



QCIC Data Request Procedure

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Approval:

MINISTRY OF PUBLIC HEALTH
**PLANNING & QUALITY
DEPARTMENT**

Revision History

| Revision No. | Reviewed by | Approved by | Effective Date | Remarks |
|--------------|--|--|----------------|-----------------|
| 00 | Amid Abu Hmaidan Division Head  | Dr. Salih Ali Al-Marri Director  | 24 SEP 2020 | Initial release |

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1. Purpose

- 1.1. This process aims to facilitate the process of cancer data requests from Qatar Cancer Information Center QCIC.

2. Scope

- 2.1. This procedure is applicable to all institutions, associations, agencies and individuals requesting cancer data from the QCIC.

3. Definition(s)

- 3.1. **Primary Site:** refers to the main organ of the origin of the cancer.
- 3.2. **QCIC:** Qatar Cancer Information Center
- 3.3. **CIGB:** Cancer Information Governance Board
- 3.4. **QNCR:** Qatar National Cancer Registry
- 3.5. **Data Request Form:** represents the form to be completed at the time of request of data.

4. Resources

- 4.1. Communication tools such as computer, fax, printer, telephone, etc.

5. List of Job Titles

- 5.1. Data Requester.
- 5.2. CIGB Admin Officer.
- 5.3. QNCR Manager.
- 5.4. QCIC Biostatistician.
- 5.5. CIGB Ad-Hoc Head.

6. Description of Activities

- 6.1. Data Requester completes the Data Request Form (QF-NC-0201), signs and submits it as soft copy to the CIGB Admin Officer.
- 6.2. In case of the purpose of the data request was research, then the following documents shall be submitted:
 - 6.2.1. IRB Approval Letter.
 - 6.2.2. Study synopsis.
- 6.3. CIGB Admin Officer reviews the request to check on completeness and clarity of information requested, then adds it to the Data Request Master File (QF-NC-0202) and generate the data request number, then sends it to the QNCR Manager.
- 6.4. QNCR Manager carefully assigns the appropriate Review Status, following the below criteria:

