cases coded according to ICD-O-3.1 are assigned to the appropriate ICCC-3 group.

>The ICCC-3 codes are based on the ICD-O-3, and updates in the latter necessitate updates in the former.

## ICCC-3 code\*

**Variable number:** 3.9.2

Item length: 4

Item format: Alphanumeric

### Definition

This data item records detailed division of the diagnostic group according to the third revision of the 1996 International Classification of Childhood Cancer (ICCC-3).

### Rational

ICCC-3 classifies tumours coded according to ICD-O-3 into 12 main groups, which are split further into 47 subgroups. These 2 levels of the ICC-3 allow standardised comparisons of the broad categories of childhood neoplasms. ICC-3 was designed for use in international, population-based, epidemiological studies and cancer registries. In paediatric oncology the low frequency of cases requires the use of an international classification system to ensure data comparability between countries.

Code examples <sup>#</sup>	Label	Description
Ia	Lymphoid leukaemias	ICD-O-3 codes: 9820, 9823, 9826, 9827, 9831–9837, 9940, 9948.
XIIb	Other unspecified malignant tumours	ICD-O-3 codes: 8000-8005
...		

#: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT. The NKRS-ONEC-SNRT uses ICD-O information in statistics for children and adolescents.

### References

>Steliarova-Foucher E et al. 2005. International Classification of Childhood Cancer, Third Edition. Cancer 2005; 103:1457–67.

### Notes

>There has been no update in ICC-3 since 2005. Cases coded according to ICD-O-3.1 are assigned to the appropriate ICC-3 group.

>The ICC-3 codes are based on the ICD-O-3, and updates in the latter necessitate updates in the former.

## ICCC-3 extended code\*

**Variable number:** 3.9.3

Item length: 7

Item format: Alphanumeric

### Definition

This data item records detailed division of the diagnostic group according to the third revision of the 1996 International Classification of Childhood Cancer (ICCC-3).

### Rational

ICCC-3 classifies tumours coded according to ICD-O-3 into 12 main groups, which are split further into 47 subgroups. These 2 levels of the ICC-3 allow standardised comparisons of the broad categories of childhood neoplasms. The 16 most heterogeneous subgroups are broken down further into 2–11 divisions to allow the study of important entities or homogeneous collections of tumours characterized at the cytogenetic or molecular level. ICC-3 was designed for use in international, population-based, epidemiological studies and cancer registries. In paediatric oncology the low frequency of cases requires the use of an international classification system to ensure data comparability between countries.

Code examples <sup>#</sup>	Label	Description
la.1	Precursor cell leukaemias	ICD-O-3 codes: 9835-9837
la.2	Mature B-cell leukaemias	ICD-O-3 codes: 9823, 9826, 9832, 9833, 9940
...		

<sup>#</sup>: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT. The NKRS-ONEC-SNRT uses ICD-O information in statistics for children and adolescents.

### References

>Steliarova-Foucher E et al. 2005. International Classification of Childhood Cancer, Third Edition. Cancer 2005; 103:1457–67.

### Notes

>There has been no update in ICC-3 since 2005. Cases coded according to ICD-O-3.1 are assigned to the appropriate ICC-3 group.

>The ICC-3 codes are based on the ICD-O-3, and updates in the latter necessitate updates in the former.

## STAGE, GRADE

> It is not required to generate information solely 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.



## UICC TNM version

**Variable number:** 4.1

Item length: 3

Item format: Number

### Definition

The data item records the edition of the UICC (International Union Against Cancer) TNM Classification of Malignant Tumours. The classification is updated at irregular intervals.

### Rational

The UICC TNM Classification describes the anatomical extent (termed 'stage') of the disease. It also takes a number of non-anatomical prognostic factors into account. The data item is used to compare cancer rates and outcomes by stage. Stage is also useful for the evaluation of screening programs, and other studies.

Code	Label
010	Edition 1 (1968)
020	Edition 2 (1974)
030	Edition 3 (1987)
031	Edition 3, enlarged and revised (1982)
040	Edition 4 (1987)
042	Edition 4, enlarged and revised (1992)
050	Edition 5 (1997)
060	Edition 6 (2002)
070	Edition 7 (2009/2010)
071	Edition 7, enlarged and revised (2011)
080	Edition 8 (2017)

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

## y-Prefix of cTNM

**Variable number:** 4.2

Item length: 1

Item format: Number

### Definition

The data item records the time of TNM assignment relative to therapy.

### Rational

To identify cases where T, N, and M classifications have been assigned during or following initial treatment as part of the first treatment complex. They can deviate from T, N, and M classifications at the time of diagnosis.

Code	Label	Description
0	No	TNM assigned before any therapy.
1	Yes	TNM assigned during or after neoadjuvant therapy.
9	Unknown	It cannot be assessed whether TNM was assigned before, during or after therapy.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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**Variable number:** 4.3  
 Item length: 10  
 Item format: Alphanumeric

### Definition

The data item records tumour size based on clinical investigation, imaging, endoscopy, biopsy or surgical exploration.

### Rational

Treatment decisions are based on pre-therapeutic clinical assessment of tumour size. Clinical categories replace pathological categories if pathological data is not available or validated following neoadjuvant therapy.

Code examples <sup>#</sup>	Label	Description
X	cTX	Primary tumour cannot be assessed.
0	cT0	No evidence of primary tumour.
is	cTis	Carcinoma in situ.
1	cT1	Confined to organ or part of the organ, small size lesion.
...		
88	NA	Not applicable. TNM classification not defined for this type of cancer.
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## cN

**Variable number:** 4.4

Item length: 10

Item format: Alphanumeric

### Definition

The data item records regional lymph nodes involvement based on clinical investigation, imaging, endoscopy, biopsy or surgical exploration. Metastasis in any lymph node other than regional is classified as a distant metastasis.

### Rational

Treatment decisions are based on pre-therapeutic clinical assessment of regional lymph nodes involvement. Clinical categories replace pathological categories if pathological data is not available or validated following neoadjuvant therapy.

Code examples <sup>#</sup>	Label	Description
X	cNX	Regional lymph nodes cannot be assessed
0	cN0	No regional lymph node metastasis
1	cN1	
...		
88	NA	Not applicable. TNM classification not defined for this type of cancer.
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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**Variable number:** 4.5  
 Item length: 10  
 Item format: Alphanumeric

### Definition

The data item records the absence or presence of distant metastases based on clinical investigation, imaging, endoscopy, surgical exploration without biopsy.

### Rational

Treatment decisions are based on pre-therapeutic clinical assessment of distant metastases.

Code examples#	Code	Description
0	cM0	No distant metastasis.
1	cM1	Distant metastasis.
88	NA	Not applicable. TNM classification not defined for this type of cancer.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

- >MX for distant metastases cannot be assessed: not allowed for TNM editions 7 or higher.

## a-Prefix of pTNM

**Variable number:** 4.6

Item length: 1

Item format: Number

### Definition

The prefix a indicates that classification is first determined at autopsy.

### Rational

The information is used to stage cases of cancer by post mortem examination, using pathologic information obtained at the time of death.

Code	Label	Description
0	No	pTNM classification is not determined at autopsy.
1	Yes	pTNM classification is first determined at autopsy.
9	Unknown	No information whether pTNM is determined at autopsy or not.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## y-Prefix of pTNM

**Variable number:** 4.7

Item length: 1

Item format: Number

### Definition

The data item indicates whether TNM classification is performed during or following multimodality therapy (neoadjuvant radio- and/or chemotherapy prior to surgery).

### Rational

To identify cases where T, N, and M classifications have been assigned during or following initial treatments as part of the first treatment complex. They can deviate from T, N, and M classifications at the time of diagnosis.

Code	Label	Description
0	No	TNM assigned before any therapy.
1	Yes	TNM assigned during or after neoadjuvant therapy.
9	Unknown	It cannot be assessed whether TNM was assigned before, during or after therapy.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## pT

**Variable number:** 4.8

Item length: 10

Item format: Alphanumeric

### Definition

This data item records the extent of the primary tumour based on pathological (histological) evidence after completion of surgical therapy.

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples <sup>#</sup>	Label	Description
X	pTX	Primary tumour cannot be assessed histologically.
0	pT0	No histological evidence of primary tumour.
is	pTis	Carcinoma in situ.
1	pT1	Confined to organ or part of the organ, small size lesion.
...		
88	NA	Not applicable. TNM classification not defined for this type of cancer.
99	Unknown	Not stated / Not assessed.

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## m-Suffix of pT

**Variable number:** 4.9  
Item length: 3  
Item format: Alphanumeric

### Definition

The suffix m, in parentheses, is used to indicate the presence of multiple primary tumours at a single site. In the case of multiple primary tumours in one organ, the tumour with the highest T category should be classified and the multiplicity or the number of tumours should be indicated in parenthesis, e.g., T2(m) or T2(5). In simultaneous bilateral primary cancers of paired organs, each tumour should be classified independently.

### Rational

In tumours of the liver, ovary and fallopian tube, multiplicity is a criterion of T classification, and in tumours of the lung multiplicity may be a criterion of the M classification.

Code examples <sup>#</sup>	Label	Description
m	(m)	Unspecified multiplicity.
2	(2)	Two primary tumours.
...	...	
99	(99)	99 or more primary tumours.
999	Missing	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## pN

**Variable number:** 4.10

Item length: 10

Item format: Alphanumeric

### Definition

The data item records the absence or presence and extent of regional lymph node metastasis, based on pathological evidence after completion of surgical therapy.

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples <sup>#</sup>	Label	Description
X	pNX	Regional lymph nodes cannot be assessed histologically.
0	pN0	No regional lymph node metastasis histologically.
1	pN1	
...		
88	NA	Not applicable. TNM classification not defined for this type of cancer.
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## Number of involved regional lymph nodes

**Variable number:** 4.11

Item length: 3

Item format: Number

### Definition

The data item records the number of regional lymph nodes examined by the pathologist and found to contain metastases.

