Adolescent and young adult cancer (clinical) NBPDS

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Identifying and definitional attributes

Metadata item type:	Data Set Specification
METEOR identifier:	599629
Registration status:	Health, Standard 14/05/2015
DSS type:	Data Set Specification (DSS)

Scope:

The purpose of the Adolescent and young adult cancer (clinical) National best practice data set (AYANBPDS) is to define data standards for the national collection of data for adolescents and young adults (commonly defined as a person between 15 and 29 years of age) with cancer so that data collected is consistent and reliable. It provides definitions and detailed instructions for coding cancer clinical information for adolescent and young adults with cancer and contains generic data elements for adolescent and young adults with cancer, most of which would be relevant to each patient regardless of organ site of cancer or histology type.

Collection of this data set is not mandated but 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.

The AYANBPDS is used in conjunction with the Cancer (clinical) National best practice dat set (CCNBPDS). 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 CCNBPDS 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 AYANBPDS will support prospective data collection from the time an AYA person with cancer symptoms is referred or first presents to a hospital or specialist through the entire duration of their illness.

The definitions used in the AYANBPDS 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, such as survival, and patterns of care can be monitored to understand both the effectiveness and appropriateness 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 their 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 availability of nationally consistent data on cancer, stage of cancer at diagnosis, other prognostic features, treatment and patient outcomes is fundamental for monitoring appropriateness and quality of cancer services and for pooling data for research. For many years clinical databases have been developed locally, and while of local value, differences in content and data definitions have reduced their value for national applications.

Collection and usage attributes

Collection methods: The AYANBPDS 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 adolescent and young adult cancer data set specification should be considered. The AYANBPDS 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 Adolescent and young adult cancer (clinical) DSS Health, Superseded 14/05/2015

See also Cancer (clinical) NBPDS Health, Standard 14/05/2015

Metadata items in this Data Set Specification

Seq No.	Metadata item	Obligation	Max occurs
1	Person—main language other than English spoken at home, code (ASCL 2011) NN{NN}	Mandatory	1
2	Person with cancer—setting of death, code N[N] ***Conditional obligation:*** Recorded for persons who have died.	Conditional	1
3	Person—first degree relative cancer history indicator, yes/no/not applicable/unknown/not stated/inadequately described code N	Mandatory	9
4	Person—second degree relative cancer history indicator, yes/no/not applicable/unknown/not stated/inadequately described code N	Mandatory	19
5	Person with cancer—family history of hereditary genetic events indicator, yes/no/unknown/not stated/inadequately described code N	Mandatory	9
6	Person with cancer—hereditary genetic events type, code N[N] ***Conditional obligation:*** Complete if Person with cancer—family history of hereditary genetic events indicator, yes/no/unknown/not stated/inadequately described code N equals 'yes'.	Conditional	9
7	Person with cancer—hereditary genetic events type, text X[X(39)] ***Conditional obligation:*** Complete if Person with cancer—family history of hereditary genetic events indicator, yes/no/unknown/not stated/inadequately described, code N equals 'yes' and Person with cancer—hereditary genetic events type, code N[N] equals 'other'.	Conditional	9
8	Person with cancer—personal genetic syndrome indicator, yes/no/unknown/not stated/inadequately described code N	Optional	1

Seq No.	Metadata item	Obligation	Max occurs
9	Person with cancer—personal genetic syndrome type, genetic event type code N[N] ***Conditional obligation:*** Complete if Person with cancer—personal genetic syndrome indicator, yes/no/unknown/not stated/inadequately described, code N equals 'yes'.	Conditional	9
10	Person with cancer—personal genetic syndrome type, text X[X(39)] ***Conditional obligation:*** Complete if Person with cancer—personal genetic syndrome indicator, yes/no/unknown/not stated/inadequately described code N equals 'yes' and Person with cancer—personal genetic syndrome type, code N[N] equals 'other genetic events or syndromes'.	Conditional	9
11	Person with cancer—date of cancer symptom onset, DDMMYYYY	Mandatory	1
12	Person with cancer—date of initial primary health care consultation, DDMMYYYY	Mandatory	1
13	Person with cancer—date of initial medical specialist consultation, DDMMYYYY	Mandatory	1
14	Person with cancer—adolescent and young adult cancer healthcare provider type, code N[N]	Mandatory	1
15	Person with cancer—shared care arrangement indicator, yes/no/unknown code N	Mandatory	1
16	Cancer treatment—treatment funding source, code N ***DSS specific information:*** Record this data element for the initial course of treatment for cancer.	Mandatory	1
17	Cancer treatment—multidisciplinary team review indicator, yes/no/unknown code N ***DSS specific information:*** A multidisciplinary team is a team of medical professionals and/or allied health professionals who are working to provide multidisciplinary care to a patient. The specific disciplines represented in a multidisciplinary team will vary based on the disease type. In relation to cancer treatment, the disciplines represented in a core multidisciplinary team should minimally include surgery, oncology (radiation and medical oncology), pathology, radiology and supportive care, and may be expanded or contracted to include services, such as genetics, psychiatry, physiotherapy and nuclear medicine.	Mandatory	1
18	Cancer treatment—specialist support services indicator, yes/no/unknown code N	Mandatory	1
19	Cancer treatment—specialist support services type, code N[N] ***Conditional obligation:*** Complete if Cancer treatment— specialist support services indicator, yes/no/unknown code N equals 'yes'.	Conditional	19

