QUEENSLAND CANCER REGISTER

INSTRUCTION MANUAL

FOR NOTIFYING CANCER

NURSING HOMES

April 2018

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

Email: QCR@health.qld.gov.au

PH (07) 3176 4400

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. 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.

Non-admitted patient facilities such as nursing homes can notify on the standard paper notification form, rather than in the electronic format.

3. BUSINESS RULES

3.1 What Hospitals should notify?

All nursing homes 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 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 addressed as follows:

CONFIDENTIAL
The Queensland Cancer Register
Cancer Alliance Queensland
Level 1, Burke Street Centre
C/O Princess Alexandra Hospital
Woolloongabba Q 4102
or
Email 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.

3.5 When and how should a notification be sent?

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

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. COMPLETING THE PAPER FORM

4.1 HOSPITAL/INSTITUTION

The name of nursing home and the Queensland Health 5 digit numerical code that uniquely identifies the health care facility.

Nursing home residents should be reported under the facility number of the nursing home.

4.2 PATIENT DETAILS

4.2.0 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.

4.2.1 UR number

A unique number allocated to each patient by the hospital or nursing home. Allocation might be done manually or automatically by the computer.

4.2.2 Patient Surname/Family Name

The current surname of the patient.

4.2.3 Given Names

The current given names of the patient.

4.2.4 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).

4.3 ADDRESS AT USUAL RESIDENCE

4.3.1 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
- Approach – APP
- Arcade - ARC
- Avenue – AV
- Bend - BND
- Boulevard – BVD
- Break/Brook – BR
- Broadway – BWY
- Brow – BRW
- Bypass – BPS
- Centre – CTR
- Chase – CH
- Circle – CIR
- Circuit – CCT
- Circus - CRC
- Close – CL
- Concourse – CNC
- Copse – CPS
- Corner – CNR
- Corso - CSO
- Court – CT
- Courtyard – CYD
- Cove - COV
- Crescent – CR
- Crest – CST
- Cross – CS
- Crossing – CSG
- Dale – DLE
- Downs – DN
- Drive – DR
- Edge – EDG
- Elbow – ELB
- Entrance – ENT
- Esplanade – ESP
- Expressway – EXP
- Freeway – FWY
- Retreat – RT
- Ridge – RDG
- Rise - RI
- Road – RD
- Roadway – RDY
- Route – RTE
- Square – SQ
- Street – ST
- Tarn – TN
- Terrace – TCE
- Frontage – FR
- Garden/s – GDN
- Gate/s – GTE
- Glade – GLD
- Glen – GLN
- Grange – GRA
- Green – GRN
- Grove - GR
- Heights - HTS
- Highway – HWY
- Junction – JNC
- Lane – LA
- Link – LK
- Loop – LP
- Mall – ML
- Meander – MDR
- Mews – MW
- Motorway – MWY
- Nook – NK
- Outlook - OUT
- Parade – PDE
- Park – PK
- Parkway – PKY
- Pass – PS
- Pathway – PWY
- Place – PL
- Plaza – PLZ
- Pocket – PKT
- Port/Point – PT
- Promenade – PRM
- Quadrant – QD
- Quay – QY
- Ramble – RA
- Reach – RCH
- Reserve – RES
- Rest – RST
- Track – TR
- Trail – TRI
- Underpass – UPS
- Vale – VA
- View – VW
- Vista – VST
- Walk – WK
- Walkway – WKY
- Way – WY
- Wynd - WYN

• Tollway – TWY	

4.3.2 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.

4.3.3 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

4.4 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.

4.5 Sex

Tick the sex of the patient using the following:

Male
Female

4.6 Country of birth

Tick the country of birth Australia, or specify other

4.7 Marital status
Tick the following to record the current marital status of the patient:

Never married
Married
De facto
Widowed
Divorced
Separated
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).

4.8 Indigenous status
Tick the following to record indigenous status:

Indigenous-Aboriginal but not Torres Strait Islander origin.
Indigenous-Torres Strait Islander but not Aboriginal origin.
Indigenous-Aboriginal and Torres Strait Islander origin.
Not indigenous-not Aboriginal or Torres Strait Islander origin.
Not Stated

5. ADMISSION DETAILS

5.1 Admission date
Record the full date (that is, ddmmmyyyy) of admission to nursing home.

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

5.3 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.