### Rational

This information serves as a quality measure for pathologic reports.

Code examples <sup>#</sup>	Label	Description
0	None	No regional lymph node invaded.
1	1 node	One regional lymph node invaded.
...	...	
999	Unknown	No information whether regional lymph nodes were invaded or not. OR Regional lymph nodes were invaded, but no information on the number.

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## Number of examined regional lymph nodes

**Variable number:** 4.12

Item length: 3

Item format: Number

### Definition

The data item records the total number of regional lymph nodes that were excised and examined by the pathologist.

### Rational

This information serves as a quality measure of the pathologic and surgical evaluation and treatment of the patient.

Code examples <sup>#</sup>	Label	Description
0	None	No regional lymph node examined.
1	1 node	One regional lymph node examined.
...	...	
999	Unknown	No information whether regional lymph nodes were examined or not. OR Regional lymph nodes were examined, but no information on the number.

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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**Variable number:** 4.13

Item length: 10

Item format: Text

### Definition

The data item records the absence or presence of distant metastasis, based on pathological evidence after completion of surgical therapy or microscopic examination of metastasis.

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples <sup>#</sup>	Label	Description
0	pM0	Is only to be used after autopsies.
1	pM1	Distant metastasis microscopically confirmed.
88	NA	Not applicable. TNM classification not defined for this type of cancer.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

>MX (“distant metastases cannot be assessed”) is not allowed for TNM 7<sup>th</sup> Edition or higher.

## Lymphatic invasion

**Variable number:** 4.14

Item length: 1

Item format: Number

### Definition

The data item indicates the presence or absence of tumour cells in lymphatic vessels within and at the margins of the primary tumour, as well as afferent and efferent lymphatics, as noted microscopically by the pathologist.

### Rational

This information is an indicator for prognosis. It is recommended as an essential tumour related prognostic factor in breast cancer by UICC TNM-8.

Code	Label	Description
0	L0	No lymphatic invasion.
1	L1	Lymphatic invasion.
8	LX	Lymphatic invasion cannot be assessed.
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## Venous invasion

**Variable number:** 4.15

Item length: 1

Item format: Number

### Definition

The data item indicates the presence or absence of tumour cells in the walls of venous blood vessels, as noted microscopically by the pathologist. There is no classification for invasion of arteries.

### Rational

This information is an indicator for prognosis. It is recommended as an essential tumour related prognostic factor in breast cancer by UICC TNM-8.

Code	Label	Description
0	V0	No venous invasion.
1	V1	Microscopic venous invasion.
2	V2	Macroscopic venous invasion.
8	VX	Venous invasion cannot be assessed.
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## Perineural invasion

**Variable number:** 4.16

Item length: 1

Item format: Number

### Definition

Perineural invasion is the process of neoplastic invasion of nerves.

### Rational

This information is an indicator for prognosis.

Code	Label	Description
0	Pn0	No perineural invasion.
1	Pn1	Perineural invasion.
8	PnX	Perineural invasion cannot be assessed.
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## TNM stage group

**Variable number:** 4.17  
Item length: 10  
Item format: Alphanumeric

### Definition

The data item records the UICC TNM stage group.

### Rational

For purposes of tabulation and analysis, it is useful to condense the anatomical extent of disease categories T, N, and M into groups.

Code examples#	Label	Description
0	0	Carcinoma in Situ.
I	I	Tumour localized to the organ of origin.
IV	IV	Distant metastasis.
...		
88	NA	Not applicable. TNM classification not defined for this type of cancer.
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## Ann Arbor staging

**Variable number:** 4.18

Item length: 10

Item format: Alphanumeric

### Definition

This data item is a last modification of the Ann Arbor classification for lymphoma.

### Rational

This information is increasingly used for prognosis estimation, pretreatment risk stratification, and selection of therapy and for outcome analysis. Ann Arbor is also part of International Prognostic Index (IPI) and modifications (mIPI, FLIPI etc.) for NHL.

Code examples <sup>#</sup>	Label	Description
I	Stage I	Cancer is located in a single lymph node region or single organ.
I+A	Stage I+A	Stage I without general symptoms.
IE+B	Stage IE+B	Stage I extralymphatic with general symptoms like weight loss, fever, night sweats etc.
IIIS+A	Stage IIIS+A	Stage III + spleen involvement without general symptoms.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Carbone PP, Kaplan HS, Musshoff K, Smithers DW, Tubiana M (November 1971). "Report of the Committee on Hodgkin's Disease Staging Classification". *Cancer Res.* 31 (11): 1860–1. PMID 5121694.
- >O'Sullivan B (ed. In chief), Brierley JD, D'Cruz AK, Fey MF, Pollock R, Vermorken JB, Huang SH (2015). *Manual of Clinical Oncology*. Ninth Edition. UICC. Wiley Blackwell & Sons, Ltd.
- >Bruce D. Cheson, Richard I. Fisher et al. Recommendations for Initial Evaluation, Staging, and Response Assessment of Hodgkin and Non-Hodgkin Lymphoma: The Lugano Classification. *J Clin Oncol* 32:3059-3067. © 2014
- >Sobin, Gospodarowicz, Wittekind (eds.): *UICC TNM Classification of Malignant Tumours*, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

### Notes

>A or B symptoms will be recorded for Hodgkin Lymphoma (HL) only.

## COG staging

**Variable number:** 4.19

Item length: 10

Item format: Alphanumeric

### Definition

This data item records staging of Wilms' tumour for pediatric patients acc. to pre-chemotherapy staging system developed by the National Wilms' Tumor Study Group (NWTSG). Based exclusively on the anatomic extent of the tumour, without consideration of genetic, biologic, or molecular markers.

### Rational

This staging system has been proven valuable in predicting outcomes.

Code	Label	Description
I	Stage I	Limited to kidney, not ruptured, no residual tumor.
II	Stage II	Extends beyond the kidney but is completely excised.
III	Stage III	Residual tumor confined to the abdomen. Micro/macrosopic remains of a tumour.
IV	Stage IV	Hematogenous / distant lymph nodes metastases.
V	Stage V	Bilateral renal involvement at diagnosis.
99	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Metzger ML, Dome JS. Current therapy for Wilms' tumour. *Oncologist* 2005;10: 815-26.

>Orkin S, Fisher D, Look A, Lux S, Ginsberg D, Nathan D. *Oncology of Infancy and Childhood*. Philadelphia, PA: Saunders, 2009.

### Notes

>Used after surgical resection only, prior to chemotherapy.

## COG ALL staging

**Variable number:** 4.20

Item length: 10

Item format: Alphanumeric

### Definition

COG ALL staging (for childhood B- precursor acute lymphoblastic leukemia, B-ALL) allows a uniform assessment of the extent of CNS involvement based on presence of blasts in the diagnostic cerebrospinal fluid fluid (CSF).

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples <sup>#</sup>	Label	Description
CNS1	CNS1	No blasts in the CSF, regardless of WBC and RBC.
CNS2a	CNS2a	<5 WBC/mL + blasts + < 10 RBC/mL.
CNS3c	CNS3c	Clinical signs of CNS leukemia.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Schulz KR, Pullen DJ, Sather HN et al. 2007 Risk- and response-based classification of childhood B-precursor acute lymphoblastic leukemia: a combined analysis of prognostic markers from the Pediatric Oncology Group (POG) and Children's Cancer Group (CCG) Blood. 2007 Feb 1; 109(3): 926–935.
- >Winick N, Devidas M, Chen S et al. 2017 Impact of Initial CSF Findings on Outcome Among Patients With National Cancer Institute Standard- and High-Risk B-Cell Acute Lymphoblastic Leukemia: A Report From the Children's Oncology Group 2017 J Clin Oncol 35:2527-2534.

### Notes

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## FIGO staging

**Variable number:** 4.21  
Item length: 10  
Item format: Alphanumeric

### Definition

FIGO Staging of gynecologic tumours is based on clinical staging, careful clinical examination before therapy, and surgical exploration.

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples <sup>#</sup>	Label	Description
I	Stage I	Tumour limited to organ of origin.
II	Stage II	Extension beyond organ.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

>Cervix carcinoma: FIGO is based on clinical staging.

## INRGSS staging

**Variable number:** 4.22  
Item length: 10  
Item format: Alphanumeric

### Definition

This data item records the paediatric stage classification of the International Neuroblastoma Risk Group Staging System (INRGSS).

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes. INRGSS is recommended by UICC TNM-8.

Code	Label	Description
L1	Stage L1	Localized tumour not involving vital structures as defined by the list of image-defined risk factors and confined to one body compartment.
L2	Stage L2	Locoregional tumor with presence of one or more image-defined risk factors.
M	Stage M	Distant metastatic disease (except stage MS).
MS	Stage MS	Metastatic disease in children younger than 18 months with metastases confined to skin, liver, and/or bone marrow.
99	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Monclair T, Brodeur GM, Ambros PF, Brisse HJ, Cecchetto G, Holmes K, u. a. The International Neuroblastoma Risk Group (INRG) Staging System: An INRG Task Force Report. *J Clin Oncol.* 10. Januar 2009;27(2):298–303.
- >Brierley, Gospodarowicz, Wittekind (eds.): *UICC TNM Classification of Malignant Tumours*, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

>Patients with multifocal primary tumors should be staged according to the greatest extent of disease as defined in the table.

## IRSS staging

**Variable number:** 4.23

Item length: 10

Item format: Alphanumeric

### Definition

The paediatric International Retinoblastoma Staging System is based on extent of disease and the presence of overt extra-ocular extension after enucleation.

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples <sup>#</sup>	Label	Description
0	Stage 0	Patients treated conservatively.
I	pStage I	Eye enucleated with negative margins (R0).
IV	cStage IV	Metastatic disease.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Chantada G, Doz F, Antoneli CBG et al. A Proposal for an International Retinoblastoma Staging System *Pediatr Blood Cancer* 2006;47:801–805.