Seq No.	Metadata item	Obligation	Max occurs
20	Cancer treatment—specialist support services type, text X[X(99)] ***Conditional obligation:*** Complete if Cancer treatment— specialist support services indicator, yes/no/unknown code N equals 'yes' and Cancer treatment— specialist support services type, code N[N] equals 'other'.	Conditional	19
21	Person with cancer—care coordinator assignment indicator, yes/no/pending code N	Mandatory	1
22	Cancer treatment—variation from planned treatment indicator, yes/no/unknown code N ***Conditional obligation:*** This is to be collected for the intial course of treatment. ***DSS specific information:*** Record this data element for the initial course of treatment for cancer.	Conditional	1
23	Cancer treatment—treatment plan modification, text X[X(149)] ***Conditional obligation:*** Complete if Cancer treatment—variation from planned treatment indicator, yes/no/unknown code N equals 'yes'.	Conditional	9
24	Person with cancer—fertility counselling offered indicator, yes/no/unknown code N	Mandatory	1
25	Person with cancer—fertility counselling provided indicator, yes/no/unknown code N ***Conditional obligation:*** Complete if Person with cancer—fertility counselling offered indicator, yes/no/unknown code N equals 'yes'.	Conditional	1
26	Person with cancer—fertility preservation procedure indicator, yes/no/unknown code N	Mandatory	1
27	Person with cancer—fertility preservation procedure type, code N[N] ***Conditional obligation:*** Complete if Person with cancer—fertility preservation procedure indicator, yes/no/unknown code N equals 'yes'.	Conditional	9
28	Person with cancer—fertility preservation procedure type, text X[X(99)] ***Conditional obligation:*** Complete if Person with cancer—fertility preservation procedure indicator, yes/no/unknown code N equals 'yes' and Person with cancer—fertility preservation procedure type, code N[N] equals 'other'.	Conditional	9

Seq No.	Metadata item	Obligation	Max occurs
29	Person with cancer—fertility preservation utilised indicator, yes/no/not applicable code N ***Conditional obligation:*** Complete if Person with cancer—fertility preservation procedure indicator, yes/no/unknown code N equals 'yes'.	Conditional	1
30	Person with prior cancer diagnosis—pregnancy outcome indicator, yes/no code N	Mandatory	1
31	Person with cancer—performance status score at diagnosis, Eastern Cooperative Oncology Group code N	Mandatory	1
32	Cancer staging—date of cancer staging, DDMMYYYY	Optional	19
33	Person with cancer—distant metastatic site(s) at diagnosis, topography code (ICD-O-3) ANN.N	Mandatory	19
34	Person with cancer—comorbidities, Colinet defined comorbidities code N[N]	Conditional	9
35	Person with cancer—comorbidities, text X[X(99)] ***Conditional obligation:*** Complete when Person with cancer—comorbidities, Colinet defined comorbidities code N[N] equals 'other'.	Conditional	9
36	Person with cancer—research trial type, code N ***DSS specific information:*** This item should be recorded for clinical trials relating to the initial course of treatment and clinical trials relating to the first recurrence of cancer where applicable.	Mandatory	19
37	Person with cancer—clinical trial identifier, text X[X(399)] ***Conditional obligation:*** Complete when Person with cancer—research trial type, code N equals 'clinical trial'. ***DSS specific information:*** This item should be recorded for clinical trials relating to the initial course of treatment and clinical trials relating to the first recurrence of cancer where applicable.	Conditional	9
38	Person with cancer—clinical trial phase, code N ***Conditional obligation:*** Complete when Person with cancer—research trial type, code N equals 'clinical trial'. ***DSS specific information:*** This item should be recorded for clinical trials relating to the initial course of treatment and clinical trials relating to the first recurrence of cancer where applicable.	Conditional	9

