



Government of **Western Australia**
Department of **Health**

Synthetic WA Cancer Registry – Unlinked Melanoma 2010-2020

Data Dictionary

January 2026

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Owner:	Department of Health, Western Australia
Contact:	Information and Performance Governance Unit
Approved by:	Hamza Cakan
Original Approval date:	2023
Current version:	2.0
Links to:	Information Management Policy Framework https://ww2.health.wa.gov.au/About-us/Policy-frameworks/Information-Management

VERSION	DATE	AUTHOR	COMMENTS
1.0	2023	Richard Trevithick	Original set up of the document
2.0	14/01/2026	Andrew Tjea	Updated for broad uses

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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AJCC	American Joint Committee on Cancer
COB	Country Of Birth
DOH	Department of Health Western Australia
FNA	Fine Needle Aspiration
ICD-O	International Classification of Disease- Oncology
ICD-10	International Classification of Disease 10 th Revision
MRI	Magnetic Resonance Imaging
NOS	Not Otherwise Specified
WA	Western Australia
WACR	Western Australian Cancer Registry

Purpose

The purpose of this *WA Cancer Registry Data Dictionary* is to detail the data elements captured in the WA Cancer Registry (WACR) unlinked synthetic data.

Background

Since 1982, the Western Australian Cancer Registry has collected population-based incidence and mortality cancer data for use in the planning of health care services and the support of cancer monitoring, evaluation and research at local, national and international levels.

Examining specialists who identify the presence of malignancy in specimens are legally compelled to notify the WA Cancer Registry who will register the case, collecting a suite of demographic and clinical information according to national and international collection rules.

Generation of data

The generation of WACR Synthetic data at the Department of Health is performed in accordance with the data definitions.

The scope of the synthetic data is Melanoma cases, diagnosed in WA, from 2010 to 2020. The size of the synthetic melanoma data is 13,747 records, which is similar to the size of source melanoma data.

A special note regarding the imputation of melanoma staging data is required. As only two years, 2019 and 2020, were available at the time of synthetic data generation, staging data were modelled (imputed) for previous years to ensure provision of a complete dataset.

Data definitions

This section provides specific information about data elements captured in the synthetic WACR, including definitions, permitted values, guide for use, and operational information.

All information relating to data elements in this data dictionary is specific to the synthetic WACR, and caution should be taken if these data elements are compared with those of other data collections. Where relevant, related national definitions have been referenced.

Aboriginal Status

Field Name:	aboriginal_status
Definition:	Whether a person identifies as being of Aboriginal and/or Torres Strait Islander origin.
Data Type:	N
Format:	N(1)
Permitted Values:	1 Aboriginal and/or Aboriginal Torres Strait Island origin 4 Non-indigenous 9 Unknown / not stated NULL - not collected

Guide for use

Aboriginal Status is provided on most pathology reports and may be updated from hospital notifications.

This metadata item is based on the Australian Bureau of Statistics (ABS) standard for Indigenous status.

There are five categories captured in the registry. The values 1,2,3, and 5 are often combined to represent Aboriginal and/or Torres Strait Islander status. For the synthetic dataset, values 1,2,3,5 have been combined into the single value 1 to represent people of Aboriginal and/or Torres Strait Islander background.

Examples

	Aboriginal Status
A person who identifies as Aboriginal has a specimen collected and sent to a pathology lab for investigation.	1 Aboriginal Torres Strait Islander origin
A person has a pathology specimen collected and sent to a lab for investigation but does not indicate their Aboriginal status.	9 Unknown/ not stated

Person Identifier

Field Name:	synth_person_ID
Definition:	This ID can be used to represent a single person in the WACR melanoma dataset. This is a unique sequential ID derived from the original Person_ID, which itself is a derived ID for each person registered in the WACR.
Data Type:	String
Format:	X(6)
Permitted Values:	N/A

This data element is synthesised by the DoH and used for synthetic data only.

Sex

Field Name:	sex
Definition:	Description associated with patient's collected sex.
Data Type:	N
Format:	N(1)
Permitted Values:	1 Male 2 Female

Guide for use

This is the sex as reported on the initial notification provided to the registry. Missing fields may be updated from hospitalisation data sources.

Age Range

Field Name:	age
Definition:	Patient age at the time of tumour diagnosis.
Data Type:	Numeric
Format:	X(3)
Permitted Values:	N/A

Guide for use

Ages are grouped in 5-year brackets and displayed as the lowest number in the bracket

Ages between 0-4 Age in data set = 0

Ages between 5-9 Age in data set = 5

Ages between 10-14 Age in data set = 10

Ages between 15-19 Age in data set = 15

Ages between 20-24 Age in data set = 20

Ages between 25-30 Age in data set = 25

continuing until 100, all patients aged over 100 are recorded as 100

Country of Birth

Field Name:	country_of_birth
Definition:	Country of Birth is the description on the name of the country where the patient was born. ABS standard
Data Type:	X
Format:	X(4)
Permitted Values:	As per ABS standard

Guide for use

Country of birth is collected from secondary sources including the hospital morbidity data system (hospitalisations).