### Notes

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## Lugano staging

**Variable number:** 4.24

Item length: 10

Item format: Alphanumeric

### Definition

The data item is a modification of the Ann Arbor classification for lymphoma.

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples <sup>#</sup>	Label	Description
I	Stage I	Cancer is located in a single lymph node region or single organ.
I+A	Stage I+A	Stage I without general symptoms
IE+B	Stage IE+B	Stage I extralymphatic with general symptoms like weight loss, fever, night sweats etc.
II bulky	Stage II bulky	Stage II + single nodal mass >10 cm in max dimension or > a third of the thoracic diameter as assessed on CT.
IIIS+A	Stage IIIS+A	Stage III + spleen involvement without general symptoms
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Cheson BD, Fisher RI, Barrington SF, et al. Recommendations for initial evaluation, staging, and response assessment of Hodgkin and non Hodgkin lymphoma: the Lugano classification. *J Clin Oncol* 2014; 32: 3059–3068.
- >Brierley, Gospodarowicz, Wittekind (eds.): *UICC TNM Classification of Malignant Tumours*, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

>A or B symptoms will be recorded for Hodgkin Lymphoma (HL) only.



## PRETEXT staging

**Variable number:** 4.25

Item length: 10

Item format: Alphanumeric

### Definition

The PRETEXT (PRE-Treatment EXTent of tumor) staging system is used for malignant primary liver tumours of childhood before any therapy. The PRETEXT hepatoblastoma staging is based on Couinaud's system of segmentation of the liver.

### Rational

This staging system has very good prognostic value.

Code examples <sup>#</sup>	Label	Description
I	PRETEXT I	One section is involved and three adjoining sections are free.
II	PRETEXT II	One or two sections are involved, but two adjoining sections are free.
...		
C1	C1	Additional criteria: Tumour involving the caudate lobe.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Roebuck DJ, Aronson D, Clapuyt P, et al. 2005 PRETEXT: a revised staging system for primary malignant liver tumours of childhood developed by the SIOPEL group. *Pediatric Radiol* 2007; 37: 123–132.
- >Towbin AJ, Meyers RL, Woodley H, et al. 2017 PRETEXT: radiologic staging system for primary hepatic malignancies of childhood revised for the Paediatric Hepatic International Tumour Trial (PHITT). *Pediatric Radiology* (2018) 48:536–554.

### Notes

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## Rai staging

**Variable number:** 4.26

Item length: 10

Item format: Alphanumeric

### Definition

This classification for Chronic Lymphocytic Leukaemia (CLL) includes 4 stages based on blood and bone marrow cell count (lymphocytes, platelets), haemoglobin/haematocrit, LN involvement, hepato- and/or splenomegaly. The staging allows classification of patients into three risk categories (low, intermediary, high risk with median survival >12y, >8y and >2y, respectively).

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples <sup>#</sup>	Label	Description
0	Stage 0	Lymphocytosis, lymphocytes in the blood >15.000/ $\mu$ L and >40% lymphocytes in the bone marrow. Low risk.
I	Stage I	Stage 0 with enlarged LN. Intermediary risk.
III	Stage III	Stage 0-II with Hb <11.0 g/dl or hematocrit <33%. High risk.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Rai KR. A critical analysis of staging in CLL. In: Gale RP, Rai KR, eds. Chronic Lymphocytic Leukemia: Recent Progress and Future Directions. New York, NY: Liss; 1987:253-264.
- >Rai KR, Sawitsky A, Cronkite EP, Chanana AD, Levy RN and Pasternack BS. Clinical staging of chronic lymphocytic leukemia. Blood 1975; 46: 219-234.

### Notes

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## Binet staging

**Variable number:** 4.27

Item length: 2

Item format: Alphanumeric

### Definition

This data item records the stage of Chronic Lymphocytic Leukaemia (CLL) based on the cell count in the blood and bone marrow (lymphocytes, platelets), haemoglobin/ haematocrit, lymph nodes involvement, hepato- and/or splenomegaly.

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code	Label	Description
A	Stage A	Hb $\geq$ 10.0 g/dl, thrombocytes $\geq$ 100 $\times$ 10 <sup>9</sup> /l, <3 lymph node regions.
B	Stage B	Hb $\geq$ 10.0 g/dl, thrombocytes $\geq$ 100 $\times$ 10 <sup>9</sup> /l, $\geq$ 3 lymph node regions.
C	Stage C	Hb < 10.0 g/dl, thrombocytes <100 $\times$ 10 <sup>9</sup> /l, any number of lymph node regions.
99	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Binet JL, Auquier A, Dighiero G, Chastang C, Piguët H, Goasguen J et al. A new prognostic classification of chronic lymphocytic leukemia derived from a multivariate survival analysis. *Cancer* 1981; 48: 198-206.

### Notes

>Binet's lymphoid areas consist in: lymphadenopathy either uni- or bilateral in (1) cervical, (2) axillary, (3) inguinal areas, (4) spleen, (5) liver.

## Rhabdomyosarcoma site staging

**Variable number:** 4.28

Item length: 3

Item format: Alphanumeric

### Definition

Rhabdomyosarcoma staging is based on the classic TNM staging taking into account favourable/non favourable tumour sites. It is used in paediatric oncology.

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples <sup>#</sup>	Label	Description
I	Stage I	Organ confined, low-grade
IV	Stage IV	Any T, Any N, M1, Any Grade
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

>The prognostic grouping for rhabdomyosarcoma includes favourable anatomic sites and unfavourable anatomic sites.

>Favourable anatomic sites: orbit, head and neck (excluding parameningeal tumours) and genitourinary sites (excluding bladder and prostate tumours).

>Non-favourable sites: bladder, prostate, extremity, cranial, parameningeal, trunk, retroperitoneum and all other sites not noted as favourable

## ISS staging

**Variable number:** 4.29

Item length: 3

Item format: Alphanumeric

### Definition

The data item records the International Staging System (ISS) for multiple myeloma.

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes. Simple and powerful prognostic staging system.

Code	Label	Description
I	Stage I	Serum $\beta$ 2-microglobulin level < 3.5 mg/L and serum albumin level > 3.5 g/dL.
II	Stage II	(Not ISS stage I or III).
III	Stage III	Serum $\beta$ 2-microglobulin level $\geq$ 5.5 mg/L.
99	Unknown	Not stated / Not assessed.

### References

>Greipp PR, Miguel JS, Durie BGM, Crowley JJ, Barlogie B, Bladé J, et al. International Staging System for Multiple Myeloma. *J Clin Oncol* 2005; **23**(15):3412–20.

### Notes

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## DSSplus

**Variable number:** 4.30

Item length: 5

Item format: Alphanumeric

### Definition

The DSSplus (Durie-Salmon Plus staging system) is the revised Durie-Salmon staging system for multiple myeloma classification, based on MRI findings, FDG PET/CT findings, or both.

### Rational

This information is used to estimate prognosis, evaluate optimal therapy, and analyse outcomes.

Code	Label	Description
IA	Stage IA	Smoldering or indolent. Can have single plasmocytoma or limited disease at imaging; Normal renal function (serum creatinine level < 2.0 mg/dL).
IB	Stage IB	< 5 focal lesions, mild diffuse disease; Abnormal renal function (serum creatinine level ≥ 2.0 mg/dL).
IIA	Stage IIA	5–20 focal lesions; moderate diffuse disease; Normal renal function (serum creatinine level < 2.0 mg/dL).
IIB	Stage IIB	5–20 focal lesions; moderate diffuse disease; Abnormal renal function (serum creatinine level ≥ 2.0 mg/dL).
IIIA	Stage IIIA	> 20 focal lesions; moderate diffuse disease; normal renal function (serum creatinine level < 2.0 mg/dL).
IIIB	Stage IIIB	> 20 focal lesions; moderate diffuse disease; Abnormal renal function (serum creatinine level ≥ 2.0 mg/dL).
99	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Durie BG , Kyle RA , Belch A , et al . Myeloma management guidelines: a consensus report from the scientific advisors of the International Myeloma Foundation. *Hematol J* 2003; **4** (6): 379 – 398.

### Notes

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## SIOP staging

**Variable number:** 4.31

Item length: 10

Item format: Alphanumeric

### Definition

This data item records staging of Wilms' tumor for pediatric patients acc. to post-chemotherapy staging system developed by the International Society of Pediatric Oncology (SIOP). Based exclusively on the anatomic extent of the tumor, without consideration of genetic, biologic, or molecular markers.

### Rational

This staging system has been proven valuable in predicting outcomes.

Code examples#	Label	Description
yl	Stage y-I	Confined to kidney, capsule not exceeded, tumour can be completely removed.
yII	Stage y-II	Tumour infiltrates adjacent organs but is completely resected.
yIII	Stage y-III	Incomplete removal, no hematogenous metastases. Regional lymph nodes involved.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Metzger ML, Dome JS. Current therapy for Wilms' tumor. *Oncologist* 2005;10: 815-26.

>Orkin S, Fisher D, Look A, Lux S, Ginsberg D, Nathan D. *Oncology of Infancy and Childhood*. Philadelphia, PA: Saunders, 2009.

### Notes

>Used after chemotherapy only, prior to chemotherapy.

## St. Jude / Murphy staging

**Variable number:** 4.32

Item length: 5

Item format: Alphanumeric

### Definition

The St Jude/Murphy staging system for childhood NHL is based on clinical-pathological features like physical examination, CBC, imaging, bone marrow, CSF examinations etc.

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples <sup>#</sup>	Label	Description
I	Stage I	Single tumor (extranodal) or single anatomical area (nodal), with exclusion of mediastinum or abdomen.
IV	Stage IV	Involvement of bone marrow and/or central nervous system.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Murphy S. Classification, staging and end results of treatment in childhood non-Hodgkin's lymphoma: dissimilarities from lymphomas in adults. *Semin Oncol.* (1980); **7**:332–9.