Seq No.	Metadata item	Obligation	Max occurs
39	Person with cancer—clinical trial funding basis, code N	Conditional	9
	Conditional obligation: Complete when Person with cancer—research trial type, code N equals 'clinical trial'. ***DSS specific information:*** This item should be recorded for applicable trials relating to the initial course of treatment or the first recurrence of cancer.		
40	Person with cancer—supportive care trial name, text X[X(39)]	Conditional	9
	Conditional obligation: Complete when Person with cancer—research trial type, code N equals 'supportive care trial'. ***DSS specific information:*** This item should be recorded for applicable trials relating to the initial course of treatment or the first recurrence of cancer.		
41	Person with cancer—research enrolment name, text X[X(39)]	Conditional	9
	Conditional obligation: Complete when Person with cancer—research trial type, code N equals 'other research'. ***DSS specific information:*** This item should be recorded for research studies that relate to the initial course or first recurrence of cancer.		
42	Patient—intention of treatment, code N	Mandatory	1
43	Person with cancer—referral to palliative care services indicator, yes/no/unknown code N	Mandatory	1
44	Person with cancer—date of referral to palliative care services, DDMMYYYY	Conditional	1
	Conditional obligation: Complete if Person with cancer—referral to palliative care services indicator, yes/no/unknown code N equals 'yes'.		
45	Cancer treatment—external beam radiotherapy type, code N[N]	Conditional	5
	Conditional obligation: Collect this data element if Cancer treatment—radiotherapy treatment type, code N[N] indicates the use of external beam radiotherapy.		

Seq No.	Metadata item	Obligation	Max occurs
46	Cancer treatment—brachytherapy dose rate, code N	Conditional	9

Conditional obligation:

Complete this item if Cancer treatment—radiotherapy treatment type, code N[N] indicates the use of brachytherapy.

DSS specific information:

This is to be collected for the intial course of treatment.

47	Cancer treatment—date of treatment outcome, DDMMYYYY	Mandatory	1

DSS specific information:

Collect this item for outcome of treatment relating to the initial cancer primary and the outcome of treatment relating to the first recurrence of cancer.

48	Patient—immediate/short term treatment complication indicator, yes/no/not applicable/unknown/not stated/inadequately described code N	Optional	1

Conditional obligation:

Record this data element in relation to any immediate or short-term treatment complications that were experienced by the patient during medical treatment. This includes adverse events taking place within 30 days of treatment.

49	Patient—treatment complication date, DDMMYYYY	Conditional	19

Conditional obligation:

Complete if Patient—treatment complication indicator, yes/no/not applicable/unknown/not stated/inadequately described code N equals 'yes'.

DSS specific information:

Record this data element for any immediate or short-term treatment complications that were experienced by the patient during medical treatment. This includes any adverse events taking place within 30 days of treatment.

50	Cancer treatment—treatment complication outcome, code N	Conditional	19

Conditional obligation:

Complete if Patient—treatment complication indicator, yes/no/not applicable/unknown/not stated/inadequately described code N equals 'yes'.

DSS specific information:

Record this data element for any immediate or short-term treatment complications that were experienced by the patient during medical treatment. This includes any adverse events taking place within 30 days of treatment.

51	Cancer treatment—treatment complication type, text X[X(149)]	Conditional	19

Conditional obligation:

Complete if Patient—treatment complication indicator, yes/no/not applicable/unknown/not stated/inadequately described code N equals 'yes'.

Seq No.	Metadata item	Obligation	Max occurs
52	Patient—adverse event indicator, yes/no code N	Mandatory	1
53	Patient—date of adverse event, DDMMYYYY	Conditional	19
	Conditional obligation: Collect this item if Patient—adverse event indicator, yes/no code N equals 'yes'.		
54	Health service event—adverse event grade, code N	Conditional	19
	Conditional obligation: Complete if Patient—adverse event indicator, yes/no code N equals 'yes'.		
55	Cancer treatment—cancer treatment type, code N[N]	Conditional	5
	Conditional obligation: Complete when there is a first recurrence of cancer. ***DSS specific information:*** Complete this in relation to treatment for a first recurrence of cancer.		
56	Cancer treatment—other cancer treatment, text X[X(149)]	Conditional	9
	Conditional obligation: Complete when there is a first recurrence of cancer. ***DSS specific information:*** Complete this in relation to treatment for a first recurrence of cancer.		
57	Person with cancer—late effect indicator, yes/no/unknown/not stated/inadequately described code N	Mandatory	1
58	Person with cancer—date of late effect, DDMMYYYY	Conditional	19
	Conditional obligation: Complete when Person with cancer—late effects indicator, yes/no/unknown/not stated/inadequately described code N equals 'yes'.		
59	Person with cancer—late effect type, text X[X(399)]	Conditional	19
	Conditional obligation: Complete when Person with cancer—late effects indicator, yes/no/unknown/not stated/inadequately described code N equals 'yes'.		

Seq No.	Metadata item	Obligation	Max occurs
60	Person—distress status in past week, distress thermometer code N[N]	Optional	99

DSS specific information:

It is recommended that this item is collected within 2 weeks of diagnosis, 6-8 weeks post diagnosis, and 6 months post diagnosis. Any further screening should take place at the clinician's discretion or the patient's request. At a minimum, this should occur at remission, recurrence, or progression.

For more information regarding the use of the distress thermometer with Adolescent and Young Adults with cancer, please consult the *Psychosocial Management of AYAs diagnosed with cancer: Guidance for health professionals* (http://wiki.cancer.org.au/australia/COSA:Psychosocial_management_of_AYA_cancer_patients/Information_and_resources).