Data Set Specification

Cancer (clinical)

Excerpt from the

**National Health Data Dictionary
Version 12 Supplement**

Health Data Standards Committee

2004

Australian Institute of Health and Welfare

Canberra

Suggested citation

Health Data Standards Committee 2004. Data Set Specification, Cancer (clinical), National Health Data Dictionary Version 12, Supplement. AIHW Cat. No. HWI 71. Canberra: Australian Institute of Health and Welfare.

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Preface

This publication consists of data elements included in the *National Health Data Dictionary Version 12 Supplement* that relate specifically to the Cancer (clinical) Data Set Specification. It is included as a separate publication to facilitate the use of these standards by clinicians involved in the care of cancer patients. Data Set Specifications (DSS) are data sets that are not mandated for collection, but are recommended as best practice. It is hoped that the Cancer (clinical) DSS will contribute to uniform data collection and research collaboration, greater accuracy in evaluating the impact of the expanding therapeutic options in these clinical areas, as well as leading to improvements in the quality of care through standardised outcome evaluation.

The Cancer (clinical) DSS was endorsed by the National Health Information Group (NHIG) on the 4th of June 2004.

The following pages contain the Cancer (clinical) DSS its associated data elements and data element concepts. It is recommended that if collecting data for the purposes of primary patient care, planning or analysis, the entire DSS be collected.

An electronic version of this data set (DSS—Cancer (clinical)) is available from the AIHW Knowledgebase at <www.aihw.gov.au/pls/nhik/nhik_agreements.agreements_search>. An electronic version of this publication is available at <www.aihw.gov.au/publications/index.cfm/title/10028>.

Introduction

Data Set Specifications are data sets that are not mandated for collection, but are recommended as best practice. This is the first such specification specific to cancer. Since 1982, Australia has had full coverage of cancer incidence by population–based state cancer registries allowing trends to be monitored. Mortality and overall survival rates by type of cancer are also assessed but this information is insufficient to assess how the diagnosis, treatment and outcome of cancer patients compare to best practice. For this, information on the extent of cancer at diagnosis (the 'stage' of the cancer) and on the main treatments used is required.

In 1997 the National Cancer Control Initiative (NCCI) made several recommendations to meet urgent national needs for improved data collection[1]. It set up multidisciplinary groups to review the content of existing hospital and registry data collections and to derive a set of key data items necessary to assess cancer management routinely. Professor Alan Coates, a medical oncologist and CEO of The Cancer Council Australia, was commissioned to undertake a wide ranging consultation to review data collected on cancer care in Australia and overseas, and to recommend items for a Clinical Cancer Core Data Set and definitions for these items. In compiling his report, Professor Coates sought input from population–based cancer registries, oncology units, hospital–based cancer registries and Health Departments in all Australian states and territories, and from many international cancer registries and data systems. The data items proposed reflected 'a reasonable compromise between a set too large to be attainable and one too small to be interesting' and included items relating to the stage of cancer at diagnosis, initial treatment details, and treatment outcomes [2], [3].

This report, after further review by key stakeholders and at workshops, led to the selection of data items to form the NCCI Clinical Cancer Core Data Set, and a proposal that the data set should be incorporated into the *National Health Data Dictionary* (NHDD). An NCCI working party then refined the data definitions and formatted them to the requirements of the *NHDD*. The draft dictionary was circulated for comment, and the comments incorporated into the first version of the data dictionary, released in November 2001.

Initial steps towards having the NCCI Clinical Cancer Core Data Set included in the NHDD began in July 2002 with submission of the draft dictionary to the National Health Data Committee. In June 2004, all but two of the proposed data items and definitions were finally approved for the NHDD under the designation of Cancer (Clinical) Data Set. Several items in the data set are also collected by the population–based state and territory cancer registries, using concordant definitions. The New South Wales Department of Health has developed a Clinical Cancer Data Collection for NSW, and there is consistency between these data sets wherever practicable.

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[1] National Cancer Control Initiative. National cancer control plan and implementation strategy. 1–196. 1997. Melbourne, National Cancer Control Initiative.

[2] Coates, A. A clinical cancer registration common data set. 1–43. 1999. Melbourne, National Cancer Control Initiative.

[3] Staples MP, Elwood JM, Coates AS, Kenny LM. Developing a core clinical data set for cancer. Med J Aust 2003;178:95.

The full NCCI Clinical Cancer Core Data and Data Dictionary is now (July 2004) in version 5 and consists of the approved data items given in this document as well as Cause of death and Performance status score at diagnosis of cancer, which are not defined here. It is available at <www.ncci.org.au> [4]. The data set is designed to be augmented by other items of special interest to individual users and will be kept under review, with further items incorporated if they are recommended as being important in the monitoring of cancer treatment and outcome. Further versions and any changes will be notified on the NCCI website as well as the AIHW Knowledgebase. The NCCI encourages the use of the Clinical Cancer Core Data Set by hospitals and clinicians on a voluntary basis, as essential data applicable to all cancers and all health care facilities.

The NCCI urges those collecting clinical cancer data to do so according to the standardised definitions given in this document to help ensure that the data collected are comparable.

Mark Elwood, Margaret Staples,

National Cancer Control Initiative

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[4] National Cancer Control Initiative. NCCI Clinical Cancer Core Data Set and data dictionary. Ed., Staples, M. Version 5, 1–115. 2004. Melbourne, National Cancer Control Initiative.

Contents

Cancer (clinical) DSS

Admin status:	CURRENT	04/06/2004	*Version number:*	1

Metadata type: Data Set Specification

Start date: 04/06/2004

Scope: This Cancer (clinical) data set specification is not mandated for collection but is recommended as best practice if cancer clinical data are to be collected.

The Cancer (clinical) data set underpins the evaluation of cancer treatment services and this can occur at a number of levels; the individual clinician, the health care institution, at state or territory level and ultimately at a national level.

Clinicians use such data for ongoing patient management and the ability to link patient management to outcomes allows treatments or outcomes to be identified and assessed. Institutions can monitor through–put in their centres for planning and resource allocation purposes to obtain optimum return for cancer expenditure. End–points can be monitored to ensure that objectives are being met.

The principal aim of good–quality and consistent data is to provide information that can lead to improved quality and length of life for all patients by providing a systematic foundation for evidence–based medicine, informing quality assurance and improvement decisions and guiding successful planning and evaluation of cancer control activities.

Collection methodology: This data set is primarily concerned with the clinical use of cancer data. It can also be used by a wider range of health and health–related establishments that create, use, or maintain records on health–care clients.

Data elements included: Address line, version 1

Cancer initial treatment — completion date, version 1

Cancer initial treatment — starting date, version 1

Cancer staging — M stage code, version 1

Cancer staging — N stage code, version 1

Cancer staging — T stage code, version 1

Cancer staging — TNM Stage grouping code, version 1

Cancer treatment type, version 1

Cancer treatment — target site, version 1

Date of birth, version 5

Date of death, version 1

Date of diagnosis of cancer, version 1

Date of diagnosis of first recurrence, version 1

Date of surgical treatment for cancer, version 1

Establishment number, version 4

Family name, version 2

Given name(s), version 2

Data elements included (continued):	Histopathological grade, version 1
	Intention of treatment for cancer, version 1
	Laterality of primary cancer, version 1
	Medicare card number, version 2
	Morphology of cancer, version 1
	Most valid basis of diagnosis of cancer, version 1
	Oestrogen receptor assay status, version 1
	Outcome of initial treatment, version 1
	Person identifier, version 2
	Primary site of cancer, version 1
	Progesterone receptor assay status, version 1
	Radiotherapy treatment type, version 1
	Received radiation dose, version 1
	Region of first recurrence, version 1
	Regional lymph nodes examined, version 1
	Regional lymph nodes positive, version 1
	Sex, version 4
	Staging basis, version 1
	Staging scheme source, version 1
	Staging scheme source edition number, version 1
	Surgical treatment procedure for cancer, version 1
	Systemic therapy agent name, version 1
	Tumour size at diagnosis – solid tumours, version 1
	Tumour thickness at diagnosis – melanoma, version 1
Supporting data elements and data element concepts:	Initial treatment episode for cancer, version 1
Scope links with other metadata sets:	
Source organisation:	National Cancer Control Initiative (NCCI).
Comments:	

Address line

Identifying and Definitional attributes

Knowledgebase ID: **000786**   *Version number:*   **1**

Metadata type: Data element

Definition:	A composite of one or more standard address components that describes a low level of geographical/physical description of a location that, 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.
Context:	

Relational and representational attributes

Data type: Alphanumeric   *Maximum field size:*   180

Representational class: Text   *Format:*   AN(180)

Data domain:	A composite of one or more standard address components.

Guide for use: When addressing an Australian location, following are the standard address data elements that may be concatenated in the Address line:

    Building/complex sub–unit type—abbreviation

    Building/complex sub–unit number

    Building/property name

    Floor/level number

    Floor/level type

    House/property number

    Lot/section number

    Street name

    Street type code

    Street suffix code

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.

Verification rules:

| *Collection methods:* | The following concatenation rules should be observed when collecting address lines addressing an Australian location. |

Building/complex sub–unit type is to be collected in conjunction with Building/complex sub–unit number and vice versa.

Floor/level type is to be collected in conjunction with Floor/level number and vice versa.

Street name is to be used in conjunction with Street type code and Street suffix code.

Street type code is to be used in conjunction with Street name and Street suffix code.

Street suffix code is to be used in conjunction with Street name and Street type code.

House/property number is to be used in conjunction with Street name.

| *Related metadata:* | Relates to the data element concept Address, version 2. |

Relates to the data element Australian state/territory identifier, version 4.

Relates to the data element Building/complex sub–unit type — abbreviation, version 1.

Relates to the data element Building/complex sub–unit number, version 1.

Relates to the data element Building/property name, version 1.

Relates to the data element Floor/level type, version 1.

Relates to the data element Floor/level number, version 1.

Relates to the data element House/property number, version 1.

Relates to the data element Lot/section number, version 1.

Relates to the data element Postcode — Australian, version 3.

Relates to the data element Street name, version 1.

Relates to the data element Street type code, version 1.

Relates to the data element Street suffix code, version 1.

Relates to the data element Suburb/town/locality name, version 2.

Information model link: NHIM   Address element

Data Set Specifications:		*Start date*	*End date*
DSS —	Cancer (clinical)	04/06/2004	
DSS —	Health care client identification	25/02/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	25/02/2004

Source organisation:	Standards Australia.
	Health Data Standards Committee.

| *Source document:* | AS 5017 Health Care Client Identification. |

| *Registration authority:* | National Health Information Group. |

| *Steward:* | Health Data Standards Committee. |
| *Comments:* | |

Cancer initial treatment — completion date

Identifying and Definitional attributes

Knowledgebase ID: **001055**   *Version number:*   **1**

Metadata type: Data element

Definition:	The date on which the initial non–surgical treatment for cancer was completed.
Context:	This item is collected for the analysis of outcome by treatment type.
	Collected for radiation therapy and systemic therapy.
	Collecting dates for radiotherapy treatment and systemic therapy agent treatment will allow evaluation of treatments delivered and of time intervals from diagnosis to treatment, from treatment to recurrence and from treatment to death.

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   8

Representational class: Date   *Format:*   DDMMYYYY

Data domain:	Valid date.

Guide for use:

Verification rules: This field must:

   —   be greater than or equal to Date of diagnosis of cancer

   —   be greater than or equal to Cancer initial treatment — starting date

Collection methods:

Related metadata: Relates to the data element concept Initial treatment episode for cancer, version 1.

Relates to the data element Radiotherapy treatment type, version 1.

Relates to the data element Systemic therapy agent name, version 1.

Relates to the data element Cancer initial treatment — starting date, version 1.

Information model link: NHIM   Exit/leave from service event

Data Set Specifications:	*Start date*	*End date*
DSS — Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status: CURRENT   *Effective Date:*   04/06/2004

Source organisation: Commission on Cancer, American College of Surgeons.

Source document: Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).

Registration authority: National Health Information Group.

Steward:

Comments

Cancer initial treatment — starting date

Identifying and Definitional attributes

Knowledgebase ID: **001056**   *Version number:*   **1**

Metadata type: Data element

Definition:	The start date of the initial course of non–surgical treatment for cancer.
Context:	This item is collected for the analysis of outcome by treatment type.
	Collected for radiation therapy and systemic therapy.
	Collecting dates for radiotherapy treatment and systemic therapy agent treatment will allow evaluation of treatments delivered and of time intervals from diagnosis to treatment, from treatment to recurrence and from treatment to death. Date of surgical treatment is collected as a separate item.

