Cancer (clinical) DSS

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Identifying and definitional attributes

Metadata item type: Data Set Specification

METEOR identifier: 560813

Registration status: Health!, Superseded 14/05/2015

DSS type: Data Set Specification (DSS)

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

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

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

The majority of data items in the Cancer (clinical) data set specification are applicable to most solid tumours while many are also relevant to the haematopoietic malignancies such as leukaemia and lymphoma. Data set specifications for specialist tumour streams are also under development and these will contain supplementary data elements that will capture the special features of specific cancer types.

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

The data elements specified provide a framework for:

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

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

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

The working group formed under the stewardship of Cancer Australia was diverse and included representation from the following organisations: Cancer Australia, University of Sydney-Department of Gynaecological Oncology, Westmead Institute for Cancer Research, Cancer Council Victoria, Royal Brisbane & Women's Hospital, National Breast and Ovarian Cancer Centre, The Royal Women's Hospital, Queensland Health, Ministry of Health, NSW Health, TROG Cancer

Research, and the Cancer Institute NSW.

To ensure the broad acceptance of the data set specification, the proposed list of data items was circulated to members of Cancer Australia's National Cancer Data Strategy Advisory Group, a multidisciplinary group with a broad spectrum of epidemiological knowledge and expertise, and the inter-governmental Strategic Forum, comprising clinicians and senior health department officials from the Australian Government and from each state and territory government, and with strong community representation. The working group also sought consultation from cancer registry data managers, clinical leaders, pathologists, medical oncologists and radiation oncologists to achieve consensus when required.

The Cancer (clinical) data set specification is intended to only describe data collected in relation to the **initial course of cancer treatment**. The initial course of treatment includes all treatments administered to the patient from diagnosis and before disease progression or recurrence.

Collection and usage attributes

Guide for use:

The Cancer (clinical) data set specification contains six data clusters relating to cancer treatment. To ensure a complete description of the clinical management of cancer, it is recommended that if the patient has had the specific treatment modality the cluster refers to, each data item within the cluster should be completed.

The data clusters are as follows:

- Chemotherapy for cancer cluster
- Hormone therapy for cancer cluster
- Immunotherapy for cancer cluster
- Radiotherapy for cancer cluster
- Surgery for cancer cluster
- Systemic therapy procedure for cancer cluster

Collection methods:

Data is to be collected for the initial course of cancer treatment. The initial course of treatment includes all treatments administered to the patient from diagnosis and before disease progression or recurrence.

This data set is primarily directed at the clinical and clinical epidemiological use of cancer data. Treatment centres such as hospitals, radiotherapy centres and cancer specialist practices are the settings in which implementation of the core Cancer (clinical) data set specification should be considered. The data set specification can also be used by a wider range of health and health-related establishments that create, use, or maintain records on health-care clients.

Source and reference attributes

Submitting organisation: Cancer Australia

Relational attributes

Related metadata references:

Supersedes Cancer (clinical) DSS
Health!, Superseded 08/05/2014

Has been superseded by Cancer (clinical) NBPDS
Health!, Standard 14/05/2015

Implementation in Data Set Specifications:

Adolescent and young adult cancer (clinical) DSS
Health!, Superseded 14/05/2015

Gynaecological cancer (clinical) DSS
Health!, Superseded 14/05/2015

DSS specific information: The Cancer (clinical) data set specification is intended to only describe data collected in relation to the initial course of cancer treatment. The initial course of treatment includes all treatments administered to the patient from diagnosis and before disease progression or recurrence.

Lung cancer (clinical) DSS
Health!, Superseded 14/05/2015

DSS specific information: The Cancer (clinical) data set specification is intended to only describe data collected in relation to the initial course of cancer treatment. The initial course of treatment includes all treatments administered to the patient from diagnosis and before disease progression or recurrence.

