Testicular Cancer Data Set Specification

Long form

Exported from METeOR (AIHW's Metadata Online Registry)

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Data Set Specification contents

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Metadata items

Metadata items in this Data Set Specification

Seq No.	*Metadata item*	*Obligation*	*Max occurs*
1	Person—prior testicular cancer indicator, yes/no/unknown code N	Mandatory	1
2	Person with cancer—performance status score at diagnosis, Eastern Cooperative Oncology Group code N	Mandatory	0
3	Person with cancer—serum tumour marker test indicator, yes/no/not stated/inadequately described code N	Mandatory	0
4	Person with cancer—serum tumour marker test date, date DDMMYYYY	Conditional	99
5	Person with cancer—serum germ cell tumour marker test type, code N	Conditional	99
6	Person with cancer—immunohistochemistry indicator, yes/no/not stated/inadequately described code N	Mandatory	99
7	Person with cancer-diagnostic histology, yes/no/unknown code N	Mandatory	1
8	Person with testicular cancer-diagnostic histology location, code N	Conditional	99
9	Person—diagnostic imaging, testicular cancer diagnostic imaging type, code NN	Mandatory	9
10	Person—tissue sample collected indicator, yes/no code N	Mandatory	1
11	Tissue sample—malignancy and position, code NN	Conditional	29
12	Organisation—organisation name, text [X(200)]	Conditional	29
13	Person—blood sample indicator, yes/no code N	Conditional	1
14	Person—blood sample type, code N	Conditional	99
15	Person with cancer-extragonadal tumour indicator, yes/no/unknown/not stated/inadequately described code N	Mandatory	1
16	Person with cancer—extragonadal cancer site, code N	Conditional	4
17	Person with cancer—testicular cancer germ cell tumour histology type, code N	Mandatory	19
18	Person with cancer—germ cell tumour percentage, N[N].N	Mandatory	19
19	Person with cancer-International Germ Cell Cancer Collaborative Group Classification, Code N	Mandatory	19
20	Person with cancer—lymphovascular invasion, code N	Optional	1
21	Person with cancer—scrotal wall invasion, code N	Optional	1
22	Person with cancer—tunica albuginea invasion, code N	Optional	1
23	Person with cancer—tunica vaginalis invasion, code N	Optional	1
24	Person with cancer—epididymis invasion, code N	Optional	1
25	Person with cancer—rete testis invasion, code N	Optional	1
26	Person with cancer—spermatic cord invasion, code N	Optional	1
27	Person with cancer—intratubular germ cell neoplasia indicator, absent/present/unknown code N	Mandatory	1
28	Person with cancer—distant metastatic site(s) at diagnosis, code N[N]	Conditional	9
29	Patient—intention of treatment, code N	Conditional	1
30	Person with cancer—clinical trial entry status, code N	Mandatory	1
31	Person with cancer—clinical trial identifier, text X[X(399)]	Conditional	9
32	Cancer treatment—surgical procedure for testicular cancer, code N	Mandatory	9
33	Cancer treatment—testicular prosthesis indicator, yes/no/not applicable/not stated/inadequately described code N	Mandatory	2
34	Cancer treatment—retroperitoneal lymph node dissection node type, code N	Conditional	0
35	Cancer treatment—distance of closest surgical margin, total millimetres N[N]	Mandatory	0
36	Cancer treatment—spermatic cord margin at surgery indicator, positive/negative/unknown code	Mandatory	0
37	Person—sexual dysfunction indicator, yes/no/not stated/inadequately described code N	Mandatory	1
38	Person—testicular cancer sexual dysfunction type code N	Mandatory	9
39	Person—sexual dysfunction type, text X[X(149)]	Conditional	9
40	Person—sexual dysfunction treatment, text X[X(149)]	Conditional	19

41	Person—testosterone deficiency indicator, yes/no/not stated/inadequately described code N	Mandatory	1
42	Person—testosterone deficiency treatment, text X[X(149)]	Conditional	9
43	Person with cancer—bleomycin lung toxicity indicator, yes/no/not applicable code N	Mandatory	9
44	Person with cancer—fertility testing indicator, yes/no code N	Mandatory	1
45	Person with cancer—fertility testing date, DDMMYYYY	Conditional	10
46	Person—infertility indicator, yes/no/unknown code N	Conditional	0
47	Person with cancer—fertility preservation procedure indicator, yes/no/unknown code N	Mandatory	1
48	Person with cancer—fertility preservation procedure type, code N[N]	Conditional	0
49	Cancer treatment—cancer treatment type, code N[N]	Mandatory	0
50	Person with cancer—fertility preservation procedure type, text X[X(99)]	Conditional	0
51	Cancer treatment—other cancer treatment, text [X(150)]	Conditional	0
52	Person with cancer—distant metastatic cancer indicator, yes/no/not stated/inadequately described code N	Mandatory	1

Testicular Cancer Data Set Specification

Identifying and definitional attributes

Metadata item type: Data Set Specification

METeOR identifier: 555947

Registration status: *No registration status*

DSS type: Data Set Specification (DSS)

Scope: The purpose of the Testicular cancer (clinical) data set specification (TCDSS) is to define data standards for the national collection of testicular cancer clinical data so that data collected is consistent and reliable. Collection of this data set specification is not mandated but it is recommended as best practice if clinical cancer data for testicular cancer are to be collected. It will facilitate more consistent data collection while enabling individual treatment centres or health service areas to develop data extraction and collection processes and policies that are appropriate for their service settings.

The TCDSS is used in conjunction with the Cancer (clinical) data set specification (CCDSS). Mandatory reporting regulations have enabled population-based cancer registries in Australia to collect standard information on all incident cases of cancer apart from non-melanoma skin cancers, from which incidence, mortality and overall survival have been determined and trends monitored. The CCDSS provides a framework for the collection of more detailed and comprehensive clinical data such as stage of cancer at diagnosis, other prognostic characteristics, cancer treatment and patient outcomes.

The TCDSS will support prospective data collection from the time a person with cancer symptoms is referred or first presents to a hospital or specialist through the entire duration of their illness.

The definitions used in this data set specification are designed to capture the provision of cancer care on a day-to-day level. They relate to the cancer care pathway and the need to optimise care by correctly diagnosing, evaluating and managing patients with cancer. In addition, end-points and patterns of care can be monitored to understand both the appropriateness and effectiveness of cancer care.

The data elements specified provide a framework for:

- promoting the delivery of evidence-based care to patients with cancer
- facilitating the ongoing improvement in the quality and safety of cancer management in treatment settings
- improving the epidemiological and public health understanding of cancer
- informing treatment guidelines and professional education
- guiding resource planning and the evaluation of cancer control activities

They will facilitate the aggregation of data across different treatment centres.

The underlying long-term goal is to provide data support to improve outcomes for patients by increasing the quality and length of life. For example, a comparison of the actual management of patients with best practice guidelines may identify shortfalls in treatment and limitations in access to treatment modalities for some patients.

Collection and usage attributes

Implementation start date: 09/12/2013

Source and reference attributes

Submitting organisation: Cancer Australia

Cancer treatment—cancer treatment type, code N[N]

Identifying and definitional attributes

Short name: Cancer treatment type

METeOR identifier: 450298

Registration status: *No registration status*

Definition: The type of treatment administered for cancer, as represented by a code.

