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

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

NATIONAL CANCER DATA DICTIONARY

V 1.1

Part C

Shortlist of reportable Clinical Data

BASIC VARIABLES

and

SUPPLEMENTARY VARIABLES

for

for Adults, Adolescents, and Children

15.10.2019

Abbreviations

AIDS	Acquired immunodeficiency syndrome
CHOP	Swiss Classification for Treatment Procedures
COG	Children's Oncology Group
DSSplus	Durie-Salmon Plus staging system
EBV	Epstein Barr virus
FIGO	International Federation of Gynecology and Obstetrics
hCG	Human chorionic gonadotropin
HPV	Human papillomavirus
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
NACR	National Agency for Cancer Registration
PRETEXT	PRE-Treatment EXTent of tumor
PSA	Prostate Specific Antigen
R-ISS	Revised International Staging System
SIOP	International Society of Pediatric Oncology
SIOPEL	International Childhood Liver Tumor Strategy Group (Société Internationale d'Oncologie Pédiatrique – Epithelial Liver Tumor Study Group)
TNM	Classification of Malignant Tumours
UICC	Union for International Cancer Control
WHO	World Health Organization

Changes made between versions 1.0 and 1.1 are indicated by a bar at the left-hand side of the text.

The following is based on Table 1 in “Erläuterungen zur Verordnung über die Registrierung von Krebserkrankungen (KRV)”, «Rapport explicatif OEMO», or «Commenti ORMT». Only clinical parameters are listed, patient data is excluded.

Categories	Variables (number – name)
Diagnostic data (all ages)	
Disease type: tumour properties	2.10 - Rank of diagnosis 3.1 - ICD version 3.2 - ICD-O version 3.3 - ICD code 3.4 - ICD-O Topography 3.5 - ICD-O Morphology 3.6.1 - ICD-O Behaviour 3.6.2 - Associated in situ tumour 3.7 - ICD-O Histological grade 3.8 - Laterality 3.9.1 - ICCC-3 main group 3.9.2 - ICCC-3 code* 3.9.3 - ICCC-3 extended code*

Disease extent at time of diagnosis; Disease stage	TNM stage: 4.1 - UICC TNM version 4.2 - y-Prefix of cTNM 4.3 - cT 4.4 - cN 4.5 - cM 4.6 - a-Prefix of pTNM 4.7 - y -Prefix of pTNM 4.8 - pT 4.9 - m-Suffix of pT 4.10 - pN 4.11 - Number of involved regional lymph nodes 4.12 - Number of examined regional lymph nodes 4.13 - pM 4.14 - Lymphatic invasion 4.15 - Venous invasion 4.16 - Perineural invasion 4.17 - TNM stage group Other staging systems: 4.18 - Ann Arbor staging 4.19 - COG staging 4.20 - COG ALL staging

Disease extent at time of diagnosis; Disease stage (continued)	4.21 - FIGO staging 4.22 - INRGSS staging 4.23 - IRSS staging 4.24 - Lugano staging 4.25 - PRETEXT staging 4.26 - Rai staging 4.27 - Binet staging 4.28 - Rhabdomyosarcoma site staging 4.29 - ISS staging 4.30 - DSSplus 4.31 - SIOP staging 4.32 - St. Jude / Murphy staging 4.33.1 - Toronto Tier II staging 4.33.2 - Toronto Tier II (manual) staging Tumour grading systems: 4.34 - Creasman grading system 4.35 - Elston/Ellis grading system 4.36 - SalzerKuntschik grading system 4.37 - Shimada grading system 4.38 - WHO(CNS) grading system Other: 4.39 - Clinical tumour size 4.40 - Pathological tumour size 4.41 - Metastases at diagnosis indicator 4.42 - Topography of metastases at diagnosis 6.1 - Residual invasive tumour 6.2 - Residual in-situ tumour 6.3 - Resection margin invasive tumour 6.4 - Resection margin in-situ tumour 6.5 - Sentinel lymph node assessment 6.6 - Number of examined sentinel lymph nodes 6.7 - Number of positive sentinel lymph nodes

Tumour-specific prognostic factors	Breast cancer: 5.1.1 - Oestrogen receptor status 5.1.2 - Progesterone receptor status 5.1.3 - Her2 receptor status 5.1.4 - Tumour proliferation labelling Prostate cancer: 5.2.1 - Pretreatment Prostate Specific Antigen (PSA) 5.2.2 - Gleason biopsy most common grade* 5.2.3 - Gleason biopsy second most common or highest grade* 5.2.4 - Gleason excision most common grade* 5.2.5 - Gleason excision second most common or highest grade* 5.2.6 - Gleason score 5.2.7 - WHO grade group Melanoma: 5.3.1 - Breslow thickness Colorectal cancer: 5.4.1 - Circumferential resection margins 5.4.2 - Microsatellite instability Testicular cancer: 5.5.1 - α-fetoprotein 5.5.2 - hCG 5.5.3 - LDH 5.5.4 - Serum tumour markers Head/Neck cancer: 5.6.1 - HPV/p16 5.6.2 - EBV
Basis of diagnosis	2.7 - Most valid basis of diagnosis 2.8 - Diagnostic method(s) used 2.9 - Diagnostic institution(s)*
Method of first detection	2.6 - Method of first detection
Date of informing the patient	2.1 - Date of informing the patient*
Metachronous metastases and recurrences	8.1 - Type of event(s) 8.2 - Date of event(s) 8.3 - Event ICD-O version 8.4 - Morphology term before change of main diagnosis* 8.5 - Morphology term after Transformation 8.6 - Topography(s) of post-diagnosis metastases

