Victorian Consensus Data Set

Generic (Core) Data Items

Version 1.2.1

2010

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This document may also be downloaded from the Cancer Council Victoria website at:
cancervic.org.au/about-our-research/victorian_cancer_registry/vcds-project/

Document version history

Version number	Description of change	Updated
1.0	Initial creation	12 July 2010
1.1	Revisions to front matter Data elements updated: • Primary site – option for using ICD-O-3 classification added	29 September 2010
1.2	Reformatting of layout	22 October 2010
1.2.1	Typographical errors corrected in data elements: Consent to discuss case at multidisciplinary meeting Systemic therapy – related toxicity	9 February 2011

Contents

About the Victorian Consensus Data Sets (VCDS)

Cancer care is complex, and consistency of meaning is vital to enhance information sharing among users of the data.

The VCDS are data set specifications that provide standard definitions for each of the 10 Victorian tumour streams.

These tumour streams were recommended by the Ministerial Taskforce for Cancer in July 2005 (http://www.health.vic.gov.au/cancer/docs/faqs-docs/faqstumourstreams.pdf) to support management of cancer patients and service improvement.

The aim of developing standard definitions is to allow the collection of consistent data in a range of IT systems. Among other benefits, it will expand the evidence base to enhance health planning and clinical care.

The 10 tumour streams are:

- Breast
- Central nervous system
- Colorectal
- Genitourinary
- Gynaecology
- Haematological malignancies
- Head and neck (including thyroid)
- Lung (including mesothelioma)
- Skin (malignant melanoma)
- Upper gastrointestinal (including pancreas, liver and other associated organs)

Each of the above tumour streams will have a specialist VCDS data set specification.

The data set specifications can be downloaded from the VCDS Project website at cancervic.org.au/about-our-research/victorian_cancer_registry/vcds-project/

How to use the VCDS

Please note: The specialist tumour stream VCDS must be used with the Generic VCDS, which is the core data set specification. The Generic VCDS contains data elements that are collected for each cancer patient, regardless of tumour stream.

The generic (or core) data elements are grouped in sections on, for example: Patient identification details, consultation and referral details, patient history, diagnosis, care planning, treatments, side effects, outcome, contact with patient, recurrence.

The specialist tumour stream VCDS contain supplementary data elements, which aim to capture the specialist treatment and care planning required for patients with cancers from the specific tumour stream.

Is the use of the VCDS mandatory?

The VCDS are not mandatory or minimum data sets. Databases or registries developed across any jurisdiction may be subsets or supersets of the data elements as defined in the VCDS (as determined by the intention of the database and resources available). However, to ensure consistency across data collections, the definitions for the data elements included should be those of the VCDS.

Development of the VCDS

Agreement is reached after wide ranging consultation on the items to be included and their definitions. Wherever possible, data elements are consistent with national standards (Australian Institute of Health & Welfare) and structured pathology reporting protocols for cancer (Royal College of Pathologists Australia). Please refer to the source documents provided in the reference section for each data element for more information.

VCDS funding bodies and steering committee

The VCDS Project is jointly funded by the Western and Central Melbourne Integrated Cancer Services (WCMICS) and the Cancer Council Victoria (CCV).

The governance committee overseeing the project is represented by the following organisations:

- Cancer Council Victoria (CCV)
- Metropolitan Integrated Cancer Services (ICS)
- Regional Integrated Cancer Services (ICS)
- Victorian Cooperative Oncology Group (VCOG)
- BioGrid
- Victorian Department of Health
- Consumer representatives

Accessing VCDS publications

The VCDS specification can be downloaded from the VCDS Project web page, at http://www.cancervic.org.au/about-our-research/victorian_cancer_registry/vcds-project/

Guide to the VCDS data element attributes (data standards)

The VCDS development is based, where possible, on using existing national health data standards. To read more about the national health metadata standards, please visit meteor.aihw.gov.au/content/index.phtml/itemId/276533

This guide provides an overview of the types of data attributes and their definitions for each of the VCDS data elements.

DATA ELEMENT NAME

Identifying and definitional attributes

Definition	A statement that expresses the essential nature of a data element and its differentiation from all other data elements.
Rationale	The reason for collecting this data element.

Representational attributes

Data type	The type of symbol or character, or other designation used to represent the data element, for example, Number.
Representation class	Describes whether the valid values for the data item take the form of a code set or free text. If the form is described as 'Code' the relevant code set or sets will be specified in the Data domain section.
Field size maximum	The maximum number of characters allowable to represent the data element.
Format	A generic example of what the data element should look like in the unit record. For example, dates should be represented in the format of DDMMYYYY where DD represents the day, MM represents the month, and YYYY represents the four-digit numeric for the year. The Data type indicates whether it is alphabetic or alphanumeric.
Data domain	The set of possible values for the data item. This may take the form of a code set, or a description of the possible values. Domain values are only specified where size of the code set is small enough to be reasonably reproduced in the document. In other instances the domain may be indicated by reference to a source document.
Guide for use	These are comments designed to assist in further defining aspects of the data domain.
Validation rules	These are included to assist in reducing input error. Where validation rules are known to exist, they have been included to assist with the programming.
Related data element data element	Data elements that have some direct relationship with the data element being described.

Additional information

References	Documents listed here have been used as references when designing the specified item. Also listed are names of the organisations that developed the source document or provided advice on the data item.

Contact details

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GENERIC (CORE) DATA ELEMENTS

PATIENT IDENTIFICATION

Family name

Identifying and definitional attributes

Definition	That part of a name a person usually has in common with some other members of his/her family, as distinguished from his/her given names, as represented by text.
Justification	Collected for administrative purposes and individual identification.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	40
Format	X[X(39]
Guide for use	Family name should be recorded in the format preferred by the person. The format should be the same as that written by the person on a (pre) registration form or in the same format as that printed on an identification card, such as Medicare card, to ensure consistent collection of name data. Family name should be recorded in the format preferred by the person. For further details of usage and data collection refer to AIHW METeOR data element Person (name) – family name.
Validation rules	
Related data element	Given name(s)

Administrative information

References	AIHW – Family name METeOR ID: 286953

Given name(s)

Identifying and definitional attributes

Definition	The person's identifying name within the family group or by which the person is socially identified, as represented by text.
Justification	Collected for administrative purposes and individual identification.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	40
Format	X[X(39]
Guide for use	The agency or establishment should record the person's full given name(s) on their information systems. A person may have more than one given name. All given names should be recorded. This field should include the person's 'first' and 'middle' names in that order. Punctuation should follow the guide for use for Family name. If the person's given name is not known, but the first letter (initial) of the given name is known, record the first letter in the 'Given name' field. Do not record a full stop following the initial. Some people do not have a family name and a given name; they have only one name by which they are known. If the person has only one name, record it in the 'Family name' field and leave the 'Given name' blank. For details of usage and data collection refer to AIHW METeOR data element Person (name) – given name.
Validation rules	
Related data element	Family name

Administrative information

References	AIHW – Given name(s) METeOR ID: 287035

Person identifier

Identifying and definitional attributes

Definition	Person identifier unique within an establishment or agency (such as unit record or laboratory number).
Justification	Collected for administrative purposes and individual identification.

Representational attributes

Data type	String
Representational class	Identifier
Field size maximum	20
Format	XXXXXX[X(14)]
Guide for use	Individual agencies, establishments or collection authorities may use their own alphabetic, numeric or alphanumeric coding systems.
Validation rules	
Related data element	Establishment name

Administrative information

References	AIHW – Person identifier METeOR ID: 290046

Date of birth

Identifying and definitional attributes

Definition	The date of birth of the person.
Justification	Collected for administrative purposes, to assist in individual identification and for derivation of age in demographic analyses.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	For details of usage and data collection refer to AIHW METeOR data element Person – date of birth.
Validation rules	• <= All other dates
Related data element	

Administrative information

References	AIHW – Date of birth METeOR ID: 287007

Sex

Identifying and definitional attributes

Definition	The biological distinction between male and female.
Justification	Collected to determine sex specific treatment. It is also a core element in a wide range of social, labour and demographic statistics.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Male
2	Female
3	Intersex or indeterminate
9	Not stated/inadequately described

Guide for use	Diagnosis and procedure codes should be checked against the national ICD-10-AM sex edits, unless the person is undergoing, or has undergone a sex change or has a genetic condition resulting in a conflict between sex and ICD-10-AM code. For further details of usage and data collection refer to AIHW METeOR data element Person – sex.
Validation rules	
Related data element	

Administrative information

References	AIHW – Sex METeOR ID: 287316

Address line

Identifying and definitional attributes

Definition	A composite of one or more standard address components that describes a low level of geographical/physical description of a location, as represented by text. Used in conjunction with the other high-level address components i.e. Suburb/town/locality, Postcode—Australian, Australian state/territory, and Country, forms a complete geographical/physical address of a person.
Justification	Collected for administrative purposes, individual identification, referral patterns and allows for analysis of cancer clusters. A high-level address component is defined as a broad geographical area that is capable of containing more than one specific physical location. Used in conjunction with other address components i.e. Suburb/town/locality, Postcode – Australian and Australian state/territory forms a complete geographical/physical address of a person.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	180
Format	[X(180)]
Guide for use	When addressing an Australian location, standard address data elements that may be concatenated in the address line. One complete identification/description of a location/site of an address can comprise one or more than one instance of address line. For further details of usage and data collection refer to AIHW METeOR data element Person (address) – address line.
Validation rules	
Related data element	Address line – suburb/town/locality

Administrative information

References	AIHW – Address line (person) METeOR ID: 286620

Address line – suburb/town/locality

Identifying and definitional attributes

Definition	The full name of the locality contained within the specific address of a person.
Justification	Collected for administrative purposes, individual identification, referral patterns and allows for analysis of cancer clusters. Used in conjunction with other address components i.e. number/street, postcode and Australian state/territory, forms a complete geographical/physical address of a person.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	50
Format	[A(50)]
Guide for use	For other details of usage and data collection refer to AIHW METeOR data element Person (address) – suburb/town/locality.
Validation rules	
Related data element	Address line – number/street

Administrative information

References	AIHW – Suburb/town/locality (person) METeOR ID: 287326

Postcode

Identifying and definitional attributes

Definition	The numeric descriptor for a postal delivery area, aligned with locality, suburb or place for the address of a person.
Justification	Collected for administrative purposes, individual identification, referral patterns and allows for analysis of cancer clusters. Used in conjunction with other address components i.e. number/street, suburb/town/locality, Australian state/territory, and country, forms a complete geographical/physical address of a person.