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   8

Representational class: Date   *Format:*   DDMMYYYY

Data domain:	Valid date.

Guide for use: The start date of the treatment is recorded regardless of whether it is completed as intended or not. Treatment subsequent to a recurrence will not be recorded.

Verification rules: This field must:

-          be greater than or equal to Date of diagnosis of cancer

-          be less than or equal to Cancer initial treatment — completion date

Collection methods:

Related metadata: Relates to the data element Radiotherapy treatment type, version 1.

Relates to the data element Systemic therapy agent name, version 1.

Relates to the data element Date of diagnosis of cancer, version 1.

Relates to the data element Cancer initial treatment — completion date, version 1.

Information model link: NHIM   Request for/entry into service event

Data Set Specifications: *Start date*   *End date*

   DSS —   Cancer (clinical)   04/06/2004

Administrative attributes

Admin status: CURRENT   *Effective Date:*   04/06/2004

Source organisation: Commission on Cancer, American College of Surgeons.

Source document: Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).

Registration authority: National Health Information Group.

Steward:

Comments

Cancer staging — M stage code

Identifying and Definitional attributes

Knowledgebase ID: **001057**   *Version number:*   **1**

Metadata type: Data element

Definition:	M stage is the coding system used to record the absence or presence of distant metastases at the time of diagnosis of the primary cancer. It is part of the TNM cancer staging system.
Context:	For survival analysis adjusted by stage at diagnosis and distribution of cancer cases by type and stage.

Relational and representational attributes

Data type: Alphanumeric   *Maximum field size:*   3

Representational class: Code   *Format:*   AAA

Data domain:	Valid M codes from the current edition of the *UICC TNM Classification of Malignant Tumours.* 88 Not applicable

Guide for use: Refer to the UICC reference manual, *TNM Classification of Malignant Tumours* for coding rules.

Choose the lower (less advanced) M category when there is any uncertainty.

Verification rules:

Collection methods: From information provided by the treating doctor and recorded on the patient's medical record.

Related metadata: Relates to the data element Cancer staging — T stage code, version 1.

Relates to the data element Cancer staging — N stage code, version 1.

Relates to the data element Staging basis, version 1.

Relates to the data element Cancer staging — TNM stage grouping code, version 1.

Relates to the data element Staging scheme source, version 1.

Relates to the data element Staging scheme edition number, version 1.

Information model link: NHIM   Physical wellbeing

Data Set Specifications:	*Start date*	*End date*
DSS — Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status: CURRENT   *Effective Date:*   04/06/2004

Source organisation: International Union Against Cancer (UICC).

Commission on Cancer, American College of Surgeons.

Source document:	UICC *TNM Classification of Malignant Tumours* (5th Edition) *(1997).*
	Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II *(1998).*
Registration authority:	National Health Information Group.
Steward:	
Comments	Cancer prognosis and survival can be related to the extent of the disease at diagnosis. Survival rates are generally higher if the disease is localised to the organ of origin compared with cases in which the tumour has spread beyond the primary site. Staging systems seek to classify patients having a similar prognosis into groups or stages. TNM staging is an internationally agreed staging classification system based on the anatomical site of the primary tumour and its extent of spread. The T component refers to the size of the tumour and whether or not it has spread to surrounding tissues. The N component describes the presence or absence of tumour in regional lymph nodes. The M component refers to the presence or absence of tumour at sites distant from the primary site.
	TNM staging applies to solid tumours excluding brain tumours.

Cancer staging — N stage code

Identifying and Definitional attributes

Knowledgebase ID: **001058** *Version number:* **1**

Metadata type: Data element

Definition:	N stage is the coding system used to denote the absence or presence of regional lymph node metastases. It classifies the extent of regional lymph node metastases at the time of diagnosis of the primary cancer. It is a part of the TNM cancer staging system.
Context:	For survival analysis adjusted by stage at diagnosis and distribution of cancer cases by type and stage.

Relational and representational attributes

Data type: Alphanumeric   *Maximum field size:* 3

Representational class: Code   *Format:* AAA

Data domain:	Valid N codes from the current edition of the *UICC TNM Classification of Malignant Tumours.*
	88 Not applicable

Guide for use: Refer to the UICC reference manual, *TNM Classification of Malignant Tumours* for coding rules.

Choose the lower (less advanced) N category when there is any uncertainty.

Verification rules:

Collection methods: From information provided by the treating doctor and recorded on the patient's medical record.

Related metadata: Relates to the data element Cancer staging — T stage code, version 1.

Relates to the data element Cancer staging — M stage code, version 1.

Relates to the data element Staging basis, version 1.

Relates to the data element Cancer staging — TNM stage grouping code, version 1.

Relates to the data element Staging scheme source, version 1.

Relates to the data element Staging scheme edition number, version 1.

Information model link: NHIM   Physical wellbeing

Data Set Specifications: *Start date*   *End date*

    DSS —   Cancer (clinical)   04/06/2004

Administrative attributes

Admin status: CURRENT   *Effective Date:* 04/06/2004

Source organisation: International Union Against Cancer (UICC).

Commission on Cancer, American College of Surgeons.

Source document:	UICC *TNM Classification of Malignant Tumours* (5th Edition) *(1997).*
	Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II *(1998).*
Registration authority:	National Health Information Group.
Steward:	
Comments	Cancer prognosis and survival can be related to the extent of the disease at diagnosis. Survival rates are generally higher if the disease is localised to the organ of origin compared with cases in which the tumour has spread beyond the primary site. Staging systems seek to classify patients having a similar prognosis into groups or stages. TNM staging is an internationally agreed staging classification system based on the anatomical site of the primary tumour and its extent of spread. The T component refers to the size of the tumour and whether or not it has spread to surrounding tissues. The N component describes the presence or absence of tumour in regional lymph nodes. The M component refers to the presence or absence of tumour at sites distant from the primary site.
	TNM staging applies to solid tumours excluding brain tumours.

Cancer staging — T stage code

Identifying and Definitional attributes

Knowledgebase ID:	*001059*	*Version number:*	*1*
Metadata type:	Data element		

Definition:	T stage is the coding system used to identify the presence the primary tumour. It reflects the tumour size and extent of the primary cancer at the time of diagnosis. It is a part of the TNM cancer staging system.
Context:	For survival analysis adjusted by stage at diagnosis and distribution of cancer cases by type and stage.

Relational and representational attributes

Data type:	Alphanumeric	*Maximum field size:*	3
Representational class:	Code	*Format:*	AAA

Data domain:	Valid T codes from the current edition of the *UICC TNM Classification of Malignant Tumours*.
	88 Not applicable

Guide for use:	Refer to the UICC reference manual, *TNM Classification of Malignant Tumours* for coding rules.
	Choose the lower (less advanced) T category when there is any uncertainty.
Verification rules:	
Collection methods:	From information provided by the treating doctor and recorded on the patient's medical record.
Related metadata:	Relates to the data element Cancer staging — N stage code, version 1.
	Relates to the data element Cancer staging — M stage code, version 1.
	Relates to the data element Staging basis, version 1.
	Relates to the data element Cancer staging — TNM stage grouping code, version 1.
	Relates to the data element Staging scheme source, version 1.
	Relates to the data element Staging scheme edition number, version 1.
Information model link:	NHIM Physical wellbeing

Data Set Specifications:		*Start date*	*End date*
DSS — Cancer (clinical)		04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004
Source organisation:	International Union Against Cancer (UICC).		
	Commission on Cancer, American College of Surgeons.		

Source document:	*UICC* TNM Classification of Malignant Tumours *(5th Edition) (1997)* Commission on Cancer.
	Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS) Volume II (1998).
Registration authority:	National Health Information Group.
Steward:	
Comments	Cancer prognosis and survival can be related to the extent of the disease at diagnosis. Survival rates are generally higher if the disease is localised to the organ of origin compared with cases in which the tumour has spread beyond the primary site. Staging systems seek to classify patients having a similar prognosis into groups or stages. TNM staging is an internationally agreed staging classification system based on the anatomical site of the primary tumour and its extent of spread. The T component refers to the size of the tumour and whether or not it has spread to surrounding tissues. The N component describes the presence or absence of tumour in regional lymph nodes. The M component refers to the presence or absence of tumour at sites distant from the primary site.
	TNM staging applies to solid tumours excluding brain tumours.

Cancer staging — TNM stage grouping code

Identifying and Definitional attributes

Knowledgebase ID: **001060**   *Version number:*   **1**

Metadata type: Data element

Definition:	The stage grouping defines the anatomical extent of disease at diagnosis based on the previously coded T, N and M stage categories.
Context:	For survival analysis adjusted by stage at diagnosis and distribution of cancer cases by type and stage.

Relational and representational attributes

Data type: Alphanumeric   *Maximum field size:*   4

Representational class: Code   *Format:*   AN(4)

Data domain:	Valid stage grouping codes from the current edition of the UICC TNM Classification of Malignant Tumours.
	8888 Not applicable
	9999 Unknown, Stage X

Guide for use: Refer to the UICC reference manual *TNM Classification of Malignant Tumours* for coding rules.

Choose the lower (less advanced) stage grouping when there is any uncertainty.

Verification rules:

Collection methods: From information provided by the treating doctor and recorded on the patient's medical record.

Related metadata: Relates to the data element Cancer staging — T stage code, version 1.

Relates to the data element Cancer staging — N stage code, version 1.

Relates to the data element Cancer staging — M stage code, version 1.

Relates to the data element Staging basis, version 1.

Relates to the data element Staging scheme source, version 1.

Relates to the data element Staging scheme edition number, version 1.

Information model link: NHIM   Physical wellbeing

Data Set Specifications: *Start date*   *End date*

   DSS — Cancer (clinical)   04/06/2004

Administrative attributes

Admin status: CURRENT   *Effective Date:*   04/06/2004

Source organisation: International Union Against Cancer (UICC).

Commission on Cancer, American College of Surgeons.

Source document:	UICC *TNM Classification of Malignant Tumours* (5th Edition) (1997).
	Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).
Registration authority:	National Health Information Group.
Steward:	
Comments	

Cancer treatment type

Identifying and Definitional attributes

Knowledgebase ID: **001061**   *Version number:*   **1**

Metadata type: Data element

Definition:	The type of treatment for cancer given as initial treatment for the particular patient.
Context:	This item is collected for surgical treatment, radiation therapy and systemic therapy. It is used for correlating outcome with original intent of the treatment.

Relational and representational attributes

Data type: Alphanumeric   *Maximum field size:*   1

Representational class: Code   *Format:*   N

Data domain:		
	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

Guide for use:

Verification rules:

Collection methods:

Related metadata: Relates to the data element concept Initial treatment episode for cancer, version 1.

                       Relates to the data element Intention of treatment for cancer, version 1.

                       Relates to the data element Surgical treatment procedure for cancer, version 1.

                       Relates to the data element Date of surgical treatment for cancer, version 1.

                       Relates to the data element Radiotherapy treatment type, version 1.

                       Relates to the data element Systemic therapy agent name, version 1.

                       Relates to the data element Cancer initial treatment — starting date, version 1.

                       Relates to the data element Cancer initial treatment — completion date, version 1.

Information model link: NHIM   Exit/leave from service event

Data Set Specifications:	*Start date*	*End date*
DSS − Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: Commission on Cancer, American College of Surgeons.

New South Wales Health Department.

Source document: Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).

Public Health Division NSW *Clinical Cancer Data Collection for Outcomes and Quality. Data Dictionary* Version 1 Sydney NSW Health Dept (2001).

Registration authority: National Health Information Group.

Steward:

Comments

Cancer treatment — target site

Identifying and Definitional attributes

Knowledgebase ID: **001062**   *Version number:*   **1**

Metadata type: Data element

Definition:	The site or region of cancer which is the target of a particular surgical or radiotherapy treatment.
Context:	This information is collected for surgical and radiotherapy treatments.

Relational and representational attributes

Data type: Alphanumeric   *Maximum field size:*   3

Representational class: Code   *Format:*   ANN

Data domain:	Current edition of ICD–O topography codes (Major organ only – first 3 characters).
	Current edition of ICD–10–AM.

Guide for use:

Verification rules:

Collection methods:

Related metadata: Relates to the data element concept Initial treatment episode for cancer, version 1.

