QUEENSLAND CANCER REGISTER

INSTRUCTION MANUAL

FOR NOTIFYING CANCER

PRIVATE HOSPITALS

April 2018

Queensland Cancer Register
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Version 1.0

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1. INTRODUCTION

1.1 Establishment of the Cancer Register

The Queensland Cancer Register (QCR) operates under the *Public Health Act 2005,* to receive information on cancer in Queensland. The Cancer Register is a population-based register and maintains a Register of all cases of cancer diagnosed in Queensland since the beginning of 1982. Cancer is a notifiable disease in all States and Territories and is the only major disease category from which an almost complete coverage of incidence data is available. It is also the only major cause of death in Australia that is continuing to increase. Through the National Cancer Statistics Clearing House – a collaborative enterprise of the Australian Association of Cancer Registries and the Australian Institute of Health and Welfare, Queensland data is used in the compilation of Australia-wide figures and can be compared with cancer statistics from other States.

1.2 Aims of the Register

The main aim of the Register is to collect data to describe the nature and extent of cancer in Queensland. This can be combined with related data to assist in the control and prevention of cancer. To this end, Queensland Cancer Register data is available for use:
- in research projects on the causes, treatment and prevention of cancer,
- in the planning and assessment of cancer treatment and prevention services,
- in monitoring survival times of cancer patients, and
- for the education of health professionals and members of the general public.

1.3 Notification and sources of data

Notification of cancer is a statutory requirement for all public and private hospitals, nursing homes and pathology services. Notifications are received for all persons with cancer separated from public and private hospitals and nursing homes. Queensland pathology laboratories provide copies of pathology reports for cancer specimens. Data on all persons who die of cancer or cancer patients who die of other diseases are abstracted from the mortality files of the Registrar of Births, Deaths and Marriages and linked to hospital and pathology data.

1.4 The Act and Regulations

The *Public Health Act 2005,* Division 3 – Notifications about cancer 234 and 235 that the person in charge of a hospital or residential care facility must give a notification to the chief executive of Queensland Health if a person known to be suffering from cancer who is a patient in the hospital or a resident of the residential care facility, or under the direction of the chief executive to Metro South Hospital and Health Service ('the contractor'), within one month.

The legislation may be viewed on the following website:

https://www.health.qld.gov.au/system-governance/legislation/health-portfolio

1.5 Confidentiality of data

All unit record information collected by the Queensland Cancer Register is treated as strictly confidential. All information collected is used for statistical or research purposes only.

1.6 Enquiries

If you would like more information about the Queensland Cancer Register or you wish to obtain any publications you may contact the:

Senior Director
Cancer Alliance Queensland
Level 1, B2, 2 Burke St
Woolloongabba Q 4102

PH (07) 3176 4400
Email QCR@health.qld.gov.au

Further information about cancer may also be obtained from the following web sites:

www.qccat.health.qld.gov.au   (Queensland Health site, QCR data)
www.aihw.gov.au/cancer/index.html   (AIHW site, national data)

2. ELECTRONIC NOTIFICATION

2.1 Background

Since early 2002, the Register has been receiving data electronically on a monthly basis from all public hospitals in Queensland. Notifying cancer electronically is also available for private hospitals. However we understand that private hospitals utilise different electronic systems and each system has unique functionality and specifications for notifying cancer to the Register.

Small private hospitals that don't have functionality to send cancer notification electronically can notify on the standard paper notification form, rather than in the electronic format.

3. BUSINESS RULES

3.1 What Hospitals should notify?

All private hospitals in Queensland are required to report cancer details to the Queensland Cancer Register.

3.2 What cancers should be notified?

All cancers as defined in Part 2 Division 1, Section 229 of the *Public Health Act* 2005 are to be notified. The Act defines cancer as:

(a) a neoplasm of human tissue—
- (i) in which cell multiplication is uncontrolled and progressive; and
- (ii) that, if unchecked, may invade adjacent tissues or extend beyond its site of origin; and
- (iii) that has the propensity to recur, either locally or remotely in the body;

(b) skin cancer and non-invasive carcinoma, other than skin cancer and non-invasive carcinoma of a type prescribed under a regulation.

Therefore, all invasive cancers are to be reported (excluding Basal Cell Carcinomas and Squamous Cell Carcinomas of the skin where the ICD-10-AM site code range is C44.0 to C44.9 and morphology is M805 to M811). Merkel cell tumours of the skin and Kaposi's Sarcoma are also to be reported.

Please report any cancer with uncertain behaviour.

Please notify **all** in-situ conditions as well. The Register collects for example, in-situ cancers of the cervix (CIN III - cervical intra-epithelial neoplasm), vagina (VAIN III - vaginal intra-epithelial neoplasm), vulva (VIN III - vulval intra-epithelial neoplasm), prostate (PIN - prostatic intra-epithelial neoplasm) bladder, breast and in-situ melanomas.

Benign central nervous system and brain tumours are also of interest to the Register and must be reported.

Non-malignant conditions, such as CIN I or II, VAIN I or II, VIN I or II, solar keratosis or keratoacanthoma, are outside the scope of the collection.

3.3 When should a notification be completed

A notification should be completed and sent **within 30 days** for each of the following events:

(i)   at discharge or transfer of a patient being **first** diagnosed with cancer, or when a **new site** is diagnosed, or the same site but a **different histological type** of cancer is diagnosed.

(ii)   a patient's **first** date of attendance in each calendar year for chemotherapy or radiotherapy.

(iii)   at the **death** of a patient suffering from or with a **history** of cancer, where the patient died within the hospital.

(iv)   at discharge or transfer from the **first** admission for each calendar year for all other patients suffering from or with a history of cancer. This includes patients who may be being treated for their cancer at that admission or where the cancer is incidental to that admission. It is a requirement to follow current coding standards and to only code history of cancer in the ICD-10-AM diagnosis codes where it is relevant to the admission. It is desirable for the cancer register to still receive a notification through separately 'filing' a cancer registration notification.