First treatment complex data (all ages)	
Type of treatment (for each treatment as part of the first treatment complex)	7.4 - First treatment complex CHOP code(s)
First treatment complex goal (for each treatment as part of the first treatment complex)	7.3 - First treatment complex goal(s)
Basis of first treatment complex decision (for the entire first treatment complex)	7.1 - Basis of first treatment complex decision 7.2 - Date of first treatment complex decision
First treatment complex start date (for each treatment as part of the first treatment complex)	7.5 - First treatment complex start date(s)

Supplementary data in Adults: Predispositions and Comorbidities Restricted to malignant colorectal, breast, and prostate cancer	
Inherited Predisposition(s)	Variable 9.1 with the following categories: - Familial ovarian cancer - Familial prostate cancer - Hereditary breast and ovarian cancer syndrome (HBOC) - Hereditary breast cancer - Li-Fraumeni syndrome - Nijmegen breakage syndrome - Saethre-Chotzen syndrome - Familial adenomatous polyposis - Juvenile gastrointestinal polyposis - Peutz-Jeghers syndrome - Hyperplastic polyposis syndrome - Hereditary mixed polyposis syndrome - Familial or hereditary nonpolyposis colorectal cancer (HNPCC) - McCune-Albright syndrome - Bannayan-Riley-Ruvalcaba syndrome - Cowden syndrome - Bloom syndrome

Comorbidities	10.1 - Diabetes mellitus 10.2 - Liver Disease 10.3 – HIV/AIDS 10.4 - Moderate to Severe Chronic Kidney Disease 10.5 - Congestive Heart Failure 10.6 - Myocardial infarction 10.7 - Chronic Pulmonary Disease 10.8 - Peripheral Vascular Disease 10.9 - Cerebrovascular Accident or Transient Ischemic Attack 10.10 - Dementia 10.11 - Hemiplegia / Paraplegia 10.12 - Connective Tissue Disease - Rheumatic disease 10.13 - Peptic Ulcer Disease 10.14 - Charlson Index

Supplementary data in Children and Adolescents: Medical Conditions	
Predispositions, prior diseases & comorbidities	9.1 – Inherited predispositions (same as for adults) * 9.2 - Type of medical condition (3 categories as shown left) * 9.3 – Medical condition ICD version* 9.4 – Medical condition ICD code* 9.5 - Medical condition OMIM® code*
Late effects	9.6 – Late effect date of diagnosis* 9.7 – Late effect ICD version* 9.8 – Late effect ICD code*
Diagnosis (Additional prognostic factors collected for malignancies in children and adolescents only)	
Tumour specific prognostic factors (Molecular genetics markers, methylation status and/or karyotype of the tumour or malignant cells)	Childhood and adolescent cancers 5.7.1 – Molecular or cytogenetic marker(s) tested* 5.7.2 – Molecular or cytogenetic marker(s) test result*
Further treatments (All additional treatments in children and adolescents will be collected as for the first treatment complex in adults)	
Basis of treatment decision	7.1 - Basis of treatment decision* 7.2 - Date of treatment decision*
Goal of treatment	7.3 -Treatment goal*

Type of treatment	7.4 –CHOP treatment code(s) *
Treatment start date	7.5 –Start date of treatment*
Treatment institution	7.6 -Treatment institution*
Other standard chemotherapy or systemic therapy (collected for all therapies not following a study protocol)	11.1 - Standard drug combinations (e.g. VIDE BEACOPP, R-CVP) * 11.2 – ATC Code(s) (for drugs or systemic therapy given outside standard drug combinations) *
Treatment end dates (collected for the first treatment complex and the end of all treatments for this case)	11.3 -First treatment complex end date* 11.4-Treatment end date*
Treatment details	
Study participation (enrolled as a study patient in a clinical trial or register, treated according to protocol, or not treated according to protocol)	12.1 – Study patient*
Type of study	12.2 – Type of study*
Name of study protocol (including regimen/arm)	12.3 – Protocol* 12.4 –Regimen* 12.5 -Protocol modified*
Date patient left study (If patient left study early)	12.6 –Date patient left study*
Remission status and follow-up	
Date and remission status at time of assessment	13.1 –Date of remission status or clinical follow-up* 13.2 –Remission status*
Disease specific complete remission status (Complete remission or MRD recorded for leukaemia, lymphoma, multiple myeloma only)	14.1 –Date of complete remission assessment* 14.2 -Type of complete remission* 14.3 –Result*

Note: Variables labelled with a star (*) will not be submitted to the NACR.

END