Data Element Concept: Cancer treatment—cancer treatment type

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N[N]

Maximum character length: 2

Permissible values:

Value	Meaning
1	Surgery only
2	Radiotherapy only
3	Systemic agent therapy only
4	Surgery and radiotherapy
5	Surgery and systemic agent therapy
6	Radiotherapy and systemic agent therapy
7	Surgery, radiotherapy and systemic agent therapy

Supplementary values:

97	Not applicable—treatment was not administered
98	Unknown whether treatment was administered
99	Treatment was administered but the type was not stated/inadequately described

Collection and usage attributes

Guide for use: More than one treatment type may be administered during a course of cancer treatment; select the appropriate code value.

Systemic agent therapy refers to:

- chemotherapy
- hormone therapy
- immunotherapy

Surgery includes:

- surgical procedure for cancer
- systemic therapy procedure involving surgery

A systemic therapy procedure is a medical, surgical or radiation procedure that has an effect on the hormonal or immunologic balance of the patient.

Treatments other than surgery, radiotherapy or systemic agent therapy administered as part of the treatment are recorded separately.

Source and reference attributes

Submitting organisation: Cancer Australia

Reference documents: American College of Surgeons 2002. Facility Oncology Registry Data Standards (FORDS), 2009 revision. Commission on Cancer, 28E

Data set specification specific attributes

Testicular Cancer Data Set Specification

DSS specific information: Use this element to record any treatment used for the recurrence of a testicular cancer.

Data element attributes

Collection and usage attributes

Guide for use: All treatments administered to the patient during a course of cancer treatment should be recorded.

When the patient has received treatment for cancer and codes 1 to 7 are recorded, the relevant treatment information for each treatment modality should also be collected.

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

Comments: The collection of specific treatment information is useful to evaluate patterns of care, the effectiveness of different treatment modalities, and treatment by patient outcome.

Source and reference attributes

Submitting organisation: Cancer Australia

Origin: Commission on Cancer, American College of Surgeons

New South Wales Health Department

Reference documents: American College of Surgeons 1998. Standards of the Commission on Cancer: Registry Operations and Data Standards (ROADS), Volume II. Commission on Cancer

Public Health Division 2001. NSW Clinical Cancer Data Collection for Outcomes and Quality. Data Dictionary Version 1. Sydney: NSW Health Department

Cancer treatment—other cancer treatment, text [X(150)]

Identifying and definitional attributes

Short name: Other cancer treatment description

METeOR identifier: 561623

Registration status: Health, Standard 08/05/2014

Definition: The cancer-directed treatment administered during the course of treatment for cancer, other than surgery, radiotherapy or systemic therapy, as represented by text.

Data Element Concept: Cancer treatment—other cancer treatment

Value domain attributes

Representational attributes

Representation class: Text

Data type: String

Format: [X(150)]

Maximum character length: 150

Source and reference attributes

Submitting organisation: Cancer Australia

Data set specification specific attributes

Testicular Cancer Data Set Specification

DSS specific information: Use this element to record any treatment used for the recurrence of a testicular cancer not outlined in Cancer treatment—cancer treatment type, code N[N].

Data element attributes

Collection and usage attributes

Guide for use: This data item is to record cancer-directed treatments that cannot be appropriately assigned to the specific treatment codes in the cancer treatment data items for surgery, radiotherapy, systemic therapy agents and systemic therapy procedures.

Cancer-directed treatments refer to those treatments that destroy or modify cancer tissue anywhere in the body. The exception to this is treatments for hematopoietic diseases (refer to additional notes below).

Cancer-directed treatments may be palliative (to control symptoms, alleviate pain, or make the patient more comfortable) or curative.

Record all other treatments administered during the course of treatment.

Each treatment event delivered to the patient should be recorded; multiple entries are permitted.

Record antibody treatments, vaccine treatments, and those targeted therapies that use drugs or substances other than chemotherapy agents in this data item. Targeted therapies using chemotherapy agents are recorded in the data items for chemotherapy. Targeted therapies are treatments that use drugs or other substances to identify and attack specific cancer cells.

Do not record ancillary drugs. For example, allopurinol, which is commonly used as prophylaxis with chemotherapy agents to prevent severe hyperuricemia. A list of drugs regarded as ancillary is available in the SEER*Rx-Interactive Antineoplastic Drugs Database Version 1.4.1.

Treatment events may include (for example):

- Treatment unique to hematopoietic diseases, for example, phlebotomy, transfusions or aspirin. ONLY record aspirin therapy used to thin the blood for symptomatic control of thrombocythemia. Do not record aspirin used for pain or cardiovascular protection.
- Embolisation that is performed using alcohol as an embolising agent or for embolisation to a site other than the liver where the embolising agent is unknown. Embolisation using chemotherapeutic agents is coded separately with chemotherapy, and embolisation using a radioactive agent or seeds is coded with brachytherapy-radiation treatment.
- Any experimental or newly developed treatment that cannot be appropriately assigned to other specific treatment data items.
- A double-blind clinical trial. Record the treatment actually administered to the patient in the appropriate treatment data item when the double-blind trial code is broken.
- Cancer treatments administered by non-medical personnel. This includes unconventional methods whether administered as single therapy or in combination with conventional therapies. Record alternative therapies only if the patient doesn't receive any other type of treatment.

Collection methods: The information should be obtained from the patient's medical record.

Comments: Information on other cancer treatments is used to describe and evaluate the quality of care and treatment practices.

Source and reference attributes

Submitting organisation: Cancer Australia

Reference documents: American College of Surgeons 2002. Facility Oncology Registry Data Standards (FORDS), 2009 revision. Commission on Cancer

American College of Surgeons 1998. Standards of the Commission on Cancer: Registry Operations and Data Standards (ROADS), Volume II. Commission on Cancer

Johnson CH & Adamo M (Editors) 2007. SEER Program Coding and Staging Manual 2007, MD 2008 revision. Bethesda:National Cancer Institute, NIH Publication number 07-5581

Relational attributes

Related metadata references: See also Cancer treatment—cancer treatment type, code N[N] Health, Standard 08/05/2014

Supersedes Cancer treatment—other cancer treatment, text [X(150)] Health, Superseded 08/05/2014

Implementation in Data Set Specifications: Cancer (clinical) DSS Health, Standard 08/05/2014

Gynaecological cancer (clinical) DSS Health, Standard 08/05/2014

Cancer treatment—spermatic cord margin at surgery indicator, positive/negative/unknown code

Identifying and definitional attributes

Short name: Spermatic cord margin

METeOR identifier: 564640

Registration status: *No registration status*

Definition: An indicator of the presence tumour at the margin of the spermatic cord at the time of surgery in a person with testicular cancer, as represented by a code.

Data Element Concept: Cancer treatment—spermatic cord margin at surgery indicator

Value domain attributes

Representational attributes

Representation class: Code

Data type: Boolean

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Positive
2	Negative

Supplementary values:

8	Unknown

Data element attributes

Collection and usage attributes

Guide for use: Record whether the tumour is present/involved with the spermatic cord margin, at the time of surgery.

When the tumour is involved with the spermatic cord this should be recorded as 'positive'. When the tumour is not involved with the spermatic cord this should be recorded as "negative. If there is no indication of the involvement of the tumour and the spermatic cord record unknown.

Collection methods: This information should be sought from the patient's surgical pathology report.