### Notes

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## Toronto Tier II staging

**Variable number:** 4.33.1

Item length: 16

Item format: Text

### Definition

The Toronto Paediatric Cancer Stage Guidelines recommend the malignancy-specific staging system most suitable for use by population registries for 16 of the most common childhood malignancies. The Guidelines include a two-tiered approach that provides less detailed criteria for registries with limited resources and/or limited data access (Tier 1) based on collapsing of the more detailed criteria (Tier 2).

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

The appropriate staging system will be used to generate Toronto Tier II staging, e.g. Ann Arbor for Hodgkin's lymphomas, St.Jude-Murphy for non-Hodgkin lymphoma, TNM for rhabdomyosarcoma, etc.

Code examples <sup>#</sup>	Label	Description
CNS1	Stage CNS1	Toronto Tier II Stage grouping for CNS negative acute lymphoblastic leukaemia.
L1	Stage L1	INRGSS—localised stage L1 for neuroblastoma (localised tumour not involving a vital structure as defined by the list of image-defined risk factors and confined to one compartment).
IIA	Stage IIA	Ann Arbor stage IIA, to be used for Hodgkin lymphoma.
...		
99	Unknown	Not stated / Not assessed.

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Gupta S, Aitken JF, Bartels U, Brierley J, Dolendo M, Friedrich P, et al. Paediatric cancer stage in population-based cancer registries: the Toronto consensus principles and guidelines. *The Lancet Oncology*. 2016;17(4):e163-72.

### Notes

>Toronto Tier I will be generated from Toronto Tier II.

## Toronto Tier II (manual) staging

**Variable number:** 4.33.2

Item length: 10

Item format: Text

### Definition

The Toronto Paediatric Cancer Stage Guidelines recommend the malignancy-specific staging system most suitable for use by population registries for 16 of the most common childhood malignancies. The Guidelines include a two-tiered approach that provides less detailed criteria for registries with limited resources and/or limited data access (Tier 1) based on collapsing of the more detailed criteria (Tier 2).

### Rational

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes. This variable will be used where no other standard staging system is available, e.g. for medulloblastomas and other CNS embryonal tumours.

Code examples <sup>#</sup>	Label	Description
M3	Metastatic M3	Used for medulloblastoma with macroscopic spinal metastases at diagnosis.
Metastatic	Metastatic	Used for Ewing's sarcoma with distant metastases present at diagnosis. Although more detailed staging systems exist their clinical and prognostic value is limited, multi-tiered staging systems were not deemed appropriate.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Gupta S, Aitken JF, Bartels U, Brierley J, Dolendo M, Friedrich P, et al. Paediatric cancer stage in population-based cancer registries: the Toronto consensus principles and guidelines. *The Lancet Oncology*. 2016;17(4):e163-72.

### Notes

>Toronto Tier I will be generated from Toronto Tier II.

## Creasman grading system

**Variable number:** 4.34

Item length: 1

Item format: Number

### Definition

This data item records histopathological grade for uterine or endometrial cancer.

### Rational

Creasman grading is recommended as an essential tumour related prognostic factor by UICC TNM-8.

Code	Label	Description
1	G1	≤5% of a nonsquamous or nonmorular solid growth pattern
2	G2	6–50% of a nonsquamous or nonmorular solid growth pattern
3	G3	>50% of a nonsquamous or nonmorular solid growth pattern
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Creasman WT, Odicino F, Maisonneuve P, Quinn MA, Beller U, Benedet JL, Heintz APM, Ngan HYS, Pecorelli S. FIGO Annual Report on the results of treatment in gynaecological cancer. Vol. 26. Carcinoma of the corpus uteri. Int J Gynecol Obstet 2006; 95 (Suppl. 1): 105–143.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## Elston/Ellis grading system

**Variable number:** 4.35

Item length: 1

Item format: Number

### Definition

This data item records the histopathological grade for breast cancer. It is also called the Nottingham Histological Score. The grade for an individual tumour is derived from an assessment of three morphological features (Tubule formation, Nuclear pleomorphism, Mitotic count), each of which is scored 1-3.

### Rational

The information is recommended as an essential tumour related prognostic factor by UICC TNM-8.

Code	Label	Description
1	grade I	well-differentiated
2	grade II	moderately differentiated
3	grade III	poorly differentiated
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Elston CW, Ellis IO. Pathological prognostic factors in breast cancer. I. The value of histological grade in breast cancer: experience from a large study with long term follow up. *Histopathology* 1991; 19: 403–410.
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## SalzerKuntschik grading system

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**Variable number:** 4.36

Item length: 1

Item format: Number

### Definition

This data item records the grade of morphological regression for malignant bone tumour in children after chemotherapy.

### Rational

This information is an important prognostic factor, as well as for planning surgical treatment.

Code	Label	Description
1	R1	No vital tumour cells.
2	R2	Single vital tumour cells or vital cell clusters <0.5 cm.
3	R3	<10% vital tumour in the total tumor mass.
4	R4	10-50% vital tumour in the total tumor mass.
5	R5	>50% vital tumour cells in the total tumor mass.
6	R6	No tumour response.
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Salzer-Kuntschik M et al. Morphological grades of regression in osteosarcoma after polychemotherapy - study COSS 80. J Cancer Res Clin Oncol 1983;106 Suppl:21-4.

### Notes

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## Shimada grading system

**Variable number:** 4.37

Item length: 1

Item format: Number

### Definition

This data item records the grade for neuroblastoma, a frequent childhood cancer. Based on a grade of neuroblastic differentiation and mitosis-karyorrhexis index [MKI]) along with patient age at the time of diagnosis.

### Rational

Important prognostic factor for neuroblastoma.

Code	Label	Description
1	Favourable Histology	Age <1.5 yrs: Poorly differentiated or differentiating and low or intermediate MKI tumor. Age 1.5–5.0 yrs: Differentiating and low MKI tumor.
2	Unfavourable Histology	Age < 1.5 yrs 1) Undifferentiated tumor; 2) high MKI (mitosis-karyorrhexis index) tumor. Age 1.5–5.0 yrs 1) Undifferentiated or poorly differentiated tumor; 2) intermediate or high MKI tumor. Age > 5.0 yrs: All tumors.
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Shimada H, Ambros IM, Dehner LP et al. The International Neuroblastoma Pathology Classification (the Shimada System) Cancer 1999; 86:364–72.

### Notes

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## WHO(CNS) grading system

**Variable number:** 4.38

Item length: 1

Item format: Number

### Definition

Primary brain tumours are grouped according to the WHO classification based on the cell of origin, and the histological aggressiveness.

### Rational

The grade is widely used to evaluate prognosis, as well as to plan treatment.

Code	Label	Description
1	Grade I	Tumours with low proliferative potential and possibility of cure after resection.
2	Grade II	Tumours are infiltrative in nature and often recur despite low level of proliferation, or progress to higher grades.
3	Grade III	Clear evidence of malignancy, incl. nuclear atypia and brisk mitotic activity.
4	Grade IV	Cytologically malignant, mitotic active, necrosis-prone lesions with widespread infiltration of surrounding tissue and a propensity of craniospinal dissemination.
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>WHO Classification of Tumours of the Central Nervous System, Revised Fourth Edition. Louis, D.N., Ohgaki, H., Wiestler, O.D., Cavenee, W.K. IARC Lyon 2016.

### Notes

>WHO grading system for CNS is a malignancy scale, rather than a strict histological grading system, and therefore does not parallel the ICD-O-3 grade code.

## Clinical tumour size

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**Variable number:** 4.39

Item length: 3

Item format: Number

### Definition

The data item records the largest preoperative dimension or diameter of the tumour, in mm.

### Rational

This numeric information serves to cross-check the categorical information submitted as cT. It also serves to code the size of tumours where cT does not apply (e.g. brain cancer).

Code examples <sup>#</sup>	Label	Description
001		Size is 1 mm.
002		Size is 2 mm.
...		
998		Size is 998 mm or more.
999	Unknown	Not stated / Not assessed.

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## Pathological tumour size

**Variable number:** 4.40

Item length: 3

Item format: Number

### Definition

The data item records the the largest postoperative dimension or diameter of the tumour, in mm.

### Rational

This numeric information serves to cross-check the categorical information submitted as pT. It also serves to code the size of tumours where pT does not apply (e.g. brain cancer).

Code examples <sup>#</sup>	Label	Description
001		Size is 1 mm.
002		Size is 2 mm.
...		
998		Size is 998 mm or more.
999	Unknown	Not stated / Not assessed.

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT

### References

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### Notes

>If tumor size is given in tenths of millimeters, record size as 001 if largest dimension or diameter of tumor is between 0.1 and 0.9 mm. If the size is larger than 1.0 mm, round to the nearest integer.

## Metastases at diagnosis indicator

**Variable number:** 4.41

Item length: 1

Item format: Number

### Definition

The data item identifies the presence of metastases at time of diagnosis.

### Rational

This variable serves also to register metastases for sites such as CNS tumours, where TNM is not applicable.

Code	Label	Description
0	No	
1	Yes	
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- > Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- > Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

### Notes

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## Topography of metastases at diagnosis

**Variable number:** 4.42

Item length: 2

Item format: Number

### Definition

The data item identifies the distant site(s) of metastatic involvement at time of diagnosis.

### Rational

The topography of metastases at diagnosis is an independent prognostic indicator. This variable serves also to record metastases for leukaemias or CNS tumours where TNM is not applicable.

Code	Label	Description
1	PUL	Pulmonary (C34).
2	OSS	Osseous (C40, 41).
3	HEP	Hepatic (C22).
4	BRA	Brain (C71).
5	LYM	Lymph nodes (C77).
6	MAR	Bone marrow (C42.1).
7	PLE	Pleura (C38.4).
8	PER	Peritoneum (C48.1, 2).
9	ADR	Adrenals (C74).
10	SKI	Skin (C44).
11	OTH	Others.
99	UNK	No information on the topography of metastases available.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

### Notes

>If the patient has multiple metastases, more than one topography is registered for the primary tumour.