A **separate notification** is required for each primary site.

3.4 Deletions

If you have sent a notification it will be reported through to the Register. If you would like to delete it after it has been sent electronically, a manual notification is then required if the record is to be deleted from the QCR. This can be done by printing the notification prior to deleting or photocopying the relevant notification and crossing it with DELETED. If possible, a reason should be added, eg duplicate patient, not cancer, etc.

3.5 Further information required

After processing a cancer notification the Register may identify a need for further information. A response to the request for further information is required within 30 days and should be supplied electronically eg. updated cancer notification and/or supporting information to email address QCR@health.qld.gov.au

It is recommended that hospitals maintain a record of the completion and dispatch of the responses to the requests for further information.

3.6 When and how should a notification be sent?

Ideally, notifications should be sent on a monthly basis, with an extract sent on a certain day of the month eg. the 10th day of each month. The extract should include all notifications completed in the previous month.

The dates for sending the notifications, methods and the format of how these will be sent can be discussed with QCR.

Each set of cancer registration extract files will contain a header (HDR) details file. The HDR file will provide counts of the total number of records for that facility (including nil returns).

The paper form used to report cancer notifications to the Queensland Cancer Register is a standard form. To obtain the form, download from the website https://qccat.health.qld.gov.au or contact the QCR (see section 1.6 for contact details).

Completed Cancer Notification paper forms must be sent via secure post or email and marked "Queensland Cancer Register - Private and Confidential". Contact details for the QCR are provided in Section 1.6.

4 FACILITY DETAILS

4.1 Facility number
The facility number is a numerical code that uniquely identifies each health care facility.

Patients moving between these hospitals are counted as separate admissions and separations and are therefore reported by both facilities.

Nursing home residents should be reported under the facility number of the nursing home. Nursing home residents moving from a nursing home bed to an acute bed at another facility should be admitted as an acute patient from the date that they occupy the acute bed and reported as such.

This is not to be confused with a person's status as a nursing home type patient in an acute bed.

5 PATIENT DETAILS

5.1 Patient Number (UR number)
A unique number allocated to each patient by the hospital. Allocation might be done manually or automatically by the computer. The number is used for each admission to identify the patient within the facility.

5.2 Patient Surname/Family Name
The current surname of the patient.

5.3 Given Names

5.3.1 First name
The current given name of the patient.

5.3.2 Second name
Second names or initials where known.

5.4 Former names/alias
Record any previous surname or other names that the patient or resident is now or has previously been known as. Record the complete name (first name, second name and surname).

5.5 Sex
Record the sex of the patient using the following:

  M= Male
  F= Female
  I= Indeterminate / Intersex

To avoid problems with edits, transsexuals undergoing a sex change operation should have their sex at the time of the hospital admission recorded.

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

5.6 Date of birth
Record the date of birth of patient using the full date (i.e. ddmmmyyyy).

- 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 in the CAN file.

5.7 Address of usual residence

5.7.1 Number and street of usual residence
Record the building number and street name of the usual residential address of the patient. The usual residence is where the patient lives. For example, it is not the address where the patient might be staying temporarily before or after the period of hospitalisation.

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, for example:

• Alley - AL	• Frontage – FR
• Approach – APP	• Garden/s – GDN
• Arcade - ARC	• Gate/s – GTE
• Avenue – AV	• Glade – GLD
• Bend - BND	• Glen – GLN
• Boulevard – BVD	• Grange – GRA
• Break/Brook – BR	• Green – GRN
• Broadway – BWY	• Grove - GR
• Brow – BRW	• Heights - HTS
• Bypass – BPS	• Highway – HWY

• Centre – CTR	• Junction – JNC
• Chase – CH	• Lane – LA
• Circle – CIR	• Link – LK
• Circuit – CCT	• Loop – LP
• Circus - CRC	• Mall – ML
• Close – CL	• Meander – MDR
• Concourse – CNC	• Mews – MW
• Copse – CPS	• Motorway – MWY
• Corner – CNR	• Nook – NK
• Corso - CSO	• Outlook - OUT
• Court – CT	• Parade – PDE
• Courtyard – CYD	• Park – PK
• Cove - COV	• Parkway – PKY
• Crescent – CR	• Pass – PS
• Crest – CST	• Pathway – PWY
• Cross – CS	• Place – PL
• Crossing – CSG	• Plaza – PLZ
• Dale – DLE	• Pocket – PKT
• Downs – DN	• Port/Point – PT
• Drive – DR	• Promenade – PRM
• Edge – EDG	• Quadrant – QD
• Elbow – ELB	• Quay – QY
• Entrance – ENT	• Ramble – RA
• Esplanade – ESP	• Reach – RCH
• Expressway – EXP	• Reserve – RES
• Freeway – FWY	• Rest – RST
• Retreat – RT	• Track – TR
• Ridge – RDG	• Trail – TRI
• Rise - RI	• Underpass – UPS
• Road – RD	• Vale – VA
• Roadway – RDY	• View – VW
• Route – RTE	• Vista – VST
• Square – SQ	• Walk – WK
• Street – ST	• Walkway – WKY
• Tarn – TN	• Way – WY
• Terrace – TCE	• Wynd - WYN
• Tollway – TWY	

5.7.2 Suburb/Town of usual residence

Record the location of the usual residence of the patient as the suburb or town in which the patient usually lives. Do not record the location of temporary accommodation, or a (farm) property name in this field.

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.

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.

5.7.3   Postcode of usual residence

Record the postcode of the usual residential address of the patient.

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

5.8 Medicare number
If the patient is eligible for Medicare, record the Medicare number from the patient's Medicare card.

If the person does not have an Australian Medicare Number or if it is not available, leave this blank.

5.9 Marital status
Use the following to record the current marital status of the patient:

    NM= Never married
    M= Married
    F=De facto
    W= Widowed
    D= Divorced
    A= Separated
    N= Unknown

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).