Source and reference attributes

Submitting organisation: Cancer Australia

Reference documents: Royal College of Pathologists of Australasia 2011. Testicular tumours structured reporting protocol (1st Edition). Sydney: RCPA

American College of Surgeons 2002. Facility Oncology Registry Data Standards (FORDS), 2011 revision. Commission on Cancer, page 211

Relational attributes

Related metadata references: See also Cancer treatment—lung cancer surgical margin qualifier, code N[N] Health, Standard 08/05/2014

Cancer treatment—surgical procedure for testicular cancer, code N

Identifying and definitional attributes

Short name: Surgical procedure for cancer

METeOR identifier: 567709

Registration status: *No registration status*

Definition: The testicular cancer-directed surgical procedure performed during the primary course of treatment for cancer, as represented by a code.

Data Element Concept: Cancer treatment—surgical procedure for cancer

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 2

Permissible values:

Value	Meaning
01	Simple orchidectomy
02	Partial orchidectomy
03	Inguinal (radical) orchidectomy
04	Lymph node biopsy
05	Retroperitoneal lymph node dissection
06	Debulking
07	Exploratory
08	Other
09	Orchidectomy - type unspecified

Supplementary values:

00	Not applicable
99	Not stated/inadequately described

Collection and usage attributes

Guide for use: Use this codeset to record the surgical procedure used in the treatment of prostate cancer. Where "other" is recorded, please complete Cancer treatment—other cancer treatment, text [X(150)].

Code 00 (not applicable) applies where no surgery has been completed, and code 99 (not stated/inadequately described) applies when surgery has been completed but they type of surgery is not able to be determined.

Source and reference attributes

Submitting organisation: Cancer Australia

Data element attributes

Collection and usage attributes

Guide for use: The procedure code is collected for all cancer-directed surgery performed during initial treatment for testicular cancer. The initial treatment includes all treatments performed from diagnosis and before disease progression or recurrence.

Testicular cancer-directed surgery refers to all surgery that destroys, removes or modifies testicular cancer tissue, including the primary site, lymph nodes and other associated tissue.

Cancer-directed surgery may be palliative (to control symptoms, alleviate pain, or make the patient more comfortable), or curative.

The procedure code for each surgical treatment episode should be entered separately.

Collection methods: This information should be obtained from the patient's medical record, specifically the anatomical (surgical) pathology report.

Comments: The collection of specific treatment information is useful to evaluate patterns of care, the effectiveness of different treatment modalities, and treatment by patient outcome.

Source and reference attributes

Submitting organisation: Cancer Australia

Relational attributes

Related metadata references: See also Cancer treatment—surgical procedure date, DDMMYYYY Health, Superseded 08/05/2014

See also Surgical procedure Health, Standard 07/12/2011

Cancer treatment—testicular prosthesis indicator, yes/no/not applicable/not stated/inadequately described code N

Identifying and definitional attributes

Short name:	Testicular prosthesis indicator
METeOR identifier:	567762
Registration status:	*No registration status*
Definition:	An indicator of whether a testicular prosthesis was implanted as part of a surgical procedure for cancer, as represented by a code.
Data Element Concept:	Cancer treatment—Testicular prosthesis indicator

Value domain attributes

Representational attributes

Representation class:	Code
Data type:	Number
Format:	N
Maximum character length:	1

Permissible values:

Value	Meaning
1	Yes
2	No

Supplementary values:

7	Not applicable
9	Not stated/inadequately described

Source and reference attributes

Submitting organisation:	Australian Institute of Health and Welfare

Data element attributes

Collection and usage attributes

Guide for use:	Record whether a testicular prosthesis was implanted as part of a surgical procedure for cancer. A testicular prosthesis is implanted for aesthetic purposes.

Source and reference attributes

Submitting organisation:	Cancer Australia

Organisation—organisation name, text [X(200)]

Identifying and definitional attributes

Short name:	Organisation name
Synonymous names:	Business name; Entity name
METeOR identifier:	453823
Registration status:	Community Services, Standard 06/02/2012 Health, Standard 08/05/2014 Early Childhood, Standard 09/03/2012
Definition:	The full title of an organisation's name by which it trades or is recognised, as represented by text.
Data Element Concept:	Organisation—organisation name

Value domain attributes

Representational attributes

Representation class:	Text
Data type:	String
Format:	[X(200)]
Maximum character length:	200

Data set specification specific attributes

Testicular Cancer Data Set Specification

Conditional obligation:	Record this item if tissue related to diagnostic histology has been stored.
DSS specific information:	Record the name of the biospecimen bank that is storing tissue relating to diagnostic histology.

Data element attributes

Collection and usage attributes

Guide for use:	An organisation may have multiple names. Naming standards for incorporated companies are defined in the Australian Securities and Investments Commission (ASIC), Schedule 6 of the Corporation Regulations.
Collection methods:	If special characters or symbols form part of the name they should be included. This includes all characters from the standard printable ASCII character set such as the letters A-Z, hyphens, commas, apostrophes, @, # etc, as well as the non-standard or extended ASCII characters such as ü, á, é, ®, ™etc. Mixed case should be used rather than upper case only.

Source and reference attributes

Submitting organisation:	Australian Institute of Health and Welfare
Origin:	Standards Australia 2006. AS 4590—2006 Interchange of client information. Sydney: Standards Australia.

Relational attributes

Related metadata references:	Supersedes Service provider organisation (name)—organisation name, text [X(200)] Community Services, Superseded 06/02/2012, Health, Superseded 08/05/2014, Early Childhood, Superseded 09/03/2012
Implementation in Data Set Specifications:	Early Childhood Education and Care: Aggregate NMDS 2014 Early Childhood, Standard 28/05/2014 Early Childhood Education and Care: Unit Record Level NMDS 2014 Early Childhood, Standard 28/05/2014 Gynaecological cancer (clinical) DSS Health, Standard 08/05/2014

Patient—intention of treatment, code N

Identifying and definitional attributes

Short name: Intention of treatment

METeOR identifier: 448134

Registration status: Health, Standard 07/12/2011

Definition: The reason treatment is provided to a patient, as represented by a code.

Data Element Concept: Patient—intention of treatment

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Prophylactic
2	Curative
3	Palliative

Supplementary values:

9	Not stated/inadequately described

Collection and usage attributes

Guide for use:

CODE 1 Prophylactic

This code is used for treatment to prevent the occurrence or spread of disease.

CODE 2 Curative

This code is used when treatment is given for control of the disease.

CODE 3 Palliative

This code is used when treatment is given primarily for the purpose of pain control. Other benefits of the treatment are considered secondary contributions to quality of life.

CODE 9 Not stated/inadequately described

This code is used when treatment was administered and the intention was not stated or was inadequately described. This code is not intended for use in primary data collection but can be assigned for reporting purposes where there is missing data.

Data element attributes

Relational attributes

Implementation in Data Set Specifications:

Lung cancer (clinical) DSS Health, Standard 08/05/2014

Radiotherapy waiting times DSS 2012-13 Health, Standard 07/12/2011

Person with cancer-diagnostic histology, yes/no/unknown code N

Identifying and definitional attributes

Technical name: Person with cancer-diagnostic histology, yes/no/unknown code N

METeOR identifier: 487283

Registration status: *No registration status*

Definition: Whether a tissue specimen was collected and examined histologically for the purpose of cancer diagnosis, as outlined by a code.

Data Element Concept: Person with cancer—diagnostic histology

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Yes
2	No

Supplementary values:

8	Unknown

Data element attributes

Collection and usage attributes

Guide for use: This data item can be completed for any tissue source, including orchidectomy, collected for the purposes of diagnosis.

Record whether a tissue specimen was collected and examined histologically for the purpose of cancer diagnosis.

Collection methods: Collect from patient medical records or pathology reports.