Country of birth should align with the ABS standard however please note that that some differences may apply as minimal validation is applied to this item. This field has been supplied to provide some measure of cultural and linguistically diverse patients.

Diagnosis Postcode

Field Name:	diagnosis_postcode
Definition:	Postcode of residence at time of diagnosis.
Data Type:	String
Format:	X(4)
Permitted Values:	aligned with Australia Post postcode listings

Guide for use

This post codes relates to the post code reported by the patient as their residence at the time the tumour is diagnosed. The post codes are drawn from the Australia Post postcode listings.

Year of Diagnosis

Field Name:	diagnosis_year
Definition:	The year the tumour was diagnosed
Data Type:	N
Format:	N(4)
Permitted Values:	2010 to 2020

Guide for use

The earliest date associated with the tumour diagnosis is determined by the earliest health information notification received by the registry which confirms the presence of a malignancy. Typically this will be determined from the pathology reports.

This data set contains tumours diagnosed in the years from and including 2010 to 2020

Tumour Site - Code

Field Name:	tumour_site_code
Definition:	ICD-O code assigned to the tumour topography or anatomical location on the body
Data Type:	String
Format:	X(4)
Permitted Values:	C440 Skin of Lip, NOS C441 Eyelid C442 External ear C443 Skin of other and unspecified parts of the face C444 Skin of the scalp and neck C445 Skin of trunk C446 Skin of Upper limb and shoulder C447 Skin of lower limb and hip C449 Skin NOS

Guide for use

Tumour site refers to the anatomical part of the body where the tumour is located. Each part of the body is assigned a specific code

Codes beginning C44 relate to the skin the 3rd number describes the specific area of the skins.

The data present is coded according to ICD-O Version 3.2

Codes contain updates agreed and applied as per National Australian Association of Cancer Registries meetings.

Morphology - Code

Field Name:	morphology_code																														
Definition:	ICD-O code of behaviour of tumour morphology																														
Data Type:	String																														
Format:	X(4)																														
Permitted Values:	<table><tr><td>8720</td><td>Malignant melanoma, NOS</td></tr><tr><td>8721</td><td>Nodular melanoma</td></tr><tr><td>8723</td><td>Malignant melanoma, regressing</td></tr><tr><td>8727</td><td>Dysplastic naevus</td></tr><tr><td>8730</td><td>Amelanotic melanoma</td></tr><tr><td>8740</td><td>Malignant melanoma in junctional nevus</td></tr><tr><td>8742</td><td>Lentigo maligna melanoma</td></tr><tr><td>8743</td><td>Superficial spreading melanoma</td></tr><tr><td>8744</td><td>Acral melanoma</td></tr><tr><td>8745</td><td>Desmoplastic melanoma</td></tr><tr><td>8750</td><td>Intradermal naevus</td></tr><tr><td>8760</td><td>Compound naevus</td></tr><tr><td>8770</td><td>Malignant spitz tumour</td></tr><tr><td>8771</td><td>Epithelioid cell melanoma</td></tr><tr><td>8772</td><td>Spindle cell melanoma</td></tr></table>	8720	Malignant melanoma, NOS	8721	Nodular melanoma	8723	Malignant melanoma, regressing	8727	Dysplastic naevus	8730	Amelanotic melanoma	8740	Malignant melanoma in junctional nevus	8742	Lentigo maligna melanoma	8743	Superficial spreading melanoma	8744	Acral melanoma	8745	Desmoplastic melanoma	8750	Intradermal naevus	8760	Compound naevus	8770	Malignant spitz tumour	8771	Epithelioid cell melanoma	8772	Spindle cell melanoma
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8770	Malignant spitz tumour																														
8771	Epithelioid cell melanoma																														
8772	Spindle cell melanoma																														

Guide for use

Morphology codes record the type of cancerous cells which form the tumour that has developed, and how the tumour is behaving at the time of diagnosis.

Coded to ICD-O Version 3.2

Codes contain updates agreed and applied as per National Australian Association of Cancer Registries meetings.

Note on morphology behaviour

Typically the morphology behaviour is captured in the behaviour field to identify whether a registered tumour is malignant, benign, in-situ or uncertain. However, as this synthesised dataset includes only malignant cases the behaviour field has been omitted.

