Person with cancer—personal genetic syndrome indicator, yes/no/unknown/not stated/inadequately described code N

Exported from METEOR (AIHW's Metadata Online Registry)

Person with cancer—personal genetic syndrome indicator, yes/no/unknown/not stated/inadequately described code N

Identifying and definitional attributes

Metadata item type: Data Element

Short name: Personal genetic syndrome indicator

METEOR identifier: 457065

Registration status: Health, Standard 04/02/2015

Definition: An indicator of whether the person with cancer has been diagnosed with a **genetic syndrome**, as represented by a code.

Data element concept attributes

Identifying and definitional attributes

Data element concept: Person with cancer—personal genetic syndrome indicator

Synonymous names: Personal genetic syndrome indicator

METEOR identifier: 457070

Registration status: Health, Standard 04/02/2015

Definition: An indicator of whether the person with cancer has been diagnosed with a **genetic syndrome**.

Object class: Person with cancer

Property: Personal genetic syndrome indicator

Source and reference attributes

Submitting organisation: Cancer Australia

Value domain attributes

Identifying and definitional attributes

Value domain: Yes/no/unknown/not stated/inadequately described code N

METEOR identifier: 546669

Registration status: Health, Standard 11/04/2014
Indigenous, Standard 05/12/2017
Australian Institute of Health and Welfare, Qualified 17/01/2024
Early Childhood, Recorded 16/05/2024

Definition: A code set representing 'yes', 'no', 'unknown' and 'not stated/inadequately described' responses.

Representational attributes

Representation class: Code

Data type: Number

Format: N

Maximum character length: 1

	Value	Meaning
Permissible values:	1	Yes
	2	No
Supplementary values:	8	Unknown
	9	Not stated/inadequately described

Source and reference attributes

Submitting organisation: Australian Institute of Health and Welfare

Data element attributes

Collection and usage attributes

Guide for use:

Record yes when a person has been diagnosed with any genetic syndrome.

This includes, but is not exclusive to:

• Peutz-Jehgers syndrome

• B-Raf mutation

• Undescended testes

• Von Recklinghausen syndrome

• Xeroderma pigmentosa

• Bloom syndrome

• Ataxia telangiectasia

• Beckwith-Wiedemann syndrome

• Down syndrome

• Klinefelter syndrome

• Neurofibromatosis type I (NF-1)

• Von Hippel–Lindau disease (VHL)

• RET proto-oncogene

• Adenomatous polyposis coli (APC)

• Hereditary nonpolyposis colorectal cancer (HNPCC or Lynch syndrome)

• Breast cancer gene 1 (BRCA1)

• Breast cancer gene 2 (BRCA2)

• Neurofibromatosis

• Li-Fraumeni syndrome

• Fanconi anaemia

If Yes is selected for personal genetic syndrome indicator, record the type of specific syndrome/s at Person with cancer—hereditary genetic events type, code N[N] or Person with cancer—hereditary genetic events type, text X[X(39)].

Collection methods: Collect from patient medical records.

Source and reference attributes

Submitting organisation: Cancer Australia

Relational attributes

Related metadata references:

See also Person with cancer—personal genetic syndrome type, genetic event type code N[N]
Health, Standard 04/02/2015

See also Person with cancer—personal genetic syndrome type, text X[X(39)]
Health, Standard 04/02/2015

Implementation in Data Set Specifications:

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

Adolescent and young adult cancer (clinical) NBPDS
Health, Standard 14/05/2015