5.10 Country of birth
Record the country of birth of the patient using the appropriate numerical codes (as found in the Australian Standard Classification of Countries for Social Statistics ASCCSS)) eg:

- If the patient was born in Australia, use code 1101;

- If the patient was born in New Zealand, use code 1201.

5.11 Indigenous status
Use the following to record indigenous status:

    11= Indigenous-Aboriginal but not Torres Strait Islander origin.
    12= Indigenous-Torres Strait Islander but not Aboriginal origin.
    13= Indigenous-Aboriginal and Torres Strait Islander origin.
    14= Not indigenous-not Aboriginal or Torres Strait Islander origin.
    19= Not Stated

5.12 Occupation
Record the patient's occupation. Use the codes from the Australian Standard Classification of Occupations (ASCO). Ideally the Register would like principal lifetime occupation. Only use pensioner/ housewife/retired if lifetime occupation is unable to be ascertained.

6.   ADMISSION DETAILS

6.1 Admission number (Episode Number)
The admission number denotes a specific admission at the facility. 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.

6.2 Admission date
Record the full date (that is, ddmmmyyyy) of admission to hospital.

6.3 Separation Date
At separation, record the full date (that is, ddmmmyyyy). This is the date that the patient was discharged, transferred or died.

6.4 Mode of separation (Discharge Status)
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.

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

6.5 Transferring to facility
Record the facility number (extended source code) for the hospital, nursing home or correctional facility to which the patient is referred as an admitted patient.

6.6 Treating doctor
To assist in improving the quality of this data, all fields should be completed.

Record the individual doctor chiefly responsible for treating the patient e.g. the Senior Treating Medical Officer, Specialist or Consultant in charge of the care. This is not the registrar or resident medical officer.

6.7 Cause of death
If the patient died in the hospital, the description for the principal diagnosis 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.

6.8 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.

6.9 Diagnosis at separation
The principle diagnosis ICD-10-AM code for this admission.

7. CANCER DETAILS

7.1 Multiple primary site

This is a two digit item field, indicating multiple primary sites of cancer for any single patient.

7.2 Primary site of cancer
A primary site is defined as the site at which a neoplasm originated. Thus, a cancer CASE 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 3.2 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".

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.

7.3 Morphology
See Section 3.2 for the cancers in the scope of the collection.

The behaviour code (5th digit) should relate to the primary cancer. 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.

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 leukaemias, 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.

7.4 Date of first diagnosis
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.

7.5 Date of first diagnosis 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.

7.6 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
    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

7.7 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
    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

7.8 Laterality of cancer

Where possible, for cancers of paired organs, such as Breast (C50), Lung (C34), Kidney (C64), Ovary (56), 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:

    R   Right
    L   Left
    B   Bilateral
    N   Not Applicable
    U   Unknown

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)).

Not applicable is the default value. This should be recorded for all non-paired organ sites.

Unknown: It is unknown whether, for a paired organ, the origin of the cancer was on the left or right side of the body.

7.9 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**
Usually 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 (ie 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 (eg 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.

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, eg. Prostate specific antigen (PSA) for prostate.

6. **Cytology or haematology**
Tumour diagnosed using particular laboratory techniques only, eg. 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.

9. **Autopsy and histology**
When histology is performed on a tissue sample taken during an autopsy.

7.10 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   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 / Chemo / RT (Specify details)

Patients with a clinical admission for chemotherapy should be recorded with a code 09 and chemotherapy specified.

7.11 Details for clinical diagnosis

This free text field allows the user to provide the relevant details as outlined above in Reasons for Clinical Diagnosis.

7.12 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

7.13 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   Auslab
02   S & N
03   QML
04   Private Laboratory
05   Other

7.14 Laboratory specimen number

The lab specimen number will record the specimen lab number (e.g. report number) and any other comments required (e.g. if Other lab is recorded, then the user can record the actual lab name along with the Laboratory specimen number). This is a non-mandatory free text field, and only becomes enabled when the codes of 06, 07 08 or 09 is entered into field 7.13.

Appendix A – File Formats

All fields are to be provided in the extract in the format specified in the Requested Format column, unless otherwise stated in the Source/Description column. The files will be supplied in ascii comma delimited format with double quotes as a text delimiter. Field which are reported with double quotes as text delimiters will have any embedded double quotes replaced by single quotes. Other punctuation, including commas, will not be stripped from the data.

Header Details (HDR) File

Data Item	Requested Format	Source/Description
Facility number	5 num Right adjusted and zero filled from left	The facility code for the set of files being reported.
Number of CAD records	5 num Right adjusted and zero filled from left; zero if null	Total number of cancer admission records for that facility.
Number of CAN records	5 num Right adjusted and zero filled from left; zero if null	Total number of cancer primary site records for that facility.
Number of FAN records	5 num Right adjusted and zero filled from left; zero if null	Total number of former/alias name records for that facility.
Number of CDX records	5 num Right adjusted and zero	Total number of reasons for clinical diagnosis records for that facility.

	filled from left; zero if null	

File Names

The following file names are used when sending the data to the Register.
- the first five digits denote the Institution number
- the range of the month will change as per which month you are sending
- please ensure the file names are in CAPITALS.

0011901OCT200231OCT2002HDR.QCR
0011901OCT200231OCT2002CAD.QCR
0011901OCT200231OCT2002CAN.QCR
0011901OCT200231OCT2002CDX.QCR
0011901   OCT200231OCT2002   FAN.QCR

institution   month range   file type

Example of data in the HDR file
00000,00008,00009,00007,00003

Cancer Admission Details (CAD) File

Data Item	Requested Format	Source/Description
Patient Identifier (UR Number)	8 char Right adjusted and zero filled from left. Mandatory data item.	The unique number to identify the patient within the facility.
Admission Number	12 char Right adjusted and zero filled from left. Mandatory data item.	The admission number denotes a specific admission at the facility. Recording the admission number assists in identifying specific admissions as the patient can have one or more admissions within a certain time period and will have different cancer details for each admission. This is used to link each of the files for an admission when sending data to the Register.
Multiple Primary Site Count	2 num Right adjusted and zero filled from left. Mandatory data item.	The total number of primary sites for the cancer registration (ie. for the patient) will be reported. Only a single CAD file will be reported for the cancer registration, even if there are multiple primary sites.
Medicare Number	11 num Blank if not available or if null. Desirable - if available.	The Medicare number of patient. The field will not be zero or space filled. This comprises the 10 digit Medicare number and then the 1 digit reference number together.
Patient Surname	24 char Mandatory data item.	The current surname of the patient or resident. The field will not be zero or space filled.