Source and reference attributes

Submitting organisation: Cancer Australia

Relational attributes

Related metadata references:

See also Person with cancer—biopsy tumour extent, percentage N[NNN] *No registration status*

See also Person with prostate cancer—tissue collection method code N *No registration status*

See also Person with testicular cancer-diagnostic histology location, code N *No registration status*

Person with cancer-extragonadal tumour indicator, yes/no/unknown/not stated/inadequately described code N

Identifying and definitional attributes

Technical name: Person with cancer-extragonadal tumour indicator, yes/no/unknown/not stated/inadequately described code N

METeOR identifier: 558156

Registration status: *No registration status*

Definition: An indicator of the existence of germ cell cancer outside of the gonads in a person with cancer, as outlined by a code.

Data Element Concept: Person with cancer-extragonadal tumour indicator

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Yes
2	No

Supplementary values:

3	Unknown
9	Not stated/inadequately described

Source and reference attributes

Submitting organisation: Australian Institute of Health and Welfare

Data element attributes

Collection and usage attributes

Guide for use: Report whether a germ cell tumour has been found outside of the gonads in a person with cancer.

Source and reference attributes

Submitting organisation: Cancer Australia

Person with cancer—bleomycin lung toxicity indicator, yes/no/not applicable code N

Identifying and definitional attributes

Technical name:	Person with cancer—bleomycin lung toxicity indicator, yes/no/not applicable code N
METeOR identifier:	582905
Registration status:	*No registration status*
Definition:	An indicator of whether a person with cancer has indications of bleomycin lung toxicity, as represented by a code.
Data Element Concept:	Person with cancer—bleomycin lung toxicity indicator

Value domain attributes

Representational attributes

Representation class:	Code
Data type:	Number
Format:	N
Maximum character length:	1

Permissible values:

Value	Meaning
1	Yes
2	No

Supplementary values:

9	Not applicable

Source and reference attributes

Submitting organisation:	Australian Institute of Health and Welfare

Data element attributes

Collection and usage attributes

Guide for use:	Report whether a person with cancer has indications of bleomycin lung toxicity. Indications of bleomycin lung toxicity include the following symptoms: reduced lung function, fever, rash, dermatographism, hyperpigmentation, alopecia, Raynaud's phenomenon and oxygen toxicity after treatment with bleomycin. This may result also in pulmonary fibrosis. Record *not applicable* when the person with cancer has not been treated using bleomycin.
Collection methods:	Collection from patient medical records.

Source and reference attributes

Submitting organisation:	Cancer Australia

Person with cancer—clinical trial entry status, code N

Identifying and definitional attributes

Short name: Clinical trial entry status

Synonymous names: Clinical trial use

METeOR identifier: 430028

Registration status: Health, Standard 08/05/2014

Definition: The status of clinical trial acceptance for the person with cancer, as represented by a code.

Data Element Concept: Person with cancer—clinical trial entry status

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Clinical trial entry not offered
2	Clinical trial entry offered and accepted
3	Clinical trial entry offered and declined
4	Clinical trial not available

Supplementary values:

8	Unknown whether clinical trial entry offered
9	Clinical trial entry offered but patient response not stated/inadequately described

Source and reference attributes

Submitting organisation: Cancer Australia

Reference documents: Royal College of Physicians of London 1999. Lung cancer: a core data set. London: Royal College of Physicians of London

Data element attributes

Collection and usage attributes

Guide for use: Record the appropriate code number for clinical trial proposed or entered throughout the course of treatment for cancer.

If this data item is coded as 2 Clinical trial entry offered and accepted, Person with cancer—clinical trial identification, text [X(399)] must also be completed.

Collection methods: This information should be sought from the patient's medical record.

Comments: A measurement of the percentage of patients entering clinical trials may have implications for access to, and the provision of, cancer services.

The collection of specific treatment information is useful to evaluate patterns of care, the effectiveness of different treatment modalities, and treatment by patient outcome.

Source and reference attributes

Submitting organisation: Cancer Australia

Reference documents: Royal College of Physicians of London 1999. Lung cancer: a core data set. London: Royal College of Physicians of London

Stedman TL 2006. Stedman's Medical Dictionary. 28th edition. Maryland: Lippincott Williams & Wilkins

Relational attributes

Related metadata references:	See also Person with cancer—clinical trial identifier, text X[X(399)] Health, Standard 08/05/2014 See also Person with cancer—date clinical trial entered, DDMMYYYY Health, Standard 08/05/2014
Implementation in Data Set Specifications:	Lung cancer (clinical) DSS Health, Standard 08/05/2014

Person with cancer—clinical trial identifier, text X[X(399)]

Identifying and definitional attributes

Short name: Clinical trial name and number

METeOR identifier: 430953

Registration status: Health, Standard 08/05/2014

Definition: The scientific/public title and/or registration number of the clinical trial(s) in which the person with cancer is enrolled, as represented by text.

Data Element Concept: Person with cancer—clinical trial identifier

Value domain attributes

Representational attributes

Representation class: Text

Data type: String

Format: X[X(399)]

Maximum character length: 400

Data set specification specific attributes

Testicular Cancer Data Set Specification

Conditional obligation: Collect if Person with cancer—clinical trial entry status, code N equals 2 (clinical trial offered and accepted).

Data element attributes

Collection and usage attributes

Guide for use: Record the scientific/public title and/or registration number of the clinical trial(s) in which the person with cancer is enrolled.

This item is completed when a person with cancer has been offered and accepted clinical trial entry.

Where available record the title in line with the Australian New Zealand Clinical Trials Register (ANZCTR) public title and universal trial number (UTN).

Collection methods: This information should be sought from the patient's medical record.

Comments: Information regarding the types of clinical trials patients are enrolled in may have implications for access to, and the provision of, cancer services.

The collection of specific treatment information may also be useful to evaluate patterns of care, the effectiveness of different treatment modalities, and treatment by patient outcome.

Source and reference attributes

Submitting organisation: Cancer Australia

Reference documents: National Breast and Ovarian Cancer Centre 2009. Breast cancer specific data items for clinical cancer registration. Surry Hills, NSW: National Breast and Ovarian Cancer Centre

Relational attributes

Related metadata references: See also Person with cancer—clinical trial entry status, code N Health, Standard 08/05/2014

See also Person with cancer—date clinical trial entered, DDMMYYYY Health, Standard 08/05/2014

See also Person with cancer—research trial type, code N Health, Recorded 14/04/2014

Implementation in Data Set Lung cancer (clinical) DSS Health, Standard 08/05/2014

Specifications:

Person with cancer—distant metastatic site(s) at diagnosis, code N[N]

Identifying and definitional attributes

Short name: Distant metastatic site

METeOR identifier: 424239

Registration status: Health, Standard 08/05/2014

Definition: The anatomical position (topography) of the secondary or distant metastatic site(s) identified in the person with cancer at diagnosis, as represented by a code.

Data Element Concept: Person with cancer—distant metastatic site(s) at diagnosis

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N[N]

Maximum character length: 2

Permissible values:

Value	Meaning
1	Lung
2	Liver
3	Bowel
4	Bone
5	Brain
88	Other

Supplementary values:

99	Metastatic spread indicated but site not stated/inadequately described

Collection and usage attributes

Guide for use: This code set represents common sites of cancer metastasis. Where multiple sites occur, all should be recorded.

