

Measures for Maintaining Confidentiality

Confidentiality is maintained as follows through the following measures:

- Asking the staff to sign a confidentiality pledge or declaration at the time of employment, which remains in force after the cessation of employment at the Hospital or Registry.
- Maintaining a list, with Security, of all employees authorized to enter the Registry.
- Not letting anyone in the office, the staff does not know.
- Escorting visitors back and forth to the door.
- Providing proof of identification to staff engaged in registration.
- Keeping the forms and folders locked in cabinets in the Cancer Registry and Clinical Data Management unit.
- Locking the office at the end of the day, depositing the key with Security, and maintaining a list of employees allowed to access the key.
- Allowing Registry staff to use a specific username (ID) and password to start the computer and another user-password-controlled log-on to access the Hospital Information System, thus, the Cancer Registry and Clinical Data Management software.
- Locking the computer by using CTL-ALT-DEL to bring up the Windows Security screen and clicking on the “Shut down” button when leaving the office.
- Picking up all the printouts about the Registry promptly.
- Refraining from discussing confidential data in the halls or from carrying it to break rooms or restrooms.
- Allowing only authorized individuals to examine the collated results.
- Separating tumor-related data from key personal identifiers such as name, ID, and address when reporting the results.
- Highlighting that if personally identifiable information needs to be reported, it is the responsibility of all professionals to ensure confidentiality.
- Enforcing the same confidentiality standards for data on deceased individuals as those on living individuals.
- Treating all data in the Registry as confidential, whether the data items are personal identifiers or not.
- Defining “data” as all information, documents, reports, and files.
- Avoiding the transmission of information over the telephone.
- Keeping all the data in the software and discarding paper-based forms after it is determined that they are no longer necessary.

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Release of Registry Data:

- Publishing yearly results (January 1–December 31) and the collated data for the entire period the Registry has existed.
- Obtaining written requests for the release of Registry data for research or healthcare planning.
- Ensuring that ethical aspects related to the release of information are taken care of.
- Refusing requests for information on identifiable data concerning individuals (who may or may not have a cancer recorded at the Registry) from agencies dealing with pension, healthcare cost reimbursement, industrial disease compensation panels, and life insurance, and directing the inquirer to obtain information directly from the subject or the subject's treating physician.
- Asking nominated professionals to manage inquiries from the press about the Registry.

Note:

- These measures also apply to preserving the confidentiality of patients with non-cancerous diseases, as the Registry is also a repository for such cases.
- Identifiable data may be provided to clinicians for use in the treatment of patients, but only the data necessary for the stated purpose will be released.

Reference:

Guidelines on Confidentiality for Population-Based Cancer Registration: International Association of Cancer Registries: IACR, Lyon, 2004: Internal Report No. 2004/03.

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Cancer Registry and Clinical Data Management Section

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