Data Item	Requested Format	Source/Description
		Double quotes will be used as a text delimiter.
Patient First name	15 char If Unknown put 'Unknown' Mandatory data item.	The current given names of the patient or resident. The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Patient Second name	15 char Blank if null. Desirable – if applicable.	Second names or initials where known. The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Address of Usual Residence	50 char Mandatory data item. If Unknown type "Unknown"	Number and street of usual residential address of patient. Note: this is NOT a Post Office box or Mail Service No. - identify street name where possible. The field will not be zero or space filled. Double quotes will be used as a text delimiter. Use Street Directory abbreviations (eg. St- street, Av- Avenue etc. see section 5.7.1)
Location (suburb/ town) of Usual Residence	40 char Mandatory data item.	Name of suburb, town or locality of usual residence. Note: this item is mandatory even if patient has a Property Name or mail service number. The field will not be zero or space filled. Double quotes will be used as a text delimiter. Must be in CAPITALS.
Postcode of Usual Residence	4 num Mandatory data item.	Australian postcode corresponding to Address of usual residence. 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 The field will not be zero or space filled.
Date of Birth	9 date ddmmmyyyy Mandatory data item.	Full date of birth of patient. If year is unknown, estimate the year. If the DOB is unknown, specify 15-JUN-1900. In addition, specify in the comments in the CAN file that the DOB is estimated.
Occupation (before retirement) Description	50 char Left adjusted, blank if null. Desirable – if known.	Means principal lifetime occupation. The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Sex	1 char	The sex of the person. Only use the following:

Data Item	Requested Format	Source/Description
	Mandatory data item.	M= Male F= Female I= Indeterminate / Intersex
Country of Birth Code	4 num Right adjusted and zero filled from left. Mandatory data item.	The country in which the person is born. 4 digit code from the Australian Standard Classification of Countries for Social Statistics (ASCCSS).
Marital Status	2 char Mandatory data item.	The patients current marital status. Only use the following: NM= never married M= married F= Defacto W= widowed D= divorced A= separated N= not stated/unknown The field will not be zero or space filled.
Indigenous Status	2 num Mandatory data item	This item must be asked of the patient to collect the category to which the patient considers himself/herself to belong. 11=Indigenous-Aboriginal but not Torres Strait Islander origin. 12=Indigenous-Torres Strait Islander but not Aboriginal origin. 13=Indigenous-Aboriginal and Torres Strait Islander origin. 14=Not indigenous-not Aboriginal or Torres Strait Islander origin. 19=Not Stated The field will not be zero or space filled.
Admission Date	9 date ddmmmyyyy Mandatory data item.	This is the date on which an admitted patient commences an episode of care. Enter the full date of admission. DDMMMYYYY.
Separation Date	9 date ddmmmyyyy Mandatory data item.	This is the date that the patient was discharged, transferred or died. DDMMMYYYY.
Mode of Separation	2 char Mandatory data item.	Code which indicates the place to which a patient is referred immediately following separation from hospital. 01=Home/usual residence 04=Other health care establishment 05=Died in hospital 06=Care Type change 07=Discharge at own risk 09=Non return from leave 12=Correctional facility

Data Item	Requested Format	Source/Description
		13=Organ procurement 14=Boarder 15=Residential aged care service 16=Transferred to another hospital 19=Other 99=Unknown The field will not be zero or space filled.
Transferring to Facility	5 char Mandatory - If Transferred (Mode 16)	If the patient was transferred please complete facility number of the receiving facility. The field will not be zero or space filled.
Autopsy Flag	1 char Blank if null. Mandatory – If Died (Mode 05)	Record whether an autopsy or coroners inquiry is to be/has been undertaken with a Y or N.
Cause of Death	50 char Left adjusted, blank if null. Mandatory – If Died (Mode 05)	Please only complete the cause of death if the patient dies in the hospital or nursing home. The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Treating Doctor Title	4 char Left adjusted, blank if null. Mandatory data item.	Refers to the Tile of the Senior Treating Medical Officer, Specialist or Consultant in charge of the care of the patient during this admission. This is not the registrar or resident medical officer. The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Treating Doctor Initials	9 char Left adjusted, blank if null. Mandatory data item.	Refers to the Initials of the Senior Treating Medical Officer, Specialist or Consultant in charge of the care of the patient during this admission. This is not the registrar or resident medical officer. The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Treating Doctor Given Names	55 char Left adjusted, blank if null. Mandatory data item.	Refers to the Given Names of the Senior Treating Medical Officer, Specialist or Consultant in charge of the care of the patient during this admission. This is not the registrar or resident medical officer. The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Treating Doctor Surname	29 char Left adjusted.	Refers to the Surname of the Senior Treating Medical Officer, Specialist or Consultant in charge of the care of the patient during this

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Data Item	Requested Format	Source/Description
	Mandatory data item.	admission. This is not the registrar or resident medical officer. The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Diagnosis at Separation	9 char Left adjusted. Mandatory data item.	The principle diagnosis ICD 10-AM code for this admission. The field will not be zero or space filled.

