

Adolescent and young adult cancer (clinical) NBPDS

Identifying and definitional attributes

Metadata item type:	Data Set Specification
METEOR identifier:	599629
Registration status:	<ul style="list-style-type: none">• 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 data 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 [Show more detail](#)

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	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	9
7	Person with cancer—hereditary genetic events type, text X[X(39)]	Conditional	9
8	Person with cancer—personal genetic syndrome indicator, yes/no/unknown/not stated/inadequately described code N	Optional	1
9	Person with cancer—personal genetic syndrome type, genetic event type code N[N]	Conditional	9
10	Person with cancer—personal genetic syndrome type, text X[X(39)]	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	Mandatory	1
17	Cancer treatment—multidisciplinary team review indicator, yes/no/unknown code N	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	19
20	Cancer treatment—specialist support services type, text X[X(99)]	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	1
23	Cancer treatment—treatment plan modification, text X[X(149)]	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	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	9
28	Person with cancer—fertility preservation procedure type, text X[X(99)]	Conditional	9
29	Person with cancer—fertility preservation utilised indicator, yes/no/not applicable code N	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	9
36	Person with cancer—research trial type, code N	Mandatory	19
37	Person with cancer—clinical trial identifier, text X[X(399)]	Conditional	9
38	Person with cancer—clinical trial phase, code N	Conditional	9
39	Person with cancer—clinical trial funding basis, code N	Conditional	9
40	Person with cancer—supportive care trial name, text X[X(39)]	Conditional	9
41	Person with cancer—research enrolment name, text X[X(39)]	Conditional	9
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
45	Cancer treatment—external beam radiotherapy type, code N[N]	Conditional	5
46	Cancer treatment—brachytherapy dose rate, code N	Conditional	9
47	Cancer treatment—date of treatment outcome, DDMMYYYY	Mandatory	1
48	Patient—immediate/short term treatment complication indicator, yes/no/not applicable/unknown/not stated/inadequately described code N	Optional	1
49	Patient—treatment complication date, DDMMYYYY	Conditional	19
50	Cancer treatment—treatment complication outcome, code N	Conditional	19
51	Cancer treatment—treatment complication type, text X[X(149)]	Conditional	19
52	Patient—adverse event indicator, yes/no code N	Mandatory	1
53	Patient—date of adverse event, DDMMYYYY	Conditional	19
54	Health service event—adverse event grade, code N	Conditional	19
55	Cancer treatment—cancer treatment type, code N[N]	Conditional	5
56	Cancer treatment—other cancer treatment, text X[X(149)]	Conditional	9

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
59	Person with cancer—late effect type, text X[X(399)]	Conditional	19
60	Person—distress status in past week, distress thermometer code N[N]	Optional	99