

Guide for Data Request from the National Cancer Registry

Introduction

Overview of the National Cancer Registry

The National Cancer Registry publishes an island-wide surveillance report on cancer incidence and cancer mortality. It is the only existing data source on cancer incidence and mortality together for the entire country. It is a rich data source on cancer morbidity and mortality in the country and it has been published regularly since 1985 by the National Cancer Control Programme, Ministry of Health.

Purpose of the Guide

This guide gives information on data availability at the National Cancer Registry, the method of data collection, procedures to follow in obtaining cancer registry data, terms and regulations on using cancer registry data, and ethical and administrative considerations in obtaining and using cancer registry data.

Understanding the National Cancer Registry

Cancer surveillance (Cancer registration) is a systematic, continuous collection, storage, analysis, interpretation, and dissemination of epidemiological information on cancers occurring in a country or a specific geographic area.

Data on patients, newly diagnosed or registered for treatment, are collected at pathology laboratories, cancer treatment centres, and Oral and Maxillo Facial (OMF) units. Data on newly diagnosed cancers from pathology labs are recorded in 'Cancer Return Form - 1' (H-1290) as a hard copy or a soft copy of Microsoft Excel sheet. Those are sent to the central level for coding according to the International Classification of Diseases for Oncology – 3rd Edition (ICD-O3) and uploaded to CanReg5 software. Data on patients registered at cancer treatment centres or OMF units are extracted using the National Cancer Surveillance Form – H 1256' and entered into CanReg5 software by a trained designated officer. Data are transferred to the central level as an Excel file for quality checking and uploading to CanReg5 software via 'Rupantharan' software. Identification and removal of duplicates and quality checking are done using software and manual methods before proper data analysis.

In addition, the Registrar Generals' Department and the Department of Census and Statistics actively contribute to cancer mortality data.

The information generated from cancer registration is essential for the planning, implementation, monitoring and evaluation of cancer control activities in the country. And it is a rich database available to be used by any interested parties within the limits of ethical and legal boundaries.

Accessing National Cancer Registry Data

Eligibility Criteria for Data Seekers

Any Research Institution, Government Agency, Healthcare Organization/ Institution, or interested researcher can request data from the National Cancer Registry through NCCP.

Researchers who are not experienced in human research must have a supervisor who is experienced in human research to request data.

Registration and Approval Process

Application for data should be submitted to the NCCP (as a hard copy or an email with attachments) with the required documents as indicated in the Data Request Form.

Such applications and documents will be reviewed by a committee appointed by the Technical Advisory Committee for the Cancer Registry. The committee's decision on the request will be informed within one month.

Applicant should sign a Memorandum of Understanding (MOU) with NCCP regarding data sharing and data usage.

Following the signing of the MOU, NCCP will provide the applicant with the requested data as approved by the committee mentioned above.

Data Use Agreements and Compliance

Data users should adhere to the data protection measures described in the book 'Guidelines on Confidentiality for Population-based Cancer Registration' published by the International Agency for Research on Cancer (IARC).

https://encr.eu/sites/default/files/pdf/ENCR_Eurocouse_GuidelinesConfidentialityEthics.pdf

Data users should comply with the legal framework of the country and adhere to all ethical principles and conducts in handling personal data.

The data requesting party is responsible for ensuring adherence to legal frameworks and ethical conduct regarding human studies.

Data Retrieval and Customization

Cumulative data on the following variables is freely available as cancer registries at the NCCP website and can be accessed through link <https://www.nccp.health.gov.lk/en/incidenceData>

- Cumulative number of cancers with breakdown for.
 - Age
 - Sex
 - Cancer site
 - Morphology
- Crude Incidence Rates of Cancers for different Sites
- Age Standardized Rates of Cancers for different Sites
- District distribution of cancer incidence for different sites

Individual-level data is available for the following variables and a formal data request must be submitted to obtain individual-level data. Anonymized data will be provided with these variables on the approval of the request by the evaluation committee.

- Age
- Birthday
- Sex
- Resident District
- Resident Divisional Secretariate
- Resident Grama Niladhari (GN) Division
- Occupation
- Ethnicity
- Religion
- Marital status
- Family history of cancers
 - Relationship
 - Cancer site
- Cancer site (Topography)
- Histology (Morphology)
- Behaviour of cancer
- Differentiation/ Grade of cancer
- Laterality of cancer
- Basis of diagnosis
- Incidence date
- TNM status
- Clinical staging/ risk categorization (for haematological malignancies)
- Treatment given
- Date of completion of treatment
- Last date of contact
- Status as of last contact date
- If multiple primaries are present
 - Site
 - Histology
 - Date of diagnosis
- If recurrence is present
 - Site
 - Date

Data in the last five years from the latest published registry will be available on request. Additional data requests will be considered case by case and approved by the committee.

Personally identifiable data will not be provided under any circumstances

Feedback and Continuous Improvement

Data seekers are expected to submit immediate feedback on the receipt of data and biannual progress reports until the completion of the research. The final report or the publications based on data should be shared with NCCP. Acknowledgement of the data source as “National Cancer Programme, Ministry of Health” should be included in the publications.