Example of data in a CAD file

00000695,000000000002,01,,"LION","LARRY",,"15 DEN
ROAD","JINDALEE",4074,23JUN1940,,M,1101,D,14,20MAY1999,20JUL1999,01,,,,"DR","J","JO
HN","FROGLE",J46
00001204,000000000001,01,,"NOODLEMAN","HERMAN",,"123 EAGLE
PDE","ASPLEY",4034,01APR1955,,M,1101,M,14,01JAN2003,10JAN2003,01,,,,"DR","LORNE","
LORNE","BLAKE",C91.01

00001205,000000000001,01,,"CARACKAS","CRANKY",,"123 SMITH
ST","ASPLEY",4034,01MAR1944,,M,1101,N,19,02JAN2003,02JAN2003,05,,Y,"DEATH

POSTOP","DR","L","LORNE","BLAKE",C34.1

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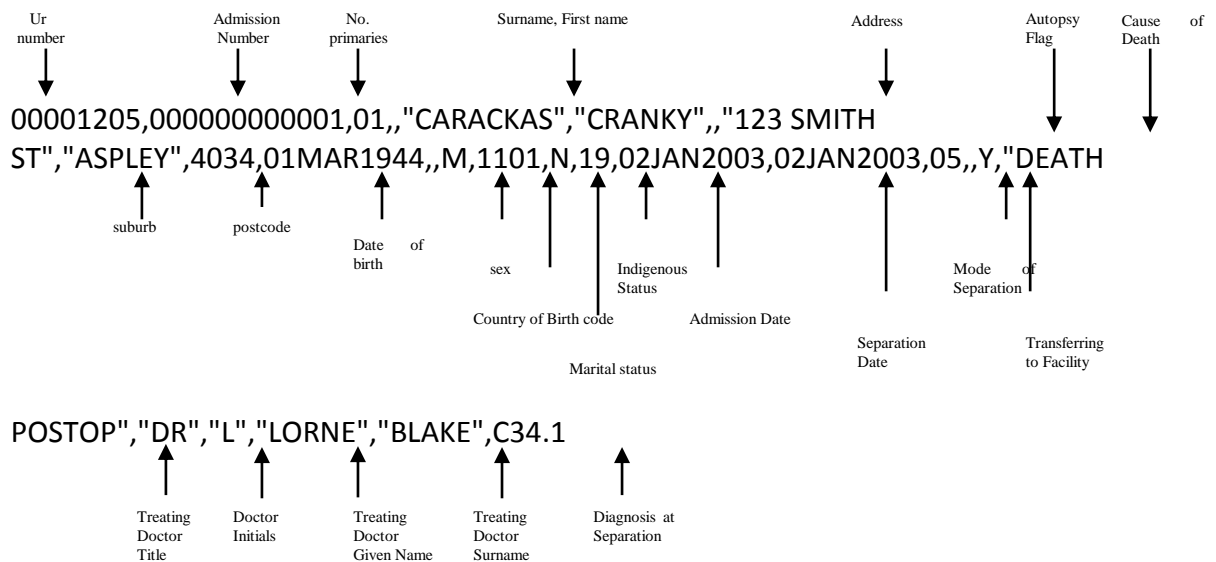
Cancer Details (CAN) File

Data Item	Requested Format	Source/Description
Patient Identifier (UR number)	8 char Right adjusted and zero filled from left. Mandatory data item.	A unique number to identify the patient within the facility.
Admission Number	12 char Right adjusted and zero filled from left. Mandatory data item.	The admission number denotes a specific admission at the facility. Recording the admission number assists in identifying specific admissions as the patient can have one or more admissions within a certain time period and will have different cancer details for each admission. This is used to link each of the files for an admission when sending data to the Register.
Multiple Primary Site Number	2 num Right adjusted and zero filled from left. Mandatory data item.	Each primary site for the cancer registration for that admission (for the patient) will be reported in a separate CAN record. Therefore, the patient, for that admission, may have one or many CAN records.
Primary Site of Cancer Code	9 char Left adjusted Mandatory data item.	Indicates the site where the neoplasm originated. Punctuation will not be stripped from the code. The field will not be zero or space filled.
Primary Site of Cancer Description	40 char Left adjusted. Mandatory data item.	Where possible, be specific when describing the primary site, for example, if known, state site as "upper or lower lobe of lung" or "upper-inner quadrant of breast". The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Morphology Code	7 char Mandatory data item.	4 digit Morphology code from ICD 10 AM and 5th digit indicting the behaviour of the tumour, for example invasive or insitu etc. Punctuation will not be stripped from the code. The field will not be zero or space filled.
Date of First Diagnosis	9 date ddmmmyyyy Mandatory data item.	Try to accurately identify the full date of original diagnosis for this cancer where possible. If the date is unknown, the users will be required to enter 15 JUN 1900 in this field.
Date of First Diagnosis Flag	1 char Blank if null. Mandatory data item.	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.

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Data Item	Requested Format	Source/Description
Location (suburb/ town) of usual residence at diagnosis	40 char Mandatory data item.	Name of suburb or town of usual residence at the <u>time of first diagnosis of this cancer</u>. The field will not be zero or space filled. Double quotes will be used as a text delimiter. Must be in CAPITALS.
Postcode of Usual Residence at Diagnosis	4 num Mandatory data item.	Australian postcode corresponding to Address of usual residence at the time of first Diagnosis of cancer. 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 The field will not be zero or space filled.
Laterality of Cancer	1 char Mandatory data item.	Where possible, for cancers of paired organs, such as ovary, breast, kidney and lung, indicate which the side is affected by the tumour. R= Right L= Left B= Bilateral N= Not applicable U= Unknown Please see the explanation at the front of this document. For all non-paired organ sites, not applicable is the default. Unknown is used for paired organs only.