Information model link: NHIM   Physical wellbeing

Data Set Specifications: *Start date*   *End date*

   DSS –   Cancer (clinical)   04/06/2004

Administrative attributes

Admin status: CURRENT   *Effective Date:*   04/06/2004

Source organisation: World Health Organisation

Source document: Current edition of *International Classification of Diseases for Oncology* (ICD–O), World Health Organisation.

                            Current edition of *International Classification of Diseases* (ICD–10–AM), Australian Modification, National Centre for Classification in Health, Sydney.

Registration authority: National Health Information Group.

Steward:

Comments

Date of birth

Identifying and Definitional attributes

Knowledgebase ID: **002005**   *Version number:*   *5*

Metadata type: Data element

Definition:	The date of birth of the person.
Context:	Required for a range of clinical and administrative purposes.
	Date of birth enables derivation of age for use in demographic analyses, assists in the unique identification of clients if other identifying information is missing or in question, and may be required for the derivation of other data elements (e.g. Diagnosis related group for admitted patients).

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   8

Representational class: Date   *Format:*   DDMMYYYY

Data domain:	Valid date.

Guide for use:	If date of birth is not known or cannot be obtained, provision should be made to collect or estimate age. Collected or estimated age would usually be in years for adults, and to the nearest three months (or less) for children aged less than two years. Additionally, an estimated date flag should be reported in conjunction with all estimated dates of birth.
	For data collections concerned with children's services, it is suggested that the estimated Date of birth of children aged under 2 years should be reported to the nearest 3 month period, i.e. 0101, 0104, 0107, 0110 of the estimated year of birth. For example, a child who is thought to be aged 18 months in October of one year would have his/her estimated Date of birth reported as 0104 of the previous year. Again, an estimated date flag should be reported in conjunction with all estimated dates of birth.
Verification rules:	
Collection methods:	Information on Date of birth can be collected using the one question:
	What is your/(the person's) date of birth? In self–reported data collections, it is recommended that the following response format is used: Date of birth: _ _ / _ _ / _ _ _ _ This enables easy conversion to the preferred representational layout (DDMMYYYY).
	Estimated dates of birth should be identified by an appropriate estimated date flag to prevent inappropriate use of Date of birth data for record identification and/or the derivation of other data elements that require accurate date of birth information.
	NHDD specific:
	NMDS – Perinatal:
	Data collection systems must be able to differentiate between the date of birth of the mother and the baby(s). This is important in the Perinatal data collection as the date of birth of the baby is used to determine the antenatal length of stay and the postnatal length of stay.

Related metadata:	Supersedes previous data element Date of birth, version 4.
	Is used in the derivation of Diagnosis related group, version 1.
	Is qualified by Estimated date flag, version 1.
	Is used in the derivation of Length of stay (antenatal), version 1.
	Is used in the derivation of Length of stay (postnatal), version 1.

Information model link: NHIM   Demographic characteristic

Data Set Specifications:		*Start date*	*End date*
NMDS –	Admitted patient care	01/07/2004	
NMDS –	Admitted patient mental health care	01/07/2004	
NMDS –	Admitted patient palliative care	01/07/2004	
NMDS –	Alcohol and other drug treatment services	01/07/2004	
NMDS –	Community mental health care	01/07/2004	
NMDS –	Health labour force	01/07/2004	
NMDS –	Non–admitted patient Emergency Department care	01/07/2004	
NMDS –	Perinatal	01/07/2004	
NMDS –	Residential mental health care	01/07/2004	
DSS –	Acute coronary syndrome (clinical)	04/06/2004	
DSS –	Cancer (clinical)	04/06/2004	
DSS –	Cardiovascular disease (clinical)	02/09/2003	
DSS –	Diabetes (clinical)	02/09/2003	
DSS –	Health care client identification	02/09/2003	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	02/09/2003

| *Source organisation:* | Health Data Standards Committee. |
| | National Community Services Data Committee. |

Source document: AIHW: 2003. *National Health Data Dictionary*, Version 12.

| *Registration authority:* | National Health Information Group. |
| | National Community Services Information Management Group. |

Steward:

Comments:	This metadata item is common to both the *National Health Data Dictionary* and the *National Community Services Data Dictionary*.
	Privacy issues need to be taken account in asking persons their date of birth.
	Wherever possible and wherever appropriate, Date of birth should be used rather than Age because the actual date of birth allows more precise calculation of age.

When Date of birth is estimated or default value, national health and community services collections typically use 0101 or 0107 or 3006 as the estimate or default for DDMM.

It is suggested that different rules for reporting data may apply when estimating the Date of birth of children aged under 2 years because of the rapid growth and development of children within this age group which means that a child's development can vary considerably over the course of a year. Thus, more specific reporting of estimated age is suggested.

NHDD **specific:**

DSS — Health care client identification:

Any new information collection systems should allow for 0000YYYY. (Refer to Standards Australia AS5017—2002 Health Care Client Identification).

DSS — Cardiovascular disease (clinical)

Age is an important non–modifiable risk factor for cardiovascular conditions. The prevalence of cardiovascular conditions increases dramatically with age. For example, more than 60% of people aged 75 and over had a cardiovascular condition in 1995 compared with less than 9% of those aged under 35. Aboriginal and Torres Strait Islander peoples are more likely to have cardiovascular conditions than other Australians across almost all age groups. For example, in the 25–44 age group, 23% of Indigenous Australians reported cardiovascular conditions compared with 16% among other Australians (Heart, Stroke and Vascular Diseases: Australian Facts 2001. AIHW).

Date of death

Identifying and Definitional attributes

Knowledgebase ID:	**001063**	*Version number:*	*1*
Metadata type:	Data element		

Definition:	The date of death of the person.
Context:	Required for statistical survival analysis for derivation of the length of time between diagnosis with primary cancer and death.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	8
Representational class:	Date	*Format:*	DDMMYYYY

Data domain:	Valid date.

Guide for use:	Recorded for patients who have died.
Verification rules:	This field must be greater than or equal to Date of diagnosis of primary cancer.
Collection methods:	It is recommended that in cases where all components of the date of death are not known or where an estimate is arrived at from age, a valid date be used together with a flag to indicate that it is an estimate.
Related metadata:	
Information model link:	NHIM Demographic characteristic

Data Set Specifications:	*Start date*	*End date*
DSS – Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004
Source organisation:	Health Data Standards Committee.		
Source document:			
Registration authority:	National Health Information Group.		
Steward:			
Comments:			

Date of diagnosis of cancer

Identifying and Definitional attributes

Knowledgebase ID: **000771**   *Version number:*   **1**

Metadata type: Data element

Definition:	The date when the cancer was first diagnosed (whether at its primary site or as a metastasis).
Context:	Patient administration systems, cancer notification systems, population cancer statistics, research.

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   8

Representational class: Date   *Format:*   DDMMYYYY

Data domain:	Valid date

Guide for use: Date of diagnosis must be:

>= Date of birth

<= Date of death

Diagnosis of cancer after death:

If the patient is first diagnosed with the cancer in an autopsy report the date of diagnosis is the date of death as stated on the patient's death certificate.

Incidental diagnosis of cancer:

If a patient is admitted for another condition (e.g. a broken leg or pregnancy), and a cancer is diagnosed incidentally then the date of diagnosis is the date the cancer was diagnostically determined, not the admission date.

Verification rules:

Collection methods: Reporting rules:

The date of diagnosis is the date of the pathology report, if any, that first confirmed the diagnosis of cancer. This date may be found attached to a letter of referral or a patient's medical record from another institution or hospital. If this date is unavailable, or if no pathological test was done, then the date may be determined from one of the sources listed in the following sequence:

Date of the consultation at, or admission to, the hospital, clinic or institution when the cancer was first diagnosed. Note: DO NOT use the admission date of the current admission if the patient had a prior diagnosis of this cancer.

Date of first diagnosis as stated by a recognised medical practitioner or dentist. Note: This date may be found attached to a letter of referral or a patient's medical record from an institution or hospital.

Date the patient states they were first diagnosed with cancer. Note: This may be the only date available in a few cases (for example, patient was first diagnosed in a foreign country).

If components of the date are not known, an estimate should be provided where possible with an estimated date flag to indicate that it is estimated. If an estimated date is not possible, a standard date of 15 June 1900 should be used with a flag to indicate the date is not known.

Related metadata: Relates to the data element Date of birth, version 5.

Relates to the data element Estimated date flag, version 1.

Information model link: NHIM   Request for/entry into service event

Data Set Specifications:	*Start date*	*End date*
DSS – Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	01/07/2002

Source organisation: International Agency for Research on Cancer.

World Health Organization.

International Association of Cancer Registries.

Source document: Modified from the definition presented by the New South Wales Inpatient Statistics Collection Manual 2000/2001

Registration authority: National Health Information Group.

Steward:

Comments

Date of diagnosis of first recurrence

Identifying and Definitional attributes

Knowledgebase ID:	**001064**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	The date a medical practitioner confirms the diagnosis of a recurrent or metastatic cancer of the same histology.
Context:	This item is collected for determining the time interval from diagnosis to recurrence, from treatment to recurrence and from recurrence to death.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	8
Representational class:	Date	*Format:*	DDMMYYYY

Data domain:	Valid date.

Guide for use:	The term 'recurrence' defines the return, reappearance or metastasis of cancer (of the same histology) after a disease free period.
Verification rules:	This field must:

— be greater than Date of diagnosis of cancer

— be greater than Cancer initial treatment — completion date (if less than Cancer initial treatment — completion date, the patient was never disease–free)

Collection methods:	
Related metadata:	Relates to the data element Region of first recurrence, version 1.
Information model link:	NHIM Request for/entry into service event

Data Set Specifications:	*Start date*	*End date*
DSS — Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004
Source organisation:	Commission on Cancer, American College of Surgeons.		
Source document:	Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II *(1998).*		
Registration authority:	National Health Information Group.		
Steward:			
Comments			

Date of surgical treatment for cancer

Identifying and Definitional attributes

Knowledgebase ID: **001065**   *Version number:*   **1**

Metadata type: Data element

Definition:	The date on which the cancer–directed surgical treatment was performed.
Context:	This item is collected for analyses of outcome by treatment type.

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   8

Representational class: Date   *Format:*   DDMMYYYY

Data domain:	Valid date.

Guide for use: The date of each surgical treatment episode should be entered separately. Collected for curative and palliative surgery prior to the first recurrence.

Verification rules: This field must be greater than or equal to Date of diagnosis of cancer.

Collection methods:

Related metadata: Relates to the data element concept Initial treatment episode for cancer, version 1.

                             Relates to data element Surgical treatment procedure for cancer, version 1.

Information model link: NHIM   Service provision event

Data Set Specifications: *Start date*   *End date*

   DSS –   Cancer (clinical)   04/06/2004

Administrative attributes

Admin status: CURRENT   *Effective Date:*   04/06/2004

Source organisation: Commission on Cancer, American College of Surgeons.

Source document: Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).

Registration authority: National Health Information Group.

Steward:

Comments:

Establishment number

Identifying and Definitional attributes

Knowledgebase ID:	*000377*	*Version number:*	*4*
Metadata type:	Data element		

Definition:	An identifier for an establishment, unique within the state or territory.
Context:	All health services.

Relational and representational attributes

Representational class:	Identification number	*Format:*	NNNNN
Data type:	Numeric	*Maximum field size:*	5

Data domain:	Valid establishment number.

Guide for use:

Verification rules:

Collection methods:

Related metadata: Is a composite part of Establishment identifier, version 4.

                              Supersedes previous data element Establishment number, version 3.

Information model link: NHIM   Organisation characteristic

Data Set Specifications:	*Start date*	*End date*
NMDS — Admitted patient care	01/07/2004	
DSS — Cancer (clinical)	04/06/2004	
DSS — Health care client identification	01/01/2003	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	01/01/2003

Source organisation:

Source document:

Registration authority: National Health Information Group.

Steward:

Comments: Establishment number should be a unique code for the health care establishment used in that Australian state/territory or uniquely at a national level.

Family name

Identifying and definitional attributes

Knowledgebase ID:	*002007*	*Version number:*	*2*
Metadata type:	Data element		

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.
Context:	Administrative purposes and individual identification.

Relational and representational attributes

Data type:	Alphanumeric	*Maximum field size:*	40
Representational class:	Text	*Format:*	AN(40)

Data domain:	Text.

Guide for use: The agency or establishment should record the client's full 'Family name' on their information systems.

