Cancer Data Notification Policy

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Revision History

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00	**Shk Mohamed Hamad JT Al Thani**	**Dr Salih Ali AA Almarri**	22-Sep-21	Initial release
01	**Shk Mohamed Hamad JT Al Thani**	**Shk Mohamed Hamad JT Al Thani**	07-Jul-25	Alignment with MOPH new branding
02	**Shk Mohamed Hamad JT Al Thani** Director	**Shk Mohamed Hamad JT Al Thani** Director	01 DEC 2025	Updated according to National Policies for data security

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1. Purpose

1.1. To describe the conditions and rules related to the notification of cancer data to Qatar National Cancer Registry QNCR within the Qatar Cancer Information Center (QCIC) at the Ministry of Public Health

2. Scope and applicability

2.1. This policy applies to all Healthcare providers in the State of Qatar who are involved in the provision of cancer services: Awareness, Prevention, Early Detection, Screening, Diagnosis, Treatment and Follow up. The policy will be used by all providers and Qatar National Cancer Registry QNCR staff.

2.2. Specific agencies are assigned responsibility within the policy objectives, they include:

2.2.1. Ministry of Public Health (MoPH)

2.2.2. National Planning Council (NPC)

2.2.3. Hamad Medical Corporation (HMC)

2.2.4. Primary Health Care Corporation (PHCC)

2.2.5. Sidra Medicine

2.2.6. Private Providers of Cancer Care and Treatment and diagnosis

2.2.7. Private and Public Providers of Cancer Screening services

2.2.8. Charity and civil society organizations

3. Acronyms, terms, and definitions

3.1. Qatar National Cancer Registry (QNCR): National population-based registry for all cancer incidence data notified to healthcare providers and specific agencies.

3.2. Qatar Cancer Information Center – The National repository of cancer related information in the State of Qatar, housing the Qatar National Cancer Registry and Screening Program.

3.3. Cancer Data refers to any data related to cancer, under all conditions, covering the complete patient pathway, including but not limited to awareness, early detection, screening, diagnosis, treatment and follow up.

3.4. Protected Health Information (PHI) - Protected Health Information is an individual's health, treatment, and any information that could be used to identify the individual. Referring to any Information in a medical record or designated healthcare setting that can be used to identify an individual and is created, received, used, or maintained by a healthcare provider, health plan, employer, or healthcare.

3.5. Minimum Data Set refers to the group of data items that are mandatory when reporting any cancer case, regardless of the type of cancer or condition of the case set out in the Data Dictionary.

3.6. Notification Criteria: Any cancer case that meets the Notification Criteria outlined in section 4.5, shall be registered at the Qatar National Cancer Registry QNCR through the online cancer case notification system QNCR hosted on the QCIC.

3.7. Date of diagnosis refers to the first date ever, when a recognized medical practitioner diagnoses a cancer, regardless of the country of diagnosis.

3.8. Data Owner - The National Cancer Program Head is the person responsible for the data owned by the organization and is the one who has the right to make decisions in determining the value of the data in view of the business process in the organization. The data owner is often responsible for the business unit of the organization and therefore has sufficient knowledge of the value of the data and can make decisions at the level of its classification. The data owner is also responsible for ensuring and naming records for data classification when they are created and can assign these tasks to (Data Classification Specialist).

3.9. Data Custodian: The QCIC Manager along with the Applications Team in MOPH Information Systems Department are the persons responsible for protecting data by making the decision to use security controls commensurate with the classification and have the technical expertise and the necessary knowledge of the best practices used in the application of security controls and data protection at its various stages in accordance with the policies and standards adopted.

3.10. Data Users: The Cancer Registrar is the person who deals with, uses and processes data according to the workflow entrusted to him, and he must be knowledgeable, sufficiently informed, and responsible for adhering to the optimal way to use and protect data according to the policies followed in the organization and to abide by the tasks entrusted to him during the stages of data management data and not expose it to potential risks.