Source and reference attributes

Reference documents: Pecorelli, S. 25th Annual Report on the Results of Treatment in Gynecological Cancer. International Journal of Gynecology & Obstetrics 2003, 83 (Supp 1): 1-230

Endometrial Cancer Structured Reporting Protocol (1st Edition 2010) © RCPA 2010

The new FIGO staging system for cancers of the vulva, cervix, endometrium and sarcomas; Gynecologic Oncology 115 (2009) 325–328

Data element attributes

Collection and usage attributes

Guide for use: Record sites of metastases. Where multiple sites occur, all should be recorded.

Collection methods: Collect from patient medical records.

Source and reference attributes

Submitting organisation: Cancer Australia

Reference documents: Pecorelli, S. 25th Annual Report on the Results of Treatment in Gynecological Cancer. International Journal of Gynecology & Obstetrics 2003, 83 (Supp 1): 1-230. RCPA (2011). Endometrial Cancer Structured Reporting Protocol (1st Edition 2011)

Mutch, D G (2009). The new FIGO staging system for cancers of the vulva, cervix, endometrium and sarcomas. Gynecologic Oncology. 115: 325–328

Relational attributes

Implementation in Data Set Specifications: Gynaecological cancer (clinical) DSS Health, Standard 08/05/2014

Person with cancer—epididymis invasion, code N

Identifying and definitional attributes

Short name: Epididymis invasion

METeOR identifier: 558480

Registration status: *No registration status*

Definition: The presence or absence of the invasion of cancer cells into the epididymis, as represented by a code.

Data Element Concept: Person with cancer—epididymis invasion

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Present
2	Absent
3	Suspicious

Supplementary values:

9	Not stated or unknown

Collection and usage attributes

Guide for use:

Source and reference attributes

Submitting organisation: Cancer Australia

Data element attributes

Collection and usage attributes

Guide for use: The presence of epididymis invasion should be recorded as Code 1, regardless of whether the extent of the invasion is described or not.

Collection methods: 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 pathology report pertaining to initial diagnosis is for a metastasis, and not the primary tumour, record as 9.

Comments: This item is included in data items defined for reporting in the pathology reporting guidelines as prepared by the Royal College of Pathologists of Australasia.

Source and reference attributes

Submitting organisation: Cancer Australia

Origin: Royal College of Pathologists of Australasia (RCPA)

Reference documents: Royal College of Pathologists of Australasia 2011. *Testicular tumours structured reporting protocol (1st Edition). Sydney: RCPA*

Person with cancer—extragonadal cancer site, code N

Identifying and definitional attributes

Technical name: Person with cancer—extragonadal cancer site, code N

METeOR identifier: 558168

Registration status: *No registration status*

Definition: The site in which an extragonadal germ cell cancer is located in a person with cancer, as outlined by a code.

Data Element Concept: Person with cancer—extragonadal cancer site

Value domain attributes

Representational attributes

Representation class: Average

Data type: Boolean

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Retroperitoneum
2	Mediastinum
3	Pineal gland
4	Other

Supplementary values:

8	Unknown
9	Not stated/inadequately described

Source and reference attributes

Submitting organisation: Cancer Australia

Data set specification specific attributes

Testicular Cancer Data Set Specification

Conditional obligation: Collect this item when Person with cancer-extragonadal tumour indicator, yes/no/unknown/not stated/inadequately described code N indicates the existence of an extragonadal germ cell cancer.

Data element attributes

Collection and usage attributes

Guide for use: Report whether an extragonadal germ cell tumour has been found in a person with cancer.

Source and reference attributes

Submitting organisation: Cancer Australia

Person with cancer—germ cell tumour percentage, N[N].N

Identifying and definitional attributes

Short name:	Germ cell tumour percentage
METeOR identifier:	564596
Registration status:	*No registration status*
Definition:	The percentage of a germ cell tumour that is involved by a particular histology type in a person with cancer, as outlined by a code.
Data Element Concept:	Person with cancer—germ cell tumour percentage

Value domain attributes

Representational attributes

Representation class:	Percentage
Data type:	Number
Format:	N[N].N
Maximum character length:	3

Supplementary values:

Value	Meaning
99.9	Not stated/inadequately described

Data element attributes

Collection and usage attributes

Guide for use:	Record the percentage of a germ cell tumour that is involved by a particular histology type in a person with cancer. This needs to be recorded in conjunction with Person with cancer—testicular cancer germ cell tumour histology type, code N or Person with cancer—morphology of cancer, code (ICD-O-3) NNNN/N to define which histology type each percentage refers to. If the germ cell tumour is mixed and multiple histology types are available this item should be recorded multiple times.
Collection methods:	Collect from patient pathology reports and medical records.

Person with cancer—immunohistochemistry indicator, yes/no/not stated/inadequately described code N

Identifying and definitional attributes

Short name: Immunohistochemistry yes/no/pending

METeOR identifier: 390595

Registration status: Health, Proposed 13/01/2012

Definition: An indicator of whether immunohistochemistry tests have been undertaken in relation to a person with cancer, outlined by a code.

Data Element Concept: Person with cancer—immunohistochemistry

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Yes
2	No

Supplementary values:

9	Not stated/inadequately described

Collection and usage attributes

Guide for use:

CODE 9 Not stated/inadequately described

This code is not for use in primary data collections.

Data element attributes

Collection and usage attributes

Guide for use: Record whether any immunohistochemistry tests have been, or intend to be undertaken in relation to a person with cancer.

Immunohistochemistry is a technique used in the evaluation of pathology specimens to analyse and identify cell types based on the binding of antibodies to specific components (antigens) of the cell. Immunohistochemistry may be useful, for example, to distinguish between primary and metastatic tumours, identify where the tumour originated if the primary is unknown, and help reach a diagnosis when there is limited biopsy material available for morphological assessment.
Examples of immunohistochemistry test types include c-kit; CD30; cytokeratin AE1/3; glypican-3; human chorionic gonadotropin; OCT3/4; NONOG; p36; placenta-like alkaline phosphotase; topoisomerase 11 and VASA

Collection methods: This information should be sought from the patient's medical record and pathology reports.

Source and reference attributes

Submitting organisation: Cancer Australia

Relational attributes

Related metadata references: See also Person with cancer—immunohistochemistry stains, text X[(100)] Health, Proposed 13/01/2012

Person with cancer—germ cell neoplasia in situ indicator, absent/present/unknown code N

Identifying and definitional attributes

Short name: Germ cell neoplasia in situ

METeOR identifier: 564624

Registration status: *No registration status*

Definition: An indicator of the presence of germ cell neoplasia in situ (GCNIS) in a person with cancer, as represented by a code.

Data Element Concept: Person with cancer—germ cell neoplasia in situ indicator

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Absent
2	Present

Supplementary values:

8	Unknown

Data element attributes

Collection and usage attributes

Guide for use: Indicate whether the presence of germ cell neoplasia in situ (GCNIS) has been found in as part of diagnostic procedures for a person with cancer.

Collection methods: Collection of this data item should only be from pathology reports or patient medical records.

Source and reference attributes

Submitting organisation: Cancer Australia

Origin: Royal College of Pathologists of Australasia (RCPA)

Reference documents: Royal College of Pathologists of Australasia 2011. *Testicular tumours structured reporting protocol (1st Edition). Sydney: RCPA*

Person with cancer—lymphovascular invasion, code N

Identifying and definitional attributes

Short name:	Lymphovascular invasion
METeOR identifier:	370618
Registration status:	Health, Standard 06/03/2009
Definition:	The presence or absence of the invasion of cancer cells into blood vessel(s) and/or the lymphatic system, as represented by a code.
Data Element Concept:	Person with cancer—lymphovascular invasion

Value domain attributes

Representational attributes

Representation class:	Code
Data type:	Number
Format:	N
Maximum character length:	1

Permissible values:

Value	Meaning
1	Present
2	Absent
3	Suspicious

Supplementary values:

9	Not stated or unknown

Data element attributes

Collection and usage attributes

Guide for use:

The presence of lymphovascular invasion (which may be synonymous with vascular invasion in pathology reports) should be recorded as Code 1, regardless of whether the extent of the invasion is described or not.