NCSDD **specific:**

In instances where there is uncertainty about which name to record for a person living in a remote Aboriginal or Torres Strait Islander community, Centrelink follows the practice of recording the Indigenous person's name as it is first provided to Centrelink. Or, where proof of identity is required, as the name is recorded on a majority of the higher point scoring documents that are produced as proof of identity.

Verification rules:

Collection methods: This data element should be recorded for all clients.

Mixed case should be used.

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.

It is acknowledged that some people use more than one family name (e.g. formal name, birth name, married/maiden name, tribal name) depending on the circumstances. Each name should be recorded against the appropriate Name Type (see Comments).

A person is able to change his or her name by usage in all States and Territories of Australia with the exception of Western Australia, where a person may only change his or her name under the Change of Name Act. Care should be taken when recording a change of name for a minor. Ideally, the name recorded for the minor should be known to both of his/her parents, so the minor's records can be retrieved and continuity of care maintained, regardless of which parent accompanies the minor to the agency or establishment.

Collection methods:	A person should generally be registered using their preferred name as it is more likely to be used in common usage and on subsequent visits to the agency or establishment. The person's preferred name may in fact be the name on their Medicare card. The Name type data element can be used to distinguish between the different types of names that may be used by the person. The following format may assist with data collection:

What is your family name? _____

Are you known by any other family names that you would like recorded? If so, what are they

_____

Please indicate, for each name above, the 'type' of family name that is to be recorded:

(a) Medicare Card Name (if different to preferred name).

(b) Alias (any other name that you are known by). Whenever a person informs the agency or establishment of a change of family name (e.g. following marriage or divorce), the former name should be recorded as an alias name. A full history of names should be retained. e.g. 'Mary Georgina Smith' informs the hospital that she has been married and changed her family name to 'Jones'. Record 'Jones' as her preferred family name and record 'Smith' as an alias name.

Hyphenated family names:

Sometimes persons with hyphenated family names use only one of the two hyphenated names. It is useful to record each of the hyphenated names as an alias. If the person has a hyphenated family name, e.g. 'Wilson-Phillips' record 'Wilson-Phillips' in the preferred family name field and record 'Wilson' and 'Phillips' separately as alias family names.

Punctuation:

If special characters form part of the family name they should be included, e.g. hyphenated names should be entered with a hyphen.

Examples:

— hyphen, e.g. Wilson-Phillips

Do not leave a space before or after a hyphen, i.e. between the last letter of 'Wilson' and the hyphen, nor a space between the hyphen and the first letter of 'Phillips'.

— apostrophe, e.g. O'Brien, D'Agostino

Do not leave a space before or after the apostrophe, i.e. between the 'O' and the apostrophe, nor a space between the apostrophe and 'Brien'.

— full stop, e.g. St. John, St. George

Do not leave a space before a full stop, i.e. between 'St' and the full stop. Do leave a space between the full stop and 'John'.

— space, e.g. van der Humm, Le Brun, Mc Donald

If the health care client has recorded their family name as more than one word, displaying spaces in between the words, record their family name in the same way leaving one space between each word.

Registered unnamed newborn babies:

When registering a newborn, use the mother's family name as the baby's family name unless instructed otherwise by the mother. Record unnamed babies under the newborn Name Type.

Collection methods: Persons with only one name:

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' field blank.

Registering an unidentified health care client:

The default for unknown family name, should be unknown in all instances and the name recorded as an alias name. Don't create a 'fictitious' family name   such as 'Doe' as this is an actual family name. When the person's name becomes known, record it as the preferred family name and do not overwrite the alias name of unknown.

Registering health care clients from disaster sites:

Persons treated from disaster sites should be recorded under the alias Name Type. Local business rules should be developed for consistent recording of disaster site person details.

Care should be taken not to use identical dummy data (family name, given name, date of birth, sex) for two or more persons from a disaster site.

If the family name needs to be shortened:

If the length of the family name exceeds the length of the field, truncate the family name from the right (that is, dropping the final letters). Also, the last character of the name should be a hash (#) to identify that the name has been   truncated.

Use of incomplete names or fictitious names:

Some health care facilities permit persons to use a pseudonym (fictitious or partial name) in lieu of their full or actual name. It is recommended that the person be asked to record both the pseudonym (Alias Name) in addition to the person's Medicare card name.

Baby for adoption:

The word adoption should not be used as the family name, given name or alias for a newborn baby. A newborn baby that is for adoption should be registered in the same way that other newborn babies are registered. However, if a baby born in the hospital is subsequently adopted, and is admitted for treatment as a child, the baby is registered under their adopted (current) name, and the record should not be linked to the birth record. This should be the current practice. Any old references to adoption in client registers (for names) should also be changed to unknown. Contact your State or Territory adoption information service for further information.

Prefixes:

Where a family name contains a prefix, such as one to indicate that the person is a widow, this must be entered as part of the 'Family Name' field. When widowed, some Hungarian women add 'Ozvegy' (abbreviation is 'Ozy') before their married family name, e.g. 'Mrs Szabo' would become 'Mrs Ozy Szabo'. That is, 'Mrs Szabo' becomes an alias name and 'Mrs Ozy Szabo' becomes the preferred name.

Ethnic Names:

The Centrelink publication, Naming Systems for Ethnic Groups, provides the correct coding for ethnic names.

Collection methods:	Misspelled family name:

If the person's family name has been misspelled in error, update the family name with the correct spelling and record the misspelled family name as an alias name. Recording misspelled names is important for filing documents that may be issued with previous versions of the person's name. Discretion should be used regarding the degree of recording that is maintained.

Often people use a variety of names, including legal names, married/maiden names, nicknames, assumed names, traditional names, etc. Even small differences in recording — such as the difference between MacIntosh and McIntosh— can make record linkage impossible. To minimise discrepancies in the recording and reporting of name information, agencies or establishments should ask the person for their full (formal) 'Given name' and 'Family name'. These may be different from the name that the person may prefer the agency or establishment workers to use in personal dealings. Agencies or establishments may choose to separately record the preferred names that the person wishes to be used by agency or establishment workers. In some cultures it is traditional to state the family name first. To overcome discrepancies in recording/reporting that may arise as a result of this practice, agencies or establishments should always ask the person to specify their first given name and their family name or surname separately. These should then be recorded as 'Given name' and 'Family name' as appropriate, regardless of the order in which they may be traditionally given.

Related metadata:	Supersedes the data element Family name, version 1.
	Relates to the data element concept Name, version 1.
Information model link:	NHIM Person characteristic

Data Set Specifications:	*Start date*	*End date*
DSS — Cancer (clinical)	04/06/2004	
DSS — Health care client identification	02/09/2003	

Administrative attributes

Admin. status	CURRENT	***Effective Date:***	02/09/2003

Source organisation:	Australian Government Department of Health and Ageing.
	Australian Institute of Health and Welfare.
	Standards Australia.
	Health Data Standards Committee.
	National Community Services Data Committee.
Source document:	Australian Government Department of Health and Ageing 1998, *Home and Community Care Data Dictionary* Version 1.0. Canberra: DHFS.
	Australian Institute of Health and Welfare Australian Standard AS5017—2002 Health Care Client Identification. Sydney: Standards Australia.
Registration authority:	National Health Information Group
	National Community Services Information Management Group
Steward:	

Comments:	This metadata item is common to both the *National Health Data Dictionary* and the *National Community Services Data Dictionary*.

NCSDD **specific:**

Selected letters of the family name in combination with selected letters of the 'Given name',' Date of birth' and 'Sex', may be used for record linkage for statistical purposes only.

Name type is a metadata item in Australian Standard AS5017—2002 Health care client identification (Standards Australia 2002) and in the *National Health Data Dictionary*, Version 12 (NHDC 2003). In both cases the Data domain refers to Code A Alias name; Code M Medicare card name; Code N Newborn name; and Code P Preferred name. A name type data element is being considered for inclusion in a future version of the *National Community Services Data Dictionary*.

Given name(s)

Identifying and Definitional attributes

Knowledgebase ID:	*002008*	*Version number:*	*2*
Metadata type:	Data element		

Definition:	The person's identifying name(s) within the family group or by which the person is socially identified.
Context:	Administrative purposes and individual identification.

Relational and representational attributes

Data type:	Alphanumeric	*Maximum field size:*	40
Representational class:	Text	*Format:*	AN(4)

Data domain:	Text.

Guide for use:	The agency or establishment should record the client's full given name(s) on their information systems.
	NCSDD **specific:**
	In instances where there is uncertainty about which name to record for a person living in a remote Aboriginal or Torres Strait Islander community, Centrelink follows the practice of recording the Indigenous person's name as it is first provided to Centrelink. Or, where proof of identity is required, as the name is recorded on a majority of the higher point scoring documents that are produced as proof of identity.
	NHDD **specific:**
	Health care establishments may record given names (first and other given names) in one field or several fields. This data element definition applies regardless of the format of data recording.
	A full history of names is to be retained.
Verification rules:	
Collection methods:	This data element should be recorded for all clients.
	Given name(s) 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.
	It is acknowledged that some people use more than one given name (e.g. formal name, birth name, nick name or shortened name, or tribal name) depending on the circumstances. A person is able to change his or her name by usage in all States and Territories of Australia with the exception of Western Australia, where a person may only change his or her name under the Change of Name Act.

Collection methods: A person should generally be registered using their preferred name as it is more likely to be used in common usage and on subsequent visits to the agency or establishment. The person's preferred name may in fact be their legal (or Medicare card) name. The Name Type data element (see Comments) can be used to distinguish between the different types of names that may be used by the person.

The following format may assist with data collection:

What is the given name you would like to be known by?

_____

Are you known by any other given names that you would like recorded?

If so, what are they

_____

Please indicate the 'type' of given name that is to be recorded:

(a) Medicare card name (if different to preferred name).

(b) Alias (any other name that you are known by).

Whenever a person informs the agency or establishment of a change of given name (e.g. prefers to be know by their middle name), the former name should be recorded according to the appropriate name type. Do not delete or overwrite a previous given name e.g. 'Mary Georgina Smith' informs the hospital that she prefers to be known as 'Georgina'. Record 'Georgina' as her preferred 'Given Name' and record 'Mary' as the Medicare card 'Given Name'.

e.g. The agency or establishment is informed that 'Baby of Louise Jones' has been named 'Mary Jones'. Retain 'Baby of Louise' as the newborn name and also record 'Mary' as the preferred 'Given Name'.

Registering an unidentified health care client:

If the person is a health care client and her/his given name is not known record unknown in the 'Given Name' field and use alias name type. When the person's name becomes known, add the actual name as preferred Name Type (or other as appropriate). Do not delete or overwrite the alias name of unknown.

Use of first initial:

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 preferred 'Given Name' field. Do not record a full stop following the initial.

Persons with only one name:

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.

Multiple given names (middle, second, third etc names):

All of the person's given names should be recorded in the 'Given Name' field, leaving a space between each name.

Record complete information:

If the person has many given names and all of them cannot fit in the field, record as many names in full as possible, in preference to recording initials.

Collection methods: Shortened or alternate first given name:

If the person uses a shortened version or an alternate version of their first given name, record their preferred name, the actual name as their Medicare card name and any alternative versions as alias names as appropriate.

e.g. The person's given name is Jennifer but she prefers to be called Jenny. Record 'Jenny' as the preferred 'Given Name' and 'Jennifer' as her Medicare card name.

e.g. The person's given name is 'Giovanni' but he prefers to be called 'John'.

Record 'John' as the preferred 'Given Name' and 'Giovanni' as the Medicare card name.

Punctuation:

If special characters form part of the given names they shall be included, e.g. hyphenated names shall be entered with the hyphen.

— Hyphen eg. Anne-Maree, Mary-Jane

Do not leave a space before or after the hyphen, i.e. between last letter of 'Anne' and the hyphen, nor a space between the hyphen and the first letter of 'Maree'.

— spaces e.g. Jean Claude

If the person has recorded their given name as more than one word, displaying spaces in between the words, record their given names in data collection systems in the same way.

e.g. Oscar Peter, Wendy Hilda

Leave a single space between the person's first name and each of their middle names.

Registering an unnamed newborn baby:

An unnamed (newborn) baby is to be registered using the mother's given name in conjunction with the prefix 'Baby of'. For example, if the baby's mother's given name is Fiona, then record 'Baby of Fiona' in the preferred 'Given Name' field for the baby. This name is recorded under the newborn Name Type. If a name is subsequently given, record the new name as the preferred given name and retain the newborn name.

