QCR Queensland Cancer Register

Appendix A

Cancer Registration Data Dictionary

Supporting document to: *QCR Notifier Guidelines - Public and Private Hospitals*

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Queensland Cancer Register

Cancer Alliance Queensland

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Appendix A – Cancer Registration Data Dictionary

The definitions provided below for *Facility Details*, *Patient Details* and *Admission Details* are sourced directly from the Queensland Hospital Admitted Patient Data Collection (QHAPDC) Manual and the Queensland Health Data Dictionary (QHDD) to ensure consistency with statewide data standards. Definitions relating specifically to *Cancer Details* have been developed by the Queensland Cancer Register to support hospitals and administration staff responsible for completing a cancer registration. Public hospitals using the Hospital Based Corporate Information System (HBCIS) should also refer to the HBCIS Technical Guide for system-specific instructions and operational requirements.

Note: The terms 'patient' and 'person' are used throughout the Cancer Registration Data Dictionary to represent the subject of care. These terms are considered synonymous and may be used interchangeably. For the purposes of this document, the terms 'cancer' and 'neoplasm' are also considered synonymous and may be used interchangeably.

Facility details	
Item	**Description**
Facility code (Facility number)	The facility number is a numerical code that uniquely identifies each Queensland Health care facility. Health care facilities are public and private hospitals.

Patient details	
Item	**Description**
Patient identifier (UR number)	The patient identifier (UR number) is a unique record number assigned to a person for the purpose of uniquely identifying them within a healthcare facility. A patient ID number may be generated manually, or system generated. The number is used for each admission to identify the patient. The unit record number may be numeric or alphanumeric.
Patient surname/family name	The patient's full family name should be recorded. Some people do not have a family name and a given name. They have only one name by which they are known. If the patient has only one name, record it as the family name.
Given names	A patient may have more than one given name. A patient's full given name(s) should be recorded. Where applicable it is essential that the given names are recorded for the first 3-recorded given names of a patient and desirable for the fourth and subsequent given names. Some people do not have a family name and a given name and they have only one name by which they are known. If the patient has only one name, record it as the family name.
Former names/alias	Any name that a person is also known by, or has been known by in the past; that is, all other recorded name for a person that are not classified under any other code. This includes misspelt names or name variations (for example a cultural or overseas name)

Patient details

	that are to be retained as they have been used to identify this person. More than one alias name may be recorded for a person.
Sex	A patient's sex is based on their sex characteristics such as their chromosomes, hormones and reproductive organs. While typically based upon the sex characteristics observed and recorded at birth or infancy, this may change over the course of a patient's lifetime (Australian Bureau of Statistics (ABS) 2020). Gender is a social and cultural concept relating to social and cultural differences. Sex and gender are often used interchangeably. However, they are two distinct concepts (ABS 2020). The Statistical Services Branch (SSB) reports data for the data element Sex according to the definition and permissible values in the National Health Data Dictionary, which are aligned with those used by the ABS. Sex is relevant to morbidity in a range of subject areas (e.g. cancer). Record the code for the sex of the patient using one of the following codes:

Description	HBCIS code	Other hospitals
Male *Persons who have male or predominantly masculine sex characteristics or male sex assigned at birth.*	M	1
Female	F	2

Patient details

Persons who have female or predominantly feminine sex characteristics or female sex assigned at birth.		
X *Persons who have mixed or non-binary biological characteristics (if known), or a non binary sex assigned at birth.*	I	3
Not Stated/Inadequately Described *This supplementary value is used to code inadequately described responses and non-responses for sex. It is not to be used on primary collection forms. It is primarily for use in administrative collections when transferring data from data sets where the item has not been collected.*	N/A	9

To avoid problems with edits, transgender individuals undergoing gender affirmation surgery should have their sex at birth recorded.

Note that indeterminate will generally only be used for neonatal patients where the sex has not been determined.

Date of birth	The date of birth of the patient..