CODE 3 Suspicious applies if the wording for invasion implies uncertainty (i.e.: it is not clear if invasion is present or absent)

Collection methods:

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.

For testicular cancer, lymphovascular invasion would be assessed following surgery (not from a biopsy).

If pathology report pertaining to initial diagnosis is for a metastasis, and not the primary tumour, record as 9.

Comments:

Invasion of the lymphatics or blood vessels by cancer cells is an important prognostic factor that indicates that the tumour is likely to spread. This item is included in data items defined for reporting in the pathology reporting guidelines as prepared by the National Breast and Ovarian Cancer Centre and Australian Cancer Network.

Source and reference attributes

Origin:

National Breast and Ovarian Cancer Centre (NBOCC)

Australasian Association of Cancer Registries (AACR)

Australian Institute of Health and Welfare (AIHW)

Reference documents:

National Breast and Ovarian Cancer Centre and Australian Cancer Network. The Pathology reporting of breast cancer. A guide for pathologists, surgeons, radiologists and oncologists (3rd edition). National Breast and Ovarian Cancer Centre, Surry Hills, NSW, 2008.

Relational attributes

Specifications:

Implementation in Data Set

Person with cancer—rete testis invasion, code N

Identifying and definitional attributes

Short name: Rete testis invasion

METeOR identifier: 558390

Registration status: *No registration status*

Definition: The presence or absence of the invasion of cancer cells into the rete testis, as represented by a code.

Data Element Concept: Person with cancer—rete testis invasion

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Present
2	Absent
3	Suspicious

Supplementary values:

9	Not stated or unknown

Collection and usage attributes

Guide for use: Rete testis invasion is the direct invasion of tumour into the stroma of the rete testis and does not include pagetoid spread of ITGCN into the tubules of the rete.

Source and reference attributes

Submitting organisation: Cancer Australia

Data element attributes

Collection and usage attributes

Guide for use: The presence of rete testis invasion should be recorded as Code 1, regardless of whether the extent of the invasion is described or not.

Collection methods: 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 pathology report pertaining to initial diagnosis is for a metastasis, and not the primary tumour, record as 9.

Comments: This item is included in data items defined for reporting in the pathology reporting guidelines as prepared by the Royal College of Pathologists of Australasia.

Source and reference attributes

Submitting organisation: Cancer Australia

Origin: Royal College of Pathologists of Australasia (RCPA)

Reference documents: Royal College of Pathologists of Australasia 2011. *Testicular tumours structured reporting protocol (1st Edition). Sydney: RCPA*

Person with cancer—serum germ cell tumour marker test type, code N

Identifying and definitional attributes

Short name: Serum tumour marker test type

METeOR identifier: 564294

Registration status: *No registration status*

Definition: The type of test taken to determine whether specific markers of a germ cell tumour are present in blood of a person with cancer, as represented by a code.

Data Element Concept: Person with cancer—serum tumour marker test type

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Alpha-fetoprotein (AFP)
2	Beta-human chrorionic gonadotrophin (beta-hCG)
3	Lactate dehydrogenase (LDH)
4	Other

Supplementary values:

9	Not stated/inadequately described

Collection and usage attributes

Guide for use: A codeset outlining the common test types for germ cell tumour markers. Record other if the specific test type is not included. This should be recorded multiple times if multiple tumour markers have been assessed in a single test.

Source and reference attributes

Submitting organisation: Cancer Australia

Data set specification specific attributes

Testicular Cancer Data Set Specification

Conditional obligation: Collect if Person with cancer—serum tumour marker test indicator, yes/no/not stated/inadequately described code N equals yes.

Data element attributes

Collection and usage attributes

Guide for use: Record the type of test completed to determine if specific markers of a germ cell tumour are present in a blood sample of a person with cancer. This item should be recorded in conjunction with Person with cancer—serum tumour marker test indicator, yes/no/not stated/inadequately described code N and Person with cancer—serum tumour marker test date, date DDMMYYYY.

The presence and level of these tumour markers is an indicator of the presence of a germ cell tumour and may indicate the germ cell tumour type. If elevated at diagnosis changes in the levels of these markers may be indicative of the tumour's response to treatment.

Collection methods: This should be obtained from patient medical records or pathology reports.

Source and reference attributes

Submitting organisation: Cancer Australia

Person with cancer—serum tumour marker test date, date DDMMYYYY

Identifying and definitional attributes

Short name: Serum tumour marker test date

METeOR identifier: 564278

Registration status: *No registration status*

Definition: The date that a test to determine whether specific markers of tumours are present in blood was completed for a person with cancer, as represented by a code.

Data Element Concept: Person with cancer—serum tumour marker test date

Value domain attributes

Representational attributes

Representation class: Date

Data type: Date/Time

Format: DDMMYYYY

Maximum character length: 8

Data set specification specific attributes

Testicular Cancer Data Set Specification

Conditional obligation: Collect if Person with cancer—serum tumour marker test indicator, yes/no/not stated/inadequately described code N equals yes.

Data element attributes

Collection and usage attributes

Guide for use: Record the date that a test to determine if specific markers of a tumour are present in blood has been completed for a person with cancer. This item should be recorded in conjunction with...

Collection methods: This should be obtained from patient medical records or pathology reports.

Source and reference attributes

Submitting organisation: Cancer Australia

Person with cancer—serum tumour marker test indicator, yes/no/not stated/inadequately described code N

Identifying and definitional attributes

Short name: Serum tumour marker test indicator

METeOR identifier: 564264

Registration status: *No registration status*

Definition: An indicator outlining if a test to determine whether specific markers of a tumour are present in blood has been completed for a person with cancer, as represented by a code.

Data Element Concept: Person with cancer—serum tumour marker test indicator

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Yes
2	No

Supplementary values:

9	Not stated/inadequately described

Collection and usage attributes

Guide for use: CODE 9 Not stated/inadequately described

This code is not for use in primary data collections.

Data element attributes

Collection and usage attributes

Guide for use: Record whether a test to determine if specific markers of a tumour are present in blood has been completed for a person with cancer. This item should be recorded in conjunction with Person with cancer—serum tumour marker test date, date DDMMYYYY.

Examples of serum tumour marker tests include alpha-fetoprotein (AFP); beta human chorionic (beta-HCG); and lactate dehydrogenase (LHD).

Collection methods: This should be obtained from patient medical records or pathology reports.

Source and reference attributes

Submitting organisation: Cancer Australia

Person with cancer—spermatic cord invasion, code N

Identifying and definitional attributes

Short name: Spermatic cord invasion

METeOR identifier: 558499

Registration status: *No registration status*

Definition: The presence or absence of the invasion of cancer cells into the spermatic cord, as represented by a code.

Data Element Concept: Person with cancer—spermatic cord invasion

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Present
2	Absent
3	Suspicious

Supplementary values:

9	Not stated or unknown

Collection and usage attributes

Guide for use:

Source and reference attributes

Submitting organisation: Cancer Australia

Data element attributes

Collection and usage attributes

Guide for use: The presence of spermatic cord invasion should be recorded as Code 1, regardless of whether the extent of the invasion is described or not.