Registering unnamed multiple births:

An unnamed (newborn) baby from a multiple birth should use their mother's given name plus a reference to the multiple birth. For example, if the baby's mother's given name is 'Fiona' and a set of twins is to be registered, then record 'Twin 1 of Fiona' in the Given Name field for the first born baby, and 'Twin 2 of Fiona' in the 'Given Name' field of the second born baby. Arabic numbers (1, 2, 3 ...) are used, not Roman Numerals (I, II, III ......).

Collection methods:	In the case of triplets or other multiple births the same logic applies. The following terms should be use for recording multiple births:

- Twin

  Use Twin i.e. Twin 1 of Fiona
- Triplet

  Use Trip i.e. Trip 1 of Fiona
- Quadruplet

  Use Quad i.e. Quad 1 of Fiona
- Quintuplet

  Use Quin i.e. Quin 1 of Fiona
- Sextuplet

  Use Sext i.e. Sext 1 of Fiona
- Septuplet

  Use Sept i.e. Sept 1 of Fiona.

These names should be recorded under the newborn Name Type. When the babies are named, the actual names should be recorded as the preferred name. The newborn name is retained.

Aboriginal/Torres Strait Islander names not for continued use:

For cultural reasons, an Aboriginal or Torres Strait Islander may advise an agency or establishment that they are no longer using the given name that they had previously registered and are now using an alternative current name.

Record their current name as the preferred 'Given Name' and record their previous used given name as an alias name.

Ethnic Names:

The Centrelink Naming Systems for Ethnic Groups publication provides the correct coding for ethnic names. Refer to Ethnic Names Condensed Guide for summary information.

Misspelled given names:

If the person's given name has been misspelled in error, update the Given Name field with the correct spelling and record the misspelled given name as an Alias Name. Recording misspelled names is important for filing documents that may be issued with previous versions of the client's name. Discretion should be used regarding the degree of recording that is maintained.

Often people use a variety of names, including legal names, married/maiden names, nicknames, assumed names, traditional names, etc. Even small differences in recording—such as the difference between Thomas and Tom—can make Record linkage impossible. To minimise discrepancies in the recording and reporting of name information, agencies or establishments should ask the person for their full (formal) Given name and Family name. These may be different from the name that the person may prefer the agency or establishment workers to use in personal dealings. Agencies or establishments may choose to separately record the preferred name that the person wishes to be used by agency or establishment workers. In some cultures it is traditional to state the family name first. To overcome discrepancies in recording/reporting that may arise as a result of this practice, agencies or establishments should always ask the person to specify their first given name and their family or surname separately. These should then be recorded as Given name and Family name as appropriate, regardless of the order in which they may be traditionally given.

		Start date	End date

Related metadata: Supersedes the previous data element Given name(s), version 1.

Relates to the data element concept Name, version 1.

Information model link: NHIM   Person characteristic

Data Set Specifications:		*Start date*	*End date*
DSS — Cancer (clinical)		04/06/2004	
DSS — Health care client identification		02/09/2003	

Administrative attributes

Admin status: CURRENT   *Effective Date:*   02/09/2003

Source organisation: Australian Institute of Health and Welfare.

Standards Australia.

Health Data Standards Committee.

National Community Services Data Committee.

Source document: Australian Government Department of Health and Ageing 1998, *Home and Community Care Data Dictionary* Version 1.0. Canberra.

Standards Australia 2002. Australian Standard AS5017—2002 Health Care Client Identification. Sydney: Standards Australia.

Registration authority: National Health Information Group.

National Community Services Information Management Group.

Steward:

Comments: This metadata item is common to both the *National Health Data Dictionary* and the *National Community Services Data Dictionary*.

NCSDD **specific:**

Selected letters of the Given name in combination with selected letters of the Family name, Date of birth and Sex may be used for Record linkage for statistical purposes only (see data concept Record linkage).

Name type is a metadata item in Australian Standard AS5017—2002 Health care client identification (Standards Australia 2002) and in the *National Health Data Dictionary* Version 12 (NHDC 2003). In both cases the Data domain refers to Code A Alias name; Code M Medicare card name; Code N Newborn name; and Code P Preferred name. A name type data element is being considered for inclusion in a future version of the *National Community Services Data Dictionary*.

Histopathological grade

Identifying and Definitional attributes

Knowledgebase ID: **001066**   *Version number:*   **1**

Metadata type: Data element

Definition:	The histopathological grade, differentiation or phenotype describes how little the tumour resembles the normal tissue from which it arose.
Context:	

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   1

Representational class: Code   *Format:*   N

Data domain:	The sixth digit of the ICD-O morphology code	
	1 Grade 1:	Well differentiated, differentiated, NOS
	2 Grade 2:	Moderately differentiated, moderately well differentiated, intermediate differentiation
	3 Grade 3:	Poorly differentiated
	4 Grade 4:	Undifferentiated, anaplastic
	Lymphomas and leukaemias	
	5 T-cell:	T-cell
	6 B-cell:	B-cell, Pre-B, B-Precursor
	8 NK:	Natural killer cell
	Unknown or not stated	
	9 Grade/differentiation unknown: Grade/cell type not determined, not stated or not applicable	

Guide for use: Only one code can be recorded.

Verification rules:

Collection methods:

Related metadata: Relates to the data element Morphology of cancer, version 1.

Relates to the data element Date of diagnosis of cancer, version 1.

Relates to the data element Primary site of cancer, version 1.

Information model link: NHIM   Assessment event

Data Set Specifications:		*Start date*	*End date*
DSS — Cancer (clinical)		04/06/2004	

Administrative attributes

Admin status: CURRENT   *Effective Date:*   04/06/2004

Source organisation:	World Health Organisation.
	Commission on Cancer, American College of Surgeons.
Source document:	World Health *Organisation International Classification of Diseases Oncology*, Third edition (ICD-O-3) *(2000)*.
	Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II *(1998)*.
Registration authority:	National Health Information Group.
Steward:	
Comments	

Initial treatment episode for cancer

Identifying and Definitional attributes

Knowledgebase ID: **001067**   ***Version number:***   **1**

Metadata type: Data element concept

Definition:	The initial course of cancer directed treatment or treatments, with defined dates of commencement and cessation, given to the patient by a treatment provider or team of providers. 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.
Context:	This concept is required to provide the basis for a standard approach to recording and monitoring patterns of initial treatment for cancer patients.

Relational and representational attributes

Data type: *Maximum field size:*

Representational class: *Format:*

Data domain:

Guide for use:

Verification rules:

Collection methods:

Related metadata: Relates to the data element Intention of treatment for cancer, version 1.

Relates to the data element Cancer treatment — target site, version 1.

Relates to the data element Cancer treatment type, version 1.

Relates to the data element Surgical treatment procedure for cancer, version 1.
Relates to the data element Radiotherapy treatment type, version 1.

Relates to the data element Received radiation dose, version 1.

Relates to the data element Systemic therapy agent name, version 1.

Relates to the data element Date of surgical treatment for cancer, version 1.

Relates to the data element Cancer initial treatment—starting date, version 1.
Relates to the data element Cancer initial treatment—completion date, version 1.

Information model link: NHIM   Request for/entry into service event

Administrative attributes

Admin status: CURRENT   ***Effective Date:***   04/06/2004

Source organisation: Commission on Cancer, American College of Surgeons.

Source document: Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).

                              Commission on Cancer, *Facility Oncology Registry Data Standards* (2002).

Registration authority: National Health Information Group.

Steward:

Comments

Intention of treatment for cancer

Identifying and Definitional attributes

Knowledgebase ID: **001068**   *Version number:*   **1**

Metadata type: Data element

Definition:	The intention of the initial treatment for cancer for the particular patient.
Context:	This item is collected for surgical treatment, radiation therapy and systemic therapy agent treatment. It is used for correlating outcome with original intent of the treatment.

Relational and representational attributes

Data type: Alphanumeric   *Maximum field size:*   1

Representational class: Code   *Format:*   N

Data domain:	0	Did not have treatment
	1	Prophylactic
	2	Curative
	3	Non-curative or palliative
	9	Not stated.

Guide for use:	Code 0	Did not have treatment, is used when the patient did not have treatment as part of the initial management plan.
	Code 1	Prophylactic, is used when the cancer has not developed
	Code 2	Curative, is used when treatment is given for control of the disease.
	Code 3	Non-curative or palliative, is used when the 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.
	Code 9	Intention was not stated. Patient had treatment for cancer but the intention was not stated.

Verification rules:

Collection methods:

Related metadata: Relates to the data element Cancer treatment type, version 1.

Relates to the data element concept Initial treatment episode for cancer, version 1.

Relates to the data element Surgical treatment procedure for cancer, version 1.

Relates to the data element Radiotherapy treatment type, version 1.

Information model link: NHIM   Exit/leave from service event

Data Set Specifications:	*Start date*	*End date*
DSS – Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: Commission on Cancer, American College of Surgeons.

New South Wales Health Department.

Source document: Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS) Volume II (1998).*

Public Health Division NSW *Clinical Cancer Data Collection for Outcomes and Quality. Data Dictionary* Version 1 Sydney NSW Health Dept (2001).

Registration authority: National Health Information Group.

Steward:

Comments

Laterality of primary cancer

Identifying and Definitional attributes

Knowledgebase ID:	**000774**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	Laterality describes which side of a paired organ is the origin of the primary cancer. Each side of a paired organ is considered separately and described as lateral when occurring unless a physician determines that it is bilateral.
	A paired organ is one in which there are two separate organs of the same kind, one on either side of the body (e.g. kidney, breast, ovary, testis and lung).
Context:	This information is collected for the purpose of differentiating the site of the primary cancer. For example, a woman may present with a primary cancer in the left breast. She may return at a later stage with a new primary cancer in the right breast.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	1
Representational class:	Code	*Format:*	N

Data domain:	1	Left
	2	Right
	3	Bilateral (Note: Bilateral cancers are very rare)
	9	Not known
	Null	Not applicable

Guide for use:	The valid International Classification of Diseases for Oncology values for the variable are provided in the list below:
	1 Left:
	Origin of primary site is on the left side of a paired organ
	Paired organs are: Breast (C50), Lung (C34), Kidney (C64), Ovary (C56), Eyes (C69), Arms (C76.4, C44.6, C49.1, C47.1, C40.0, C77.3,), Legs (C76.5, C44.7, C49.2, C47.2, C40.2, C77.4), Ears (C44.2, C49.0, C30.1), Testicles (C62), Parathyroid glands (C75.0), Adrenal glands (C74.9, C74.0, C74.1), Tonsils (C09.9, C02.4, C11.1, C09.0, C09.1, C03.9), Ureter (C66.9), Carotid body (C75.4), Vas deferens (C63.1), Optic nerve (C72.3)
	2 Right:
	Origin of primary site is on the right side of a paired organ
	3 Bilateral:
	Includes organs that are bilateral as a single primary (e.g. bilateral retinoblastoma (M9510/3, C69.2), (M9511/3, C69.2), (M9512/3, C69.2), (C69.6, C48.0), bilateral Wilms tumours (C64.9, M8960/3))
	9 Unknown:
	It is unknown whether, for a paired organ the origin of the cancer was on the left or right side of the body.

Verification rules:

Collection methods:	This information should be obtained from the patient's pathology report, the patient's medical record, or the patient's medical practitioner/nursing staff.
Related metadata:	Is qualified by Primary site of cancer, version 1.
Information model link:	NHIM Assessment event

Data Set Specifications:	*Start date*	*End date*
DSS – Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	01/07/2002
Source organisation:	World Health Organization		
Source document:	International Classification of Diseases for Oncology, Second Edition		
Registration authority:	National Health Information Group		
Steward:			
Comments			

Medicare card number

Identifying and Definitional attributes

Knowledgebase ID:	**000091**	*Version number:*	**2**
Metadata type:	Data element		

Definition:	Person identifier, allocated by the Health Insurance Commission to eligible persons under the Medicare scheme, that appears on a Medicare card.
Context:	Medicare utilisation statistics.
	Persons eligible for Medicare services

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	11
Representational class:	Code	*Format:*	N(11)

Data domain:	Full Medicare card number for an individual (i.e. family number plus person (individual reference) number).