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Data Item	Requested Format	Source/Description
Basis of Diagnosis	2 num Mandatory data item.	Refers to the basis of diagnosis AT THIS ADMISSION. 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. 01=Unknown 02=Clinical Only 03=Clinical Investigations 04=Exploratory Surgery 05=Specific Biochemical and immunological testing 06=Cytology 07=Histology of Metastasis 08=Histology of Primary Site 09=Autopsy and histology The field will not be zero or space filled. (If 02 or 03 is entered, a reason for clinical diagnosis will be displayed in the CDX file)
Comments	50 char Left adjusted, blank if null. Desirable – if applicable.	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. The field will not be zero or space filled. Double quotes will be used as a text de-limiter. If there is a Previous Pathology field or a Radiological Investigations field, this would be ideal in the comments data item, otherwise we will not know of any other tests performed if the basis of diagnosis is not clinical.
Laboratory facility number	2 char	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 Auslab 02 S & N 03 QML 04 Private Laboratory 05 Other

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Data Item	Requested Format	Source/Description
Laboratory Specimen No.	50 char	The lab specimen number will record the specimen lab number (e.g. report number) and any other comments required (e.g. if Other lab is recorded, then the user can record the actual lab name along with the Laboratory specimen number). This is a non-mandatory free text field, and only becomes enabled when the codes of 06, 07 08 or 09 is entered into field 13.

Example of CAN file

00000695,000000000002,01,C54.0,"MALIGNANT NEOPLASM OF ISTHMUS UTERI",M8140/3,01MAY1999,N,"CANBERRA ACT",2600,U,01,"HISTORY",01,07-2555500001204,000000000001,01,C91.01,"ACUTE LYMPHOBLASTIC LEUKAEMIA IN REM",M9835/3,01JAN2001,Y,"ASPLEY",4034,N,03,,,
00001205,000000000001,01,C34.1,"MALGT NEOPLM UPPER LOBE BRONCHUS OR LUNG",M8140/3,01JAN2000,N,"HAWTHORNE",4171,R,01,
00001250,000000000002,01,D39.1,"NEOPLASM UNCERTAIN OR UNKNOWN BEH OVARY",M8000/1,15JUN2002,Y,"CARINA",4152,L,02,"CHECK FOR FURTHER NOTES"

00001301,000000000003,01,C48.2,"MALIGNANT NEOPLASM PERITONEUM NOS",M8030/3,01JAN2001,N,"ALBION",4010,N,07,"MOD DIFF",01,07-2555555

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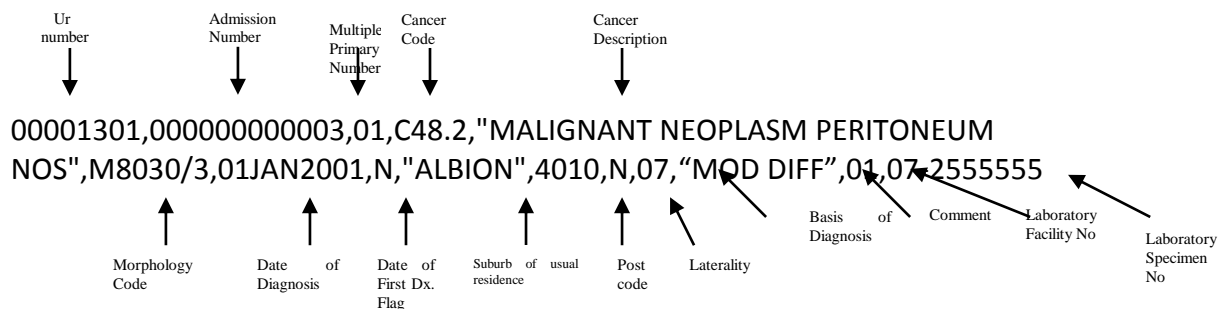
**Former/Alias Names (FAN) File
– If there are Alias Names this file is Mandatory**

Data Item	Requested Format	Source/Description
Patient Identifier (UR number)	8 char Right adjusted and zero filled from left. Mandatory data item.	A unique number to identify the patient within the facility.
Admission Number	12 char Right adjusted and zero filled from left. Mandatory data item.	The admission number denotes a specific admission at the facility. Recording the admission number assists in identifying specific admissions as the patient can have one or more admissions within a certain time period and will have different cancer details for each admission. This is used to link each of the files for an admission when sending data to the Register.
Former/Alias Name Identifier	2 num Right adjusted and zero filled from left. Mandatory data item.	Each alias entered for the patient will be reported in a separate FAN record. Therefore, the patient may have none, one or many FAN records. The alias details are linked to an individual patient but are not linked to an individual admission for that patient. Therefore, when the alias details are reported in the FAN record/s, each alias that exists for that patient will be reported, regardless of the admission number reported. If a patient has an alias and therefore a FAN record, the name identifier can not be '00'.
Patient Surname	24 char Left adjusted. Mandatory data item.	Any previous surname that the patient or resident is now or has previously been known as. The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Patient First Name	15 char Left adjusted. Mandatory data item.	Any previous first name that the patient or resident is now or has previously been known as. The field will not be zero or space filled. Double quotes will be used as a text delimiter.
Patient Second Name	15 char Left adjusted. Desirable – if applicable.	Any previous second name that the patient or resident is now or has previously been known as. The field will not be zero or space filled. Double quotes will be used as a text delimiter.

Example of FAN

00000695,000000000002,01,"LION","LENARD",

00001204,000000000001,01,"HERMIT","HERMAN",   ⟵ Same patient
00001204,000000000001,02,"NOODLEMAN","HERMIE",

00001205,000000000001,01,"PANTS","CRANKY",
00001301,000000000003,01,"ANDREWS","ANDROID",
00001301,000000000003,02,"ANDREWS","ANDREW",

