NSW Clinical Cancer Registry (2008-2012) data dictionary

Item	Variable	Description/notes	Data values/Data format
Demographic data			
1.	Sex	The sex of the person. Sex is the biological distinction between male and female. Where there is an inconsistency between anatomical and chromosomal characteristics, sex is based on anatomical characteristics.	1 – Male 2 – Female 3 – Indeterminate 9 – Not stated/inadequately described
2.	Date of birth	The date of birth of the person.	Date - DD/MM/YYYY
3.	Country of birth	The country in which the person was born. The data domain for this data field is that of the Standard Australian Classification of Countries (SACC) 1st edition, issued by the Australian Bureau of Statistics.	Numeric - NNNN
4.	Aboriginal and Torres Strait Islander status	Aboriginal and Torres Strait Islander status is a measure of whether a person identifies as being of Aboriginal or Torres Strait Islander origin.	1 – Aboriginal 2 – Torres Strait Islander 3 – Both 4 – Neither 8 – Declined to respond 9 – Not stated/inadequately described
5.	Age at diagnosis	Derived field from date of birth and date of diagnosis.	Numeric - NNN
6.	Postcode	The postcode of the physical location where the patient usually resides.	Numeric - NNNN
7.	State	The state of the physical location where the patient usually resides.	Alphanumeric
Cancer diagnosis data			
8.	Date of diagnosis	The date when the cancer was first diagnosed (whether at its primary site or as a metastasis). The date of diagnosis is the pathology report if available, otherwise the date of first consultation, admission to facility, or date of death if diagnosis occurred at autopsy.	Date - DD/MM/YYYY
9.	Cancer site code (4 digit)	The primary site is the site of origin of the tumour, as opposed to the secondary or metastatic sites. It is described by reporting the anatomical position (topography) of the tumour.	Alphanumeric - CNN.N
10.	Cancer site version	International Statistical Classification of Diseases and Related Health Problems, Australian Modification (ICD-10-AM).	ICD10V2 - ICD10V8

Item	Variable	Description/notes	Data values/Data format
11.	Morphology code (5 digit)	The morphology of a cancer refers to the histological classification of the cancer tissue (histopathological type) and a description of the course of development that a tumour is likely to take: benign or malignant (behaviour). The designation is based on a microscopic diagnosis of morphology by the pathologist (Esteban, Whelan, Laudico and Parkin 1995). The 5th digit represents behaviour.	Alphanumeric - MNNNN/N Behaviour values: 0 – benign 1 – uncertain whether benign or malignant 2 – insitu 3 – malignant, primary site 6 – malignant, metastatic site 9 – Malignant, uncertain whether primary or metastatic site
12.	Morphology code version	International Statistical Classification of Diseases and Related Health Problems, Australian Modification (ICD-10-AM). This corresponds directly to the International Classification of Diseases for Oncology (ICD-O).	ICD10V2 - ICD10V8
13.	Best basis of diagnosis	The highest level of evidence for diagnosis. The best basis states the most conclusive method of diagnosis for the primary cancer. The most conclusive method of diagnosis is histopathological, followed by cytological, and then other methods such as clinical, biochemical, imaging or autopsy.	1 – Histopathology 2 – Cytology 3 – Other
14.	Laterality	Laterality describes which side of a paired organ is the origin of the primary cancer. Each side of a paired organ is considered separately and described as lateral when occurring unless a physician determines that it is bilateral. 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).	1 – Left 2 – Right 3 – Not applicable 5 – Inconsistent 9 – Unknown
15.	Histopathological grade	The histopathological grade, differentiation or phenotype describes how little the tumour resembles the normal tissue from which it arose.	1 – Grade 1, Well differentiated 2 – Grade 2, Moderately differentiated, moderately well differentiated 3 – Grade 3, Poorly differentiated 4 – Grade 4, Undifferentiated, anaplastic 5 – T-cell 6 – B-cell, Pre-B, B-precursor lymphoma and leukaemia 7 – Null-cell, Non T- non B lymphoma and leukaemia 8 – NK, Natural killer cell lymphoma and leukaemia 9 – Grade/differentiation unknown, cell type not determined, not stated/not applicable