Guide for use:	As a person can be identified on more than one Medicare card this is not a unique identifier for a person.
	The Medicare card number should only be collected from persons eligible to receive health services that are to be funded by the Commonwealth government. The number should be reported to the appropriate government agency to reconcile payment for the service provided. 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.
	Note: Veterans may have a Medicare card number and a Department of Veterans' Affairs (DVA) number or only a DVA number.
Verification rules:	
Collection methods:	
Related metadata:	Supersedes previous data element Medicare number, version 1.
Information model link:	NHIM Recipient role

Data Set Specifications:		*Start date*	*End date*
DSS – Cancer (clinical)		04/06/2004	
DSS – Health care client identification		01/01/2003	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	01/01/2003
Source organisation:	Standards Australia		
Source document:	AS5017 Health care client identification		

Registration authority:	National Health Information Group
Steward:	
Comments	The Medicare card number is printed on a Medicare card and is used to access Medicare records for an eligible person.
	Up to 9 persons can be included under the one Medicare card number with up to five persons appearing on one physical card.
	Persons grouped under one Medicare card number are often a family, however, there is no requirement for persons under the same Medicare card number to be related.
	A person may be shown under separate Medicare card numbers where, for example, a child needs to be included on separate Medicare cards held by their parents.

Morphology of cancer

Identifying and Definitional attributes

Knowledgebase ID:	**000775**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	The morphology of a cancer refers to the histological classification of the cancer tissue (histopathological type) and a description of the course of development that a tumour is likely to take: benign or malignant (behaviour). The designation is based on a microscopic diagnosis of morphology by the pathologist (Esteban, Whelan, Laudico & Parkin 1995).
Context:	This information is collected for the purpose of: • classifying tumours into clinically relevant groupings on the basis of both their morphology (cell type) and their degree of invasion or malignancy as indicated by the behaviour code component (the last digit of the morphology code) • monitoring the number of new cases of cancer for planning treatment services.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	5
Representational class:	Code	*Format:*	NNNNN

Data domain:	The current version of the International Classification of Diseases for Oncology (ICDO).

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. The 5th-digit behaviour code numbers used in ICDO are listed below:
	
	0 Benign
	1 Uncertain whether benign or malignant
	    • borderline malignancy
	    • low malignant potential
	2 Carcinoma in situ
	    • intraepithelial
	    • non-infiltrating
	    • non-invasive
	3 Malignant, primary site
	6 Malignant, metastatic site
	    • malignant, secondary site
	9 Malignant, uncertain whether primary or metastatic site

Verification rules:

Collection methods:	Cancer registry use:
	In cancer registries morphology information should be obtained from a pathology report or pathology system, and recorded with/on the patient's medical record and/or the hospital's patient administration system. Additional information may also be sought from the patient's attending clinician or medical practitioner.
	Hospital morbidity use:
	In hospitals, the morphology code is modified for use with ICD-10-AM. The morphology code consists of histologic type (4 digits) and behaviour code (1 digit) ranging from 8000/0 to 9989/9. The '/' between the fourth and fifth digits is not supplied.

Related metadata:

Information model link: NHIM   Assessment event

Data Set Specifications:		*Start date*	*End date*
DSS – Cancer (clinical)		04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	01/07/2002

Source organisation:	World Health Organization.
	New South Wales Health Department.
	state and territory Cancer Registries.

Source document:	International Classification of Diseases for Oncology, Second Edition (ICDO-2)
	New South Wales Inpatient Statistics Collection Manual, 2000/2001

Registration authority: National Health Information Group

Steward:

Comments

Most valid basis of diagnosis of cancer

Identifying and Definitional attributes

Knowledgebase ID: **000861**   *Version number:*   **1**

Metadata type: Data element

Definition:	The basis of diagnosis of a cancer is the microscopic or non-microscopic or death certificate source of the diagnosis. The most valid basis of diagnosis is that accepted by the cancer registry as the most reliable diagnostic source of the death certificate, non-microscopic, and microscopic sources available.
Context:	Knowledge of the basis of a diagnosis underlying a cancer code is one of the most important aids in assessing the reliability of cancer statistics.

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   1

Representational class: Code   *Format:*   N

Data domain:	0 Death Certificate Only: Information provided is from a death certificate.
	Non-microscopic
	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.
	Microscopic
	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.
	Other
	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). In a cancer registry setting, this item should be revised if later information allows its upgrading.

When considering the most valid basis of diagnosis, the minimum requirement of a cancer registry is differentiation between neoplasms that are verified microscopically and those that are not. To exclude the latter group means losing valuable information; the making of a morphological (histological) diagnosis is dependent upon a variety of factors, such as age, accessibility of the tumour, availability of medical services, and, last but not least, upon the beliefs of the patient.

A biopsy of the primary tumour should be distinguished from a biopsy of a metastasis, e.g., at laparotomy; a biopsy of cancer of the head of the pancreas versus a biopsy of a metastasis in the mesentery. However, when insufficient information is available, Code 8 should be used for any histological diagnosis. Cytological and histological diagnoses should be distinguished.

Morphological confirmation of the clinical diagnosis of malignancy depends on the successful removal of a piece of tissue that is cancerous. Especially when using endoscopic procedures (bronchoscopy, gastroscopy, laparoscopy, etc.), the clinician may miss the tumour with the biopsy forceps. These cases must be registered on the basis of endoscopic diagnosis and not excluded through lack of a morphological diagnosis.

Care must be taken in the interpretation and subsequent coding of autopsy findings, which may vary as follows:

(a)   the post-mortem report includes the post-mortem histological diagnosis (in which case, one of the Histology codes should be recorded instead);

(b)   the autopsy is macroscopic only, histological investigations having been carried out only during life (in which case, one of the Histology codes should be recorded instead);

(c)   the autopsy findings are not supported by any histological diagnosis.

Verification rules:

Collection methods:

Related metadata:

Information model link: NHIM   Physical wellbeing

Data Set Specifications:		*Start date*	*End date*
DSS — Cancer (clinical)		04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	25/02/2004

Source organisation: International Agency for Research on Cancer and International Association of Cancer Registries.

Source document:

Registration authority: National Health Information Group.

Steward:

Comments: In a hospital setting this item should be collected on the most valid basis of diagnosis at this admission. If more than one diagnostic technique is used during an admission, select the higher code from 1 to 8.

Oestrogen receptor assay status

Identifying and Definitional attributes

Knowledgebase ID:	**001069**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	The results of oestrogen receptor assay at the time of diagnosis of the primary breast tumour.
Context:	Collected for breast cancers. Hormone receptor status is an important prognostic indicator for breast cancer.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	1
Representational class:	Code	*Format:*	N

Data domain:	0	Test not done (test not ordered or not performed)
	1	Test done, results positive (oestrogen receptor positive)
	2	Test done, results negative (oestrogen receptor negative)
	8	Test done but results unknown

Guide for use: The Australian Cancer Network Working Party established to develop guidelines for the pathology reporting of breast cancer recommends that hormone receptor assays be performed on all cases of invasive breast carcinoma. The report should include

- the percentage of nuclei staining positive and the predominant staining intensity (low, medium, high) and

- a conclusion as to whether the assay is positive or negative

Verification rules:

Collection methods:

Related metadata:

Information model link: NHIM   Assessment event

Data Set Specifications:		*Start date*	*End date*
DSS — Cancer (clinical)		04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004
Source organisation:	Royal College of Pathologists of Australasia		
	Australian Cancer Network		
	Commission on Cancer, American College of Surgeons		

Source document:	Royal College of Pathologists of *Australasia Manual of Use and Interpretation of Pathology Tests*: Third Edition Sydney (2001)
	Australian Cancer Network Working Party *The pathology reporting of breast cancer. A guide for pathologists, surgeons and radiologists* Second Edition Sydney (2001)
	Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998)
Registration authority:	National Health Information Group.
Steward:	
Comments	

Outcome of initial treatment

Identifying and Definitional attributes

Knowledgebase ID: **001071**   *Version number:*   **1**

Metadata type: Data element

Definition:	The outcome of initial treatment describes the response of the tumour at the completion of the initial treatment modalities.
Context:	This item is collected for assessing disease status at the end of primary treatment.

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   3

Representational class: Code   *Format:*   N.N

Data domain:	
1.0	Complete response
2.0	Incomplete response
	2.1 Partial response
	2.2 Stable or static disease
	2.3 Progressive disease
9.0	Not assessed or unable to be assessed

Guide for use:	Code 1.0	Complete disappearance of all measurable disease, including tumour markers, for at least four weeks. No new lesions or new evidence of disease.
	Code 2.1	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	No change in measurable lesions qualifying as partial response or progression and no evidence of new lesions.
	Code 2.3	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.

Verification rules:

Collection methods:

Related metadata:

Information model link: NHIM   Exit/leave from service event

Data Set Specifications:	*Start date*	*End date*
DSS — Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: NSW Health Department.

Source document: Public Health Division *NSW Clinical Cancer Data Collection for Outcomes and Quality. Data Dictionary* Version 1 *Sydney NSW Health Dept (2001).*

Registration authority: National Health Information Group.

Steward:

Comments

Person identifier

Identifying and Definitional attributes

Knowledgebase ID:	**002020**	*Version number:*	**2**
Metadata type:	Data element		

Definition:	Person identifier unique within an establishment or agency.
Context:	This item could be used for editing at the agency, establishment or collection authority level and, potentially, for episode linkage. There is no intention that this item would be available beyond collection authority level.

Relational and representational attributes

Data type:	Alphanumeric	*Maximum field size:*	20
Representational class:	Identification number	*Format:*	AN(20)

Data domain:	Valid person identification number.

Guide for use:	Individual agencies, establishments or collection authorities may use their own alphabetic, numeric or alphanumeric coding systems.
Verification rules:	Field cannot be blank.
Collection methods:	
Related metadata:	Supersedes the previous data element Person identifier, version 1.
	Is qualified by Person identifier type — health care, version 1.
Information model link:	NHIM Recipient role

Data Set Specifications:	*Start date*	*End date*
NMDS — Admitted patient care	01/07/2004	
NMDS — Admitted patient mental health care	01/07/2004	
NMDS — Perinatal	01/07/2004	
NMDS — Community mental health care	01/07/2004	
NMDS — Admitted patient palliative care	01/07/2004	
NMDS — Alcohol and other drug treatment services	01/07/2004	
NMDS — Non-admitted patient Emergency Department care	01/07/2004	
NMDS — Residential mental health care	01/07/2004	
DSS — Acute coronary syndrome (clinical)	04/06/2004	
DSS — Cancer (clinical)	04/06/2004	
DSS — Cardiovascular disease (clinical)	02/09/2003	
DSS — Health care client identification	02/09/2003	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	02/09/2003

Source organisation: Health Data Standards Committee.

National Community Services Data Committee.

Source document:

Registration authority: National Health Information Group.

National Community Services Information Management Group.

Steward:

Comments: This metadata item is common to both the *National Health Data Dictionary* and the *National Community Services Data Dictionary*.

Primary site of cancer

Identifying and Definitional attributes

Knowledgebase ID: **000776**   *Version number:*   **1**

Metadata type: Data element

Definition:	The primary site is the site of origin of the tumour, as opposed to the secondary or metastatic sites. It is described by reporting the anatomical position (topography) of the tumour.
Context:	This information is collected for the purpose of:

- classifying tumours into clinically-relevant groupings on the basis of both their site of origin and their histological type
- monitoring the number of new cases of cancer for planning treatment services
- epidemiological studies.

Relational and representational attributes

Data type: Alphanumeric   *Maximum field size:*   5

Representational class: Code   *Format:*   ANNNN

Data domain:	Cancer registries:
	The current version of *International Classification of Diseases for Oncology* (ICDO).
	Hospitals:
	The current edition of *International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision, Australian Modification (ICD-10-AM).

Guide for use: Report the primary site of cancer, if known, for patients who have been diagnosed with a cancer. In ICD-10, primary site is identified using a single four-digit code Cxx.x or Dxx.x. In ICDO, primary site is identified using both the Cxx.x code identifying site and the behaviour code to identify whether the site is the primary site. The behaviour code numbers used in ICD-O are listed below :

0   Benign

1   Uncertain whether benign or malignant

- borderline malignancy
- low malignant potential

2   Carcinoma in situ

- intraepithelial
- non-infiltrating
- non-invasive

3   Malignant, primary site

6   Malignant, metastatic site

- malignant, secondary site

9   Malignant, uncertain whether primary or metastatic site

Verification rules:

Collection methods:	Cancer registries use Site codes from the current version of ICDO.
	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. 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 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.
Related metadata:	Is a qualifier of the data element Laterality of primary cancer, version 1.
Information model link:	NHIM Assessment event

Data Set Specifications:	***Start date***	***End date***
NMDS − Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	***Effective Date:***	01/07/2002
Source organisation:	World Health Organization.		
Source document:	*International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision (ICD-10).		
	International Classification of Diseases for Oncology, Second Edition (ICDO-2).		
	Current edition of *International Classification of Diseases*, Tenth Revision, Australian Modification (ICD-10-AM). National Centre for Classification in Health, Sydney.		
Registration authority:	National Health Information Group.		
Steward:			
Comments:			

Progesterone receptor assay status

Identifying and Definitional attributes

Knowledgebase ID: *001072*   *Version number:*   *1*

Metadata type: Data element

Definition:	The results of progesterone receptor assay at the time of diagnosis of the primary breast tumour.
Context:	Collected for breast cancers. Hormone receptor status is an important prognostic indicator for breast cancer.