4. Policy statement

4.1. Policy Objectives are:

4.1.1. To receive cancer data that is accurate, reliable, complete and useful: The cancer data will be acquired, electronically only, from a variety of sources including historic records. Processing will include checking the validity and completeness of the data and a complex process of clinical data linkage and consolidation to provide information on cancers occurring in the population ensuring accurate patient matching. The accuracy, reliability and completeness of the dataset will be regularly audited as per data management procedures.

4.1.2. Cancer Data is received in a timely and systematic way: The infrastructure around the registry shall promote efficient and effective data collection throughout the cancer journey. Registrations will be based on a range of data sources to identify all new cancer cases and register all relevant patient, diagnosis and treatment details as they happen. Using the data management procedures in place to identify multiple notifications of the same patient and tumor, with the registry allocating all relevant information to the correct case. This requires PHI which will be anonymized for any outputs from the registry.

Hospital pathology reports shall provide data on approximately 85% of all new cases. Data from pathology reports and hospital Multidisciplinary Team meetings (MDT) meetings shall be registered almost immediately after diagnosis, whereas data from other sources can take longer time to report. Cases can also be reported based on clinical and radiology diagnostic methods.

Together with essential case checking and data quality assurance, the Registry shall normally produce definitive statistics for case data a maximum of 2 years following the end of year of diagnosis.

The completeness of registration will depend on data flows from Medical Treatments Abroad, Death Registry at the Ministry, and the subsequent checking of the diagnoses.

While the number of cases for certain sites may be available at an early stage, information on treatments and staging may only be obtained later from the patient's medical records.

4.1.3. Cancer Data is held in a secure area with a clear governance framework: The registry will adhere to principles of data protection and confidentiality with regard to the receipt and storage of personal data, the handling of queries and release of information.The registry will require secure accommodation used only by registry staff with coded entry facility. The system must have encrypted data storage with entry to the system only with passwords and controlled identification. There is a facility to undertake audit trails for data handling. There are daily differential database backups with a detailed schedule for encryption and onsite storage from the main registry.

The Data Sharing Policy describes the conditions and rules under which cancer data is shared between healthcare providers, individuals and services.

- The data sharing agreement manages and controls the exchange of cancer data between healthcare providers.
- The agreement further outlines the role and responsibilities of the data suppliers and individuals, ensuring transparency and a clear audit trail on information ownership.
- The Data Sharing Agreement conforms with applicable confidentiality and data protection laws in the State of Qatar and best practice, such as:
- Ministry of Communications and Information Technology ICT Qatar 'open data' policy applies
- National Health Data Policy of the National e-Health Committee
- National Cyber Security Agency policies

4.1.4. Qatar National Cancer Registry QNCR to become the Official Cancer Statistics Authority for Qatar:

The QNCR defines, provides and publishes five national key statistical measures of cancer:

- Incidence,
- Mortality,
- Survival,
- Prevalence,
- Lifetime risk

The QNCR continuously monitors these cancer statistics to assess trends and to identify population subgroups and geographic areas in which cancer control efforts need to be concentrated.

The National Planning Council (NPC) has a statutory responsibility to assess whether the Code of Practice has been complied with in relation to any official statistics, subject to a request from an appropriate authority. If the Code has been complied with, it will designate the statistics as "National Statistics", Legislation ensures that the correct authority is given to the Registry and the MOPH is responsible for establishing and creating legislation and law.

QNCR will seek to develop International links for benchmarking purposes. It will provide required anonymized information for international cancer authorities including WHO International Agency for Research on Cancer (IARC) Gulf Health Council and others. .

There is a clear guidance to NPC to provide required demographic information to the MoPH enabling the Registry to meet the above objectives, including the provision of: Population data for Qatar with estimates against age, sex and national/non-national status.

National Planning Council in Qatar (NPC)) provides the population data.

The QNCR publishes data according to a regular timescale, regulated by the Cancer Information Governance Committee (CIGC) and National Cancer Governance Board (NCGB).

Cancer registration will conform to defined quality standards that give QNCR credibility and international standing.