Patient details	
	Record the date of birth of patient using the full date (i.e. DDMMYYYY) and leading zeros where necessary. • If the year of birth is unknown, estimate the year from the age of the patient. • If the age of the patient is unknown and it is not possible to estimate an age and hence a year of birth (e.g. for unconscious patients) use 15-JUN-1900. • If estimated or unknown, specify in the comments section For HBCIS hospitals: - If the day of birth is unknown, use ** - If the month of birth is unknown, use ** - If the year of birth is unknown, estimate the year from the age of the patient Although provision is made for recording an unknown date of birth (using 15/06/1900), every effort should be made during the course of the admission to determine and record the patient's actual date of birth.
Number and street of usual residence	The number and street name of usual residential address of person, or equivalent in rural areas. Usual residence is the place where a person usually lives (resides). It is not the residence where a person might stay temporarily before or after a period of hospitalisation/treatment/contact.

Patient details	
	If the address of usual residence is not known or cannot be established (e.g. an unconscious patient is unable to provide the information), record UNKNOWN. Post Office box numbers or Mail Service Numbers should not be recorded. Use a building number and street name whenever possible. Even country properties have access roads that have names. You may use standard abbreviations, see appendix A for examples.
Suburb/Town/Locality of usual residence	The name of the suburb/town/locality of usual residence of a person. Usual residence is the place where a person usually lives (resides). It is not the residence where a person might stay temporarily before or after a period of hospitalisation/treatment/contact. ***Interstate and overseas patients*** If the patient lives interstate, the actual suburb or town of usual residence should be recorded. If the patient is from overseas, also record the country in which he/she normally resides. ***No fixed address*** Record NO FIXED ADDRESS. ***At sea*** Record AT SEA.

Patient details	
	Patients diagnosed outside Queensland, while not reported by the Register, are recorded on the Register. This assists with identifying duplicate registrations, notifying interstate cases, and assists matching for subsequent treatment notifications.
Postcode of usual residence	The postcode aligned with the suburb/town/locality of usual residence of a person. Usual residence is the place where a person usually lives (resides). It is not the residence where a person might stay temporarily before or after a period of hospitalisation/treatment/contact. If the patient is not an Australian resident or has no fixed address, use one of the supplementary codes: 0989 = not stated/unknown 9301 = Papua New Guinea 9302 = New Zealand 9399 = Overseas - other (not PNG or NZ) 9799 = at sea 9899 = Australian External Territories 9989 = no fixed address
Medicare number	A Medicare Number is a personal identifier allocated by Medicare Australia to eligible persons under the Medicare Scheme. If the patient is eligible for Medicare, record the Medicare number from the patient's Medicare card.

<table>
<tr><th colspan="2">Patient details</th></tr>
<tr><td></td><td>If the person does not have an Australian Medicare Number or if it is not available, leave this blank.</td></tr>
<tr><td>Marital status</td><td>A Marital status is a person's current relationship status in terms of a couple relationship or, for those not in a couple relationship, the existence of a current or previous registered marriage, as represented by a code.

Record the current marital status of the patient.
<table>
<tr><th>Description</th><th>HBCIS code</th><th>Other hospitals</th></tr>
<tr><td>Never married</td><td>NM</td><td>1</td></tr>
<tr><td>Married (registered and de facto)
Includes people who have been divorced or widowed but have since re-married, and should be generally accepted as applicable to all de facto couples, including of the same sex.</td><td>M</td><td>2</td></tr>
<tr><td>Widowed
This code usually refers to registered marriages but when self-reported may also refer to de facto marriages.</td><td>W</td><td>3</td></tr>
<tr><td>Divorced</td><td>D</td><td>4</td></tr>
<tr><td>Separated
This code refers to registered marriages but when self-reported may also refer to de facto marriages.</td><td>A</td><td>5</td></tr>
</table>
</td></tr>
</table>