Representational attributes

Data type	Number	
Representational class	Code	
Field size maximum	4	
Format	{NNNN}	
Data domain	**Code**	**Description**
		Valid Australian postcode
Guide for use	Leave the field blank for international, no fixed address or unknown address. For other details of usage and data collection refer to AIHW METeOR data element Postcode – Australian (person).	
Validation rules		
Related data element	Address line – suburb/town/locality	

Administrative information

References	AIHW – Postcode Australian (person) METeOR ID: 287224

Country of birth

Identifying and definitional attributes

Definition	The country in which the person was born, as represented by a code.
Justification	Country of birth is important in the study of access to services by different population sub-groups. Country of birth is the most easily collected and consistently reported of a range of possible data items that may indicate cultural or language diversity.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	4
Format	NNNN
Data domain	**Code** **Description** Valid Country Code: Standard Australian Classification of Countries, current edition
Guide for use	The Standard Australian Classification of Countries 2008 (SACC) is a four-digit, three-level hierarchical structure specifying major group, minor group and country. A country, even if it comprises other discrete political entities such as states, is treated as a single unit for all data domain purposes. Parts of a political entity are not included in different groups. Thus, Hawaii is included in Northern America (as part of the identified country United States of America), despite being geographically close to and having similar social and cultural characteristics as the units classified to Polynesia.
Validation rules	
Related data element	

Administrative information

References	AIHW – Country of birth METeOR ID: 370943

Consultant name

Identifying and definitional attributes

Definition	The name of the consulting specialist doctor.
Justification	Collected for administrative purposes and service provider identification.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	40
Format	X[X(39]
Guide for use	Generally, the complete name should be used to avoid any ambiguity in identification. More than one name can be recorded for an organisation. That is, this field is a multiple occurring field. This could be a specialist physician such as the oncologist or the surgeon. The format of data collection is less important than consistent use of conventions in the recording of the consultant's name.
Validation rules	
Related data element	

Administrative information

References

Referral receipt date

Identifying and definitional attributes

Definition	The date on which an agency receives a client referral from another party.
Justification	Many providers collect the date of referral because it has administrative importance. It can be used in the calculation of response times and for performance indicators that measure the provision of service. Can also be used to measure work-load (i.e. the number of referrals coming to a particular agency). This may be measured for particular clients or particular types of services.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	Can be collected at initial referral of a client to an agency or at each referral, although this should be done consistently within a collection. Individual collections will also need to determine what constitutes a referral for their purposes (e.g. Is it only formal referrals that are considered, or are self-referral counted as a referral also etc).
Validation rules	• <= Today's date • >= DOB, < Date of Death, Can be multiple events
Related data element	

Administrative information

References	AIHW – Referral receipt date METeOR ID: 270005

Establishment name

Identifying and definitional attributes

Definition	Name of an establishment, where a patient is being treated.
Justification	Collected for administrative purposes and service provider identification.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	40
Format	X[X(39]
Guide for use	The format of data collection is less important than consistent use of conventions in the recording of the institution's name.
Validation rules	
Related data element	

Administrative information

References

Establishment number

Identifying and definitional attributes

Definition	An identifier for an establishment, unique within the state or territory.
Justification	Collected for administrative purposes and service provider identification.

Representational attributes

Data type	Number
Representational class	Identifier
Field size maximum	5
Format	NNNNN
Guide for use	The identifier should be a unique code for the health care establishment used in that state/territory.
Validation rules	
Related data element	Establishment name

Administrative information

References	AIHW – Establishment number METeOR ID: 269975

Medicare number

Identifying and definitional attributes

Definition	Person identifier, allocated by the Health Insurance Commission to eligible persons under the Medicare scheme, that appears on a Medicare card.
Justification	Collected for administrative purposes and Medicare utilisation statistics.

Representational attributes

Data type	Number
Representational class	Identifier
Field size maximum	11
Format	[N(11)]
Guide for use	Full Medicare number for an individual (i.e. Family number plus individual reference number). The data should not be used by private sector organisations for any other purpose unless specifically authorised by law. For example, data linkage should not be carried out unless specifically authorised by law. For other details of usage and data collection refer to AIHW METeOR data element AIHW – Medicare card number
Validation rules	• May be null but where included, must be a minimum 10 digits.
Related data element	

Administrative information

References	AIHW – Medicare card number METeOR ID: 270101

Public/private patient

Identifying and definitional attributes

Definition	Description as patient's billing status as public or private patient.
Justification	Collected for administrative purposes and service utilisation statistics.

Representational attributes

Data type	Number	
Representational class	Code	
Field size maximum	2	
Format	N	
Data domain	**Code**	**Description**
	1	Public patient
	2	Private patient
	3	Variable
	9	Not stated/inadequately described
Guide for use	The status of the patient as public or private may vary over period of treatment in which case the status can be recorded as variable.	
Validation rules		
Related data element data element	Establishment name	

Administrative information

References	See also Episode of admitted patient care—patient election status, code N METeOR ID: 326619

General practitioner name

Identifying and definitional attributes

Definition	The name of the referring doctor, a General Practitioner (GP).
Justification	Collected for administrative purposes and service provider identification.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	40
Format	[X(40)]
Guide for use	Generally, the complete name should be used to avoid any ambiguity in identification. The format of data collection is less important than consistent use of conventions in the recording of the doctor's name.
Validation rules	
Related data element	General practitioner contact information

Administrative information

References

General practitioner contact information

Identifying and definitional attributes

Definition	A composite of one or more standard address components.
Justification	Collected for administrative purposes and service provider identification.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	200
Format	[X(200)]
Guide for use	One complete identification/description of a location/site of an address can comprise one or more than one instance of address line. Instances of address lines are commonly identified in electronic information systems as Address-line 1, Address-line 2, etc. The format of data collection is less important than consistent use of conventions in the recording of address data. Hence, address may be collected in an unstructured manner but should ideally be stored in a structured format. Where Address line is collected as a stand-alone item, software may be used to parse the Address line details to separate the sub-components. Multiple Address lines may be recorded as required. Include the full address of the GP including practice name, street address, city, postcode, phone numbers, fax numbers and email addressess if required.
Validation rules	
Related data element	

Administrative information

References	AIHW – Address line (service provider organisation) METeOR ID: 290315

PATIENT PSYCHOSOCIAL NEEDS

Indigenous status

Identifying and definitional attributes

Definition	Indigenous status is a measure of whether a person identifies as being of Aboriginal or Torres Strait Islander origin. This is in accord with the first two of three components of the Commonwealth definition.
Justification	Collected to provide information about people who identify as being of Aboriginal or Torres Strait Islander origin, in order to plan, promote and deliver essential services, to monitor changes in wellbeing and to account for government expenditure in this area.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Aboriginal but not Torres Strait Islander origin
2	Torres Strait Islander but not Aboriginal origin
3	Both Aboriginal and Torres Strait Islander origin
4	Neither Aboriginal nor Torres Strait Islander origin
9	Not stated/inadequately described

Guide for use	For details of usage and data collection refer to AIHW METeOR data element Person – Indigenous status.
Validation rules	
Related data element	

Administrative information

References	AIHW – Indigenous status METeOR ID: 291036

Interpreter required

Identifying and definitional attributes

Definition	Whether an interpreting service is required by or for the person.
Justification	Collected for administrative purposes and for planning for provision of clients' needs.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Yes
2	No
9	Not stated/inadequately described

Guide for use	For details of usage and data collection refer to AIHW METeOR data element Person – Interpreter services required. Interpreter services include those for verbal language, non-verbal language and languages other than English
Validation rules	
Related data element	

Administrative information

References	AIHW – Interpreter service required METeOR ID: 304294

Marital status

Identifying and definitional attributes

Definition	A person's current relationship status in terms of a couple relationship or, for those not in a couple relationship, the existence of a current or previous registered marriage.
Justification	Collected to record the type of living arrangement for a person in order to develop a sense of the level of support, both physically and emotionally, to which a person may have access.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Never married
2	Widowed
3	Divorced
4	Separated
5	Married (registered and de facto)
9	Not stated/inadequately described

Guide for use

There are two concepts of marital status: registered marital status – defined as whether a person has, or has had, a registered marriage; social marital status – based on a person's living arrangement (including de facto marriages), as reported by the person.

It is recommended that the social marital status be collected when information on social support/home arrangements is sought, whereas the registered marital status concept need only be collected where it is specifically required for the purposes of the collection.

For other details of usage and data collection refer to AIHW METeOR data element Person – marital status.