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   1

Representational class: Code   *Format:*   N

Data domain:	0	Test not done (test not ordered or not performed)
	1	Test done, results positive (progesterone receptor positive)
	2	Test done, results negative (Progesterone receptor negative)
	8	Test done but results unknown
	9	Unknown

Guide for use: The Australian Cancer Network Working Party established to develop guidelines for the pathology reporting of breast cancer recommends that hormone receptor assays be performed on all cases of invasive breast carcinoma. The report should include:

-   the percentage of nuclei staining positive and the predominant staining intensity (low, medium, high) and

-   a conclusion as to whether the assay is positive or negatice

Verification rules:

Collection methods:

Related metadata:

Information model link: NHIM   Assessment event

Data Set Specifications: *Start date*   *End date*

   DSS —   Cancer (clinical)   04/06/2004

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation:

Royal College of Pathologists of Australasia.

Australian Cancer Network.

Commission on Cancer, American College of Surgeons.

Source document:

Royal College of Pathologists of Australasia *Manual of Use and Interpretation of Pathology Tests*: Third Edition *Sydney (2001).*

Australian Cancer Network Working Party *The pathology reporting of breast cancer. A guide for pathologists, surgeons and radiologists* Second Edition *Sydney (2001).*

Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II *(1998).*

Registration authority: National Health Information Group.

Steward:

Comments

Radiotherapy treatment type

Identifying and Definitional attributes

Knowledgebase ID:	*001073*	*Version number:*	*1*
Metadata type:	Data element		

Definition:	The type of radiation therapy used in initial treatment of the cancer.
Context:	This item is collected for the analysis of outcome by treatment type.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	1
Representational class:	Code	*Format:*	N

Data domain:	0	No radiotherapy treatment given
	1	External beam radiation
	2	Brachytherapy (radioactive implants)
	3	Unsealed radioisotopes
	9	Radiotherapy was administered but method was not stated

Guide for use:	Code 2 Brachytherapy (radioactive implants) is likely to be listed as a procedure for admitted patients. Most external beam radiotherapy is delivered on an outpatient basis.
Verification rules:	If codes 1, 2, 3 or 9 are used, Received radiation dose should also be collected.
Collection methods:	
Related metadata:	Relates to the data element concept Initial treatment episode for cancer, version 1.
	Relates to the data element Cancer initial treatment — starting date, version 1.
	Relates to the data element Cancer initial treatment — completion date, version 1.
	Relates to the data element Received radiation dose, version 1.
Information model link:	NHIM Exit/leave from service event

Data Set Specifications:	*Start date*	*End date*
DSS — Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: Commission on Cancer, American College of Surgeons.

NSW Health Department.

Source document: Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).

Public Health Division *NSW Clinical Cancer Data Collection for Outcomes and Quality. Data Dictionary* Version 1 Sydney NSW Health Dept (2001).

Registration authority: National Health Information Group.

Steward:

Comments

Received radiation dose

Identifying and Definitional attributes

Knowledge base ID: **001074**   *Version number:*   **1**

Metadata type: Data element

Definition:	The received dose of radiation measured in Gray (Gy) — ICRU.
Context:	This item is collected for the analysis of outcome by treatment type.

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   5

Representational class: Quantitative value   *Format:*   NNNNN

Data domain:	Valid numbers. Unit of measurement: Gy, or
	00000 if no radiation therapy was administered
	99999 if radiation therapy was administered but the dose is unknown

Guide for use: The ICRU50 reference dose should be recorded for photon therapy if available, otherwise a description of the received dose at the centre of the planning target volume. The ICRU58 should be recorded for brachytherapy. The International Council for Radiation Protection (ICRP) recommends recording doses at the axis point where applicable (opposed fields, four field box, wedged pairs and so on). For maximum consistency in this field the IRCP recommendations should be followed whenever possible.

Verification rules:

Collection methods:

Related metadata: Relates to the data element concept Initial treatment episode for cancer, version 1.

                             Relates to the data element Radiotherapy treatment type, version 1.

                             Relates to the data element Cancer initial treatment — starting date, version 1.

                             Relates to the data element Cancer initial treatment — completion date, version 1.

Information model link: NHIM   Service provision event

Data Set Specifications: *Start date*   *End date*

   DSS —   Cancer (clinical)   04/06/2004

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: Commission on Cancer, American College of Surgeons.

Source document: Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).

Registration authority: National Health Information Group.

Steward:

Comments

Region of first recurrence

Identifying and Definitional attributes

Knowledgebase ID:	**001075**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	The term recurrence refers to the return or reappearance of the primary cancer after a disease-free intermission or remission. The cancer may recur in more than one site (eg., both regional and distant metastases).
Context:	This item is collected for the analysis of outcome by treatment type.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	1
Representational class:	Code	*Format:*	N

Data domain:	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	Unknown if recurred

Guide for use:	The region of the first recurrence following the initial diagnosis should be recorded.
	The record should not be updated with subsequent recurrences.
	Record the highest numbered applicable response.
Verification rules:	
Collection methods:	
Related metadata:	Relates to the data element Date of diagnosis of first recurrence, version 1.
Information model link:	NHIM Physical wellbeing

Data Set Specifications:	*Start date*	*End date*
DSS – Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: Commission on Cancer, American College of Surgeons.

Source document: Commission on Cancer. *Standards of the Commission on Cancer Volume II Registry Operations and Data Standards (ROADS)* (1998).

Registration authority: National Health Information Group.

Steward:

Comments

Regional lymph nodes examined

Identifying and Definitional attributes

Knowledge base ID: **001076**   *Version number:*   **1**

Metadata type: Data element

Definition:	This records the total number outcome of regional lymph nodes examined by the pathologist.
Context:	

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   2

Representational class: Code   *Format:*   N(N)

Data domain:	0	No regional lymph nodes examined
	1–89	Actual number of regional lymph nodes examined
	90	Ninety or more regional lymph nodes examined
	95	No regional lymph node(s) removed, but aspiration of regional lymph node(s) was performed
	96	Regional lymph node removal documented as sampling but number unknown/not stated
	97	Regional lymph nodes removal documented as dissection but number unknown/not stated
	98	Regional lymph nodes removal but number unknown/not stated and not documented as sampling or dissection
	99	Unknown; not stated; death certificate only

Guide for use:	Code 95	No regional lymph node(s) removed, but aspiration of regional lymph node(s) was performed, is used for a lymph node aspiration when cytology or histology is positive for malignant cells
	Code 99	Unknown; not stated; death certificate only, is used if information about regional lymph nodes is unknown or if the field is not applicable for that site or histology

Verification rules:

Collection methods:

Related metadata: Relates to the data element Cancer staging—N stage code, version 1.

Relates to the data element Regional lymph nodes positive, version 1.

Information model link: NHIM   Service provision event

Data Set Specifications:	*Start date*	*End date*
DSS — Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: Australian Cancer Network.

Commission on Cancer, American College of Surgeons.

Source document: Australian Cancer Network *The Pathology Reporting of Breast Cancer. A Guide for Pathologists, Surgeons and Radiologists* Second Edition Sydney (2001).

Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).

Registration authority: National Health Information Group.

Steward:

Comments

Regional lymph nodes positive

Identifying and Definitional attributes

Knowledgebase ID: **001077**   *Version number:*   **1**

Metadata type: Data element

Definition:	The number of regional lymph nodes examined by the pathologist and reported as containing tumour.
Context:	

Relational and representational attributes

Data type: Numeric   *Maximum field size:*   2

Representational class: Code   *Format:*   N(N)

Data domain:	0	all nodes examined negative
	1 - 95	actual number of regional lymph nodes positive
	96	ninety-six or more lymph nodes positive
	97	positive nodes but number not specified
	98	no nodes examined
	99	unknown if nodes are positive or negative; not applicable

Guide for use:	Code 97	positive nodes but number not specified, is used when the cytology or histology from a lymph node aspiration is positive for malignant cells.
	Code 98	positive nodes but number not specified, is used when no nodes are removed or examined.
	Code 99	unknown if nodes are positive or negative, is used if information about regional lymph nodes is unknown or if it is not applicable for that site or histology.

Verification rules:

Collection methods:

Related metadata: Relates to the data element Cancer staging — N stage code, version 1.

Relates to the data element Regional lymph nodes examined, version 1.

Information model link: NHIM   Physical wellbeing

Data Set Specifications:		*Start date*	*End date*
DSS — Cancer (clinical)		04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: Australian Cancer Network.

Commission on Cancer, American College of Surgeons.

Source document: Australian Cancer Network *The Pathology Reporting of Breast Cancer. A Guide for Pathologists, Surgeons and Radiologists* Second Edition Sydney (2001).

Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).

Registration authority: National Health Information Group.

Steward:

Comments

Sex

Identifying and Definitional attributes

Knowledgebase ID:	*002024*	*Version number:*	*4*
Metadata type:	Data element		

Definition:	Sex is the biological distinction between male and female. Where there is an inconsistency between anatomical and chromosomal characteristics, sex is based on anatomical characteristics.
Context:	Sex is a core data element in a wide range of social, labour and demographic statistics.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	1
Representational class:	Code	*Format:*	N

Data domain:	1	Male
	2	Female
	3	Intersex or indeterminate
	9	Not stated/inadequately described

Guide for use:	Code 3 Intersex or indeterminate, refers to a person, who because of a genetic condition, was born with reproductive organs or sex chromosomes that are not exclusively male or female or whose sex has not yet been determined for whatever reason.
Verification rules:	Code 3 should be confirmed if reported for people aged 90 days or greater.
	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 as detailed in collection methods or has a genetic condition resulting in a conflict between sex and ICD-10-AM code.
Collection methods:	Operationally, sex is the distinction between male and female, as reported by a person or as determined by an interviewer.
	When collecting data on sex by personal interview, asking the sex of the respondent is usually unnecessary and may be inappropriate, or even offensive. It is usually a simple matter to infer the sex of the respondent through observation, or from other cues such as the relationship of the person(s) accompanying the respondent, or first name. The interviewer may ask whether persons not present at the interview are male or female.
	A person's sex may change during their lifetime as a result of procedures known alternatively as Sex change, Gender reassignment, Transsexual surgery, Transgender reassignment or Sexual reassignment. Throughout this process, which may be over a considerable period of time, sex could be recorded as either Male or Female.

Collection methods:	In data collections that use the ICD-10-AM classification, where sex change is the reason for admission, diagnoses should include the appropriate ICD-10-AM code(s) that clearly identify that the person is undergoing such a process. This code(s) would also be applicable after the person has completed such a process, if they have a procedure involving an organ(s) specific to their previous sex (e.g. where the patient has prostate or ovarian cancer).
	Code 3 Intersex or indeterminate, is normally used for babies for whom sex has not been determined for whatever reason; should not generally be used on data collection forms completed by the respondent; and should only be used if the person or respondent volunteers that the person is intersex or where it otherwise becomes clear during the collection process that the individual is neither male nor female.
	Code 9 is not to be used on primary collection forms. It is primarily for use in administrative collections when transferring data from data sets where the item has not been collected.
Related metadata:	Supersedes previous data element Sex, version 3.
	Is used in the derivation of Diagnosis related group, version 1.
Information model link:	NHIM Demographic characteristic

Data Set Specifications:		***Start date***	***End date***
NMDS —	Admitted patient care	01/07/2004	
NMDS —	Admitted patient mental health care	01/07/2004	
NMDS —	Admitted patient palliative care	01/07/2004	
NMDS —	Alcohol and other drug treatment services	01/07/2004	
NMDS —	Community mental health care	01/07/2004	
NMDS —	Non-admitted patient emergency department care	01/07/2004	
NMDS —	Perinatal	01/07/2004	
NMDS —	Residential mental health care	01/07/2004	
DSS —	Acute coronary syndrome (clinical)	04/06/2004	
DSS —	Cancer (clinical)	04/06/2004	
DSS —	Cardiovascular disease (clinical)	02/09/2003	
DSS —	Diabetes (clinical)	02/09/2003	
DSS —	Health care client identification	02/09/2003	

Administrative attributes

Admin status:	CURRENT	***Effective Date:***	02/09/2003
Source organisation:	Australian Bureau of Statistics.		
Source document:	The ABS standards for the collection of Sex appear on the ABS website. Reference:		
	<http://www.abs.gov.au/Ausstats/abs@.nsf/StatsLibrary>.		
	Select: Other ABS Statistical Standards/Standards for Social, Labour and Demographic Variables/Demographic Variables/Sex.		
Registration authority:	National Health Information Group.		
	National Community Services Information Management Group.		