00001301,000000000003,03,"ANDREWS","JULIE",

↑	↑	↑	↑	↑
Ur number	Admission number	Name Identifier	Surname	First name

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Reason for Clinical Diagnosis (CDX) File
– If notifying of a Basis of Diagnosis in the CAN file of 02 or 03, then this file is Mandatory

| Data Item	Requested Format	Source/Description
Patient Identifier (UR number)	8 char Right adjusted and zero filled from left Mandatory data item.	A unique number to identify the patient within the facility.
Admission Number	12 char Right adjusted and zero filled from left. Mandatory data item.	The admission number denotes a specific admission at the facility. Recording the admission number assists in identifying specific admissions as the patient can have one or more admissions within a certain time period and will have different cancer details for each admission. This is used to link each of the files for an admission when sending data to the Register.
Multiple Primary Site Number	2 num Right adjusted and zero filled from left. Mandatory data item.	Each reason for clinical diagnosis for each primary site for the cancer registration will be reported in a separate CDX record. Therefore, the patient may have none, one or many CDX records and the patient may have none, one or many CDX records for a given primary site.
Reasons for clinical diagnosis code	2 num Right adjusted and zero filled from left. Mandatory data item.	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. Some codes for the Reasons for Clinical Diagnosis require further detail to be supplied in the Details field. The codes are as follows: 01=Pallative care admission 02=Doctors notes/Referral 03=Pathology 04=Radiological investigations 05=Other non invasive investigations 06=Invasive investigation 07=Non cancer admission 09=Other The field will not be zero or space filled. You cannot have more than one of the above codes for the same primary site. ie: for patient UR number 123456 ; primary site number 01, the code 03 cannot be used more than once. You need to use another code if there is another reason, therefore use

Data Item	Requested Format	Source/Description
		03 and 09.
Reasons for clinical diagnosis text	50 char Blank if reasons for clinical diagnosis code = 01. Desirable – if applicable.	Some codes for the Reasons for Clinical Diagnosis require further detail to be supplied in this field. The extract will simply include the details if available for that reason for clinical diagnosis item or leave the field in the CDX record blank if the details field is blank for that reason for clinical diagnosis item. The field will not be zero or space filled. Double quotes will be used as a text delimiter.

Example of CDX

00001204,000000000001,01,02,"MEDICAL RECORD NOTES"
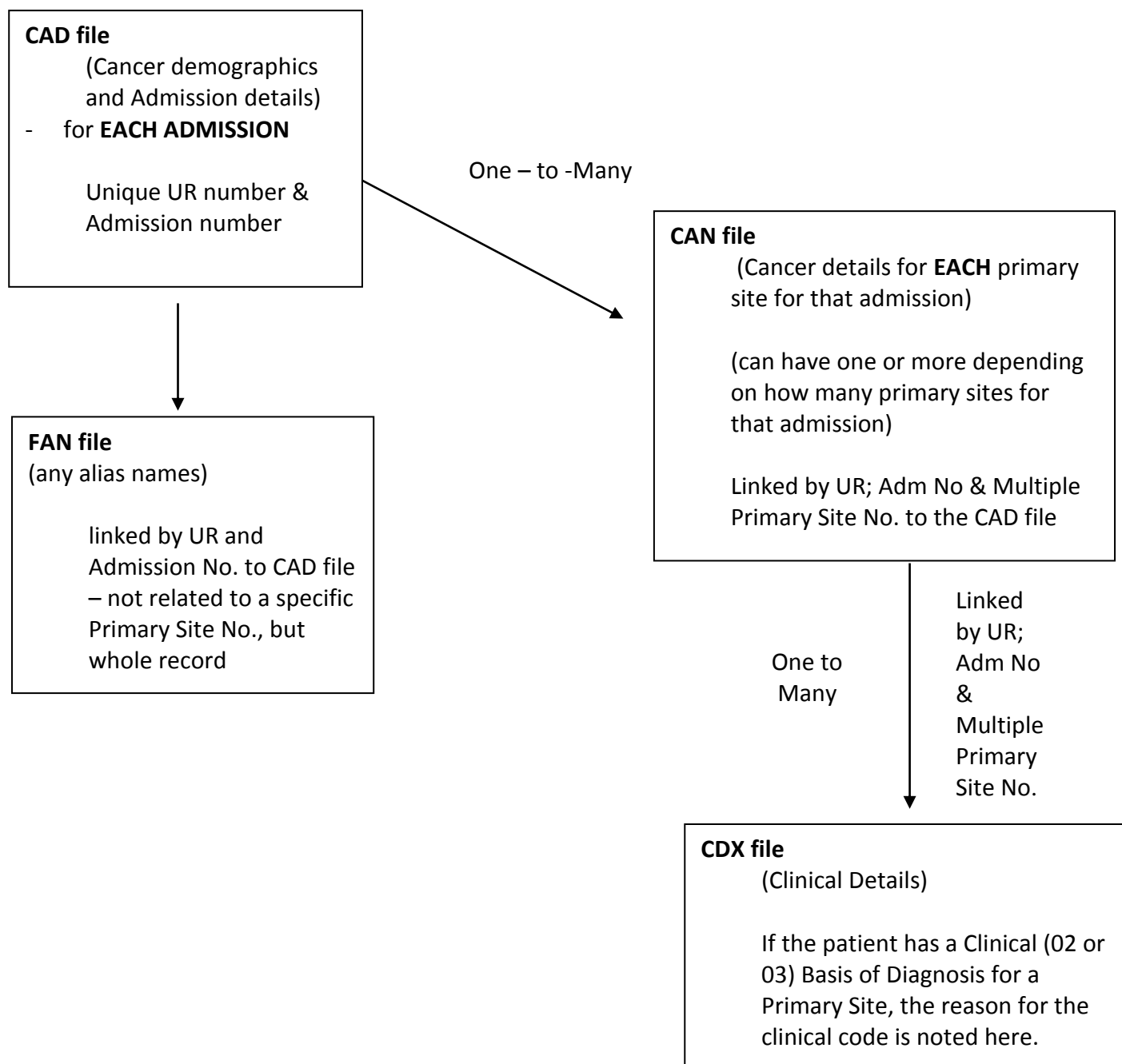00001204,000000000001,01,03,"SEE MEDICAL RECORD"

00001250,000000000002,01,04,"SEE EXAMINATION REPORT"

Ur number   Admissi   No.   Reason   for   Reason for clinical dx text
                Number   primaries   clinical dx.
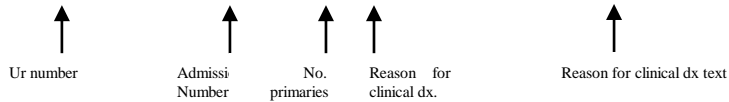
How the files are linked together?