In order for QNCR to be regarded as the official cancer statistics authority for Qatar, several criteria must be met and maintained:

- State of Qatar to maintain membership of International Agency for Research on Cancer (IARC).
- QNCR to become registered with International Association of Cancer Registries (as the official "IACR – voting" member for the State.
- QNCR to collaborate with the Gulf Health Council's Gulf Center for Disease Control – registry working groups. QNCR staff to attend regional and international conferences/events about cancer registration education and training on cancer registration by and for QNCR staff to take place.
- International collaboration on cancer research to take place, coordinated by QNCR.
- International collaboration on cancer registry publications to take place, coordinated by QNCR.

4.2. QNCR to provide official cancer statistics to National Planning Council in Qatar (NPC).

4.3. Governance Structure:

4.3.1. The QNCR is governed by the Cancer Information Governance Committee (CIGC), which reports to the National Cancer Governance Board to oversee all aspects of cancer care in the State of Qatar.

4.4. Minimum Data Set:

4.4.1. The QNCR shall publish its data dictionary and make it available to all cancer healthcare providers

4.4.2. The data dictionary contains the detailed information of the Minimum Data Set

4.4.3. The Minimum Data Set is classified in three:

- Required, and abbreviated as MDS-R: this list of data items shall be reported regardless of the cancer case or condition.

- Mandatory, and abbreviated as MDS-M: this list of data items become mandatory only if applicable, ex: treatment data are mandatory for reporting only if the case receives treatment.
- Optional, and abbreviated as MDS-O: this list of data items is open for reporting following the availability at the reporting organization.

4.5. Data Users:

4.5.1. All healthcare providers dealing with cancer care shall nominate at least one Data user / cancer registrar.

4.5.2. The data user /cancer registrar name and contact information shall be sent to the QNCR

4.5.3. The QNCR will create a secured account for the data user /cancer registrar on the Qatar Cancer Information Center to notify cases.

4.5.4. Upon request the QNCR shall provide necessary training to the data user/ cancer registrar related to cancer registration, use of the online cancer data notification system and applicable policies and procedures

4.5.5. All healthcare providers have a duty to inform the QNCR team of any changes to data access of data users.

4.6. Notification Criteria:

4.6.1. All cancer cases having the following conditions are eligible and mandatory for registration at the QNCR:

- Malignant Histologies (In Situ and Invasive).
- Benign, Non-Malignant Histologies, and Borderline of the intracranial and central nervous system (CNS).
- Diagnosis Prior to Birth: Diagnoses made in utero are reportable only when the pregnancy results in a live birth.
- Cases Diagnosed clinically: In the absence of a histologic or cytologic confirmation of a reportable cancer, accession a case based on the clinical diagnosis (when a recognized medical practitioner says the patient has a cancer or carcinoma). A clinical diagnosis may be recorded in the final diagnosis on the face sheet or other parts of the medical record.

Note: A pathology report normally takes precedence over a clinical diagnosis. If the patient has a negative biopsy, the case would not be reported.

4.6.2. **Cancer Screening Notification Criteria:** All cases receiving cancer screening services shall be registered in the QCIC.

4.7. Notification Timeline:

4.7.1. Any notifiable cancer case shall be registered at the QNCR within the first 6 months following the date of diagnosis, if the case is diagnosed in the State of Qatar. For cases of earlier diagnosis in other countries, prior to travelling to Qatar, then the case shall be registered within the first 3 months after knowledge of the cancer case.

4.8. Notification Method:

4.8.1. Any notifiable cancer case shall be entered onto the QNCR provided by the Ministry and dedicated to this purpose. The Ministry may provide paper form of the notification; this is not formal and is used only to help healthcare providers to understand the data items for proper notification.

5. Related Documents

5.1. National Data Classification Policy – National Cyber Security Agency (NCSA)

5.2. Government Website and e-Services Framework – Ministry of Communication and Information Technology

5.3. Data Use Policy – National eHealth, MOPH

5.4. Data Security & Audit Policy – National eHealth, MOPH

5.5. Information Privacy and Security Agreement – Information Systems, MOPH

5.6. Cancer Data Sharing Agreement – Cancer National Program, MOPH

5.7. Cancer Data Security Policy – Cancer National Program, MOPH