Patient details

<table>
<tr><td></td><td><table>
<tr><td>Separated means those people who are legally separated or socially separated, not persons who are temporarily living apart (e.g. construction workers living in hotels or camps).</td><td></td><td></td></tr>
<tr><td>Not stated/Unknown
This code is not for use on primary collection forms. It is primarily for use in administrative collections when transferring data from data sets where the item has not been collected.</td><td>N</td><td>9</td></tr>
</table></td></tr>
<tr><td>Country of birth</td><td>Record the country of birth of the patient using the numerical codes found in Appendix E of the Queensland Hospital Admitted Patient Data Collection (QHAPDC) Manual. For example:
if the patient was born in Australia, use code 1101
if the patient was born in New Zealand, use code 1201.</td></tr>
<tr><td>Indigenous status</td><td>Whether a person identifies as being of Aboriginal and/or Torres Strait Islander origin.

Indigenous status details should be checked for accuracy.

Use the following to record indigenous status:<table>
<tr><th>Description</th><th>HBCIS code</th><th>Other hospitals</th></tr>
<tr><td>Aboriginal but not Torres Strait Islander origin.</td><td>01</td><td>1</td></tr>
</table></td></tr>
</table>

Patient details

	Torres Strait Islander but not Aboriginal origin.	02	2
	Both Aboriginal and Torres Strait Islander origin.	13	3
	Neither Aboriginal or Torres Strait Islander origin.	14	4
	Not Stated/Unknown	N/A	9
	Not Stated/Unknown – No follow up required	29	N/A
	Not stated/Unknown – Follow up required	39	N/A
Occupation	Record the patient's occupation. Ideally the Register would like principal lifetime occupation. Only use pensioner/housewife/retired if lifetime occupation is unable to be ascertained.		

Admission details	
Item	**Description**
Admission number (Episode Number)	The identifier assigned by a hospital to an episode of care which is unique to the person within the hospital. Admission number is important as the patient can have one or more admissions within a certain time period and will have different cancer details for each admission.
Admission date	Date on which an admitted patient commences an episode of care. Record the full date (that is, DDMMYYYY) of admission to hospital. Use leading zeros where necessary.
Separation date	Date on which an admitted patient completes a hospital stay. At separation, record the full date (that is, DDMMYYYY), using leading zeros where necessary. This is the date that the patient was discharged, transferred or died.
Mode of separation (Discharge Status)	Status at separation of person (discharge/transfer/death) and place to which person is released. The mode of separation (discharge status) indicates the place to which a patient is referred immediately following formal separation from hospital or indicates whether this is a statistical separation due to a change in the type of episode of care.

Admission details

If the patient died in hospital, please record the appropriate details for whether an autopsy was held and cause of death details.

Description	HBCIS code	Other hospitals
Home/usual residence	01	01
Other health care establishment	04	04
Died in hospital	05	05
Care Type change	06	06
Discharge at own risk	07	07
Non return from leave	09	09
Correctional facility	12	12
Organ procurement (Not available on HBCIS at this stage)	N/A	13
Boarder	14	14
Transferred to another hospital	16	16
Medi-Hotel	17	17
Other	19	19
Residential aged care service, which is not the usual place of residence	21	21
Residential aged care service, which is the usual place of residence	22	22
Residential mental health care facility	31	31

Admission details	
	Note: Patients transferring between hospitals are counted as separate episodes of care and are therefore reported by both facilities.
Transferring to facility	Record the facility number (extended source code) for the hospital, residential aged care service, or correctional facility to which the patient is transferred or referred to, as an admitted patient. This item is only mandatory if the mode of separation (discharge status) is: 12 Correctional facility 16 Transferred to another hospital 21 Residential aged care service, which is not the usual place of residence 31 Residential mental health care facility Appendix A from the QHAPDC Manual contains a list of facilities and their facility numbers including the facility number to be used when a patient is transferred or referred.
Treating doctor	Facility specific code for the doctor chiefly responsible for treating the patient upon admission to an episode of admitted patient care. e.g. the Senior Treating Medical Officer, Specialist or Consultant in charge of the care. This is not the registrar or resident medical officer. To assist in improving the quality of this data, all fields (initials, given name/s, surname should be completed.