The CAD record relates to a <u>specific admission</u>, so if the patient is admitted twice in the extract period (can happen if the extract period is for a month) then there will be 2 CAD records for the patient, and subsequent CAN records from that admission.
There could also be more than one CDX file if the second CAD admission and subsequent CAN/s have a CDX (ie: Clinical Details) as well as the first admission ….as the CDX file is linked to the CAN file for that specific primary site number….

CAD file
      (Cancer demographics
      and Admission details)
-   for **EACH ADMISSION**

      Unique UR number &
      Admission number

One – to -Many

CAN file
     (Cancer details for **EACH** primary site for that admission)

     (can have one or more depending on how many primary sites for that admission)

     Linked by UR; Adm No & Multiple Primary Site No. to the CAD file

FAN file
(any alias names)

     linked by UR and Admission No. to CAD file – not related to a specific Primary Site No., but whole record

One to Many

Linked by UR; Adm No & Multiple Primary Site No.

CDX file
     (Clinical Details)

     If the patient has a Clinical (02 or 03) Basis of Diagnosis for a Primary Site, the reason for the clinical code is noted here.

Appendix B - Example of how QCR displays the data supplied in a form

QCR REGISTRATION NO:

1. Name of Hospital/Institution	00000 NOT HOSPITAL DEATH
2. Medicare Number	0000000000
3. Ur Number	00001480
4. Surname	SMITHERS
5. Given Names	SILLY
6. Former Names/Alias	SAUSAGE, SILLY
	SMITHERS, SOMEONE
	SMITHERS, SALLY
7. No. and Street	798 SIR FRED SCHONELL DRIVE
8. Suburb/Locality	ST LUCIA
9. Postcode	4067
10. Date of Birth	01–JAN–1952
11. Occupation	
12. Sex	M [–]
13. Country of Birth	1101 [Australia]
14. Marital Status	NM [–]
15. Indigenous Status	14 [–]
16. Admission Date	10–JAN–2004
17. Separation Date	13–JAN–2004
18. Separation Mode	01
If transferred, Name of Institution	
If died, was autopsy held	
19. Underlying cause of death	
20. Primary Site of Cancer	C22.9 MALIGNANT NEOPLASM OF LIVER UNSPECIFIEI
ICDO Primary Site	
21. Histological Type of Cancer	M8000/9 Neoplm, malgt, unc, primary/met
22. Date of First Diagnosis	10–JAN–2004
23. Usual Suburb at FIRST Diagnosis	ST LUCIA
24. Postcode	4067
25. Laterality	N [–]
26. More than one Primary Site	Y [02 site(s)]
27. Most valid Basis of Diagnosis	05 [SPECIFIC BIOCHEMISTRY OR IMMUNOLC
28. Reasons for Clinical Diagnosis	
COMMENT	
Diagnosis at Separation	C34.2 Malg neoplasm mid lobe bronchus or lung
29. Name of Treating Doctor	DR Lorne (LORNE) Blake

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Appendix C – ICD-10-AM neoplasm site codes required to be notified to the QCR

Private Hospitals are required to notify QCR for the following:
- All invasive cancers
- All cancers with an uncertain behaviour
- All in-situ conditions
- Benign central nervous system and brain tumours
- Do not need Basal Cell Carcinomas and Squamous Cell Carcinomas of the Skin.

(The following site codes ARE NOT required and therefore these are not in the above list:
C44 with morphology M805-8110 – BCC and SCC of skin
C77, C78 and C79 – secondary sites
D10-D31.9 – Benign, not brain
D34 – D36.9 – Benign, not brain)

These are the ranges in the ICD-10-AM neoplasm site codes (as above) that ARE required:

Invasive
C00.0 – C76.8
C80.0 – C96.9
and exclude C44.0 to C44.9 AND M80500 to M81109 (Skin SCC's and BCC's)

Insitu and Benign Brain/CNS
D00.0 – D09.9
D32.0 – D33.9
D18.02 Benign brain
and exclude D04.0 to D04.9 AND M80500 to M81109 (Skin SCC's and BCC's)

Uncertain
D37.0 to D48.9
and exclude D48.5 AND M80500 to M81109 (Skin SCC's and BCC's)

Personal history of malignant neoplasm
Z85.0, Z85.1, Z85.2, Z85.3, Z85.4, Z85.5, Z85.6, Z85.7, Z85.8

We also require ICD-10-AM Site Codes:
Q85.0
D76.0

Modifications you may like to use for your system to identify cases to be sent:

In the HBCIS system used by the public hospitals, there are **non-notifiable cancer** and **history of cancer parameter**s that are hard-coded ie: they are not modifiable by users.

1. The non-notifiable parameter lists the paired combinations of neoplasm and morphology codes that do not require cancer registration. The parameter lists the following excluded skin codes:

    - malignant neoplasm of skin codes (other than melanoma) C44.0, C44.1, C44.2, C44.3, C44.4, C44.5, C44.6, C44.7, C44.8 and C44.9.
    - carcinoma in-situ of skin codes D04.0, D04.1, D04.2, D04.3, D04.4, D04.5, D04.6, D04.7, D04.8, D04.9.
    - neoplasm of uncertain or unknown behaviour of skin D48.5

    and the following selected morphology codes:

    - basal cell and squamous cell morphologies M805, M806, M807, M808, M809, M810, M811.

2. The history of cancer parameter enables the reporting of episodes where the history of cancer has been coded and the episode is the first presentation in a calendar year. The following codes are included:

    - personal history of malignant neoplasm Z85.0, Z85.1, Z85.2, Z85.3, Z85.4, Z85.5, Z85.6, Z85.7, Z85.8. The coder is prompted if entered.

3. In addition, a prompt appears if any of the following required ICD-10-AM neoplasm site codes are entered on the screen (irrespective of the morphology code entered). These site codes follow the cancers required to be sent to the Register eg. invasive, in-situ etc. as above.

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