5.4 Transferring to facility
Record the name of the hospital, nursing home or correctional facility to which the patient is referred as an admitted patient.

5.5 Autopsy held
Tick whether an autopsy or coroners inquiry is to be/has been undertaken with a Y or N.

5.6 Underlying cause of death
If the patient died in the nursing home, the underlying cause of death on the death certificate, should be displayed in this field.

6. CANCER DETAILS

6.1 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 enter the cancer as an unknown primary site.

6.2 Histological type of cancer
Type of cancer eg Adenocarinoma

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

6.3 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.

6.4 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.

6.5 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

6.6 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
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9302 = New Zealand
9399 = Overseas - other (not PNG or NZ)
9799 = at sea
9899 = Australian External Territories

6.7 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.

Tick box:

Right
Left
Bilateral
Not Applicable
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.

6.8 Is there more than one primary site?
This indicates if there is multiple primary sites of cancer for any single patient.

6.9 Most valid 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.

6.10 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.

6.11 Details for clinical diagnosis

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

6.12 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.

Appendix A – Example of the Queensland Cancer Register paper form

QUEENSLAND CANCER REGISTI

Notification of cancer in Queensland is a statutory requirement under the Public Health Act

PLEASE USE BLOCK LETTERS

PATIENT DETAILS

1. Hospital/Institution
2. Medicare No
3. UR No
4. Surname:
5. Given Names:
6. Former Name/Alias:
7. Usual Street Address:
8. Suburb/Locality:
9. State
10. Postcode
11. Date of Birth ☐ Estimated?
12. Occupation (before retirement)
13. Sex 1☐ Male 2☐ Female
14. Country of Birth ☐ Australia ☐ Other (specify)
15. Marital Status 1☐ Never Married 2☐ Married/Defacto 3☐ Widowed 4☐ Divorced 5☐ Separated
16. Indigenous Status 1☐ Aboriginal but not Torres Strait Islander Origin 2☐ Torres Strait Islander but not Aboriginal Origin 3☐ Both Aboriginal and Torres Strait Islander Origin 4☐ Neither Aboriginal nor Torres Strait Islander Origin 9☐ Not Stated / Unknown
17a. Admission Date
17b. Separation Date
18. Separation Mode ☐ Discharged ☐ Transferred → To Institution ☐ Died → Was Autopsy Held? ☐ Yes ☐ No
19. Underlying Cause of Death

CANCER DETAILS

20. Primary Site of Cancer
21. Histological Type of Cancer
22. Date of FIRST Diagnosis of this Cancer ☐ Estimated?
23. Usual Suburb/Locality at FIRST Diagnosis of Cancer
24. State
25. Postcode
26. Laterality of Cancer 1☐ Right 2☐ Left 3☐ Bilateral 9☐ Unknown/Not Applicable
27. Is there more than one Primary Site? ☐ Yes ☐ No *If YES, complete additional form(s)*

28a. Most valid basis of Diagnosis of Cancer at THIS Admission

- 2☐ Clinical Only
- 3☐ Clinical Investigations
- 4☐ Exploratory Surgery
- 5☐ Spec. Biochemical or Immunology
- 6☐ Cytology or Haematology
- 7☐ Histology of Metastasis
- 8☐ Histology of Primary Laboratory
- 9☐ Autopsy and Histology
- 1☐ Unknown

28b. Reasons for Clinical Diagnosis

- 1☐ Palliative Care Admission
- 2☐ Doctor's Notes/Referral (specify Doctor)
- 3☐ Pathology (specify laboratory)
- 4☐ Radiological Investigation (specify)
- 5☐ Other Non-invasive Investigation (specify)
- 6☐ Invasive Investigation (specify)
- 7☐ Non Cancer Admission
- 9☐ Other/Chemo/RT (specify)

29. Name of Treating Doctor
30. Name of Person Completing this Form

Date: ...../...../.....

FOR MORE INFORMATION

Cancer Alliance Queensland
Metro South
Queensland Health
Tel: (+61) (07) 3176 4400
Email: CancerAllianceQld@health.qld.gov.au
https://qccat.health.qld.gov.au