Admission details	
Cause of death	If the patient died in the hospital, the description for the principal diagnosis ICD-10-AM code, for this admission, should be displayed in this field. Check and update the text details as required. Please only complete the cause of death if the patient dies in the hospital.
Autopsy held	Record whether an autopsy or coroners inquiry is to be/has been undertaken with a Y or N. Please only complete the autopsy held item if the patient dies in the hospital.
Diagnosis at separation	The diagnosis established after study to be chiefly responsible for occasioning an episode of admitted patient care, an episode of residential care or an attendance at a health care establishment. The principal diagnosis ICD-10-AM code for this admission.

Cancer details	
Item	**Description**
Multiple primary site	This is a two-digit item field, allowing entry of multiple primary sites of cancer for an single patient. - The first primary site recorded is always "01". - If additional primary cancers are reported, they are numbered "02", "03", and so on. Example: A patient is admitted and has lung cancer (first primary) and prostate cancer (second primary). Two registration records will be created: - Record 1, *Multiple Primary Site* = “01” lung cancer - Record 2, *Multiple Primary Site* = “02” prostate cancer
Primary site of cancer	A primary site is defined as the site at which a neoplasm **originated**. Thus, a cancer diagnosis includes each primary site in a cancer patient, and a patient with two primary sites is considered as being two different cases of cancer. A patient with one primary site and one or more secondary sites is one case of cancer only. See Section 5 for the cancers in the scope of the collection. Where possible be specific when coding the primary site, for example, if known, code site as "upper lobe of lung" or "upper-inner quadrant of breast".

Cancer details	
	If the initial diagnosis is a secondary tumour, report the primary tumour site if possible. This may be indicated by the morphology or clinical notes. If it is not possible to identify the primary tumour, then code the cancer as an unknown primary site. Details such as whether the cancer has metastasised (and to which site) should be included in the comments field. Also include details in the comments field if a more precise description exists for the cancer than can be coded in ICD-10-AM. This may include more precise topography for melanomas, connective and soft tissue sites, meninges and brain, insitu cancers, etc. The Register codes in ICD-O and has to convert or recode the ICD-10-AM codes. Any information that can assist this process would be useful.
Morphology	The morphology code of the cancer at diagnosis. Morphology codes refer to the histological classification (histopathological type) of the cancer tissue and its behaviour (e.g., benign or malignant) as seen under a microscope. For each neoplasm code, there should be a corresponding morphology code (M code). A morphology code should always be assigned directly after the neoplasm code to which it applied, i.e.: • C00-D48 Neoplasms • O01 Hydatidiform mole The Morphology code (including the behaviour) must be appropriate to the histological type of the neoplasm as displayed in the table below. For example, C50.9 Malignant

Cancer details

neoplasm of breast, unspecified should have an associated morphology code ending with a /3 behaviour character. Please refer to ICD-10-AM Appendix A: *Morphology of neoplasms* for additional information.

Morphology behaviour	
Code	**ICD-10-AM Chapter 2 Neoplasm Description**
/0	D10–D36 Benign neoplasms
/1	D37–D48 Neoplasms of uncertain and unknown behaviour
/2	D00–D09 In situ neoplasms
/3	C00–C75 Malignant neoplasms, stated or presumed to be primary , of specified sites, except of lymphoid, haematopoietic and related tissue C76 Malignant neoplasm of other and ill-defined sites C80 Malignant neoplasm without specification of site C81–C96 Malignant neoplasms of lymphoid, haematopoietic and related tissue D45 Polycythaemia vera D46 Myelodysplastic syndromes
/6	C77 Secondary and unspecified malignant neoplasm of lymph nodes C78 Secondary malignant neoplasm of respiratory and digestive organs C79 Secondary malignant neoplasm of other and unspecified sites

While the Register does not collect information on secondary sites, details such as whether the cancer has metastasised (and to which site) should be included in the comments field.