Collection methods: 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 pathology report pertaining to initial diagnosis is for a metastasis, and not the primary tumour, record as 9.

Comments: This item is included in data items defined for reporting in the pathology reporting guidelines as prepared by the Royal College of Pathologists of Australasia.

Source and reference attributes

Submitting organisation: Cancer Australia

Origin: Royal College of Pathologists of Australasia (RCPA)

Reference documents: Royal College of Pathologists of Australasia 2011. *Testicular tumours structured reporting protocol (1st Edition). Sydney: RCPA*

Person with cancer—testicular cancer germ cell tumour histology type, code N

Identifying and definitional attributes

Technical name: Person with cancer—testicular cancer germ cell tumour histology type, code N

METeOR identifier: 558345

Registration status: *No registration status*

Definition: The histology type of the germ cell tumour in a person with cancer, as outlined by a code.

Data Element Concept: Person with cancer—germ cell cancer histology type

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: NN

Maximum character length: 2

Permissible values:

Value	Meaning
1	Seminoma
2	Embryonal carcinoma
3	Yolk sac tumour
4	Choriocarcinoma
5	Teratoma
6	Teratoma with secondary somatic type malignant component
7	Monodermal teratoma
8	Spermatocytic seminoma
9	Spermatocytic seminoma with a sarcomatous component
10	Placental trophoblastic tumour
11	Mixed germ cell sex cord stromal tumour: gonadoblastoma
12	Mixed germ cell sex cord stromal tumour: other

Supplementary values:

99	Not stated/inadequately described

Collection and usage attributes

Guide for use: A codeset outlining the histology type for germ cell tumours for testicular cancer. Monodermal teratomas include carcinoid, primitive neuroectodermal tumour and other.

Source and reference attributes

Submitting organisation: Cancer Australia

Data element attributes

Source and reference attributes

Submitting organisation: Cancer Australia

Person with cancer—tunica albuginea invasion, code N

Identifying and definitional attributes

Short name: Tunica albuginea invasion ***METeOR identifier:*** 558454

Registration status: *No registration status*

Definition: The presence or absence of the invasion of cancer cells into the tunica albuginea, as represented by a code.

Data Element Concept: Person with cancer—tunica albuginea invasion

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Present
2	Absent
3	Suspicious

Supplementary values:

9	Not stated or unknown

Collection and usage attributes

Guide for use:

Source and reference attributes

Submitting organisation: Cancer Australia

Data element attributes

Collection and usage attributes

Guide for use: The presence of tunica albuginea invasion should be recorded as Code 1, regardless of whether the extent of the invasion is described or not.

Collection methods: 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 pathology report pertaining to initial diagnosis is for a metastasis, and not the primary tumour, record as 9.

Comments: This item is included in data items defined for reporting in the pathology reporting guidelines as prepared by the Royal College of Pathologists of Australasia.

Source and reference attributes

Submitting organisation: Cancer Australia

Origin: Royal College of Pathologists of Australasia (RCPA)

Reference documents: Royal College of Pathologists of Australasia 2011. *Testicular tumours structured reporting protocol (1st Edition). Sydney: RCPA*

Person with cancer—tunica vaginalis invasion, code N

Identifying and definitional attributes

Short name: Tunica vaginalis invasion

METeOR identifier: 558474

Registration status: *No registration status*

Definition: The presence or absence of the invasion of cancer cells into the tunica vaginalis, as represented by a code.

Data Element Concept: Person with cancer—tunica vaginalis invasion

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Present
2	Absent
3	Suspicious

Supplementary values:

9	Not stated or unknown

Collection and usage attributes

Guide for use:

Source and reference attributes

Submitting organisation: Cancer Australia

Data element attributes

Collection and usage attributes

Guide for use: The presence of tunica vaginalis invasion should be recorded as Code 1, regardless of whether the extent of the invasion is described or not.

Collection methods: 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 pathology report pertaining to initial diagnosis is for a metastasis, and not the primary tumour, record as 9.

Comments: This item is included in data items defined for reporting in the pathology reporting guidelines as prepared by the Royal College of Pathologists of Australasia.

Source and reference attributes

Submitting organisation: Cancer Australia

Origin: Royal College of Pathologists of Australasia (RCPA)

Reference documents: Royal College of Pathologists of Australasia 2011. *Testicular tumours structured reporting protocol (1st Edition). Sydney: RCPA*

Person with testicular cancer-diagnostic histology location, code N

Identifying and definitional attributes

Technical name: Person with testicular cancer-diagnostic histology location, code N

METeOR identifier: 558072

Registration status: *No registration status*

Definition: The location that tissue was removed from for purpose of testicular cancer diagnosis for a person with testicular cancer, as outlined by a code.

Data Element Concept: Person with testicular cancer—diagnostic histology location

Value domain attributes

Representational attributes

Representation class: Average

Data type: Boolean

Format: NN

Maximum character length: 2

Permissible values:

Value	Meaning
1	Right testicle
2	Left testicle
3	Supraclavicular lymph node
4	Retroperitoneal lymph node
5	Lung
6	Other
8	Unknown
9	Not available/inadequately specified

Collection and usage attributes

Guide for use: This data item can be completed for any tissue source, including orchidectomy, collected for the purposes of diagnosis.

A codeset outlining the location from which a biopsy was taken for the purpose of testicular cancer diagnosis and staging. Lymph node and lung locations are included as they are the most common sites of testicular cancer metastases.

Source and reference attributes

Submitting organisation: Cancer Australia

Data set specification specific attributes

Testicular Cancer Data Set Specification

Conditional obligation: Collect when Person with cancer-diagnostic histology, yes/no/unknown code N equals yes.

Data element attributes

Collection and usage attributes

Guide for use: Record the location that tissue was removed from for the purpose of testicular cancer diagnosis.

Collection methods: Collect from patient medical records or pathology reports.

Source and reference attributes

Submitting organisation: Cancer Australia

Relational attributes

Related metadata references: See also Person with cancer-diagnostic histology, yes/no/unknown code N *No registration status*

Person—blood sample indicator, yes/no code N

Identifying and definitional attributes

Short name: Blood sample collected

METeOR identifier: 446558

Registration status: Health, Proposed 13/01/2012

Definition: An indicator of whether blood or blood sample derivatives have been collected from a person for research purposes, as indicated by a code.

Data Element Concept: Person—blood sample indicator

Value domain attributes

Representational attributes

Representation class: Code

Data type: Boolean

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Yes
2	No

Data element attributes

Collection and usage attributes

Guide for use: Record whether a blood or blood sample derivative has been collected for a person for research purposes. This includes whole blood, serum, plasma, DNA, RNA and cell lines.

Collection methods: To be sought from medical, pathology, laboratory or biobank records.

Source and reference attributes

Submitting organisation: Cancer Australia

Relational attributes

Related metadata references: See also Person—blood sample type, code N Health, Proposed 13/01/2012

Person—blood sample type, code N

Identifying and definitional attributes

Short name: Blood sample type

METeOR identifier: 441120

Registration status: Health, Proposed 13/01/2012

Definition: The type of blood sample or processed blood derivatives sample collected from a patient for research purposes, as represented by a code.