## BREAST CANCER: tumour related prognostic factors

> It is not required to generate information solely 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.

## Oestrogen receptor status

**Variable number:** 5.1.1

Item length: 3

Item format: Number

### Definition

The data item records the oestrogen receptor expression status of the tumour.

### Rational

The information is listed as an essential prognostic factor in TNM-8 for breast cancer. The oestrogen receptor (ER) is a cell protein that stimulates the cell proliferation under the influence of oestrogen. The ER status predicts whether breast cancer will respond to hormonal therapy (or the removal of the ovaries) suppressing the oestrogen receptors and thus inhibiting tumour growth.

Code examples <sup>#</sup>	Label	Description
>0	Percentage value (%)	Use if quantitative information is provided.
...		
100	Percentage value (%)	Use if quantitative information is provided.
222	Receptor status negative	Use if qualitative information is provided. Use if 0% value is provided.
333	Receptor status positive	Use if qualitative information is provided.
888	Receptor status not performed	
999	Receptor status unknown	No information available.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >O'Sullivan B (ed. In chief), Brierley JD, D'Cruz AK, Fey MF, Pollock R, Vermorken JB, Huang SH (2015). Manual of Clinical Oncology. Ninth Edition. UICC. Wiley Blackwell & Sons, Ltd.
- >Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.0, 2017 AWMF Registernummer: 032-045OL, <http://www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom/> (4.5.2.7).
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## Progesterone receptor status

**Variable number:** 5.1.2

Item length: 3

Item format: Number

### Definition

The data item records the progesterone receptor expression status of the tumour.

### Rational

The information is listed as an additional prognostic factor in TNM-8 for breast cancer. The Progesterone receptor (PR) status is used to predict whether or not a patient will benefit from endocrine therapy suppressing progesterone receptors and inhibiting the tumour growth.

Code examples <sup>#</sup>	Label	Description
>0	Percentage value (%)	Use if quantitative information is provided.
...		
100	Percentage value (%)	Use if quantitative information is provided.
222	Receptor status negative	Use if qualitative information is provided. Use if 0% value is provided.
333	Receptor status positive	Use if qualitative information is provided.
888	Receptor status not performed	
999	Receptor status unknown	No information available.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >O'Sullivan B (ed. In chief), Brierley JD, D'Cruz AK, Fey MF, Pollock R, Vermorken JB, Huang SH (2015). Manual of Clinical Oncology. Ninth Edition. UICC. Wiley Blackwell & Sons, Ltd.
- >Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.0, 2017 AWMF Registernummer: 032-045OL, <http://www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom/> (4.5.2.7).
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## Her2 receptor status

**Variable number:** 5.1.3

Item length: 1

Item format: Number

### Definition

The data item records the Her2 (human epidermal growth factor receptor 2) expression status of the tumour.

### Rational

The information is listed as an essential prognostic factor in TNM-8 for breast cancer. The Her2 receptor is an oncogene that can influence cell proliferation and tumour genesis. Its overexpression is associated with aggressive histological features of the tumour and poor prognosis and allows effective cancer management by Her2-targeting therapy.

Code	Label
1	Her2 overexpressed or gene amplified
2	Her2 not overexpressed or gene not amplified
3	Not performed
9	Unknown whether performed or not

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >O'Sullivan B (ed. In chief), Brierley JD, D'Cruz AK, Fey MF, Pollock R, Vermorken JB, Huang SH (2015). Manual of Clinical Oncology. Ninth Edition. UICC. Wiley Blackwell & Sons, Ltd.
- >Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.0, 2017 AWMF Registernummer: 032-045OL, <http://www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom/> (4.5.2.7).
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## Tumour proliferation labeling

**Variable number:** 5.1.4

Item length: 3

Item format: Number

### Definition

The data item records the expression of the immunohistochemical marker of proliferation, the Ki-67 antigen.

### Rational

This variable significantly influences tumor growth rate, and thus, represent tumoral aggressiveness.

Code examples <sup>#</sup>	Label	Description
0	Percentage value (%)	
...		
100	Percentage value (%)	
999	Unknown	Not stated / Not assessed.

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>O'Sullivan B (ed. In chief), Brierley JD, D'Cruz AK, Fey MF, Pollock R, Vermorken JB, Huang SH (2015). Manual of Clinical Oncology. Ninth Edition. UICC. Wiley Blackwell & Sons, Ltd.

>Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.0, 2017 AWMF Registernummer: 032-045OL, <http://www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom/> (4.5.2.7).

### Notes

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## PROSTATE CANCER: tumour related prognostic factors

> It is not required to generate information solely 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.

## Pretreatment Prostate Specific Antigen (PSA)

**Variable number:** 5.2.1

Item length: 5

Item format: Number

### Definition

Prostate Specific Antigen (PSA) is serine protease produced and secreted by prostate gland.

### Rational

The pretreatment serum PSA level serves as a marker in diagnosis of prostate cancer and is listed as an essential prognostic factor in TNM-8 for prostate cancer.

Code examples <sup>#</sup>	Label	Description
2.5		2.5 ng/ml
...		...
15.0		15.0 ng/ml
...		...
999.7	999.7 ng/ml or higher	
999.8	Test not performed	
999.9	Test result unknown	

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>N. Mottet et al. EAU - ESTRO – SIOG guidelines on prostate cancer. European Association of Urology 2016  
<http://www.ncbi.nlm.nih.gov/pubmed/24207135>

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## Gleason biopsy most common grade\*

**Variable number:** 5.2.2

Item length: 1

Item format: Number

### Definition

The item Gleason biopsy most common grade shows Gleason grade of the most extensive pattern (primary pattern) in biopsy-detected prostate cancer.

### Rational

Gleason score of biopsy-detected PCa comprises the Gleason grade or the most extensive (primary pattern) pattern, plus the second most common pattern (secondary pattern), if two are present, or the pattern with the highest Gleason grade, if a tumour has more than 2 histological patterns.

Code	Label	Description
1	Gleason grade 1	Well differentiated tissue.
2	Gleason grade 2	Well / moderately differentiated tissue.
3	Gleason grade 3	Moderately differentiated tissue.
4	Gleason grade 4	Poorly differentiated tissue.
5	Gleason grade 5	Undifferentiated/Anaplastic tissue.

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

- >Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.
- >Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. *Am J Surg Pathol* 2016;40:244–52.
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## Gleason biopsy second most common or highest grade\*

**Variable number:** 5.2.3

Item length: 1

Item format: Number

### Definition

The item Gleason biopsy second most common or highest grade shows Gleason grade of the second most common pattern (secondary pattern), or the pattern with the highest Gleason grade in biopsy-detected prostate cancer, if a tumour has more than 2 histological patterns.

### Rational

Gleason score of biopsy-detected PCa comprises the Gleason grade or the most extensive (primary pattern) pattern, plus the second most common pattern (secondary pattern), if two are present, or the pattern with the highest Gleason grade, if a tumour has more than 2 histological patterns.

Code	Label	Description
1	Gleason grade 1	Well differentiated tissue.
2	Gleason grade 2	Well / moderately differentiated tissue.
3	Gleason grade 3	Moderately differentiated tissue.
4	Gleason grade 4	Poorly differentiated tissue.
5	Gleason grade 5	Undifferentiated/Anaplastic tissue.

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

- >Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.
- >Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. *Am J Surg Pathol* 2016;40:244–52.
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## Gleason excision most common grade\*

**Variable number:** 5.2.4

Item length: 1

Item format: Number

### Definition

The item Gleason excision most common grade shows Gleason grade of the most extensive pattern (primary pattern) in prostate cancer.

### Rational

The Gleason system is the most commonly accepted standard for prostate cancer grading and one of the most important prognostic factors for localized prostate cancer. The Gleason score of biopsy-detected PCa comprises the Gleason grade or the most extensive (primary pattern) pattern, plus the second most common pattern (secondary pattern), if two are present.

Code	Label	Description
1	Gleason grade 1	Well differentiated tissue.
2	Gleason grade 2	Well / moderately differentiated tissue.
3	Gleason grade 3	Moderately differentiated tissue.
4	Gleason grade 4	Poorly differentiated tissue.
5	Gleason grade 5	Undifferentiated/Anaplastic tissue.

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

- >Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.
- >Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. *Am J Surg Pathol* 2016;40:244–52.
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## Gleason excision second most common or highest grade\*

**Variable number:** 5.2.5

Item length: 1

Item format: Number

### Definition

The item Gleason excision second most common or highest grade shows Gleason grade of the second most common pattern (secondary pattern) or the pattern with the highest Gleason grade in prostate cancer.

### Rational

Gleason score of biopsy-detected PCa comprises the Gleason grade or the most extensive (primary pattern) pattern, plus the second most common pattern (secondary pattern), if two are present.

Code	Label	Description
1	Gleason grade 1	Well differentiated tissue.
2	Gleason grade 2	Well / moderately differentiated tissue.
3	Gleason grade 3	Moderately differentiated tissue.
4	Gleason grade 4	Poorly differentiated tissue.
5	Gleason grade 5	Undifferentiated/Anaplastic tissue.

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

- >Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.
- >Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. *Am J Surg Pathol* 2016;40:244–52.
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## Gleason score

**Variable number:** 5.2.6

Item length: 2

Item format: Number

### Definition

Gleason score comprises the Gleason grade or the most extensive (primary pattern) pattern, plus the second most common pattern (secondary pattern), if two are present, or the pattern with the highest Gleason grade, if a tumour has more than 2 histological patterns.

### Rational

Gleason score is the basis for prostate cancer grading and the most important essential prognostic factor.