Validation rules

Related data element

Administrative information

References

AIHW – Marital status
METeOR ID: 291045

Living arrangements

Identifying and definitional attributes

Definition	Whether a person usually resides alone or with others.
Justification	Collected to record the type of living arrangement for a person in order to develop a sense of the level of support, both physically and emotionally, to which a person may have access.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Lives alone
2	Lives with family not otherwise specified
3	Lives with others
4	Lives with partner
5	Lives with partner and children
6	Lives with children
9	Not stated/inadequately described

Guide for use	VCDS data domain is expanded from the METeOR data element which only describes living alone, living with family or living with others.
Validation rules	
Related data element	

Administrative information

References

AIHW – Living arrangement
METeOR ID: 270385
National Health and Medical Research Council, Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, 2003 http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm (viewed 28/1/2010)

Number and age of living children

Identifying and definitional attributes

Definition	Number and age of all living children.
Justification	Collected to record psychosocial factors affecting the patient to evaluate requirements for other ancillary services.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	50
Format	[X(50)]
Guide for use	Number and age in completed years, of all living children. For children less than one year of age, the age in completed months or weeks. The format of data collection is less important than consistent use of conventions. For example: 3 children aged 10, 8 and 6 years could be 3 (10, 8, 6). Ages of children less than one year of age, can be described as N/12 for months or N/52 for weeks (6 months as 6/12 and 6 weeks as 6/52).
Validation rules	
Related data element	

Administrative information

References	National Health and Medical Research Council, Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, 2003 http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm (viewed 28/1/2010)

Number of dependents

Identifying and definitional attributes

Definition	Number of children under the age of 21 dependent on the patient.
Justification	Collected to record psychosocial factors affecting the patient to evaluate requirements for other ancillary services.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	2
Format	N[N]
Guide for use	Record the number of children under the age of 21 financially supported by the person.
Validation rules	
Related data element	

Administrative information

References	National Health and Medical Research Council, Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, 2003 http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm (viewed 28/1/2010)

Age of youngest dependent

Identifying and definitional attributes

Definition	Age of youngest dependent supported by the person.
Justification	Collected to record psychosocial factors affecting the patient to evaluate requirements for other ancillary services.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	3
Format	{N[NN]}
Guide for use	The age of dependents greater than one year can be recorded in completed years. If age is less than one, record as zero. If age (or date of birth) is unknown or not stated, and cannot be estimated, use Code 999.
Validation rules	
Related data element	

Administrative information

References	National Health and Medical Research Council, Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, 2003 http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm (viewed 28/1/2010)

Family support

Identifying and definitional attributes

Definition	Whether a person has support of family to assist them during treatment.
Justification	Collected to record the type of living arrangement for a person in order to develop a sense of the level of support, both physically and emotionally, to which a person may have access.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Well supported
2	Supported but requires some assistance
3	Minimal support and requires assistance
4	No support and requires complete assistance
9	Not stated/inadequately described

Guide for use	Record the person's level of support as best described by one of the following categories.
Validation rules	
Related data element	

Administrative information

References	National Health and Medical Research Council, Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, 2003 http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm (viewed 28/1/2010)

Employment status

Identifying and definitional attributes

Definition	Description of person's employment in paid workforce or main source of income.
Justification	Collected to record socioeconomic and psychosocial factors affecting the patient.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	2
Format	N[N]

Data domain

Code	Description
1	Child not at school
2	Student
3	Paid employment
4	Employed but on leave without pay
5	Government benefit dependent
6	Dependent spouse/partner/family
7	Self-funded retiree/other
88	Other
99	Not stated/inadequately described

Guide for use

Record a description of the person's employment in paid workforce or main source of income.

Code 1 Child under school age

Code 2 Student at primary, secondary or tertiary institution without sufficient paid employment or source of income to be self-supporting.

Code 3 Use for those who have paid employment, including the self-employed. Includes those on paid leave such as sick leave or other paid leave.

Code 4 Use for those who are employed but are on leave without pay.

Code 5 Use for those with no paid employment whose main income is from government support such as the aged pension, disability allowances and unemployment.

Code 6 Use for those who are not students, have no paid employment or government support and are financially supported by a spouse, partner or family member whose main income is not from government support such as the aged pension, disability allowances and unemployment.

Code 7 Use for those whose main income is self-funded (such as superannuation, insurance benefits or other), have no paid employment and whose main income is not from government support such as the aged pension, disability allowances and unemployment.

Validation rules

Related data element: Investigation date

Administrative information

References

National Health and Medical Research Council, Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, 2003 http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm (viewed 28/1/2010)

Psychosocial issues

Identifying and definitional attributes

Definition	Description of self-reported psychosocial issues affecting the patient.
Justification	Collected to record psychosocial factors affecting the patient to evaluate requirements for other ancillary services.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	History of psychiatric problems (including depression, anxiety)
2	Personal history of stressful life events
3	History of drug or alcohol abuse
4	Financial difficulties/economic adversity
5	Cultural considerations
8	Other
9	Not stated/inadequately described

Guide for use	Record a description of self-reported psychosocial issues affecting the patient.
Validation rules	
Related data element	

Administrative information

References	National Health and Medical Research Council, Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, 2003 http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm (viewed 28/1/2010)

PATIENT HISTORY

Performance status score (ECOG)

Identifying and definitional attributes

Definition	An assessment of how a patient's disease affects their daily living abilities.
Justification	This data is collected for statistical analyses of cancer outcomes adjusted by performance status of the patient.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	Fully active, able to carry on all normal activity without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out light work
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours.
3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours.
4	Completely disabled. Can not carry on any self-care. Totally confined to bed or chair.
8	Not available at time of presentation
9	Not stated

Guide for use	Performance status should be recorded based on assessment by a clinician at the time of initial presentation. However, it is more commonly recorded after surgery and after the date of diagnosis but prior to systemic or radiotherapy. As it may also be recorded at follow up, so it is important to record the date of the assessment. For population studies, ECOG vaules prior to therapy will be of most value.
Validation rules	
Related data element	Investigation date

Administrative information

References	Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655, 1982. The ECOG Performance Status is in the public domain therefore available for public use.

Height

Identifying and definitional attributes

Definition	A person's height, measured in centimetres.
Justification	Collected for calculation of body surface area (BSA) for clinical purposes.

Representational attributes

Data type	Number	
Representational class	Total	
Field size maximum	4	
Format	NN[N].N	
Data domain	**Supplementary value**	**Description**
	999.9	Not measured
Guide for use	For other details of usage and data collection refer to AIHW METeOR data element Person – Height (measured), total centimetres.	
Validation rules		
Related data element		

Administrative information

References	AIHW – Height (measured) METeOR ID: 270361

Weight

Identifying and definitional attributes

Definition	A person's weight (body mass) in kilograms.
Justification	Collected for calculation of body surface area (BSA) for clinical purposes.

Representational attributes

Data type	Number	
Representational class	Total	
Field size maximum	4	
Format	N[NN].N	
Data domain	**Supplementary value**	**Description**
	999.9	Not measured
Guide for use	For details of usage and data collection refer to AIHW METeOR data element Person – Weight (measured), total kilograms	
Validation rules		
Related data element		

Administrative information

References	AIHW – Weight in kilograms (measured) METeOR ID: 270208

Tobacco smoking status

Identifying and definitional attributes

Definition	Description of the patient's tobacco smoking status.
Justification	Smoking has long been known as a health risk factor. Population studies indicate a relationship between smoking and increased mortality/morbidity.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Daily smoker
2	Weekly smoker
3	Irregular smoker
4	Ex-smoker
5	Never smoked
9	Not stated

Guide for use	Daily smoker is a person who smokes daily. Weekly smoker is a person who smokes at least weekly but not daily. rregular smoker is a person who smokes less than weekly. Ex-smoker is a person who does not smoke at all now, but has smoked at least 100 cigarettes or a similar amount of other tobacco products in his/her lifetime. Never smoked is a person who does not smoke now and has smoked fewer than 100 cigarettes or similar amount of other tobacco products in his/her lifetime.
Validation rules	
Related data element	Tobacco smoking quit age (daily smoking)

Administrative information

References	AIHW – Tobacco smoking status METeOR ID: 270311

Tobacco smoking quit age (daily smoking)

Identifying and definitional attributes

Definition	The age in years at which a person who has smoked daily in the past and is no longer a daily smoker most recently stopped smoking daily.
Justification	Smoking has long been known as a health risk factor. Population studies indicate a relationship between smoking and increased mortality/morbidity.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	2
Format	[NN]
Guide for use	If Tobacco smoking status is 4, report the age the patient most recently ceased smoking. Quit-age may be directly reported, or derived from the date the person quit smoking or the length of time since quitting, once the person's date of birth (or current age) is known. Quit-age is relevant only to persons who have been daily smokers in the past and are not current daily smokers.
Validation rules	
Related data element	Tobacco smoking status

Administrative information

References	AIHW – Tobacco smoking quit age METeOR ID: 270323

Co-morbidities

Identifying and definitional attributes

Definition	Significant condition or complaint either coexisting with the principal diagnosis or arising during the episode of admitted patient care, episode of residential care or attendance at a health care establishment.
Justification	Co-morbidities may affect patient therapy and outcome.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	6
Format	ANN{.N[N]}
Data domain	A code from the ICD-10-AM International Statistical Classification of Diseases and Related data element Health Problems, Australian Modification
Guide for use	Record each additional diagnosis relevant to the episode of care.

