

Overview of most important variables available in the Childhood cancer registry,
Status January 2022

Variable	Description	Sensitive /identifying (processed or excluded in anonymization)	Availability*
Patientendaten			
Family name(s)		X	A
Name(s)		X	A
Gender	male, female, other, unknown	X	A
Date of birth	day, month, year	only month and year kept	A
Date of death	day, month, year	only month and year kept	A
Cause of death	ICD Code		E
Address at diagnosis, Address dates		X	A
Vital status	alive, dead, lost to follow up, unknown		A
Vital status date	day, month, year	only month and year kept	A
Diagnosis			
Incidence date	day, month, year	only month and year kept	A
Age at incidence	year	year rounded	A
Method of first detection	e.g. clinical symptoms, incidental discovery, screening, death, self-examination		C
Most valid basis of diagnosis	e.g. clinical, imaging, histology, DCO		A
Diagnostic method(s) used			C
Diagnostic institution (s)		X	A
Tumour number	Rank of diagnosis		E
Classifications			
ICD Version	ICD Version 8 or 10		A
ICD Code	ICD 10 WHO		A
ICD-O Version	ICD-O Versions 3.0, 3.1, 3.2		A
ICD-O Topography	ICD-O Topography code		A
ICD-O Morphology	ICD-O Morphology code according to version		A
ICD-O Behaviour	benign, borderline, in situ, malignant, unknown		A
Associated in situ tumour	yes, no, unknown		C
ICD-O Histological grade	1-4 Grade I-IV for well differentiated to anaplastic, 5-8 for immunophenotype of leukaemias and lymphomas e.g. T-cell, B-cell, 9 for unknown		A
Laterality	the side of a paired organ or side of the body on which the reportable cancer originated. e.g. right, left, bilateral		A
ICCC-3 Main Group			A
ICCC-3 Code			A
ICCC-3 extended code			A
Tumor stage group, Stage description			B
Staging TNM/pTNM/cTNM			B
WHO(CNS) grading system	Grade I, II, III, IV, unknown		B
Metastases at diagnosis indicator	yes, no, unknown		B
Metastasis location (topography)	According to UICC TNM Staging e.g. Pulmonary PUL, osseous OSS, hepatic HEP		B

Treatment			
Basis of treatment decision	Tumorboard, other, unknown		B
Date of treatment decision	day, month, year	year kept	C
(First) treatment complex goal(s)	curative, palliative, unknown		C
Treatment code	CHOP Code(s)		A
Therapy flags (radiotherapy, chemotherapy, surgery, transplantation)			E
Treatment start date	day, month, year	only month and year kept	A
Treatment end date	Final end date for all therapies (day, month, year)	only month and year kept	B
Treatment institution/clinic		X	A
Study participation (available only for requests from SPOG clinics)			
Study patient	0= missing, 1=SP: study patient according to protocol, 2=NA: non-study patient according to protocol 3=NO: non-study patient not according to protocol 9=unknown		A
Type of study	e.g. clinical, research project, biological		A
Study protocol	Name of study protocol		A
Study regimen			B
Protocol modified			B
Remission status and follow up			
Remission or follow up status	e. g. complete remission, partial remission, stable disease, relapse		B
Remission status date	day, month, year	only month and year kept	B
Complete remission date	day, month, year	only month and year kept	B
Type of complete remission	1-morphological remission, 2-MRD (minimal residual disease)		D
The result of the complete remission assessment	e.g. positive, slow early responder, negative		D
Predispositions, prior diseases & comorbidities			
Inherited predispositions	Patient's inherited medical conditions. E.g. familial ovarian cancer, hereditary breast cancer, Li-Fraumeni syndrome, Hyperplastic polyposis syndrome and others		B
Type of medical condition	1) Predisposition (<i>condition present at birth that promotes the development of cancer</i>), 2) Prior disease (<i>Non-hereditary disease which promotes the development of cancer or is relevant for treatment decisions or possible late effects</i>) 3) Comorbidity (<i>diseases that are present at the time of the cancer diagnosis and that affect the treatment and/or the survival of the patient</i>)		F
Medical condition ICD version and code	ICD-10 WHO		B
Late effects			
Late effect (ICD version and code)	Late effects of cancer treatment can manifest themselves immediately (e.g. after surgery on the central nervous system) or be central nervous system) or may only be diagnosed after a certain period of time		B
Late effect date of diagnosis	day, month, year	only month and year kept	B

Course of disease			
Type of event	e.g progression, transformation, new distant metastasis, relapse, unknown		B
Date of event	date (dd.mm.yyyy)	only month and year kept	A
Relapce (ICD code, date, comment)			C
ICD-O Morphology pre-transformation and ICD-O Morphology post-transformation	ICD-O		C
Topography of post-diagnosis metastases	According to UICC TNM Staging e.g. Pulmonary PUL, osseous OSS, hepatic HEP		C

Legend:*

A	<i>generally available</i>
B	<i>inconsistent availability before 2020</i>
C	<i>only available from 2020 onward</i>
D	<i>only available for certain diseases</i>
E	<i>must be derived from available variables</i>
F	<i>inconsistent availability</i>