Code	Label	Description
2	1+1	1+1 (no longer assigned on biopsy, only rarely on other specimens).
3	2+1	2+1 (no longer assigned on biopsy, only rarely on other specimens).
4	2+2	2+2 (no longer assigned on biopsy, only rarely on other specimens).
5	3+2, 2+3	3+2, 2+3 (no longer assigned on biopsy, only rarely on other specimens).
6	3+3	3+3 (in practice the lowest score).
7	3+4, 4+3	3+4, 4+3
8	4+4, 3+5, 5+3	4+4, 3+5, 5+3
9	5+4, 4+5	5+4, 4+5
10	5+5	5+5
99	Unknown	

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.
- >Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. *Am J Surg Pathol* 2016;40:244–52.
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

- >Histology after surgery has priority over the biopsy, unless neoadjuvant therapy was performed prior to surgery.

## WHO grade group

**Variable number:** 5.2.7

Item length: 1

Item format: Number

### Definition

A five-grade group system based on the grading categories from Gleason score 2 to 10.

### Rational

Gleason grade groups belong to the most important prognostic factors.

Code	Label	Description
1	Grade group 1	Gleason score $\leq 6$ ( $\leq 3+3$ ). Only individual discrete well-formed glands.
2	Grade group 2	Gleason score 7 (3 + 4). Predominantly well-formed glands with lesser component of poorly formed/fused/cribriform glands.
3	Grade group 3	Gleason score 7 (4 + 3). Predominantly poorly formed/fused/cribriform glands with lesser component of well-formed glands.
4	Grade group 4	Gleason score 8 (4 + 4 or 3 + 5 or 5 + 3). - Only poorly formed/fused/cribriform glands or - Predominantly well-formed glands and lesser component lacking glands - Predominantly lacking glands and lesser component of well-formed glands.
5	Grade group 5	Gleason score 9-10. Lack of gland formation (or with necrosis) with or without poorly formed/fused/cribriform glands.
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.
- >Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. Am J Surg Pathol 2016;40:244–52.
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## MELANOMA: tumour related prognostic factors

> It is not required to generate information solely 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.

## Breslow thickness

**Variable number:** 5.3.1

Item length: 4

Item format: Number

### Definition

The Breslow thickness shows the distance from stratum granulosum to the deepest tumour cell, measured in mm.

### Rational

Most important prognostic factor listen in TNM-8 for Melanoma.

Code examples <sup>#</sup>	Label	Description
1.1		1.1 mm depth from stratum granulosum to the deepest tumour cell.
...		
99.9	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >AJCC Physician to Physician. 8th edition AJCC Melanoma Staging System. JE Gershenwald, JM Skibber University of Texas MD Anderson Cancer Center.
- >Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): Diagnostik, Therapie und Nachsorge des Melanoms, Langversion 2.0, 2016, AWMF Registernummer: 032/024OL, <http://leitlinienprogramm-onkologie.de/Melanom.65.0.html> .
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## COLORECTAL CANCER: tumour related prognostic factors

> It is not required to generate information solely 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.

## Circumferential resection margins

**Variable number:** 5.4.1

Item length: 1

Item format: Number

### Definition

The circumferential resection margin (CRM) is a surgically created plane produced during the removal of the rectum from its surroundings.

### Rational

The information is listed as an essential prognostic factor in TNM-8 for colorectal cancer. A circumferential safety margin of less than 1 mm also significantly increases the local recurrence risk for rectal cancer.

Code	Label	Description
1	0 mm	Positive, R1
2	<1 mm	Negative, R0 "close"
3	≥1 mm	Negative, R0 "wide"
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Evidenced-based Guideline for Colorectal Cancer, long version 1.0, AWMF registration number: 021-007OL, <http://leitlinienprogrammonkologie.de/Leitlinien.7.0.html>.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## Microsatellite instability

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**Variable number:** 5.4.2

Item length: 1

Item format: Number

### Definition

The data item records presence or absence of microsatellite instability.

### Rational

Microsatellite instability is listed as additional prognostic factor in TNM-8 for colorectal cancer. It is a pathology test that looks for a gene mutation associated with a particular type of hereditary colorectal cancer called HNPCC or Lynch syndrome. A high level of microsatellite instability is suggestive of HNPCC.

Code	Label	Description
0	No	
1	Yes	
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## TESTICULAR CANCER: tumour related prognostic factors

> It is not required to generate information solely 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.

## α-fetoprotein

**Variable number:** 5.5.1

Item length: 1

Item format: Number

### Definition

The data item records the serum level of the tumour marker α-fetoprotein (AFP).

### Rational

The presence of elevated α-fetoprotein (AFP) is frequent in testicular cancer, where staging is based on the determination of the anatomic extent of disease and assessment of serum tumour markers. The information is required to decide the TNM S-categories. It also helps to differentiate the histology of tumor because various germ cell tumors will show positivity for either AFP or hCG or both.

Code	Label	Description
0	AFP0	Within reference range
1	AFP1	> upper limit of reference range to < 1'000 ng/ml
2	AFP2	1'000 – 10'000 ng/ml
3	AFP3	> 10'000 ng/ml
9	AFPX	AFP not available or not performed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

>The reference range is provided by the testing laboratory and varies due to testing equipment, chemical reagents, and analytical techniques.

## hCG

**Variable number:** 5.5.2

Item length: 1

Item format: Number

### Definition

The data item records the level of serum tumour marker human chorionic gonadotropin (hCG).

### Rational

The presence of elevated human chorionic gonadotropin (hCG) is frequent in testicular cancer, where staging is based on the determination of the anatomic extent of disease and assessment of serum tumour markers. The information is required to decide the TNM S-categories. It also helps to differentiate the histology of tumor because various germ cell tumors will show positivity for either AFP or hCG or both.

Code	Label	Description
0	hCG0	Within reference range
1	hCG1	> upper limit if reference range to < 5'000 mIU/ml
2	hCG2	5'000 – 50'000 mIU/ml
3	hCG3	> 50'000 mIU/ml
9	hCGX	hCG not available or not performed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

>The reference range is provided by the testing laboratory and varies due to testing equipment, chemical reagents, and analytical techniques.



## LDH

**Variable number:** 5.5.3

Item length: 1

Item format: Number

### Definition

The data item records the levels of serum tumour marker lactate dehydrogenase (LDH).

### Rational

The presence of elevated lactate dehydrogenase (LDH) is frequent in testicular cancer, where staging is based on the determination of the anatomic extent of disease and assessment of serum tumour markers. The information is required to decide the TNM S-categories.

Code	Label	Description
0	LDH0	Within reference range
1	LDH1	> upper limit of reference range to < 1.5 x N <sup>#</sup>
2	LDH2	1.5 – 10 x N <sup>#</sup>
3	LDH3	> 10 x N <sup>#</sup>
9	LDHX	LDH not available or not performed.

#: N indicates the upper limit of normal for the LDH assay.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

>The reference range is provided by the testing laboratory and varies due to testing equipment, chemical reagents, and analytical techniques.

## Serum tumour markers

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**Variable number:** 5.5.4

Item length: 1

Item format: Number

### Definition

The data item records the TNM S-categories as combination of levels for AFP, hCG, and LDH.

### Rational

Essential for TNM prognostic staging of testicular cancer.

Code	Label	Description
0	S0	Serum marker study levels within normal limits.
1	S1	
2	S2	
3	S3	
9	SX	Serum marker studies not available or not performed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

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## HEAD/NECK CANCER: tumour related prognostic factors

> It is not required to generate information solely 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.

## HPV/p16

**Variable number:** 5.6.1

Item length: 1

Item format: Number

### Definition

HPV (Human papillomavirus) positivity is defined as showing either evidence of HPV gene expression (tested with p16 immunohistochemistry) or HPV DNA, or both.

### Rational

This information is an essential prognostic factor of squamous cell carcinoma with cervical lymph node metastases without an identified primary carcinoma, and in oropharyngeal cancer.

Code	Label	Description
0	No	HPV- or p16- negative
1	Yes	HPV- or p16- positive
9	Unknown	Not stated / Not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

>HPV status information is only mandatory for squamous cell carcinoma with cervical lymph node metastases without an identified primary carcinoma, and in oropharyngeal cancer.

## EBV

**Variable number:** 5.6.2

Item length: 1

Item format: Number

### Definition

EBV (Epstein Barr virus) positivity is defined as showing evidence of EBV antigen in a blood test, or EBV DNA or RNA by polymerase chain reaction.

### Rational

This information is an essential prognostic factor of squamous cell carcinoma with cervical lymph node metastases without an identified primary carcinoma.

Code	Label	Description
0	No	EBV- negative.
1	Yes	EBV- positive.
9	Unknown	Not stated/not assessed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

### Notes

>EBV status information is only mandatory for squamous cell carcinoma with cervical lymph node metastases without an identified primary carcinoma.

TREATMENT:  
prognostic factors  
related to treatment

> It is not required to generate information solely 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.

## Residual invasive tumour

**Variable number:** 6.1

Item length: 1

Item format: Number

### Definition

This data item records the invasive tumour status after treatment. The R classification can be used following surgical treatment alone, after radiotherapy alone, after chemotherapy alone or following multimodal therapy. The status after treatment takes distant metastases into account.

### Rational

This information is a strong indicator of prognosis and reflects the effect of treatment.

Code	Label	Description
0	R0	No residual tumour detectable by any diagnostic means. In M1 cases, the distant metastasis as well as the primary tumour must be removed completely.
1	R1	Microscopic residual tumour.
2	R2	Macroscopic residual tumour.
8	RX	Presence of residual tumour cannot be assessed.
9	Unknown	There is no information on the presence or absence of residual tumour.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Wittekind, Compton, Greene, Sobin etc.: TNM Residual Tumor Classification Revisited. *Cancer*. 2002; 94: 2511-2516.
- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## Residual in-situ tumour

**Variable number:** 6.2

Item length: 1

Item format: Number

### Definition

This data item records the in-situ tumour status after treatment. The R classification can be used following surgical treatment alone, after radiotherapy alone, after chemotherapy alone or following multimodal therapy. The status after treatment takes distant metastases into account.