Basis of diagnosis

Field Name:	basis_of_diagnosis
Definition:	The basis of diagnosis of a cancer is the microscopic or non-microscopic or death certificate source of the diagnosis. The most valid basis of diagnosis is that accepted by the cancer registry as the most reliable diagnostic source of the death certificate, non-microscopic, and microscopic sources available.
Data Type:	String
Format:	X(1)
Permitted Values:	<ul style="list-style-type: none"> 1 Histopathology 2 Cytology 5 Clinical 9 Death Certificate

Guide for use

Basis of diagnosis is a summarised field based on the highest level of verification of cancer specimens. If more than one report is received by WACR diagnosing the malignancy then it will be recorded as the highest level of verification received e.g., if a case is originally notified through cytology by way of an FNA and later an imaging report is received which contains more in-depth information on the tumour including the size and level of invasion, the basis at diagnosis is 2.

Verification levels as by numerical order below with 1 being the highest level

- 1 Histopathology: Is the examination of a section of tissue which contains different types of cells e.g., a section of skin containing a discoloured area is excised and set to a pathology laboratory to be examined and have the type of cells causing the discolouration identified.
- 2 Cytology: is the examination of individual cells or small clusters of cells Includes specimens such as FNA, smears, washings and sputum, e.g., a lymph node is aspirated, and the fluid extracted is sent to a pathology laboratory to exam what type of cells are present in the fluid.
- 5 Clinical: Refers to the clinical diagnostic techniques that identify tumours without a sample of the tissue or cells being sent to a pathology laboratory for examination. This includes the use of all types of imaging and clinical assessment e.g. A patient has a MRI scan and a mass/growth is identified as being present in an area when in normal circumstances it would not be expected to be present. Clinical diagnosis can also include physical assessment of the patient and a clinician finding a mass by palpation during the physical assessment. Clinicians can also diagnose tumours by assessment of the patient's health history, the patients current physical condition, the symptoms being experienced by the patient and the elimination of all other likely causes for the patient's current health state.
- 9 Death Certificate: This is where the first notification WACR receives of a person's malignancy diagnosis is when it is recorded on a death certificate. E.g., a patient presents to hospital in the end stages of life and is clinically diagnosed with a bowel cancer. The patient elects not to have any further investigations or treatments done for the condition. When the patient passes away the bowel cancer is recorded on the death certificate, WACR receives a copy of the certificate and will add the bowel cancer diagnosis to the collection.

Melanoma - Clark level

Field Name:	melanoma_clark_level
Definition:	The Clark's Level refers to how deep the Tumour has penetrated into the layers of the skin.
Data Type:	String
Format:	X(3)
Permitted Values:	1 Clark Level I. 2 Clark Level II. 3 Clark Level III. 4 Clark Level IV. 5 Clark Level V . UNK Missing/not applicable

Guide for use

The Clark Level is a staging system that describes the depth of melanoma as it grows in the skin.

The Clark Scale has five levels:

- Level 1: the cancer is in the epidermis only
- Level 2: the cancer has begun to spread into the papillary dermis (upper layer of the dermis)
- Level 3: the cancer has spread through the papillary dermis into the papillary-reticular dermal interface but not into the reticular dermis (lower layer of the dermis)
- Level 4: the cancer has spread into the reticular dermis
- Level 5: the cancer has spread into the subcutaneous tissue

Note that the Clark level is not related to stage as it describes the depth of the melanoma at diagnosis. This field has been provided to investigate trends, correlations or geographical patterns that may be present relating to Clark level.

Melanoma - Breslow Thickness

Field Name:	melanoma_breslow_thickness
Definition:	A measure of how deeply a melanoma tumour has grown into the skin.
Data Type:	N
Format:	N
Permitted Values:	0 to 40 Missing - unknown

Guide for use

The tumour thickness (Breslow depth) is measured in millimetres from the top of the tumour to the deepest tumour cells. If the tumour is ulcerated (the skin is broken), it is measured from the base of the ulcer to the deepest tumour cells. Breslow thickness is used to help determine the stage of cancer. Thicker tumours are linked with lower survival rates.

Stage

Field Name:	stage
Source Data Elements:	Summary stage collected for 2019 and 2020 Summary stage imputed for 2010 to 2018
Definition:	The anatomical stage at diagnosis derived by the WACR using specialized rules based on AJCC 8 th Edition.
Data Type:	N
Format:	N(1)
Permitted Values:	<ol style="list-style-type: none">1. Stage 1 Localised Disease2. Stage 2 Localised Disease3. Stage 3 Lymphovascular Invasion4. Metastatic Disease

Guide for use

WACR derives a stage at diagnosis using a system of specialised rules from the AJCC 8th Edition by using data contained in notifications made to the registry and with linked inpatient data contained in other data sets held at the DoH.

The summary stage is determined through the combination of Tumour size (T), Nodal invasion (N), and metastatic (M) fields.

Broadly stage 1 and 2 can be grouped into localised disease, stage 3 refers to lymphovascular invasion, and stage 4 refers to regional metastatic disease.

Produced by:
Information and Performance Governance
Information and System Performance Directorate
Purchasing and System Performance Division
The Department of Health Western Australia

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