Validation rules

Related data element

Administrative information

References

DIAGNOSIS

Date of diagnosis

Identifying and definitional attributes

Definition	The date when the cancer was first diagnosed (whether at its primary site or as a metastasis).
Justification	Collected for patient administration system, cancer notification system, population cancer statistics and research.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's pathology report, the patient's medical record, or the patient's medical practitioner/nursing staff. For further details of usage and data collection refer to AIHW METeOR data element Patient – diagnosis date (cancer).
Validation rules	• Date of diagnosis must be: >= date of birth, <= date of death
Related data element	Most valid basis of diagnosis

Administrative information

References	AIHW – Patient diagnosis date METeOR ID: 270061

Most valid basis of diagnosis

Identifying and definitional attributes

Definition	The most valid basis for diagnosis of a cancer.
Justification	Collected to determine certainty of diagnosis.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	Death certificate only: Information provided is from a death certificate.
1	Clinical: Diagnosis made before death, but without any of the following (codes 2-7)
2	Clinical investigation: All diagnostic techniques, including x-ray, endoscopy, imaging, ultrasound, exploratory surgery (e.g. laparotomy) and autopsy, without a tissue diagnosis
4	Specific tumour markers: Including biochemical and/or immunological markers that are specific for a tumour site
5	Cytology: Examination of cells from a primary or secondary site, including fluids aspirated by endoscopy or needle; also includes the microscopic examination of peripheral blood and bone marrow aspirates
6	Histology of metastasis: Histological examination of tissue from a metastasis, including autopsy specimens
7	Histology of a primary tumour: Histological examination of tissue from primary tumour, however obtained, including all cutting techniques and bone marrow biopsies; also includes autopsy specimens of primary tumour
8	Histology: either unknown whether of primary or metastatic site, or not otherwise specified
9	Unknown

Guide for use	The most valid basis of diagnosis may be the initial histological examination of the primary site, or it may be the post-mortem examination (sometimes corrected even at this point when histological results become available). For further details of usage and data collection refer to AIHW METeOR data element Person with cancer – Most valid basis of a diagnosis of cancer.
Related data element	Date of diagnosis

Administrative information

References	AIHW – Most valid basis of diagnosis of cancer METeOR ID: 270181

Investigations

Identifying and definitional attributes

Definition	The type of investigation undertaken to determine the size or appearance of the lesion (in the investigation of primary or secondary cancer).
Justification	Collected to determine history of cancer.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Clinical/physical/medical examination
2	Mammography
3	Magnetic resonance imaging (MRI)
4	Ultrasound (US)
5	Positron emission tomography (PET)
6	Computerised tomography (CT)
7	Surgical resection
8	Chest X-ray (CXR)
9	Fine needle aspiration cytology (FNAC)
10	Core biopsy
11	Liver scan
12	Bone scan
13	Endobronchial ultrasound (E(B)US)
14	Mediastinoscopy/mediastinotomy
99	Not stated/inadequately described

Guide for use	This information should be obtained from the patient's pathology report, the patient's medical record, or the patient's medical practitioner/nursing staff. Codes 4 to 6 are for imaging only. If a biopsy is taken using imaging techniques, code to the type of biopsy or surgical resection tundertaken Code 7 includes surgical biopsy or resection of a primary or secondary tumour with histological examination not including core biopsy.
Validation rules	
Related data element	Result of investigation, Investigation date

Administrative information

References

Investigation result

Identifying and definitional attributes

Definition	Results of an assessment of a lesion clinically, pathologically or by imaging such as mammography, magnetic resonance imaging (MRI), ultrasound, PET, US or other radiological technique.
Justification	Collected to determine history of cancer.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	No significant abnormality
2	Benign
3	Equivocal/atypical
4	Suspicious
5	Malignant
9	Not stated/inadequately described

Guide for use	This information should be obtained from the patient's pathology report, the patient's medical record, or the patient's medical practitioner/nursing staff. It will include results from a range of clinical and pathological assessments such imaging such by MRI, PET, bone and liver scans specified in the Investigations. However it does not include the mammography results, which are recorded separately.
Validation rules	
Related data element	Investigations, Investigation date

Administrative information

References

Investigation date

Identifying and definitional attributes

Definition	The date on which the patient was assessed by a clinician or laboratory.
Justification	Collected for administrative purposes and treatment identification.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This date can be the date of any investigation by a doctor, radiotherapist or pathology laboratory such as clinical assessment, magnetic resonance imaging or pathology test. However, it does not include a mammography date which is recorded separately.
Validation rules	• <= Today's date • >= DOB, < Date of Death, Can be multiple events
Related data element	Investigations, Result of investigations

Administrative information

References

Pathology provider name

Identifying and definitional attributes

Definition	Name of the pathology provider and department, where a patient's pathology testing is being undertaken.
Justification	Collected for administrative purposes and service provider identification.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	100
Format	X[X(99]
Data domain	Valid provider name
Guide for use	The format of data collection is less important than consistent use of conventions in the recording of the pathology provider and department's name. Generally, the complete name and department (where relevant) should be used to avoid any ambiguity in identification. However, pathology testing undertaken within a single institution may be identified by department name only (eg biochemistry). Pathology testing may be undertaken on multiple occasions. That is, this is a multiple occurring field.
Validation rules	
Related data element	Investigation date

Administrative information

References

Assessment comments

Identifying and definitional attributes

Definition	Any comments recorded during assessment.
Justification	Collected to determine history of cancer.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	200
Format	[X(200)]
Data domain	Free text entry
Guide for use	This information should be obtained from the patient's pathology report, the patient's medical record, or the patient's medical practitioner/nursing staff.
Validation rules	
Related data element	

Administrative information

References

Computed tomography site

Identifying and definitional attributes

Definition	Site of computed tomography (CT) assessment.
Justification	Collected to determine history of cancer.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	[N]

Data domain

Code	Description
1	Chest
2	Abdomen
3	Pelvis
4	Brain
5	Head and neck
6	Other
9	Not stated/inadequately described

Guide for use	This information should be obtained from the patient's pathology report, the patient's medical record, or the patient's medical practitioner/nursing staff.
Validation rules	
Related data element	Investigation date

Administrative information

References

Primary site (ICD-O-3 code)

Identifying and definitional attributes

Definition	The site of origin of the tumour, as opposed to the secondary or metastatic sites, as represented by an ICDO-3 code.
Justification	Collected to classify tumours into clinically-relevant groupings on the basis of both their site and histological type. It is also used for monitoring numbers of new cases of cancer for service planning and for epidemiolgical studies.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	4
Format	ANN.N
Classification scheme	Code: ICD-O-3 International Classification of Diseases for Oncology 3rd edition
Guide for use	Report the primary site of cancer, if known, for patients who have been diagnosed with a cancer. Cancer registries use Site codes from ICDO 3rd edition. For cancer registries, collection of this data item should only be from notification and pathology reports relating to initial diagnosis and not for recurrent or metastatic disease. If the primary site differs on multiple pathology or other notification reports for the same tumour, use the most specific value. For multifocal tumours with foci in more than one quadrant, use the quadrant of the largest focus.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Person with cancer—primary site of cancer, code (ICDO-3) ANN{.N[N]} METeOR ID: 370039 WHO International Classification of Diseases for Oncology 3rd edition

Primary site (ICD-10-AM 7th Edition code)

Identifying and definitional attributes

Definition	The site of origin of the tumour, as opposed to the secondary or metastatic sites, as represented by an ICD-10-AM code.
Justification	Collected to classify tumours into clinically-relevant groupings on the basis of both their site and histological type. It is also used for monitoring numbers of new cases of cancer for service planning and for epidemiolgical studies.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	4
Format	ANN.N
Classification scheme	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification 7th edition
Guide for use	Report the primary site of cancer, if known, for patients who have been diagnosed with a cancer. In a hospital setting, primary site of cancer should be recorded on the patient's medical record by the patient's attending clinician or medical practitioner, and coded by the hospital's medical records department. Hospitals use Diagnosis codes from ICD-10-AM (7th edition). Valid codes must start with C or D. In hospital reporting, the diagnosis code for each separate primary site cancer will be reported as a Principal diagnosis or an Additional diagnosis as defined in the current edition of the Australian Coding Standards. In death reporting, the Australian Bureau of Statistics uses ICD-10. Some ICD-10-AM (7th edition) diagnosis codes e.g. mesothelioma and Kaposi's sarcoma, are based on morphology and not site alone, and include tumours of these types even where the primary site is unknown.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Person with cancer—primary site of cancer, code (ICDO-3) ANN{.N[N]} METeOR ID: 370039 WHO International Classification of Diseases for Oncology 3rd edition

Morphology of cancer, code (ICDO-3)

Identifying and definitional attributes

Definition	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).
Justification	Collected to classify tumours into clinically-relevant groupings on the basis of both their morphology and degree of invasion or malignancy. It is also used for monitoring numbers of new cases of cancer for service planning and for epidemiolgical studies.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	6
Format	ANN{.N[N]}
Classification scheme	International Classification of Diseases for Oncology 3rd edition
Guide for use	ICDO morphology describes histology and behaviour as separate variables, recognising that there are a large number of possible combinations. In ICDO, morphology is a 4-digit number ranging from 8000 to 9989, and behaviour is a single digit which can be 0, 1, 2, 3, 6 or 9. Record morphology codes in accordance with ICDO coding standards. Use the 5th-digit to record behaviour.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Morphology of cancer METeOR ID: 370023 International Classification of Diseases for Oncology 3rd edition

Histopathology grade

Identifying and definitional attributes

Definition	The histopathological grade or differentiation describes how much the tumour resembles the normal tissue from which it arose.
Justification	Collected to classify tumours into clinically-relevant groupings on the basis of both their morphology and degree of invasion or malignancy. It is also used for monitoring numbers of new cases of cancer for service planning and for epidemiolgical studies.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	6
Format	N

Data domain

Code	Description
1	Grade 1: Low grade; well differentiated, differentiated, NOS
2	Grade 2: Intermediate grade, moderately differentiated, moderately well differentiated, intermediate differentiation
3	Grade 3: High grade, poorly differentiated
4	Grade 4: Undifferentiated, anaplastic
5	T-cell: T-cell
6	B-cell: B-cell, Pre-B, B-Precursor
7	Null-cell: Null cell, Non T- non B
8	NK-cell: Natural killer cell
9	Grade/differentiation unknown: Grade/cell type not determined, not stated or not applicable

Guide for use	Only one code can be recorded. This information should be obtained from the patient's pathology report.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Histopathological grade METeOR ID: 370019 International Statistical Classification of Diseases and Related data element Health Problems, Tenth Revision, Australian Modification