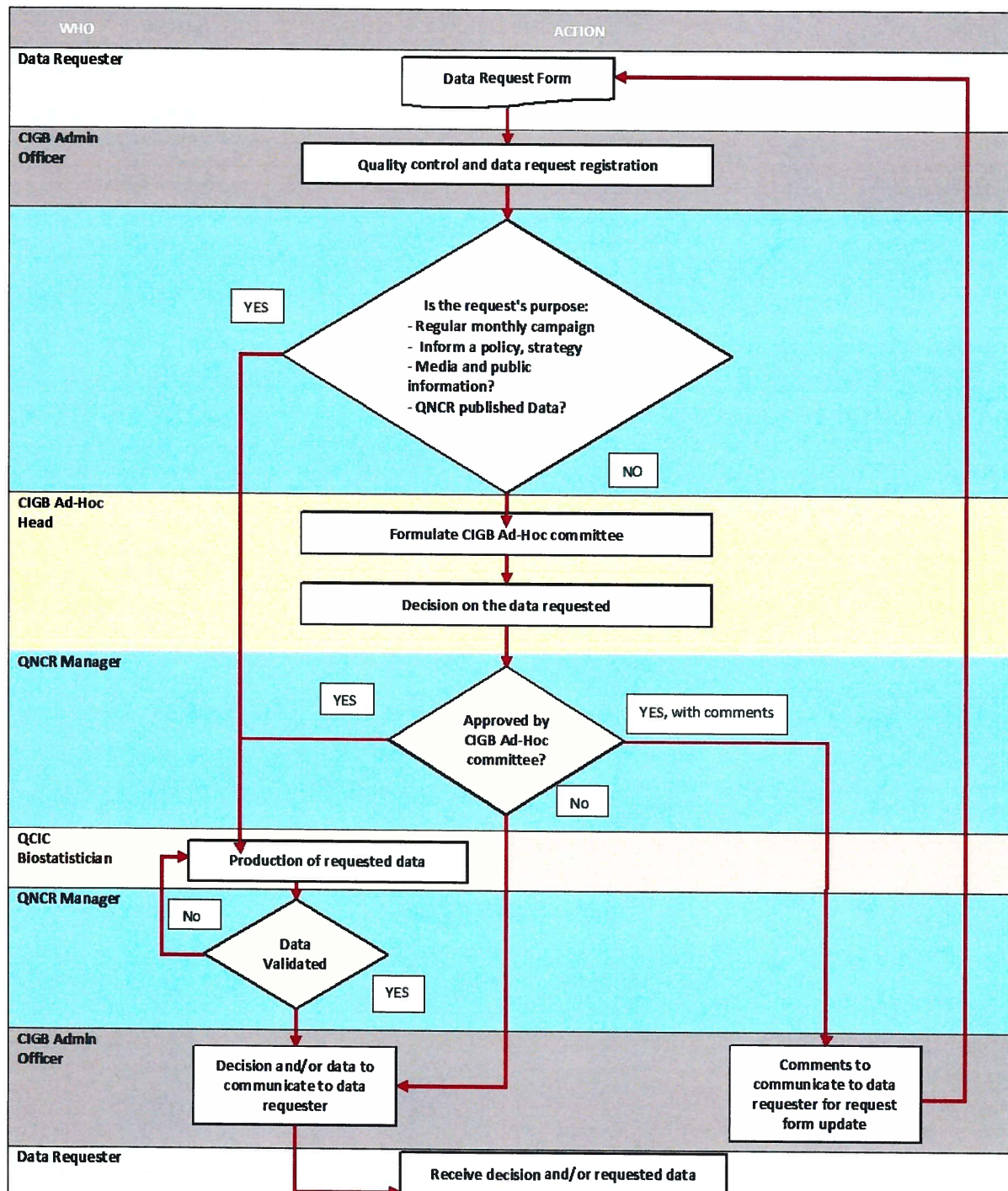
1. Review by QNCR Manager, based on:
 - 1) If the purpose of the request is one of the following:
 - Regular monthly campaign, according to the approved cancer campaign agenda
 - Inform a policy, strategy, or any other similar documents
 - Media and public information
 - 2) Requested data is already included in one of the QNCR published reports
- 6.5. Review by CIGB Ad-Hoc Head for any other condition
- 6.6. Depending on the scientific nature of the requested data, the CIGB Ad-Hoc Head will choose two members from the CIGB to review.
- 6.7. Final decision from the CIGB Ad-Hoc Head shall be sent back to the QNCR manager within three working days.
- 6.8. Decision on the data request shall be given to the Data Requester within 5 working days after assigning a Review Status. The decision can be one of the following options:
 1. **Approved:**
 - The request shall be referred to the QCIC biostatistician via the QNCR Manager to process the data within five working days the reception of the request from the QNCR Manager
 - The QCIC biostatistician will send the data back to the QNCR Manager for validation
 2. **Approved with comments:** comments shall be sent to the CIGB Admin officer who will communicate and follow up on that with the data requester
 3. **Rejected:** justifications shall be provided and sent back to the CIGB Admin Officer
- 6.9. Decisions, comments, and/or data will be sent to the CIGB Admin officer to communicate it to the data requester
- 6.10. Any request with the following criteria will be rejected:
 1. Request of providing all registry data, whether for one year of diagnosis, group of years or all years.
 2. Request of providing all registry data over a given primary site, whether for one year of diagnosis, group of years or all years.
 3. Data containing one or all of Personal Health Information PHI, as stated in the Qatar National eHealth Policies - Person Identity Management Policy.

7. Records

- 7.1. Data Request Form (QF-NC-0201).
- 7.2. Data Request Master File (QF-NC-0202).

8. Appendices

8.1. Data Request Process Map



| Data Requester | CIGB Admin Officer | QNCR Manager | QCIC Biostatistician | CIGB Ad-Hoc Head |
|--|--|---|--|--|
| 5 Working Days | | | | |
| <ul style="list-style-type: none"> • Completes, signs and submits a soft copy • Update request, if recommended by the CIGB Admin Officer | <ul style="list-style-type: none"> • Reviews the quality of the form • Adds it to the Master File and generate a number • Sends it to the QNCR Manager • Receives final decision from the QNCR Manager and sends it back to the Data Requester | <ul style="list-style-type: none"> • Assigns Review Status • If to be reviewed by the QNCR Manager, then sends to the QCIC Biostatistician • Or, sends it to the CIGB Ad-Hoc Head • Reviews and validates data after QCIC Biostatistician • Sends final result to the CIGB Admin Officer | <ul style="list-style-type: none"> • Receives the request from the QNCR Manager • Produces necessary data/Information • Sends back to the QNCR Manager for validation | <ul style="list-style-type: none"> • Receives request from QNCR Manager • Establishes the Ad-hoc • Makes a decision and sends it back to the QNCR Manager |

9. Process Indicators

- 9.1. Delay between the time of the request and the time data provided.
- 9.2. The period of time for processing a data request.

10. Related Documents

- 10.1. IRB Approval Letter.
- 10.2. Study synopsis.
- 10.3. Qatar National eHealth Policies - Person Identity Management Policy.