Metadata items in this Data Set Specification

Seq No.	Metadata item	Obligation	Max occurs
-	Chemotherapy for cancer cluster	Conditional	1
	Conditional obligation: Conditional on patient receiving chemotherapy.		
-	Cancer treatment—chemotherapy completion date, DDMMYYYY	Mandatory	1
-	Cancer treatment—chemotherapy cycles administered, number of cycles N[NN]	Mandatory	99
-	Cancer treatment—chemotherapy start date, DDMMYYYY	Mandatory	1
-	Cancer treatment—systemic therapy agent or protocol, eviQ protocol identifier NNNNNN	Conditional	3
	Conditional obligation: Conditional on the administration of systemic therapy agents according to a prespecified regimen or protocol, and on the availability of the protocol number on the eviQ website.		
-	Cancer treatment—systemic therapy agent or protocol, text X[X(149)]	Mandatory	99
-	Hormone therapy for cancer cluster	Conditional	1
	Conditional obligation: Conditional on patient receiving hormone therapy.		
-	Cancer treatment—hormone therapy completion date, DDMMYYYY	Mandatory	1
-	Cancer treatment—hormone therapy start date, DDMMYYYY	Mandatory	1
-	Cancer treatment—systemic therapy agent or protocol, eviQ protocol identifier NNNNNN	Conditional	3
	Conditional obligation: Conditional on the administration of systemic therapy agents according to a prespecified regimen or protocol, and on the availability of the protocol number on the eviQ website.		
-	Cancer treatment—systemic therapy agent or protocol, text X[X(149)]	Mandatory	99

Seq No.	Metadata item	Obligation	Max occurs
-	Immunotherapy for cancer cluster	Conditional	1
	Conditional obligation: Conditional on patient receiving immunotherapy.		
-	Cancer treatment—immunotherapy completion date, DDMMYYYY	Mandatory	1
-	Cancer treatment—immunotherapy start date, DDMMYYYY	Mandatory	1
-	Cancer treatment—systemic therapy agent or protocol, eviQ protocol identifier NNNNNN	Conditional	3
	Conditional obligation: Conditional on the administration of systemic therapy agents according to a prespecified regimen or protocol, and on the availability of the protocol number on the eviQ website.		
-	Cancer treatment—systemic therapy agent or protocol, text X[X(149)]	Conditional	99
-	Radiotherapy for cancer cluster	Conditional	1
	Conditional obligation: Conditional on the patient receiving radiotherapy.		
-	Cancer treatment—radiation dose administered, total Gray N[NN.NN]	Mandatory	99
-	Cancer treatment—radiotherapy completion date, DDMMYYYY	Mandatory	99
-	Cancer treatment—radiotherapy fractions administered, total fractions N[N]	Mandatory	99
-	Cancer treatment—radiotherapy start date, DDMMYYYY	Mandatory	99
-	Cancer treatment—radiotherapy target site, code N[N]	Mandatory	99
-	Cancer treatment—radiotherapy treatment type, code N[N]	Mandatory	99
-	Surgery for cancer cluster	Conditional	1
	Conditional obligation: Conditional on the patient receiving cancer-directed surgery.		
-	Cancer treatment—surgery target site, topography code (ICD-O-3) ANN.N	Mandatory	99
-	Cancer treatment—surgical procedure date, DDMMYYYY	Mandatory	99
-	Cancer treatment—surgical procedure for cancer, procedure code (ACHI 8th edn) NNNNN-NN	Mandatory	99
-	Systemic therapy procedure for cancer cluster	Conditional	1
	Conditional obligation: Conditional on the patient receiving a systemic therapy procedure.		
-	Cancer treatment—systemic therapy procedure date, DDMMYYYY	Mandatory	99
-	Cancer treatment—systemic therapy procedure, code N[N]	Mandatory	99
-	Cancer staging—cancer staging scheme source edition number, code N[N]	Mandatory	1
-	Cancer staging—cancer staging scheme source, code N[N]	Mandatory	1
-	Cancer staging—staging basis of cancer, code A	Mandatory	1
-	Cancer treatment—cancer treatment type, code N[N]	Mandatory	1