Item	Variable	Description/notes	Data values/Data format
16.	Degree of spread	A measure of the degree of spread or extent of disease at the time of diagnosis.	1 – Localised to the tissue of origin 2 – Invasion of adjacent tissue or organs 3 – Regional lymph nodes 4 – Distant metastases 5 – Not applicable 9 – Not known
Staging data			
17.	T stage	T stage is the coding system used to identify the presence of the primary tumour. It reflects the tumour size and extent of the primary cancer at the time of diagnosis. It is a part of the UICC TNM cancer staging system.	Alphanumeric - AAAA
18.	N stage	N stage is the coding system used to denote the absence or presence of regional lymph node metastases. It classifies the extent of regional lymph node metastases at the time of diagnosis of the primary cancer. It is a part of the UICC TNM cancer staging system.	Alphanumeric - AA
19.	M stage	M stage is the coding system used to record the absence or presence of distant metastases at the time of diagnosis of the primary cancer. It is part of the TNM cancer staging system.	Alphanumeric - AA
20.	TNM stage	TNM Staging is an internationally agreed staging classification system based on the anatomical site of the primary tumour and extent of spread. TNM staging applies to solid tumours excluding brain tumours.	1 to 31 – TNM stage 97 - Unstaged 98 - Not applicable 99 - Unknown
21.	TNM stage edition	TNM stage edition	1 – 7
22.	T stage basis	*Refer to TNM staging basis (25)*	
23.	N stage basis	*Refer to TNM staging basis (25)*	
24.	M stage basis	*Refer to TNM staging basis (25)*	
25.	TNM staging basis	This data element describes the timing and evidence for T, N and M stage values. Clinical stage is based on evidence obtained prior to treatment from physical examination, imaging, endoscopy, biopsy, surgical exploration or other relevant examinations. Pathological stage is based on histological evidence acquired before treatment, and is supplemented or modified by additional evidence acquired from surgery and from pathological examination. When more than one basis for staging is available, the highest stage in any one of the stages is used.	C - Clinical P - Pathological U - Unknown

Item	Variable	Description/notes	Data values/Data format
26.	Other staging systems	Other staging and classification systems	Various values
27.	Other staging schemes	Other staging and classification system schemes	2 - Durie and Salmon for multiple myeloma staging 3 - French American British (FAB) System for leukaemia 4 - Australian Clinico-Pathological Staging (ACPS) System 5 - Dukes for colorectal cancers 6 - Federation Internationale de Gynecolgie et d'Obstetrique (FIGO for gynaecological cancers) 8 - Small cell lung cancer 9 - Ann Arbor for Hodgkin and non-Hodgkins lymphoma 11 - Binet Staging Classification for chronic lymphocytic leukaemia 12 - Chronic myeloid leukaemia (CML) Staging System 14 - Rai Staging System for chronic lymphocytic leukaemia 17 - Masaoka for thymus cancer 18 - Barcelona for hepatocellular carcinoma (HCC) 19 - International Neuroblastoma Staging System 20 - St Jude Staging System for non-Hodgkins lymphoma 21 - National Wilms' Tumour Study group for renal tumours 22- Kadish Staging System for olfactory neuroblastoma 23- Modified Astler-Coller Classification for colorectal 24 - International Staging System (ISS) for myeloma 25 - IRSG Staging System for rhabdomyosarcoma 26 - COG-STS Pretreatment Staging System for rhabdomyosarcoma 99 - Unknown (not for primary collection)
28.	Other grading systems	Other grading systems	Various values
29.	Other grading schemes	Other grading schemes	1 - Breslow thickness for melanoma 2 - Gleason grade for prostate 3 - Clark's level for melanoma 4 - WHO for glioma 5 - Scarff-Bloom-Richardson for breast 6 - Nottingham for Breast 7 - Fuhrman for kidney 8 - Silverberg for ovarian 9 - FIGO for endometrial 10 - FNCLCC for soft tissue sarcoma 11 - Elston and Ellis modification for DCIS 12- WHO/ISUP grading system for Urothelial

Item	Variable	Description/notes	Data values/Data format
Treatment data			
30.	AMO registration number	The AMO Registration number of the doctor treating the patient.	Alphanumeric - AAANNNNNNN
31.	Treatment group	Treatment group	1 - Admitted 2 - Radiotherapy 3 - Oncology
32.	Treatment modality	The type of treatment for cancer given as initial treatment for the particular patient.	1 – Surgery 2 – Radiotherapy 3 – Medical Oncology and Haematology 4 – Admitted/Other 5 – Diagnostic 6 – End of Life Palliation
33.	Treatment start date	Treatment start date	Date - DD/MM/YYYY
34.	Treatment end date	Treatment end date End dates for systemic treatment may not be available for oral and hormonal therapies that may be taken for years.	Date - DD/MM/YYYY
35.	Radiotherapy type	The type of radiation therapy used in initial treatment of the cancer.	0 - No radiotherapy treatment given 1 – External beam radiation 2 – Brachytherapy (radioactive implants) 3 – Unsealed radioisotopes 4 – Intensity modulated radiation therapy (IMRT) 5 – Seed brachytherapy 6 – HDR brachytherapy (high dose rate) 7 – Orthovoltage 9 – Radiotherapy was administered but method was not stated 10 – Stereotactic radiotherapy
36.	Radiation dose	The received dose of radiation delivered at initial treatment measured in Gray (Gy).	Numeric - NNNN
37.	Radiation fractions	Number of radiotherapy fractions delivered in the initial course of radiation. The radiation fractions recorded should include any boost doses.	Numeric - NN
38.	Systemic therapy protocol	The standard chemotherapeutic protocol or agent used for the treatment of the primary cancer. The name of a standard treatment protocol consists of an abbreviated common name or names of anti-neoplastic agents included in the protocol. Systemic therapy includes the administration of chemotherapy agents, hormonal agents, biological response modifiers, bone marrow transplants, stem cell harvests, and surgical and/or radiation endocrine therapy.	Alphanumeric