Steward:

Comments: This metadata item is common to both the *National Health Data Dictionary* and the *National Community Services Data Dictionary*.

The definition for Intersex in Guide for use is sourced from the ACT Legislation (Gay, Lesbian and Transgender) Amendment Act 2003.

DSS - Diabetes (clinical):

Referring to the National Diabetes Register Statistical profile (December 2000), the sex ratio varied with age. For ages less than 25 years, numbers of males and females were similar. At ages 25–44 years, females strongly outnumbered males, reflecting the effect of gestational diabetes in women from this group. For older age groups (45–74 years), males strongly outnumber females and in the group of 75 and over, the ratio of males to females was reversed, with a substantially lower proportion of males in the population in this age group due to the higher female life expectancy. (AIHW National Mortality Database 1997/98; National Diabetes Register; Statistical Profile, December 2000).

Steward:

Staging basis

Identifying and Definitional attributes

Knowledge base ID:	**001079**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	This data element describes the timing and evidence for T, N and M stage values.
Context:	For survival analysis adjusted by stage at diagnosis and distribution of cancer cases by type and stage.

Relational and representational attributes

Data type:	Alphanumeric	*Maximum field size:*	1
Representational class:	Code	*Format:*	A

Data domain:	P	Pathological
	C	Clinical

Guide for use:	Clinical stage is based on evidence obtained prior to treatment from physical examination, imaging, endoscopy, biopsy, surgical exploration or other relevant examinations.
	Pathological stage is based on histological evidence acquired before treatment, supplemented or modified by additional evidence acquired from surgery and from pathological examination.
	Refer to the UICC reference manual *TNM Classification of Malignant Tumours* for coding rules.
Verification rules:	
Collection methods:	From information provided by the treating doctor and recorded on the patient's medical record.
Related metadata:	Relates to the data element Cancer staging — T stage code, version 1.
	Relates to the data element Cancer staging — N stage code, version 1.
	Relates to the data element Cancer staging — M stage code, version 1.
	Relates to the data element Cancer staging — TNM stage grouping code, version 1.
	Relates to the data element Staging scheme source, version 1.
	Relates to the data element Staging scheme edition number, version 1.
Information model link:	NHIM Physical wellbeing

Data Set Specifications:	*Start date*	*End date*
DSS — Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: International Union Against Cancer (UICC).

Source document: UICC *TNM Classification of Malignant Tumours* (5th Edition) (1997).

Registration authority: National Health Information Group.

Steward:

Comments

Staging scheme source

Identifying and Definitional attributes

Knowledgebase ID:	**001080**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	The staging scheme source is 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.
Context:	For survival analysis adjusted by stage at diagnosis and distribution of cancer cases by type and stage.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	1
Representational class:	Code	*Format:*	N

Data domain:	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
	8	other
	9	unknown

Guide for use:	It is recommended that the *TNM Manual of the UICC* be used whenever it is applicable. The classifications published in the American Joint Committee on Cancer (AJCC) *Cancer Staging Manual* are identical to the TNM classifications of the UICC.
	TNM is not applicable to all tumour sites. Staging is of limited use in acute leukaemias, although a staging system is used for chronic lymphocytic leukaemia. Separate staging systems exist for lymphomas and myeloma. The recently published *NHMRC Guidelines for the prevention, early detection and management of colorectal cancer (CRC)* support the use of the Australian Clinico-Pathological Staging (ACPS) System. A table of correspondences between ACPS and TNM classifications is available.
	The current edition of each staging scheme should be used.
Verification rules:	
Collection methods:	
Related metadata:	Relates to the data element Cancer staging—TNM stage grouping code, version 1.
	Is used in conjunction with data element Staging scheme source edition number, version 1.
Information model link:	NHIM Assessment event

Data Set Specifications:	*Start date*	*End date*
DSS – Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation:

International Union Against Cancer (UICC).

FAB (French-American-British) Group.

NSW Health Department.

National Health & Medical Research Council.

Clinical Oncological Society of Australia.

Australian Cancer Network.

Source document:

UICC *TNM Classification of Malignant Tumours (5th Edition)* (1997)

Durie BGM, Salmon SE. *A clinical staging system for multiple myeloma correlation of measured myeloma cell mass with presenting clinical features, response to treatment and survival.* Cancer 36:842–54 (1975).

Bennett JM, Catovsky D, Daniel MT, Flandrin G, Galton DA, Gralnick HR, Sultan C. *Proposed revised criteria for the classification of acute myeloid leukemia: a report of the French-American-British Cooperative Group.* Ann Intern Med 103(4): 620–625 (1985).

Cheson BD, Cassileth PA, Head DR, Schiffer CA, Bennett JM, Bloomfield CD, Brunning R, gale RP, Grever MR, Keating MJ, et. al. *Report of the National Cancer Institute-sponsored workshop on definitions of diagnosis and response in acute myeloid leukemia.* J Clin Oncol 8(5): 813–819 (1990).

Davis NC, Newland RC. *The reporting of colorectal cancer: the Australian Clinicopathological Staging system.* Aust NZ J Surg 52:395–397 (1982).
Public Health Division NSW Clinical Cancer Data Collection for Outcomes and Quality. Data Dictionary Version 1 *Sydney NSW Health Dept (2001).*

NHMRC Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer (CRC) (1999)).

Registration authority: National Health Information Group.

Steward:

Comments

Staging scheme source edition number

Identifying and Definitional attributes

Knowledgebase ID:	**001081**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	Staging scheme source edition number identifies the edition of the reference used for the purposes of staging the cancer.
Context:	For survival analysis adjusted by stage at diagnosis and distribution of cancer cases by type and stage.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	2
Representational class:	Code	*Format:*	N(N)

Data domain:	1-87	Edition number
	88	Not applicable (Cases that do not have a recommended staging scheme)
	99	Unknown edition

Guide for use:

Verification rules:

Collection methods:

Related metadata:	Used in conjunction with the data element Staging scheme source, version 1.
Information model link:	NHIM Assessment event

Data Set Specifications:	*Start date*	*End date*
DSS — Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004
Source organisation:	Commission on Cancer, American College of Surgeons.		
Source document:	Commission on Cancer, *Standards of the Commission on Cancer Registry Operations and Data Standards (ROADS)* Volume II (1998).		
Registration authority:	National Health Information Group.		
Steward:			
Comments			

Surgical treatment procedure for cancer

Identifying and Definitional attributes

Knowledgebase ID:	**001082**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	The surgical procedure(s) used in the primary treatment of the cancer.
Context:	This item is collected for determining outcome by treatment type.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	8
Representational class:	Code	*Format:*	NNNNN-NN

Data domain:	Current edition of ICD-10-AM procedure codes

Guide for use:

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 (eg., implantation of infusion pump, isolated limb parfusion/infusion, intra-operative radiotherapy) record both the surgery and the other modality.

Any systemic treatment which can be coded as a procedure through ICD-10-AM should be so coded (eg., stem cell or bone marrow infusion).

The Australian Classification of Health Interventions (ACHI), which is a part of ICD-10-AM, can be used to classify procedures.

Verification rules:

Collection methods:

Related metadata: Relates to the data element concept Initial treatment episode for cancer, version 1.

Relates to the data element Date of surgical treatment for cancer, version 1.

Relates to the data element Intention of treatment for cancer, version 1.

Information model link: NHIM   Physical wellbeing

Data Set Specifications:	*Start date*	*End date*
DSS – Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: National Centre for Classification in Health.

NSW Department of Health, Public Health Division.

Source document: Current edition of *International Classification of Diseases*, Australian Modification, National Centre for Classification in Health, Sydney (ICD-10-AM).

NSW Department of Health NSW *Clinical Cancer Data Collection for Outcomes and Quality*. Data Dictionary Version 1 (2001).

Registration authority: National Health Information Group.

Steward:

Comments

Systemic therapy agent name

Identifying and Definitional attributes

Knowledgebase ID:	**001083**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	The standard chemotherapeutic agent or anti-cancer drug used for treatment of the primary cancer.
Context:	This item is collected for the analysis of outcome by treatment type.
	Collecting dates for systemic therapy will allow evaluation of treatments delivered and of time intervals from diagnosis to treatment, from treatment to recurrence and from treatment to death.

Relational and representational attributes

Data type:	Alphanumeric	*Maximum field size:*	14
Representational class:	Code	*Format:*	AAAAAAAAAAAAAA

Data domain:	Codes from the Surveillance, Epidemiology and End Results (SEER) Program *Self-instructional manual for tumour registrars: Book 8 – Antineoplastic drugs*, third edition, National Cancer Institute.

Guide for use:	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.
	Systemic therapy often involves treatment with a combination of agents. These may be known by acronyms but since details of drugs and acronyms may vary it is recommended that each agent be recorded separately
	Oral chemotherapy normally given on an outpatient basis should also be included.
	New codes and names will need to be added as new agents become available for clinical use.
	Hormone therapy agents and immunotherapy agents should be recorded under this data element.
Verification rules:	
Collection methods:	The full name of the agent(s) should be recorded if the coding manual is not available.
Related metadata:	Relates to the data element Initial treatment episode for cancer, version 1.
	Relates to the data element Cancer initial treatment—starting date, version 1.
	Relates to the data element Cancer initial treatment—completion date, version 1.
Information model link:	NHIM — Service provision event

Data Set Specifications:	*Start date*	*End date*
DSS — Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	04/06/2004

Source organisation: National Cancer Institute Surveillance, Epidemiology and End Results (SEER) Program.

Source document: Surveillance, Epidemiology and End Results (SEER) Program *Self-instructional manual for tumour registrars: Book 8 – Antineoplastic drugs,* third Edition National Cancer Institute.

Registration authority: National Health Information Group.

Steward:

Comments

Tumour size at diagnosis – solid tumours

Identifying and Definitional attributes

Knowledgebase ID:	**000778**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	The largest dimension of a solid tumour, measured in millimetres.
Context:	This is used to measure the diameter of the largest dimension of breast cancers and other solid neoplasms for patient management, population cancer statistics and research.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	3
Representational class:	Quantitative value	*Format:*	NNN

Data domain:	Size in millimetres with valid values 001 to 997
	999 Unknown

Guide for use:	The reporting standard for the size of solid tumours is:
	Breast cancer or other solid neoplasms – the largest tumour dimension, measured to a precision of 1 mm.

Verification rules:

Collection methods:

Related metadata:

Information model link:	NHIM	Request for/entry into service event

Data Set Specifications:	*Start date*	*End date*
DSS – Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	01/07/2002

Source organisation:

Source document:

Registration authority:	National Health Information Group.

Steward:

Comments

Tumour thickness at diagnosis – melanoma

Identifying and Definitional attributes

Knowledgebase ID:	**000779**	*Version number:*	**1**
Metadata type:	Data element		

Definition:	The measured thickness of a melanoma in millimetres.
Context:	Patient management, population cancer statistics and research.

Relational and representational attributes

Data type:	Numeric	*Maximum field size:*	6
Representational class:	Quantitative value	*Format:*	NNN.NN

Data domain:	Size in millimetres – valid values are: 000.01 to 997.99
	999.99 Unknown

Guide for use:	The reporting standard for the thickness of melanoma is:
	Primary cutaneous melanoma – the depth of penetration of tumour cells below the basal layer of the skin; measured to a precision of 0.01 mm.
Verification rules:	
Collection methods:	
Related metadata:	
Information model link:	NHIM Request for/entry into service event

Data Set Specifications:	*Start date*	*End date*
DSS – Cancer (clinical)	04/06/2004	

Administrative attributes

Admin status:	CURRENT	*Effective Date:*	01/07/2002
Source organisation:			
Source document:			
Registration authority:	National Health Information Group.		
Steward:			
Comments			