Seq No.	Metadata item	Obligation	Max occurs
-	Cancer treatment—other cancer treatment, text X[X(149)]	Conditional	99
	Conditional obligation: Conditional on the patient having treatment that cannot be defined as surgery, radiotherapy or systemic therapy according to the definitions of those data items in this data set specification.		
-	Cancer treatment—outcome of treatment, code N.N	Mandatory	1
-	Date—accuracy indicator, code AAA	Mandatory	1
-	Establishment—organisation identifier (state/territory), NNNNN	Mandatory	1
-	Healthcare provider—organisation identifier, N(16)	Mandatory	1
-	Patient—cancer status, code N	Mandatory	1
-	Patient—date of last contact, DDMMYYYY	Mandatory	1
-	Patient—diagnosis date of cancer, DDMMYYYY	Mandatory	1
-	Patient—diagnosis date of first recurrence as distant metastasis, DDMMYYYY	Conditional	1
	Conditional obligation: Conditional on the patient being diagnosed with recurrence involving a distant metastasis.		
-	Patient—diagnosis date of first recurrence as locoregional cancer, DDMMYYYY	Conditional	1
	Conditional obligation: Conditional on the patient being diagnosed with recurrence of locoregional cancer.		
-	Person (address)—address line, text X[X(179)]	Mandatory	1
-	Person (name)—family name, text X[X(39)]	Mandatory	1
-	Person (name)—given name, text X[X(39)]	Mandatory	1
-	Person with cancer—distant metastasis status, M stage (UICC TNM Classification of Malignant Tumours, 7th ed) code X[XX]	Mandatory	1
-	Person with cancer—extent of primary cancer, stage grouping other, code X[XXXXX]	Mandatory	1
-	Person with cancer—extent of primary cancer, TNM stage (UICC TNM Classification of Malignant Tumours, 7th ed) code X[XX]	Mandatory	1
-	Person with cancer—histopathological grade, code N	Mandatory	1
-	Person with cancer—laterality of primary cancer, code A	Mandatory	1
-	Person with cancer—morphology of cancer, code (ICD-O-3) NNNN/N	Mandatory	1
-	Person with cancer—most valid basis of diagnosis of a cancer, code N	Mandatory	1
-	Person with cancer—most valid basis of diagnosis of the first recurrence, code N	Conditional	1
	Conditional obligation: Conditional on the return, reappearance or metastasis of cancer of the same histology after a disease-free intermission or remission.		
-	Person with cancer—number of positive regional lymph nodes, total N[N]	Conditional	1
	Conditional obligation: Conditional on the regional lymph nodes being excised and examined by a pathologist and demonstrated to be positive for malignancy.		

Seq No.	Metadata item	Obligation	Max occurs
-	Person with cancer—number of regional lymph nodes examined, total N[N] ***Conditional obligation:*** Conditional on the regional lymph nodes being excised and examined by a pathologist.	Conditional	1
-	Person with cancer—primary site of cancer, topography code (ICD-O-3) ANN.N	Mandatory	1
-	Person with cancer—primary tumour status, T stage (UICC TNM Classification of Malignant Tumours, 7th ed) code X[XXX]	Mandatory	1
-	Person with cancer—region of first recurrence as distant metastasis, topography code (ICD-O-3) ANN.N ***Conditional obligation:*** Conditional on the patient being diagnosed with recurrence of distant metastasis.	Conditional	99
-	Person with cancer—region of first recurrence as locoregional cancer, topography code (ICD-O-3) ANN.N ***Conditional obligation:*** Conditional on the patient being diagnosed with recurrence of locoregional cancer.	Conditional	99
-	Person with cancer—regional lymph node metastasis status, N stage (UICC TNM Classification of Malignant Tumours, 7th ed) code X[XX]	Mandatory	1
-	Person with cancer—solid tumour size (at diagnosis), total millimetres NNN ***Conditional obligation:*** Conditional on the histopathological examination of the tumour, and excludes Phyllodes tumours, sarcomas or lymphomas.	Conditional	1
-	Person—date of birth, DDMMYYYY	Mandatory	1
-	Person—date of death, DDMMYYYY ***Conditional obligation:*** Recorded when the patient has died. ***DSS specific information:*** This field must be greater than or equal to Date of diagnosis of primary cancer.	Conditional	1
-	Person—government funding identifier, Medicare card number N(11)	Mandatory	1
-	Person—Indigenous status, code N	Mandatory	1
-	Person—person identifier, XXXXXX[X(14)]	Mandatory	1
-	Person—sex, code N	Mandatory	1
-	Person—underlying cause of death, code (ICD-10 2nd edn) ANN-ANN ***Conditional obligation:*** Recorded when the patient has died.	Conditional	1