Cancer details	
	Also include details in the comments field if a more precise description exists for the type of cancer than can be coded in ICD-10-AM. This may include more precise details for lymphomas and leukaemia's, etc. The Register codes in ICD-O and records details down to the descriptor level. ICD-10-AM codes have to be converted or recoded to ICD-O. Any information that can assist this process would be useful.
Date of first diagnosis	The date on which a person is diagnosed with cancer, expressed as DDMMYYYY. Try to accurately identify the full date of original diagnosis for this cancer where possible. Where unknown, please provide best estimate and enter Y in the Estimated field. If you are unable to provide an estimate, enter 15 JUN 1900 and enter Y in the Estimated field.
Date of first diagnosis estimated flag	Where the full date of original diagnosis is unknown enter Y in the Estimated field. If the date of diagnosis is known enter an N. This is the default value.
Suburb/Locality at first diagnosis	Name of suburb or town of usual residence at the time of first diagnosis of this cancer. If precise details of the suburb are not known but the State is, then include 'Not stated/unknown' as the suburb descriptor and the relevant default State supplementary postcode. This enables us to identify cases diagnosed outside Queensland. Supplementary suburb/postcodes: 0989 = not stated/unknown 1989 = New South Wales 2989 = Victoria 3989 = Queensland

Cancer details	
	4989 = South Australia 5989 = Western Australia 6989 = Tasmania 7989 = Northern Territory 8989 = Australian Capital Territory 9301 = Papua New Guinea 9302 = New Zealand 9399 = Overseas - other (not PNG or NZ) 9799 = at sea 9899 = Australian External Territories 9989 = no fixed address
Postcode at first diagnosis	Australian postcode corresponding to address of usual residence at the time of first diagnosis of cancer. Do not update this field with current address details unless that is where the person lived at the time of diagnosis. If precise details of the postcode are not known but the State is, then use the relevant default State supplementary postcode. This enables us to identify cases diagnosed outside Queensland. Supplementary suburb/postcodes: 0989 = not stated/unknown 1989 = New South Wales 2989 = Victoria 3989 = Queensland

Cancer details	
	4989 = South Australia 5989 = Western Australia 6989 = Tasmania 7989 = Northern Territory 8989 = Australian Capital Territory 9301 = Papua New Guinea 9302 = New Zealand 9399 = Overseas - other (not PNG or NZ) 9799 = at sea 9899 = Australian External Territories 9989 = no fixed address
Laterality of cancer	Where possible, for cancers of paired organs, such as Breast (C50), Lung (C34), Kidney (C64), Ovary (C56), Eyes (C69), Arms (C76.4, C44.6, C49.1, C47.1, C40.0, C77.3), Legs (C76.5, C44.7, C49.2, C47.2, C40.2, C77.4), Ears (C44.2, C49.0, C30.1), Testicles (C62) indicate the side affected by the tumour. The valid inputs are: L Left R Right B Bilateral U Unknown N Not applicable