### Rational

This information is a strong indicator of prognosis and reflects the effect of treatment.

Code	Label	Description
0	R0	No residual tumour detectable by any diagnostic means. In M1 cases, the distant metastasis as well as the primary tumour must be removed completely.
1	R1	Microscopic residual tumour.
2	R2	Macroscopic residual tumour.
8	RX	Presence of residual tumour cannot be assessed.
9	Unknown	There is no information on the presence or absence of residual tumour.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- > Wittekind, Compton, Greene, Sobin etc.: TNM Residual Tumor Classification Revisited. *Cancer*. 2002; 94: 2511-2516.
- > Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- > Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- > Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- > Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.
- > Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5<sup>th</sup> Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

### Notes

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## Resection margin invasive tumour

**Variable number:** 6.3

Item length: 4

Item format: Number

### Definition

The data item indicates the minimal width of the normal tissue between the tumour and the surgical margin of the resected tumour on primary site (microscopic distance between the outermost tumour cells and the cut edge of the specimen). Measurement in millimeter.

### Rational

Most reliable parameter to infer that the patient is free from detectable tumour cells. It is recommended as an essential tumour-related prognostic factor in cancer of oral cavity or breast by UICC TNM-8.

Code examples <sup>#</sup>	Description
0.0	There are invasive tumour cell in the resection margin.
0.1	There is 0.1 mm margin between invasive tumour and the cut edge of the specimen.
...	
1.0	There is 1.0 mm margin between invasive tumour and the cut edge of the specimen.
...	
98.0	Not applicable
99.0	Unknown. Not stated / Not assessed.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## Resection margin in-situ tumour

**Variable number:** 6.4

Item length: 4

Item format: Number

### Definition

The data item indicates the minimal width of the normal tissue between the tumour and the surgical margin of the resected tumour on primary site (microscopic distance between the outermost tumour cells and the cut edge of the specimen). Measurement in millimeter.

### Rational

This information is the most reliable parameter to infer that the patient is free from detectable tumour cells. It is recommended as an essential tumour-related prognostic factor in cancer of oral cavity or breast by UICC TNM-8.

Code examples <sup>#</sup>	Description
0.0	There are in-situ tumour cell in the resection margin.
0.1	There is 0.1 mm margin between in-situ tumour and the cut edge of the specimen.
...	
1.0	There is 1.0 mm margin between in-situ tumour and the cut edge of the specimen.
...	
98.0	Not applicable
99.0	Unknown. Not stated / Not assessed.

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## Sentinel lymph node assessment

---

**Variable number:** 6.5

Item length: 1

Item format: Number

### Definition

The data item indicates whether the sentinel lymph node is excised and the result of the examination. The sentinel lymph node is the first lymph node to receive lymphatic drainage from a primary tumour.

### Rational

This information is used to evaluate the quality of diagnostic procedures and to assess the impact of sentinel lymph node procedures on outcome.

Code	Label	Description
0	N0	Sentinel lymph node not involved.
1	N1	Sentinel lymph node involved.
8	NX	Sentinel lymph node cannot be assessed.
9	Unknown	No information in the patient's reports.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## Number of examined sentinel lymph nodes

**Variable number:** 6.6

Item length: 2

Item format: Number

### Definition

The data item records the total number of sentinel lymph nodes that were excised and examined by the pathologist.

### Rational

This information is used to evaluate the quality of diagnostic procedures and to assess the impact of sentinel lymph node procedures on outcome.

Code examples <sup>#</sup>	Label	Description
0	None	No sentinel lymph node excised.
1	1 node	One sentinel lymph node excised.
...	...	
96	96 nodes	Ninety-six sentinel lymph nodes excised.
97	97 nodes or more	Ninety-seven or more sentinel lymph nodes excised.
99	Unknown	No information whether sentinel lymph nodes were excised or not. OR Sentinel lymph nodes were excised, but no information on the number.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

-

## Number of positive sentinel lymph nodes

**Variable number:** 6.7

Item length: 2

Item format: Number

### Definition

The data item records the number of sentinel lymph nodes examined by the pathologist and found to contain metastases.

### Rational

This information is used to evaluate the quality of diagnostic procedures and to assess the impact of sentinel lymph node procedures on outcome.

Code examples <sup>#</sup>	Label	Description
0	None	No sentinel lymph node invaded.
1	1 node	One sentinel lymph node invaded.
...	...	
96	96 nodes	Ninety-six sentinel lymph nodes invaded.
97	97 nodes or more	Ninety-seven or more sentinel lymph nodes invaded.
99	Unknown	No information whether sentinel lymph nodes were invaded or not. OR Sentinel lymph nodes were invaded, but no information on the number.

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

-

## FIRST TREATMENT COMPLEX

- The first treatment complex consists of all treatments planned after the diagnosis, incl. watchful waiting.
- Registration is restricted to treatments actually applied.
- It is not required to generate information solely 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.

## Basis of first treatment complex decision

---

**Variable number:** 7.1

Item length: 1

Item format: Number

### Definition

This data item records the basis of treatment decision for the entire first treatment complex. The initial treatment includes all therapy steps planned after the diagnosis. In most cases the decision for the first treatment complex is discussed and agreed at multidisciplinary tumour boards. A tumour board is an interdisciplinary medical committee that develops an individual treatment plan for patients with a malignant disease.

### Rational

The information serves to evaluate the treatment quality.

Code	Label	Description
1	Tumour board	An interdisciplinary medical committee.
2	Other (not specified)	Not a tumour board.
9	Unknown	The basis of treatment decision is unknown.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## Date of first treatment complex decision

**Variable number:** 7.2.1

Item length: 10

Item format: Date (dd.mm.yyyy)

### Definition

This data item records the date when the treatment decision was made. To be recorded for the entire first treatment complex.

### Rational

This information is used to evaluate treatment quality.

Code examples <sup>#</sup>	Description
01.01.2005	Note: for single digit day or month, record with a leading 0.
15.01.2005	Note: if exact day unknown, set day as 15 <sup>th</sup> of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30 <sup>th</sup> of June of the respective year.
...	

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT in truncated form, with day set to unknown (i.e. 15) for all cases. In addition, the accompanying age in days is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

>If the treatment decisions were made in more than one tumourboard, the date of the first tumourboard is recorded.



## Accuracy for date of 1<sup>st</sup> treatment complex decision

---

**Variable number:** 7.2.2

Item length: 1

Item format: Number

### Definition

The data item indicates the accuracy of the date when the treatment decision was made.

### Rational

The data item is used to identify groups of patients where ages or time periods are not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

-

### Notes

-

## First treatment complex goal(s)

---

**Variable number:** 7.3

Item length: 1

Item format: Number

### Definition

The data item records the goal for each treatment as part of the first treatment complex.

### Rational

Quality assessment of treatment patterns depends on the goal of the first treatment complex.

Code	Label	Description
1	Curative	A treatment approach with the aim to remove the tumour, rid the body of wandering cancer cells, and prevent a recurrence.
2	Palliative	The purpose of palliative treatment is to relieve the symptoms and to improve quality of life in cases, when curative treatment is impossible
9	Unknown	Not stated.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

>Planned but not applied treatments are not registered.

## First treatment complex code(s)

**Variable number:** 7.4

Item length: 10

Item format: Alphanumeric

### Definition

The data item records the CHOP code, or NKRS-ONEC-SNRT-assigned CHOP-like code for treatments where no CHOP code exists, for each treatment as part of the first treatment complex. CHOP is Swiss classification of surgical operations and other diagnostic and treatment procedures and interventions.

### Rational

This information is readily available at the sources (clinics, physicians) in standardized and updated form. Treatment indicators at the system level will be compared with evidence-based guidelines.

Code examples <sup>#</sup>	Label	Description
85.21	Local excision of a lesion on the breast	CHOP procedure code used by Swiss treatment institutions.
85.45.00	Radical mastectomy, not otherwise specified	CHOP procedure code used by Swiss treatment institutions.
...	...	
99.2R.01 (preliminary code)	Hormonotherapy, NOS	CHOP-like code created for cancer registration use only. [Note: preliminary coding is still under discussion].
99.9R.00 (preliminary code)	Watchful waiting	CHOP-like code created for cancer registration use only. Closely watching a patient's condition but not giving treatment unless symptoms appear or change. Watchful waiting is sometimes used in conditions that progress slowly. It is also used when the risks of treatment are greater than the possible benefits. [Note: preliminary coding is still under discussion].
...	...	
999	Unknown	

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### Notes

>Planned but not applied treatments are not registered.

## First treatment complex start date(s)

**Variable number:** 7.5.1  
Item length: 10  
Item format: Date (dd.mm.yyyy)

### Definition

The data item records the dates when each treatment of the first treatment complex has been started.

### Rational

This information is used to evaluate treatment quality. It is important to measure the delay between diagnosis and treatment, as well as the time intervals between treatments, and between treatment and recurrence.

Code examples <sup>#</sup>	Description
01.01.2005	Note: for single digit day or month, record with a leading 0.
15.01.2005	Note: if exact day unknown, set day as 15 <sup>th</sup> of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30 <sup>th</sup> of June of the respective year.
...	

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT in truncated form, with day set to unknown (i.e. 15) for all cases. In addition, the accompanying age in days is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

-

## Accuracy for date(s) of 1<sup>st</sup> treatment complex start

---

**Variable number:** 7.5.2

Item length: 1

Item format: Number

### Definition

Indicates the accuracy of the date(s) when each treatment of the first treatment complex has been started.

### Rational

The data item is used to identify groups of patients where ages or time periods are not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## First treatment complex institution(s)\*

---

**Variable number:** 7.6

Item length: 255

Item format: Text

### Definition

The data item records the name and address of the responsible person and institution submitting treatment information to the cancer registry.

### Rational

This information allows providing quality feedback to those institutions requesting it. It also allows regional and national statistical reports on the relative contribution of different types of institutions treating cancer patients.