Primary tumour status – T Stage

Identifying and definitional attributes

Definition	Extent of primary cancer including tumour size, at the time of diagnosis.
Justification	Collected to classify tumours into clinically-relevant groupings on the basis of both their morphology and degree of invasion or malignancy. It is also used for monitoring numbers of new cases of cancer for service planning and for epidemiolgical studies.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	3
Format	XX[X]
Classification scheme	International Union against Cancer (UICC) TNM Classification of Malignant Tumours 7th edition
	Supplementary values
	8888 Not applicable
	9999 Unknown
Guide for use	Valid T codes from the current edition of the UICC TNM Classification of Malignant Tumours. This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Cancer staging – T stage code METeOR ID: 341306 UICC – TNM Classification of Malignant Tumours, 7th Edition

Regional lymph node metastasis – N Stage

Identifying and definitional attributes

Definition	Extent of regional lymph node metastasis at the time of diagnosis of the primary cancer.
Justification	Collected to classify tumours into clinically-relevant groupings on the basis of both their morphology and degree of invasion or malignancy. It is also used for monitoring numbers of new cases of cancer for service planning and for epidemiolgical studies.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	3
Format	XX[X]
Classification scheme	International Union against Cancer (UICC) TNM Classification of Malignant Tumours 7th edition
	Supplementary values
	8888 Not applicable
	9999 Unknown
Guide for use	Valid N codes from the current edition of the UICC TNM Classification of Malignant Tumours. This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Cancer staging – N stage code METeOR ID: 341302 UICC – TNM Classification of Malignant Tumours, 7th Edition

Distant metastasis status – M stage

Identifying and definitional attributes

Definition	Absence or presence of distant metastasis at the time of diagnosis of the primary cancer.
Justification	Collected to classify tumours into clinically-relevant groupings on the basis of both their morphology and degree of invasion or malignancy. It is also used for monitoring numbers of new cases of cancer for service planning and for epidemiolgical studies.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	3
Format	XX[X]
Classification scheme	International Union against Cancer (UICC) TNM Classification of Malignant Tumours 7th edition
	Supplementary values
	8888 Not applicable
	9999 Unknown
Guide for use	Valid M codes from the current edition of the UICC TNM Classification of Malignant Tumours. This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Cancer staging – M stage code METeOR ID: 341300 UICC – TNM Classification of Malignant Tumours, 7th Edition

TNM stage grouping code

Identifying and definitional attributes

Definition	The anatomical extent of disease at diagnosis based on the previously coded T, N and M stage categories.
Justification	Collected to classify tumours into clinically-relevant groupings on the basis of both their morphology and degree of invasion or malignancy. It is also used for monitoring numbers of new cases of cancer for service planning and for epidemiolgical studies.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	6
Format	XXXX{[X]XX}
Classification scheme	International Union against Cancer (UICC) TNM Classification of Malignant Tumours 7th edition
	Supplementary values
	8888 Not applicable
	9999 Unknown
Guide for use	Valid stage grouping codes from UICC TNM Classification of Malignant Tumours current edition. This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Cancer staging – TNM stage grouping code METeOR ID: 341304 UICC – TNM Classification of Malignant Tumours, 7th Edition

Staging scheme source

Identifying and definitional attributes

Definition	The reference, which describes in detail the methods of staging and the definitions for the classification system used in determining the extent of cancer at the time of diagnosis.
Justification	Collected to identify which classification systems are used when determining the extent of the cancer at the time of diagnosis.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	2
Format	N[N]

Data domain

Code	Description
1	TNM Classification of Malignant Tumours (UICC)
2	Durie & Salmon for multiple myeloma staging
3	FAB for leukaemia classification
4	Australian Clinico-Pathological Staging (ACPS) System for colorectal
5	FIGO for gynaecological
6	Duke's/modified Duke's for colorectal
7	Ann Arbor for Hodgkin's and Non Hodgkin's lymphoma
8	Binet for Chronic Lymphocytic Leukaemia
9	Rai for Chronic Lymphocytic Leukaemia
88	Other
99	Not stated/inadequately described

Guide for use	This information should be obtained from the patient's pathology report. TNM classification is the most common system for solid tumours but in some circumstances, other classification schemes will be used and should be recorded to correctly distinguish the stage of disease.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Staging scheme source METeOR ID: 296988 UICC – TNM Classification of Malignant Tumours, 7th Edition

Staging scheme source edition number

Identifying and definitional attributes

Definition	The edition of the reference used for the purposes of staging the cancer.
Justification	Collected for survival analysis adjusted by stage at diagnosis and distribution of cancer cases by type and stage.

Representational attributes

Data type	Number	
Representational class	Total	
Field size maximum	2	
Format	N[N]	
Data domain	Supplementary values	Description
	88	Not applicable (Cases that do not have a recommended staging scheme
	99	Unknown edition
Guide for use	This information should be obtained from the patient's pathology report.	
Validation rules		
Related data element	Date of diagnosis	

Administrative information

References	AIHW – Staging scheme source edition number METeOR ID: 297011

Staging basis

Identifying and definitional attributes

Definition	The timing and evidence for T, N and M cancer stage values.
Justification	Collected for survival analysis adjusted by stage at diagnosis and distribution of cancer cases by type and stage.

Representational attributes

Data type	String	
Representational class	Code	
Field size maximum	1	
Format	A	
Data domain	**Code**	**Description**
	P	Pathological
	C	Clinical
Guide for use	CODE P (Pathological): Pathological stage is based on histological evidence acquired before treatment, supplemented or modified by additional evidence acquired from surgery and from pathological examination. CODE C (Clinical): Clinical stage is based on evidence obtained prior to treatment from physical examination, imaging, endoscopy, biopsy, surgical exploration or other relevant examinations. Refer to UICC TNM Classification of Malignant Tumours current edition for coding rules.	
Validation rules		
Related data element	Date of diagnosis	

Administrative information

References	AIHW – Staging basis of cancer METeOR ID: 296981 UICC – TNM Classification of Malignant Tumours, 7th Edition

Laterality of tumour

Identifying and definitional attributes

Definition	The side of a paired organ or limb that is the origin of the tumour.
Justification	Collected to determine location and history of tumour.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	1
Format	A

Data domain

Code	Description
R	Right
L	Left
B	Bilateral
N	Not applicable
U	Unknown

Guide for use	Record the side of a paired organ or limb that is the site of the origin of the tumour. This information should be obtained from the patient's pathology report, the patient's medical record, or the patient's medical practitioner/nursing staff. It may be the location of a tumour detected clinically (by clinical examination or imaging) or pathologically after surgical removal. For details of usage and data collection refer to AIHW METeOR data element Person with cancer – laterality of primary cancer.
Validation rules	
Related data element	Investigation date or Date of diagnosis

Administrative information

References	AIHW – Laterality of primary cancer METeOR ID: 270177

Tumour size at diagnosis (solid tumours)

Identifying and definitional attributes

Definition	The largest dimension of a solid tumour, measured in millimetres (mm).
Justification	Collected for patient management, population cancer statistics and research.

Representational attributes

Data type	Number	
Representational class	Total	
Field size maximum	3	
Format	NNN	
Data domain	Permissible values	001 to 997
	Supplementary values	
	990	Microinvasive breast tumour, size not stated
	999	Unknown
Guide for use	Breast cancer or other solid neoplasms - the largest tumour dimension, measured to a precision of 1 mm. Round to the nearest millimetre, rounding up if size is >= 5 mm eg 1.50 mm, 1.54 mm recorded as 2 mm, 1.47 mm recorded as 1 mm. Breast cancer: These rules are to be used only when the record pertains to an invasive breast cancer When an invasive tumour contains an in situ component, only record the size of the invasive component as stated. If the size of the invasive tumour is not recorded separately to the in-situ component, then record the total size of the tumour without any attempt to estimate the invasive component using percentage or size of the in situ component. Microinvasive tumour: For microinvasive tumours, record size in millimetres if stated. If microinvasion is stated but no size is recorded, enter 990 in size field to enable these very small tumours to be differentiated from other tumours without measured sizes. Bilateral breasts tumours: Bilateral tumours are recorded as two separate primary tumours each having their own size (and other data elements). Multifocal tumours with different morphology: Foci with different morphology should be considered to be separate primary tumours each having their own size (and other data elements). The coder needs to ascertain whether two foci with differing morphology are separate primaries with different morphology or a single multifocal primary with a mixed histology. In the latter case the rule of taking the size from the larger focus would apply as stated. For further details of usage and data collection refer to AIHW METeOR data element Person with cancer – sold tumour size.	
Validation rules		
Related data element	Date of diagnosis	

Administrative information

References	AIHW – Tumour size at diagnosis (solid tumours) METeOR ID: 370042

Multifocal tumour

Identifying and definitional attributes

Definition	Whether the tumour is multifocal at the time of diagnosis.
Justification	Collected to determine whether the tumour is a single mass or multifocal.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Yes
2	No
9	Not stated/inadequately described

Guide for use	This information should be obtained from the patient's pathology report.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References

Lymphovascular invasion

Identifying and definitional attributes

Definition	The presence or absence of the invasion of cancer cells into blood vessel(s) and/or the lymphatic system.
Justification	Collected to identify whether lymphovascular invasion has occurred. Invasion of lymphatic or blood vessels by cancer cells is an important prognostic factor that indicates that the tumour is likely to spread.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	Absent
1	Present
2	Suspicious
9	Not stated/inadequately described

Guide for use	This information should be obtained from the patient's pathology report or medical record. The presence of lymphovascular invasion should be recorded, regardless of whether the extent of the invasion is described or not.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Person with cancer – lymphovascular invasion METeOR ID: 370618

Number of regional lymph nodes examined

Identifying and definitional attributes

Definition	The total number of a person's regional lymph nodes examined by the pathologist.
Justification	Collected to identify whether tumour is present in regional lymph nodes.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	3
Format	N[NN]
Data domain	Supplementary values 997 Number of lymph nodes unknown
Guide for use	This information should be obtained from the patient's pathology report or medical record. A list of which lymph nodes are defined as regional lymph nodes for each cancer site may be found in the UICC TNM Classification of Malignant Tumours, current edition. The number includes all nodes examined regardless of whether removed/examined at a single or multiple procedures e.g. for breast cancer, record the sum of regional lymph nodes examined from node sampling/sentinel node biopsy and axillary clearance. The number of regional lymph nodes is cumulative from all procedures that removed lymph nodes through the completion of surgeries for the treatment of the cancer. For breast cancer regional lymph nodes include all ipsilateral axillary, ipsilateral infraclavicular/subclavicular, ipsilateral internal mammary and ipsilateral supraclavicaular nodes. All other nodes (including contralateral internal mammary nodes) are considered to be distant metastases and should not be recorded in this data item.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Number of regional lymph nodes examined METeOR ID: 370032 UICC – TNM Classification of Malignant Tumours, 7th edition.