Cancer details	
	Bilateral cancers are extremely rare. Includes organs that are bilateral as a single primary (e.g. bilateral retinoblastoma (M9510/3, C69.2), (M9511/3, C69.2), (M9512/3, C69.2), (C69.6, C48.0), bilateral Wilms tumours (C64.9, M8960/3)). Unknown: It is unknown whether, for a paired organ, the origin of the cancer was on the left or right side of the body. Not applicable is the default value. This should be recorded for all non-paired organ sites.
Basis of diagnosis	Refers to the most valid basis of diagnosis **AT THIS ADMISSION**. The following notes may assist. Note that the basis of diagnosis is hierarchical from 1 (least definitive) to 9 (most definitive). If more than one diagnostic technique is employed during this admission, select the higher number. **1. Unknown** Refers to a tumour which was diagnosed and treated elsewhere and the current hospital has no information regarding that treatment. This code would only apply if the current admission is unrelated to the cancer (i.e. a history of cancer only admission). Please provide details explaining unknown codes in the comments field. Any indication of where the person was diagnosed would avoid further follow-up. **2. Clinical only** When a tumour has been diagnosed by clinical examination (e.g. palpation) only at this admission or where the tumour has been diagnosed at a previous admission or different hospital and the diagnosis is supported only by clinical evidence at this admission.

Cancer details

	3. Clinical investigations When a tumour is diagnosed at this admission without invasive surgical procedures but may include diagnostic radioscopy and endoscopy. **4. Exploratory surgery** When a tumour is diagnosed at this admission by exploratory surgery without biopsy and histology. Include here an incidental autopsy finding of cancer without biopsy and histology. **5. Specific biochemical or immunological testing** Tumour diagnosed using particular laboratory techniques only, e.g. Prostate specific antigen (PSA) for prostate. **6. Cytology or haematology** Tumour diagnosed using particular laboratory techniques only, e.g. Fine needle aspiration without biopsy. **7. Histology of metastasis** When a histology is performed on a tissue sample of secondary tumour. Please identify the primary tumour if possible. **8. Histology of primary** When histology is performed on a tissue sample of primary tumour. NB: Bone marrow aspirates are considered to be histology - basis of 08.

Cancer details

	9. Autopsy and histology When histology is performed on a tissue sample taken during an autopsy.
Reasons for clinical diagnosis	Refers to reasons why a patient may be admitted to hospital where a clinical only or clinical investigations basis of diagnosis is given as the most valid basis of diagnosis. This item has been designed to reduce the number of queries back to hospitals. Multiple reasons may be completed. Some codes for the Reasons for Clinical Diagnosis require further detail to be supplied in the Details field. The codes are as follows: 01 Palliative Care Admission 02 Doctor's Notes/Referral (Provide doctor details) 03 Previous Pathology (Provide laboratory details) 04 Radiological Investigation (Specify investigation details) 05 Other Non-invasive Investigation (Specify investigation details) 06 Invasive Investigation (Specify investigation details) 07 Non-Cancer Admission (Specify details) 09 Other (Specify details) Patients with a clinical admission for chemotherapy should be recorded with a code 09 and chemotherapy specified.
Details for clinical diagnosis	This free text field allows the user to provide the relevant details as outlined above in Reasons for Clinical Diagnosis.

Cancer details	
Comments	This free text field allows the user to provide any other relevant details regarding the cancer that may assist the register staff or reduce queries for the hospital. This may include a more precise description of the cancer than is able to be coded in ICD-10-AM. Also include any indication as to whether the cancer has metastasised and to which site. Where possible, specify grading or differentiation - that is: 1 Grade I (Well) differentiated 2 Grade II Moderately (well) differentiated 3 Grade III Poorly differentiated 4 Grade IV Undifferentiated, anaplastic
Laboratory facility number	This field becomes mandatory when the codes of 06, 07, 08 or 09, is entered into field 13 (Basis of Diagnosis). The laboratory facility number field displays the laboratory where the specimen was sent to. It is linked to a reference file. The codes are as follows: 01 Pathology Queensland (Auslab) 02 S & N 03 QML 04 Private Laboratory 05 Other

Cancer details	
Laboratory specimen number	The lab specimen number will record the specific pathology specimen number collected during the current admission (e.g., report number) and any additional comments required. Please note: If “Private Laboratory” or "Other" is recorded, the user should include the actual lab name along with the laboratory specimen number (if known). This is a non-mandatory free text field, which only becomes enabled when codes 06, 07, 08, or 09 are entered into Basis of Diagnosis.