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

- >Medical practices: GLN (Global Location Number) aus refdata - [https://www.refdata.ch/content/partner\\_d.aspx](https://www.refdata.ch/content/partner_d.aspx).  
Updates via <https://refdatabase.refdata.ch/Service/Partner.aspx>.
- >Hospitals: official hospital lists <https://www.bag.admin.ch/bag/de/home/zahlen-und-statistiken/zahlen-fakten-zu-spitaelern/spital-suchen.exturl.html/aHR0cDovL3d3dy5iYWctYW53LmFkbWluLmNoLzlwMTZfdGFnbG/FilZlwMTZfc3BpdGFsc3RhdGlzdGlrL3BvcnRhbF9kZS5waHA/cD1tYXBrdCZsYW5nPWRI.html>.

### Notes

- >Addresses will be taken from national uniform lists of health service providers.
- >Metadata for the institution responsible for treatment can also be registered to facilitate the exchange of information.
- >The cancer registries define, and update on a regular basis, the official address of all responsible persons and hospital units submitting cancer information.
- >Multiple persons or institutions may optionally be registered per diagnosis.

## COURSE OF DISEASE: Recurrences/Transformations

> It is not required to generate information solely 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.

## Type of event(s)

**Variable number:** 8.1

Item length: 1

Item format: Number

### Definition

The data item records the type of first recurrence of the disease or the occurrence of a transformation.

### Rational

The information is required for the analysis of progression free survival and disease free survival.

Code	Label	Description
1	Progression	Locoregional <sup>#</sup> new findings without disease free intermission.
2	Transformation	The development of one ICD-O M term into another (for example, the change of a haematopoetic or lymphoid neoplasm from chronic to acute phase). In order to decide on haematological transformation event, adherence to the ENCR recommendation and Haemacare guideline, cited below, is mandatory.
3	Metastasis	New finding at a site distant to the primary tumour, i.e. metachronous metastasis. Either with or without disease free intermission.
4	Relapse	Locoregional <sup>#</sup> new findings after a period of documented disease free intermission or remission without detectable tumour.

#: Locoregional refers to the same or adjacent site of the original tumour or the regional lymph nodes. A list of those lymph nodes defined as regional lymph nodes for each cancer site can be found in the TNM Classification of Malignant Tumours International Union Against Cancer (UICC).

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >European Network of Cancer Registries (ENCR): Recommendations for Registration of Haematological Malignancies (2014).  
[https://www.encl.eu/sites/default/files/pdf/ENCR\\_Haematological\\_Malignancies\\_Summary\\_Recommendations\\_Feb\\_2014.pdf](https://www.encl.eu/sites/default/files/pdf/ENCR_Haematological_Malignancies_Summary_Recommendations_Feb_2014.pdf) [last access 8.2.2019].
- >Gavin, A et al. Towards optimal clinical and epidemiological registration of haematological malignancies: Guidelines for recording progressions, transformations and multiple diagnoses. *European Journal of Cancer* **51** (2015), 1109–1122.
- >Haemacare Guideline: Sant M, et al. Manual for Coding and Reporting Haematological Malignancies. *Tumori* **96**(4), (2010).

### Notes

- >More than a single event may be registered per diagnosis.



## Date of event(s)

**Variable number:** 8.2.1

Item length: 10

Item format: Date (dd.mm.yyyy)

### Definition

The data item records the date of the recurrent event or transformation.

### Rational

The information is required for the analysis of progression free survival and disease free survival.

Code examples <sup>#</sup>	Description
01.01.2005	Note: for single digit day or month, record with a leading 0
15.01.2005	Note: if exact day unknown, set day as 15 <sup>th</sup> of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30 <sup>th</sup> of June of the respective year.
...	

<sup>#</sup>: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT in truncated form, with day set to unknown (i.e. 15) for all cases. In addition, the accompanying age in days is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## Accuracy for date of event(s)

**Variable number:** 8.2.2

Item length: 1

Item format: Number

### Definition

Indicates the accuracy of the date of the recurrent event or transformation.

### Rational

The data item is used to identify groups of patients where ages or time periods are not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

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### Notes

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## Event ICD-O version

**Variable number:** 8.3  
Item length: 2  
Item format: Number

### Definition

This data item records the version of the International Classification of Diseases for Oncology (ICD-O) used to code the recurrence or transformation. Adherence to the ENCR recommendation and Haemacare guideline, cited below, is mandatory.

### Rational

The International Classification of Diseases for Oncology (ICD-O) is regularly updated to include the progress in medical knowledge.

Code	Label	Description
10	Version 1	
20	Version 2	
30	Version 3.0	WHO 2000
31	Version 3.1	Update 2011
32	Version 3.2	Update 2019

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >ICD-O: <http://codes.iarc.fr/abouticdo.php>
- >European Network of Cancer Registries (ENCR): Recommendations for Registration of Haematological Malignancies (2014).  
[https://www.encl.eu/sites/default/files/pdf/ENCR\\_Haematological\\_Malignancies\\_Summary\\_Recommendations\\_Feb\\_2014.pdf](https://www.encl.eu/sites/default/files/pdf/ENCR_Haematological_Malignancies_Summary_Recommendations_Feb_2014.pdf) [last access 8.2.2019].
- >Gavin, A et al. Towards optimal clinical and epidemiological registration of haematological malignancies: Guidelines for recording progressions, transformations and multiple diagnoses. *European Journal of Cancer* **51** (2015), 1109–1122.
- >Haemacare Guideline: Sant M, et al. Manual for Coding and Reporting Haematological Malignancies. *Tumori* **96**(4), (2010).

### Notes

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## Morphology term before change of main diagnosis\*

**Variable number:** 8.4  
Item length: 6  
Item format: Alphanumeric

### Definition

The data item records the morphology according to ICD-O in the case that the main diagnosis has been changed (e.g. because the later diagnosis was within three month after the first). Adherence to the ENCR recommendation and Haemacare guideline, cited below, is mandatory.

### Rational

This information allows to retain the earlier morphology code.

Code examples#	Label
9940/3	Hairy cell leukaemia
...	

#: only examples are shown to reduce table size

### National usage

(\*) The variable is not to be submitted to the NKRS-ONEC-SNRT.

### References

- >European Network of Cancer Registries (ENCR): Recommendations for Registration of Haematological Malignancies (2014).  
[https://www.encl.eu/sites/default/files/pdf/ENCR\\_Haematological\\_Malignancies\\_Summary\\_Recommendations\\_Feb\\_2014.pdf](https://www.encl.eu/sites/default/files/pdf/ENCR_Haematological_Malignancies_Summary_Recommendations_Feb_2014.pdf) [last access 8.2.2019].
- >Gavin, A et al. Towards optimal clinical and epidemiological registration of haematological malignancies: Guidelines for recording progressions, transformations and multiple diagnoses. *European Journal of Cancer* **51** (2015), 1109–1122.
- >Haemacare Guideline: Sant M, et al. Manual for Coding and Reporting Haematological Malignancies. *Tumori* **96**(4), (2010).

### Notes

>If there was no change of the main diagnosis, this variable remains empty.

## Morphology term after Transformation

**Variable number:** 8.5

Item length: 6

Item format: Alphanumeric

### Definition

The data item records the morphology term according to ICD-O after transformation. For haematological transformations, adherence to the ENCR recommendation and Haemacare guideline, cited below, is mandatory.

### Rational

This information allows the study how the risk of certain transformations varies over time since diagnosis, as a function of treatment, patient, and tumour characteristics.

The table provides two typical examples from clinical practice: first a haematological M term after transformation, and secondly a brain tumour M term after transformation.

Code examples#	Label	Description
9801/3	Acute leukemia, NOS	For example as a transformation from M9945/3 (Chronic myelomonocytic leukaemia).
9390/1	Atypical choroid plexus papilloma	For example as a transformation from M9390/0 (Choroid plexus papilloma, NOS).
...		

#: only examples are shown to reduce table size

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >European Network of Cancer Registries (ENCR): Recommendations for Registration of Haematological Malignancies (2014).  
[https://www.encl.eu/sites/default/files/pdf/ENCR\\_Haematological\\_Malignancies\\_Summary\\_Recommendations\\_Feb\\_2014.pdf](https://www.encl.eu/sites/default/files/pdf/ENCR_Haematological_Malignancies_Summary_Recommendations_Feb_2014.pdf) [last access 8.2.2019].
- >Gavin, A et al. Towards optimal clinical and epidemiological registration of haematological malignancies: Guidelines for recording progressions, transformations and multiple diagnoses. *European Journal of Cancer* **51** (2015), 1109–1122.
- >Haemacare Guideline: Sant M, et al. Manual for Coding and Reporting Haematological Malignancies. *Tumori* **96**(4), (2010).

### Notes

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## Topography(s) of post-diagnosis metastases

**Variable number:** 8.6  
Item length: 2  
Item format: Number

### Definition

The data item identifies the distant site(s) of metastatic involvement after disease recurrence.

### Rational

This information allows the study how the risk of distant metastasis varies over time since diagnosis, as a function of treatment, patient, and tumour characteristics.

Code	Label	Description
1	PUL	Pulmonary (C34).
2	OSS	Osseous (C40, 41).
3	HEP	Hepatic (C22).
4	BRA	Brain (C71).
5	LYM	Lymph nodes (C77).
6	MAR	Bone marrow (C42.1).
7	PLE	Pleura (C38.4).
8	PER	Peritoneum (C48.1, 2).
9	ADR	Adrenals (C74).
10	SKI	Skin (C44).
11	OTH	Others.
99	UNK	No information on the topography of metastases in the patient's reports.

### National usage

The variable is to be submitted to the NKRS-ONEC-SNRT.

### References

- >Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8<sup>th</sup> Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
- >Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4<sup>th</sup> Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
- >Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
- >Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6<sup>th</sup> Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

### Notes

>If the patient has multiple metastases, more than one topography is registered.

END