Data Element Concept: Person—blood sample type

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 2

Permissible values:

Value	Meaning
01	Serum
02	Plasma
03	Whole blood
04	Guthrie cards
05	Blood pellets
06	RNA
07	DNA
08	Cell lines

Supplementary values:

98	Unknown

Collection and usage attributes

Guide for use: CODE 01 Serum

The component that is neither a blood cell nor a clotting factor; it is the blood plasma with the fibrinogens removed. Serum includes all proteins not used in blood clotting and all the electrolytes, antibodies, antigens, hormones, and any exogenous substances (e.g., drugs and microorganisms).

CODE 02 Plasma

The liquid phase of the blood, obtained by sedimentation or centrifugation of blood treated with anticoagulant. Is the equivalent of serum plus fibrinogen and consists of water, proteins, electrolytes and other solutes.

CODE 03 Whole blood

Comprised of red blood cells, white blood cells and platelets suspended in plasma. Generally unprocessed except for the addition of anticoagulant. This can be broken down into blood components/derivatives if required.

CODE 04 Guthrie cards

A spot of whole blood on a specifically prepared (Guthrie) card.

CODE 05 Blood pellets

A concentration of cells formed from spinning down whole blood in a centrifuge and removing supernatant. Blood pellets can be in the form of whole blood pellets, red blood pellets or white blood pellets.

CODE 06 RNA

Ribonuclaese acid (RNA) that has been extracted from a blood sample.

CODE 07 DNA

Deoxyribonucleic acid (DNA) which has been extracted from a blood sample.

CODE 08 Cell lines

A defined unique population of cancer cells obtained by culture from a primary source or from Epstein-Barr virus (EBV) cell line transformations.

CODE 98 Unknown

Record this code if a blood sample or blood sample derivative has been collected but the type is unknown.

Additional fields that may be used for serum, plasma and whole blood samples are: tube used, volume of blood taken, number of aliquots taken, date of collection, time of collection, date of processing and time of processing.

Additional fields that may be used for Guthrie cards are: number of spots and date of collection.

Additional fields that may be used for blood pellets are: type of pellet collected, volume, number of aliquots and date of collection.

Additional fields that may be used for DNA and RNA samples are: date of extraction, number of aliquots and concentration.

Source and reference attributes

Submitting organisation: Cancer Australia

Data set specification specific attributes

Testicular Cancer Data Set Specification

Conditional obligation: Collect if Person—blood sample indicator, yes/no code N equals yes.

Data element attributes

Collection and usage attributes

Guide for use: Record the type of blood or blood derivative collected for research purposes. These include whole blood, blood pellets, Guthrie cards, serum, plasma, DNA, RNA and cell lines

Collection methods: To be sought from the laboratory/biobank that is collecting or deriving the sample/s.

Source and reference attributes

Submitting organisation: Cancer Australia

Relational attributes

Related metadata references: See also Person—blood sample indicator, yes/no code N Health, Proposed 13/01/2012

Person—diagnostic imaging, testicular cancer diagnostic imaging type, code NN

Identifying and definitional attributes

Short name: Testicular cancer diagnostic imaging

METeOR identifier: 558092

Registration status: *No registration status*

Definition: The imaging investigations used at diagnosis for a person with testicular cancer, as outlined by a code.

Data Element Concept: Person—diagnostic imaging type

Value domain attributes

Representational attributes

Representation class: Code

Data type: Boolean

Format: NN

Maximum character length: 2

Permissible values:

Value	Meaning
01	Abdominopelvic computed tomography (CT)
02	Brain computed tomography (CT)
03	Chest computed tomography (CT)
04	Chest X-ray
05	Testis ultrasound
06	Magnetic resonance imaging (MRI)
07	Positron emission tomography (PET) scan
08	Other
09	Imaging not performed

Supplementary values:

98	Unknown
99	Not stated/inadequately described

Source and reference attributes

Submitting organisation: Cancer Australia

Data element attributes

Collection and usage attributes

Guide for use: Record the imaging investigations used at diagnosis for a person with testicular cancer, as outlined by a code. Where multiple imaging investigations have occurred this item should be recorded for each one.

Collection methods: Collect from patient medical records or at multidisciplinary team meetings.

Source and reference attributes

Submitting organisation: Cancer AustraliA

Person—prior testicular cancer indicator, yes/no/unknown code N

Identifying and definitional attributes

Short name: Prior testicular cancer indicator

METeOR identifier: 558100

Registration status: *No registration status*

Definition: An indicator outlining whether a person has had a prior diagnosis of testicular cancer that has been successfully treated, as indicated by a code.

Data Element Concept: Person—prior testicular cancer indicator

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

Permissible values:

Value	Meaning
1	Yes
2	No

Supplementary values:

8	Unknown

Data element attributes

Collection and usage attributes

Guide for use: Recorded whether a person has had a prior diagnosis of testicular cancer that has been successfully treated. Successfully treated means that there was no evidence of testicular cancer remaining at the completion of treatment.

Source and reference attributes

Submitting organisation: Cancer Australia

Person—tissue sample collected indicator, yes/no code N

Identifying and definitional attributes

Short name:	Tissue sample collected indicator
METeOR identifier:	446565
Registration status:	Health, Standard 08/05/2014
Definition:	An indicator of whether a tissue sample has been collected from a person for research purposes, as represented by a code.
Data Element Concept:	Person—tissue sample collected indicator

Value domain attributes

Representational attributes

Representation class:	Code
Data type:	Boolean
Format:	N
Maximum character length:	1

Permissible values:

Value	Meaning
1	Yes
2	No

Data element attributes

Collection and usage attributes

Guide for use: Record whether a tissue sample has been collected from a person for research purposes.

This includes tissue that has been collected for research purposes and stored in any format, including tissue samples that have been snap frozen, stored with OCT (optimum cutting temperature compound), FFPE (formalin fixed, paraffin embedded), and if RNA and/or DNA has been extracted from tissue and stored.

Collection methods: Collect from medical, laboratory or biobank records.

Source and reference attributes

Submitting organisation: Cancer Australia

Relational attributes

Implementation in Data Set Specifications: Gynaecological cancer (clinical) DSS Health, Standard 08/05/2014

Tissue sample—malignancy and position, code NN

Identifying and definitional attributes

Short name: Type of tissue

METeOR identifier: 394129

Registration status: Health, Proposed 13/01/2012

Definition: Describes the type of tissue that has been collected for research purposes in regards to malignancy and the position in relation to the primary malignant lesion from which the sample was collected.

Data Element Concept: Tissue sample—malignancy and position

Value domain attributes

Representational attributes

Representation class: Code

Data type: Number

Format: N

Permissible values:

Value	Meaning
1	Malignant - Primary lesion
2	Malignant - Adjacent to primary malignant lesion
3	Malignant - Distant from primary malignant lesion
4	Non-malignant - Normal - Adjacent to primary malignant lesion
5	Non-malignant - Normal - Distant from primary malignant lesion
6	Non-malignant - Normal - No primary malignant lesion
7	Non-malignant - Benign - Adjacent to primary malignant lesion
8	Non-malignant - Benign - Distant from primary malignant lesion
9	Non-malignant - Benign - No primary malignant lesion
98	Unknown

Source and reference attributes

Submitting organisation: Cancer Australia

Data set specification specific attributes

Testicular Cancer Data Set Specification

Conditional obligation: Collect if Person—tissue sample collected indicator, yes/no code N equals yes.

Data element attributes

Collection and usage attributes

Guide for use: Record the type of tissue that has been collected for research purposes in regards to malignancy and the position in relation to the primary malignant lesion from which the sample was collected for a specific tissue sample.

Collection methods: Obtain from pathology reports.

Source and reference attributes

Submitting organisation: Cancer Australia