Number of regional nodes positive

Identifying and definitional attributes

Definition	The total number of regional lymph nodes reported as containing tumour after examination by a pathologist.
Justification	Collected to identify the number of regional lymph nodes with tumour present.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	3
Format	N[NN]
Data domain	Supplementary values 997 Number of lymph nodes unknown
Guide for use	This information should be obtained from the patient's pathology report or medical record. A list of which lymph nodes are defined as regional lymph nodes for each cancer site may be found in the UICC TNM Classification of Malignant Tumours, current edition. Number includes all positive nodes regardless of whether removed/examined at a single or multiple procedures eg. For breast cancer, record the sum of positive nodes detected in node sampling/sentinel node biopsy and those removed at axillary clearance. For cancer registries, collection of this data item should only be from notification and pathology reports relating to initial diagnosis and not for recurrent or metastatic disease.
Validation rules	
Related data element	Date of diagnosis

Administrative information

References	AIHW – Regional lymph nodes positive METeOR ID: 370027 UICC – TNM Classification of Malignant Tumours, 7th edition.

TREATMENT

Intention of treatment

Identifying and definitional attributes

Definition	The intention of the initial treatment for cancer for the particular patient.
Justification	Collected to determine intention of treatment.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	1
Format	N

Data domain

Code	Description
0	Did not have treatment
1	Prophylactic
2	Curative
3	Non-curative or palliative
9	Not stated

Guide for use

This information should be obtained from the patient's medical record. his information should be obtained from the patient's medical record. This item is collected for surgical treatment, radiation therapy and systemic therapy agent treatment.

Curative treatment can be neoadjuvant and adjuvant treatment. Prophylactic treatment indicates that the cancer has not developed.

Non curative or palliative treatment indicates that a cure is unlikely to be achieved and treatment is given primarily for the purpose of pain control. Other benefits of the treatment are considered secondary contributions to the patient's quality of life. Not stated indicates that treatment was given but the intention was not recorded.

Validation rules

Related data element

Administrative information

References

AIHW – Intention of treatment for cancer
METeOR Id: 288690

Neoadjuvant therapy

Identifying and definitional attributes

Definition	Whether a person with a solid tumour has received neoadjuvant therapy.
Justification	Preoperative chemotherapy and/or radiotherapy may be received after a diagnosis of cancer but before surgical treatment. The effects of chemotherapy and/or radiotherapy prior to surgery will shrink the tumour and so the size of the tumour found from the subsequent surgical excision will be smaller than the original size of the tumour at the time of diagnosis. This impacts on the TNM staging classification, and is important to take into account for analysis and research.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Yes
2	No

Guide for use

To be reported when therapy is received after a diagnosis of cancer and prior to primary surgical treatment.
This data item is used to flag cases in which tumour descriptors, for example solid tumour size, may be inaccurate due to shrinkage from neoadjuvant therapy.

Yes - indicates that the client has received neo-adjuvant therapy after a diagnosis of cancer and prior to primary surgical treatment

No - indicates that the client did not receive neo-adjuvant therapy after a diagnosis of cancer and prior to primary surgical treatment

For invasive breast cancer:
Information is obtained from

- Clinical notes on pathology report mentions that patient underwent chemotherapy prior to surgery
- Microscopy section of pathology report describes tumour changes as a result of neoadjuvant therapy (coder may be alerted to look for this detail by a long interval between biopsy and wider excision)
- Hospital notification indicates that admission if for chemotherapy only (and admission date is before that for surgery)

Validation rules

Related data element

Administrative information

References

AIHW – Neo-adjuvant therapy
METeOR Id: 370014

Target site for cancer treatment

Identifying and definitional attributes

Definition	The site or region of cancer that is the target of a particular surgical or radiotherapy treatment.
Justification	Collected to identify the target sites for surgery and or radiotherapy.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	3
Format	ANN
Classification scheme	Code: ICD-O-3 International Classification of Diseases for Oncology 3rd edition
Guide for use	Refer to the current edition of WHO International Classification of Diseases for Oncology (ICD-O) and record major organ only using first 3 characters.
Validation rules	
Related data element	

Administrative information

References	AIHW – Cancer treatment – target site METeOR ID: 293161 WHO – International Classification of Diseases for Oncology (ICD-O), 3rd edition

Clinical trial enrolment status

Identifying and definitional attributes

Definition	Whether the patient is enrolled in a clinical trial. According to WHO, a clinical trial is 'Any research project that prospectively assigns human participants or groups to one or more health relayed interventions to evaluate the effects of health outcomes'
Justification	Involvement in a clinical trial may result in the patient's treatment departing from the expected path. This item also allows for collection of information about the type of patients selected for trials.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Enrolled in clinical trial
2	Not enrolled in clinical trial
9	Not stated/inadequately described

Guide for use	This item refers to clinical trials for any aspect of treatment, such as surgical, radiation, drug or hormonal therapy, or a sentinel node trial.
Validation rules	
Related data element	Clinical trial name

Administrative information

References	NBOCC – Breast Specific Data Item Definitions for Clinical Cancer Registrations June 2009, p 16

Clinical trial name

Identifying and definitional attributes

Definition	The name of the clinical trial in which the patient is enrolled.
Justification	Allows for collection of information about types of clinical trials in which patients are enrolled.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	40
Format	[X(40)]
Guide for use	If Clinical trial enrolment status is 1, record the name of the clinical trial. The format of data collection is less important than consistent use of conventions in the recording of the clincial trial's name.
Validation rules	
Related data element	Clinical trial status

Administrative information

References	NBOCC – Breast Specific Data Item Definitions for Clinical Cancer Registrations June 2009, p 17

Clinical trial start date

Identifying and definitional attributes

Definition	Date that patient commenced treatment in a clinical trial.
Justification	Collected to determine duration of clinical trial treatment.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Guide for use	Record the date on which the patient commenced participating in a clinical trial.
Validation rules	
Related data element	Clinical trial name, Clinical trial end date

Administrative information

References

Clinical trial end date

Identifying and definitional attributes

Definition	Date that patient completed treatment in a clinical trial.
Justification	Collected to determine duration of clinical trial treatment.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Guide for use	Record the date on which the patient completed participating in a clinical trial.
Validation rules	
Related data element	Clinical trial name, Clinical trial start date

Administrative information

References

Consent to discuss case at multidisciplinary team meeting

Identifying and definitional attributes

Definition	Whether the patient has given consent to their case being discussed at Multidisciplinary Team meeting (MDT).
Justification	Patient is required to give consent for their personal details to be discussed at MDT.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Yes
2	No
9	Not stated/inadequately described

Guide for use	Record whether the patient has consented for their case to be discussed at a MDT.
Validation rules	
Related data element	

Administrative information

References

Tissue bank consent

Identifying and definitional attributes

Definition	Whether the patient has consented to donating tissue to a tissue bank for research purposes.
Justification	Patient is required to give consent for donation to a tissue bank. Because of the value of tissue for research, donation of surplus tissue after diagnostic examination is often sought. This includes tissue from cancers as well as benign and normal tissue.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Yes
2	No
9	Not stated/inadequately described

Guide for use	Record whether the patient has consented for their tissue to be donated to a tissue bank.
Validation rules	
Related data element	

Administrative information

References	NBOCC – The Pathology Reporting of Breast Cancer, A guide for pathologists, surgeons, radiologists and oncologists, p 19

Treatment types

Identifying and definitional attributes

Definition	The type of treatment for cancer given as initial treatment for the particular patient. It includes all treatments administered to the patient before disease progression or recurrence and applies to surgical treatment, radiation therapy and systemic agent therapy for cancer.
Justification	Collected for identifying surgical treatment, radiation therapy and systemic therapy. It is used for correlating outcome with original intent of the treatment.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	No treatment
1	Surgical treatment
2	Radiation therapy
3	Systemic agent therapy
4	Surgical and radiation treatment
5	Surgical treatment and systemic agent treatment
6	Radiation and systemic agent treatment
7	All three treatment types
9	Not stated/inadequately described

Guide for use: This information should be obtained from the patient's medical record.