Item	Variable	Description/notes	Data values/Data format
39.	Number of cycles of systemic therapy	The number of treatment cycles that an agent was administered in the course of treatment. The interval of a treatment cycle varies and an agent may be administered for several weeks or several years.	Numeric - NN
40.	Surgical procedure	The surgical procedure(s) for the initial management of the cancer. International Statistical Classification of Diseases and Related Health Problems, Australian Modification (ICD-10-AM).	Numeric - NNNNN-NN
41.	Local health district of facility	Local health district of facility	X630 Sydney Children's Hospitals Network X690 St Vincent's Health Network X700 Sydney LHD X710 South Western Sydney LHD X720 South Eastern Sydney LHD X730 Illawarra Shoalhaven LHD X740 Western Sydney LHD X750 Nepean Blue Mountains LHD X760 North Sydney LHD X770 Central Coast LHD X800 Hunter New England LHD X810 Northern NSW LHD X820 Mid North Coast LHD
Quality of care data			
42.	Date of referral	Date of referral to oncologist, haematologist or surgeon.	Date - DD/MM/YYYY
43.	Date of consultation	The date of the patient's first consultation with the cancer specialist (oncologist, haematologist or surgeon) for this course of treatment.	Date - DD/MM/YYYY
44.	Date of decision to treat	When the cancer specialist (oncologist, haematologist or surgeon) decides that treatment should commence (also known as "ready for care").	Date - DD/MM/YYYY
45.	Multidisciplinary consultation date	This refers to the date of the first consultation with a team of health professionals who work together to make multidisciplinary recommendations for treating clinicians regarding the diagnosis, treatment and care of the individual patients. An MDT meeting in this context is a face-to-face meeting (or via video/teleconference) held at a defined time and place for the express purpose of discussing cases and deciding treatment recommendations.	Date - DD/MM/YYYY
46.	Palliative care status	Palliative care status	1 – Yes 2 – No 3 – Not stated
47.	Date of referral to palliative care	Date the patient was referred to the palliative care physician or team during their course of treatment.	Date - DD/MM/YYYY

Item	Variable	Description/notes	Data values/Data format
48.	Performance status at diagnosis (ECOG)	The result of the appraisal of the individual's ability to manage activities of daily living, conducted at the time of diagnosis of cancer. Code set for performance status scale by USA Eastern Cooperative Oncology Group (ECOG). (Isselbacher et al, 1994)	0 – ECOG 0 Fully active, able to carry on all pre-disease performance without restriction 1 – ECOG 1 Restricted in physically strenuous activity but ambulatory, can perform light / sedentary work 2 – ECOG 2 Ambulatory and self caring, cannot work. Up and about > 50% of waking hours 3 – ECOG 3 Only limited self care, confined to bed or chair > 50% of waking hours 4 – ECOG 4 Completely disabled, cannot self care. Totally confined to bed or chair.
49.	Psycho social referral to	The health professional, support group or advisor to whom a patient is initially referred for psycho-social support or intervention.	0 – Not indicated 1 – Psychiatrist 2 – Psychologist 3 – Social worker 4 – Specialist nurse / nurse counsellor 5 – Cancer support group or volunteer support group 6 – Individual peer support 7 – Counsellor / bereavement counsellor 8 – Pastoral care / chaplain / clergy / spiritual advisor 9 – Community Service
50.	Date of death	The date of death of the person.	Date - DD/MM/YYYY
51.	Cause of death	The underlying cause of death as indicated on the death certificate.	Alphanumeric - CNN.N
52.	Cause of death version	International Statistical Classification of Diseases and Related Health Problems, Australian Modification (ICD-10-AM).	ICD10V2 - ICD10V8