For Data Requester Use – 1st Page only

Dear Data Requester,

Your request for data will receive our immediate attention. Our policy mandates delivery of data within **5 working days** after the full application, except in the case of request of data for research purposes, when review might take longer time. Data Request Form to be sent to gncr@moph.gov.qa

Please note that the criteria of the requested data must relate to the purpose, and further justifications might be requested if the details are unclear.

A - Requested data

| | | | | | |
|--------------------------|---|-----------------------------|--|---|--|
| Organ/Cancer Site | | Year(s) of diagnosis | | Form of Data | <input type="checkbox"/> Raw data <input type="checkbox"/> Charts |
| Stratification | <input type="checkbox"/> Age groups (5-year) <input type="checkbox"/> Nationality (Q-N/Q) <input type="checkbox"/> Gender | More details | | <input type="checkbox"/> Stage (cTNM) <input type="checkbox"/> Histology (ICD-O) <input type="checkbox"/> Treatment Modality | |
| Incidence Data | <input type="checkbox"/> Crude Incidence Rate <input type="checkbox"/> Age Standardized Rate ASR <input type="checkbox"/> Age Standardized Incidence Rate ASIR <input type="checkbox"/> Cumulative Mortality Risk (0-74) <input type="checkbox"/> Top 10 <input type="checkbox"/> Distribution by Age <input type="checkbox"/> Distribution by Nationality (Q/NQ) | Mortality Data | | <input type="checkbox"/> Crude Mortality Rate <input type="checkbox"/> Age Standardized Mortality Rate ASMR <input type="checkbox"/> Cumulative Mortality Risk (0-74) <input type="checkbox"/> Top 10 <input type="checkbox"/> Distribution by Age <input type="checkbox"/> Distribution by Nationality (Q/NQ) | |
| Other information | | | | | |

B- Purpose of the Request

| | | | | | |
|--|--------------------------------|--|--|--|---|
| <input type="checkbox"/> Research, please provide: • IRB approval letter • Research Proposal | <input type="checkbox"/> Media | <input type="checkbox"/> Training-Education-Workshop | <input type="checkbox"/> Feasibility Study | <input type="checkbox"/> National Campaign | <input type="checkbox"/> Inform a policy or guideline |
| <input type="checkbox"/> Other, please specify: | | | | | |

C- Data Access and Use Agreement

You must agree to the terms of use as set out below in order to receive data from the Qatar Cancer Information Center QCIC.

Any of the data supplied to you may be freely used, but remains the property of the Ministry of Public Health-QCIC. To protect the QCIC against misuse of the data, all users must agree to the following conditions:

- The Qatar Cancer Information Center QCIC is to be clearly acknowledged as the source of the data
- The QCIC is to be sent a draft copy, prior to submission to any peer reviewed journal, of any paper based on QCIC data.
- The QCIC may refuse permission for the use of the data in this way if this would not be in the interests of the QCIC.
- No presentation of the data which could potentially identify any individual patient, doctor or health care institution is to be made without the permission of the QCIC and of the person or institution concerned.
- Data released shall be only used for the purpose mentioned in this form.
- Any direct contact with the patients to collect additional or updated information is prohibited, unless it was explicitly approved by IRB.

I have read and understood the above rules and I agree to accept the responsibility for the Terms and Conditions of the released data.

| | | | |
|------------------|--|--------------------|--|
| Name | | Institution | |
| Position | | Email | |
| Signature | | Date | |

| For QCIC Use only | | | |
|-------------------------------|--|-----------------------|--|
| D - QCIC Admin Officer | | | |
| Date Received | | Request Number | |
| Date Returned | | | |
| E - QNCR Manager | | | |
| Date Received: | | Date Answered: | |
| Review Status: | <input type="checkbox"/> QNCR Manager <input type="checkbox"/> CIGB Ad-Hoc Head <input type="checkbox"/> Sent for further clarification | | |
| Final Decision | <input type="checkbox"/> Approved <input type="checkbox"/> Approved with comments: <input type="checkbox"/> Rejected, reason: <input type="checkbox"/> Request of providing all registry data, whether for one year of diagnosis, group of years or all years <input type="checkbox"/> Request of providing all registry data over a given primary site, whether for one year of diagnosis, group of years or all years <input type="checkbox"/> Other: | | |
| Signature | | Date | |
| F - CIGB Ad-Hoc Head | | | |
| Date Received: | | Date Answered: | |
| Ad hoc Members Names | 1. | 2. | |
| Final Decision | <input type="checkbox"/> Approved <input type="checkbox"/> Approved with comments: <input type="checkbox"/> Rejected, reason: <input type="checkbox"/> Request of providing all registry data, whether for one year of diagnosis, group of years or all years <input type="checkbox"/> Request of providing all registry data over a given primary site, whether for one year of diagnosis, group of years or all years <input type="checkbox"/> Other: | | |
| Signature | | Date | |