Validation rules

Related data element

Administrative information

References: AIHW – Cancer treatment type
METeOR ID: 288185

Surgical procedure date

Identifying and definitional attributes

Definition	Date on which cancer directed surgical treatment occurred.
Justification	Collected to determine dates and therefore number of surgical procedures performed. Collected for curative and palliative surgery prior to the first recurrence. For breast lesions, this may be surgery for benign breast disease.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	The date of each surgical treatment episode should be entered separately.
Validation rules	
Related data element	Surgical procedure

Administrative information

References	AIHW – Date of surgical treatment for cancer METeOR ID: 288632

Surgical procedure for cancer, procedure code

Identifying and definitional attributes

Definition	The surgical procedure used in the primary treatment of the cancer, as represented by a code.
Justification	Collected to determine types and therefore number of surgical procedures performed.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	7
Format	NNNNN-NN
Classification scheme	Australian Classification of Health Interventions (ACHI) 7th edition
Guide for use	The Australian Classification of Health Interventions (ACHI) is based on the Medicare Benefits Schedule (MBS) and was previously known as the Medicare Benefits Schedule-Extended (MBS-E). The ACHI codes have seven digits. The first five digits are the MBS item number. The two-digit extension represents specific procedures included in that item. The classification is structured by body system, site and procedure type. Each surgical treatment procedure used in the initial treatment of the cancer should be recorded. Surgical procedures performed for palliative purposes only should not be included. For surgical procedures involved in the administration of another modality (e.g. implantation of infusion pump, isolated limb perfusion/infusion, intra-operative radiotherapy) record both the surgery and the other modality. Any systemic treatment which can be coded as a procedure through ACHI should be so coded (e.g. stem cell or bone marrow infusion).
Validation rules	
Related data element	Surgical procedure date

Administrative information

References	AIHW – Surgical treatment procedure for cancer, procedure code METeOR ID: 391347 Australian Classification of Health Interventions (ACHI) 7th Edition

Systemic therapy start date

Identifying and definitional attributes

Definition	The start date of the initial course of systemic drug treatment for cancer.
Justification	Collected to provide the basis for a standard approach to recording and monitoring patterns of initial treatment for cancer patients.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	The start date of the systemic therapy is recorded regardless of whether treatment is completed as intended or not. Treatment subsequent to a recurrence will not be recorded. This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Systemic therapy completion date, Systemic therapy protocol, Systemic therapy name, Systemic therapy dose

Administrative information

References	AIHW – Cancer initial treatment starting date METeOR ID: 288103

Systemic therapy completion date

Identifying and definitional attributes

Definition	The completion date of the initial course of systemic therapy for cancer.
Justification	Collected to provide the basis for a standard approach to recording and monitoring patterns of initial treatment for cancer patients.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Systemic therapy start date, Systemic therapy protocol, Systemic therapy name, Systemic therapy dose

Administrative information

References	AIHW – Cancer initial treatment completion date METeOR ID: 288136

Systemic therapy name

Identifying and definitional attributes

Definition	The standard chemotherapeutic agent or anti-cancer drug used for treatment of cancer.
Justification	Collected for the analysis of outcome by treatment type. The purpose of collecting specific treatment information is to account for all treatment types, which may assist in evaluation of effectiveness of different treatment patterns. The actual agents used will sometimes be of interest.

Representational attributes

Data type	String
Representational class	Text
Field size maximum	100
Format	[X(100)]
Classification scheme	Tabular list of chemotherapy agents and protocols. Cancer Institute NSW: CI-SCaT: Standard Cancer Treatment protocols
Guide for use	Each chemotherapy agent used in the treatment of the cancer should be recorded. There maybe more than one agent used. This information should be obtained from the patient's medical record.
Validation rules	• Can be multiple events
Related data element	Systemic therapy start date, Systemic drug completion date

Administrative information

References	Tabular list of chemotherapy agents and protocols. Cancer Institute NSW: CI-SCaT: Standard Cancer Treatment protocols, available at https://www.eviq.org.au/

Systemic therapy dose

Identifying and definitional attributes

Definition	The standard chemotherapeutic agent or anti-cancer drug dose given to the patient.
Justification	Collected for the analysis of outcome by treatment type.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	4
Format	NNN[N]
Classification scheme	Tabular list of chemotherapy agents and protocols. Cancer Institute NSW: CI-SCaT: Standard Cancer Treatment protocols
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	• Can be multiple events
Related data element	Systemic therapy start date, Systemic therapy completion date, Systemic therapy dose unit

Administrative information

References	Tabular list of chemotherapy agents and protocols. Cancer Institute NSW: CI-SCaT: Standard Cancer Treatment protocols, available at https://www.eviq.org.au/

Systemic therapy dose unit

Identifying and definitional attributes

Definition	The unit of measurement of the standard chemotherapeutic agent or anti-cancer drug dose.
Justification	Collected for the analysis of outcome by treatment type.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	mg
2	mg/m^2
3	mg/kg
4	AUC
9	Not stated

Guide for use

This information should be obtained from the patient's medical record. Drug dose may be expressed in a variety of units:

Code 1 Total milligrams

Code 2 Milligrams per body surface area (BSA) in square metres calculated from the patients height in metres and weight in kilograms

Code 3 Milligrams per kilogram of patient weight, dose in milligrams

Code 4 Total total exposure to the drug as the area under the concentration time curve (AUC) calculated from from drug concentration and time

Validation rules

- Can be multiple events

Related data element

Systemic therapy start date, Systemic therapy completion date, Systemic therapy dose

Administrative information

References

Chemotherapy number of cycles

Identifying and definitional attributes

Definition	The standard chemotherapeutic agent or anti-cancer drug protocol used for treatment of the primary cancer.
Justification	Collected for the analysis of outcome by treatment type. The purpose of collecting specific treatment information is to account for all treatment types, which may assist in evaluation of effectiveness of different treatment patterns. The actual agents used will sometimes be of interest. Standard protocols for chemotherapy agents, doses and cycles are provided by Cancer Institute of NSW.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	3
Format	N[NN]
Classification scheme	Tabular list of chemotherapy agents and protocols. Cancer Institute NSW: CI-SCaT: Standard Cancer Treatment protocols
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Systemic therapy start date, Systemic therapy completion date

Administrative information

References	Tabular list of chemotherapy agents and protocols. Cancer Institute NSW: CI-SCaT: Standard Cancer Treatment protocols, available at https://www.eviq.org.au/

Chemotherapy dose reduction

Identifying and definitional attributes

Definition	The percentage dose reduction from the previous chemotherapy treatment plan.
Justification	Collected to determine variations in chemotherapy. Chemotherapy dose may be reduced due to toxicity.

Representational attributes

Data type	Number	
Representational class	Percentage	
Field size maximum	3	
Format	N[NN]	
Supplementary values	0	Chemotherapy treatment completed as planned (no reduction in dose)
	999	Not stated
Guide for use	This information should be obtained from the patient's medical record.	
Validation rules		
Related data element	Chemotherapy date of dose reduction	

Administrative information

References

Chemotherapy date of dose reduction

Identifying and definitional attributes

Definition	Date that chemotherapy dose was reduced from initial or subsequent doses.
Justification	Collected to determine variations in chemotherapy.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	•
Related data element	Chemotherapy dose reduction

Administrative information

References

Chemotherapy reduction specified

Identifying and definitional attributes

Definition	Description of reason for reduction in chemotherapy.
Justification	Collected to determine reasons for reduction in chemotherapy.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	2
Format	N

Data domain

Code	Description
0	No reduction in chemotherapy
1	Age of patient
2	Co-morbidities
3	Toxicity
4	Impaired organ function
8	Other
9	Not stated

Guide for use	Chemotherapy toxicity may lead to reduction in dose or cessation of treatment. This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Chemotherapy date of dose reduction

Administrative information

References

Systemic therapy - related toxicity

Identifying and definitional attributes

Definition	Description of systemic therapy (chemotherapy, hormone, immunotherapy) toxicity.
Justification	Collected for identifying systemic therapy toxicity. It is used for correlating outcome with original intent of the treatment. Toxicity may lead to reduction in dose or cessation of treatment.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	2
Format	N[N]

Data domain

Code	Description
0	No/minimal toxic effects
1	Febrile neutropenia
2	Other sepsis
3	Constipation
4	Diarrhoea
5	Nausea/vomiting
6	Mucositis/stomatitis
7	Gastro-intestinal haemorrhage
8	Neuropathy - motor
9	Neuropathy - sensory
10	Myalgia/arthralgia
11	Cardiac reduced ejection fractions
12	Alopecia
13	Drug extravasation
14	Intravenous access line complication
15	Allergic reaction
16	Tinnitus
17	Cardiac complications
18	Poor concentration
19	Memory loss
20	Admitted for complication
88	Other
99	Not stated/unknown

Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Systemic therapy protocol, Systemic therapy name, Systemic therapy dose

Administrative information

References

Granulocyte colony-stimulating factor therapy

Identifying and definitional attributes

Definition	Description of whether the patient has received granulocyte colony-stimulating factor therapy (G-CSF).
Justification	Collected to determine use of G-CSF therapy. Granulocyte colony-stimulating factor may be required to stimulate increase in neutrophils (type of white blood cells) in patient during chemotherapy. A reduction in neutrophils (neutropenia) can cause the patient to be immunocompromised and may influence therapy options.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	No G-CSF therapy required or given
1	G-CSF therapy from commencement of chemotherapy
2	G-CSF therapy after febrile neutropenia
3	G-CSF therapy because neutropenia was delaying chemotherapy
9	Not stated

Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	

Administrative information

References

Chemotherapy cessation specified

Identifying and definitional attributes

Definition	Description of the reason for cessation of chemotherapy treatment plan.
Justification	Collected to determine reasons for cessation of chemotherapy.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	Completed planned chemotherapy
1	Progressive disease
2	Toxicity
3	Patient request
4	Death due to chemotherapy toxicity
5	Death due to other cause
8	Other
9	Not stated

Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Non-surgical cancer treatment completion date

Administrative information

References

Chemotherapy completed

Identifying and definitional attributes

Definition	Whether chemotherapy was completed as planned.
Justification	Collected to determine whether chemotherapy was completed as planned.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Yes
2	No
9	Not stated

Guide for use: This information should be obtained from the patient's medical record.

