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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

<u>syndrome</u>, 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: <u>Health</u>, 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: <u>Health</u>, 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 <u>Person with cancer—hereditary genetic events type, code</u> N[N] or <u>Person with cancer—hereditary genetic events type, text X[X(39)]</u>.

Collection methods: Collect from patient medical records.

Source and reference attributes

Submitting organisation: Cancer Australia

Relational attributes

Related metadata See also Person with cancer—personal genetic syndrome type, genetic event type

references: 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 Adolescent and young adult cancer (clinical) DSS

Specifications: Health, Superseded 14/05/2015

Adolescent and young adult cancer (clinical) NBPDS

Health, Standard 14/05/2015