Validation rules

Related data element

Administrative information

References

Late toxicity date

Identifying and definitional attributes

Definition	Date of late toxicity effects on patient.
Justification	Collected to determine time of late toxicity effects on patient.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Systemic therapy protocol, Investigation date

Administrative information

References

Radiotherapy type

Identifying and definitional attributes

Definition	The type of radiation therapy used in initial treatment of the cancer.
Justification	Collected to provide the basis for a standard approach to recording and monitoring patterns of treatment for cancer patients.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	No radiotherapy treatment given
1	External radiotherapy treatment given
2	Brachytherapy (radioactive implants)
3	Unsealed radioisotopes
9	Radiotherapy was administered but method was not stated

Guide for use	This information should be obtained from the patient's medical record. Most external beam radiotherapy is delivered on an outpatient basis. Brachytherapy (radioactive implants) is likely to be listed as a procedure for admitted patients.
Validation rules	
Related data element	Radiotherapy dose

Administrative information

References	AIHW – Radiotherapy treatment type METeOR ID: 291438

Radiotherapy dose

Identifying and definitional attributes

Definition	The received dose of radiation measured in Gray (Gy) – ICRU.
Justification	Quantitative definition of the radiotherapy dose. Collected to provide the basis for a standard approach to recording and monitoring patterns of treatment for cancer patients.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	5
Format	N[NNNN]
Supplementary values	00000 - No radiation therapy was administered 99999 - Radiation therapy was administered but the dose is unknown
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Radiotherapy type

Administrative information

References	AIHW – Received radiation dose METeOR ID: 291472

Radiotherapy start date

Identifying and definitional attributes

Definition	Date when radiation therapy started.
Justification	Collected to determine duration of therapy.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Radiation therapy end date

Administrative information

References

Radiotherapy completion date

Identifying and definitional attributes

Definition	Date when radiation therapy ended.
Justification	Collected to determine duration of therapy.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Radiotherapy start date

Administrative information

References

Radiotherapy cessation specified

Identifying and definitional attributes

Definition	Description of reasons for early cessation of radiation therapy.
Justification	Collected to determine causes of incomplete planned radiation therapy.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	Completed radiotherapy as planned
1	Significant adverse effects
2	Patient request
8	Other
9	Not stated

Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	Radiation therapy start date, Radiation therapy end date

Administrative information

References

Outcome at end of initial treatment

Identifying and definitional attributes

Definition	The response of the tumour at the completion of the initial treatment modalities.
Justification	Collected to determine outcomes of treatment.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	2
Format	N.N

Data domain

Code	Description
1.0	Complete response/no evidence of disease
2.1	Partial response
2.2	Stable or static disease
2.3	Progressive disease
2.9	Incomplete response
9.0	Not assessed or unable to be assessed

Guide for use

This information should be obtained from the patient's medical record.

CODE 1.0 (Complete response) Complete disappearance of all measurable disease, including tumour markers, for at least four weeks. No new lesions or new evidence of disease. For Breast cancer, this is “No evidence of disease”.

CODE 2.1 (Partial response) A decrease by at least 50% of the sum of the products of the maximum diameter and perpendicular diameter of all measurable lesions, for at least four weeks. No new lesions or worsening of disease.

CODE 2.2 (Stable or static disease) No change in measurable lesions qualifying as partial response or progression and no evidence of new lesions.

CODE 2.3 (Progressive disease) An increase by at least 25% of the sum of the products of the maximum diameter and a perpendicular diameter of any measurable lesion, or the appearance of new lesions.

Validation rules

Related data element: Investigation date

Administrative information

References

Public Health Division NSW Clinical Cancer Data Collection for Outcomes and Quality. Data Dictionary Version 1 Sydney NSW Health Dept (2001)
AIHW – Outcome of initial treatment
METeOR ID: 289304

FOLLOW-UP

Follow-up date

Identifying and definitional attributes

Definition	Date when patient reviewed by a physician after initial treatment.
Justification	To determine timelines in patient’s treatment and outcomes.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	

Administrative information

References

Date of first distant metastasis

Identifying and definitional attributes

Definition	The date of the presence of first metastatic event of cancer, either at diagnosis or recurrence.
Justification	Collected to determine the number of patients with a history of a distant metastasis and the survival duration following a distant metastasis.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's pathology report or medical record. The date of the presence of first distant metastasis could be noted either at time of diagnosis or at time of recurrence.
Validation rules	
Related data element	Site of first distant metastasis

Administrative information

References	UICC – TNM Classification of Malignant Tumours, 7th Edition NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 44

Site of first distant metastasis

Identifying and definitional attributes

Definition	The site of the metastasis at first metastatic event of cancer either at diagnosis or recurrence.
Justification	Collected to determine the site of distant metastases.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	6
Format	ANN{.N[N]}
Classification scheme	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification 7th edition
Guide for use	This information should be obtained from the patient's pathology report or medical record. Report the site of cancer first metastasis, if known, for patients who have been diagnosed with a cancer. In ICD-10-AM, the site is identified using a single 4 digit code Cxx.x or Dxx.x.
Validation rules	
Related data element	Date of first distant metastasis

Administrative information

References	UICC – TNM Classification of Malignant Tumours, 7th Edition

Date of diagnosis of recurrence

Identifying and definitional attributes

Definition	The date a medical practitioner confirms the diagnosis of a recurrent or metastatic cancer of the same histology.
Justification	Collected to determine the time interval from diagnosis to recurrence, from treatment to recurrence and from recurrence to death.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's pathology report or medical record. The term `recurrence' defines the return, reappearance or metastasis of cancer (of the same histology) after a disease free period.
Validation rules	
Related data element	Region of recurrence

Administrative information

References	AIHW – Region of recurrence METeOR ID: 288596

Region of recurrence

Identifying and definitional attributes

Definition	The region of recurrence of disease.
Justification	Collected to determine the location of recurrence of tumour.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	None, patient is disease–free
1	Local
2	Regional
3	Both local and regional
4	Distant
5	Distant and either local or regional
6	Local, regional and distant
7	Patient was never disease–free
8	Recurred but site unknown
9	Not stated/unknown if recurred

Guide for use	This information should be obtained from the patient's pathology report or medical record.
Validation rules	
Related data element	Date of diagnosis of recurrence

Administrative information

References	AIHW – Date of diagnosis of recurrence METeOR ID: 289136

Date of last contact

Identifying and definitional attributes

Definition	The date of last contact with the patient.
Justification	Collection for patient follow up and outcome studies.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	
Related data element	

Administrative information

References	NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 49

Cancer status at last contact

Identifying and definitional attributes

Definition	Records the presence or absence of clinical evidence of the patient's tumour as applying at the date of the last contact.
Justification	Collection for patient follow up and outcome studies.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	No cancer detected
1	Local recurrence
2	Regional recurrence
3	Visceral distant metastasis
4	Other distant metastasis
5	Distant metastases, not otherwise specified
8	Cancer status unknown
9	Cancer status not stated

Guide for use

This information should be obtained from the patient's medical record or death certificate. The patient's cancer status should be changed only if new information is received from the patient's physician or other official source.

If information is obtained from the patient, a family member, or other non-physician, then cancer status is not updated. Cancer status changes if the patient has recurrence or relapse.

Code the most advanced recurrence if more than one applies. If a patient has multiple primaries, each primary could have a different cancer status. While this codes cancer status at last contact with the patient, it need not override previous record.

Retention of successive values can be considered by individual clinicians. This data item is for both invasive cancer and in situ lesions.

Validation rules

Related data element: Date of last contact

Administrative information

References: NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 50

Date of death

Identifying and definitional attributes

Definition	Patient’s date of death.
Justification	Collected to determine survival status of patient.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	[DDMMYYYY]
Data domain	Valid date
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	• >= All dates
Related data element	

Administrative information

References	AIHW – Date of death METeOR ID: 287305

Cause of death

Identifying and definitional attributes

Definition	The disease or injury, which initiated the train of morbid events leading directly to, a person's death or the circumstances of the accident or violence which produced the fatal injury (WHO 2004).
Justification	Underlying cause of death is central to mortality coding and comparable international mortality reporting. The Australian Bureau of Statistics (ABS), codes and classifies the underlying cause of death (UCOD) according to the rules and guidelines for mortality coding adopted by the World Health Assembly and set out in the World Health Organisation's International Classification of Diseases and Related data element Health Problems (ICD). The ABS uses the Mortality Medical Data System (MMDS) to process and code cause-of-death information reported on death certificates.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	6
Format	[ANN-NN]
Classification scheme	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification 7th edition
Guide for use	This information should be obtained from the patient's death certificate.
Validation rules	
Related data element	

Administrative information

References	AIHW – Underlying cause of death METeOR ID: 307931

Abbreviations

ACHI	Australian Classification of Health Interventions
ADH	Atypical Ductal Hyperplasia
AIHW	Australian Institute of Health and Welfare
ALH	Atypical Lobular Hyperplasia
ASERNIP-S	Australian Safety & Efficacy Register of New Interventional Procedures -Surgical
CCV	Cancer Council Victoria
CDS	Consensus Data Set
CT	Computerised Tomography
DCIS	Ductal Carcinoma In Situ
ER	Oestrogen Receptor
FBE	Full Blood Examination
FNAC	Fine Needle Aspiration Cytology
GP	General Practitioner
ICD	International Classification Of Diseases
ICD-O	International Classification Of Diseases For Oncology
ICRU	International Commission On Radiation Units
ICS	Integrated Cancer Services
ISH	In Situ Hybridization
LCIS	Lobular Carcinoma In Situ
LNB	Lymph node biopsy
METeOR	Metadata Online Registry
MRI	Magnetic Resonance Imaging
NBCC	National Breast Cancer Centre
NBOCC	National Breast And Ovarian Cancer Centre
NHDD	National Health Data Dictionary
PD	Progressive Disease
PET	Positron Emission Tomography
PR	Progesterone Receptor
RACS	Royal Australian College of Surgeons
SNB	Sentinel node biopsy
UICC	International Union Against Cancer
US	Ultrasound
VCDS	Victorian Consensus Data Set
VCOG	Victorian Cooperative Oncology Group
VCR	Victorian Cancer Registry
WHO	World Health Organization

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