



# National Centre for Disease Informatics and Research

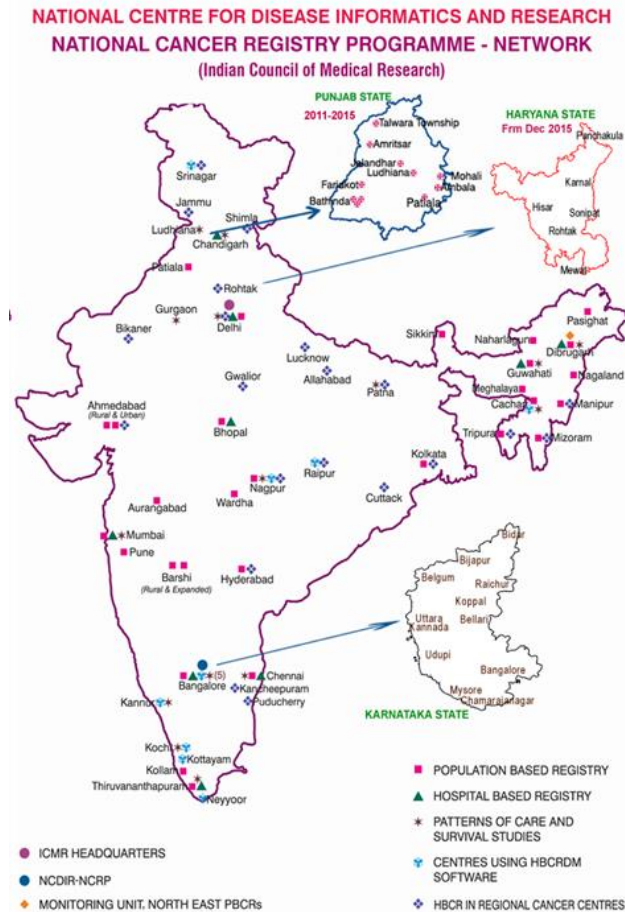
## National Cancer Registry Programme

(Indian Council of Medical Research)

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## Cancer Registration in India

### Guidelines for setting up of Population Based and Hospital Based Cancer Registries



For online Registration, Click here – [www.ncdirindia.org](http://www.ncdirindia.org)

# Cancer Registration

## Overview

Cancer registration is a process of continuing systematic collection of data on the occurrence and characteristics of reportable neoplasms. The cancer registry is central to any rational programme on cancer control. It is forerunner of studies in descriptive epidemiology of cancer, which in turn generates specific scientific hypotheses.

A cancer registry aims at:

- Systematic collection of Cancer data
- Storage
- Analysis & interpretation
- Periodic report publication and dissemination

## Types of cancer registries

- Population Based Cancer Registries (PBCRs)
- Hospital Based Cancer Registries (HBCRs).

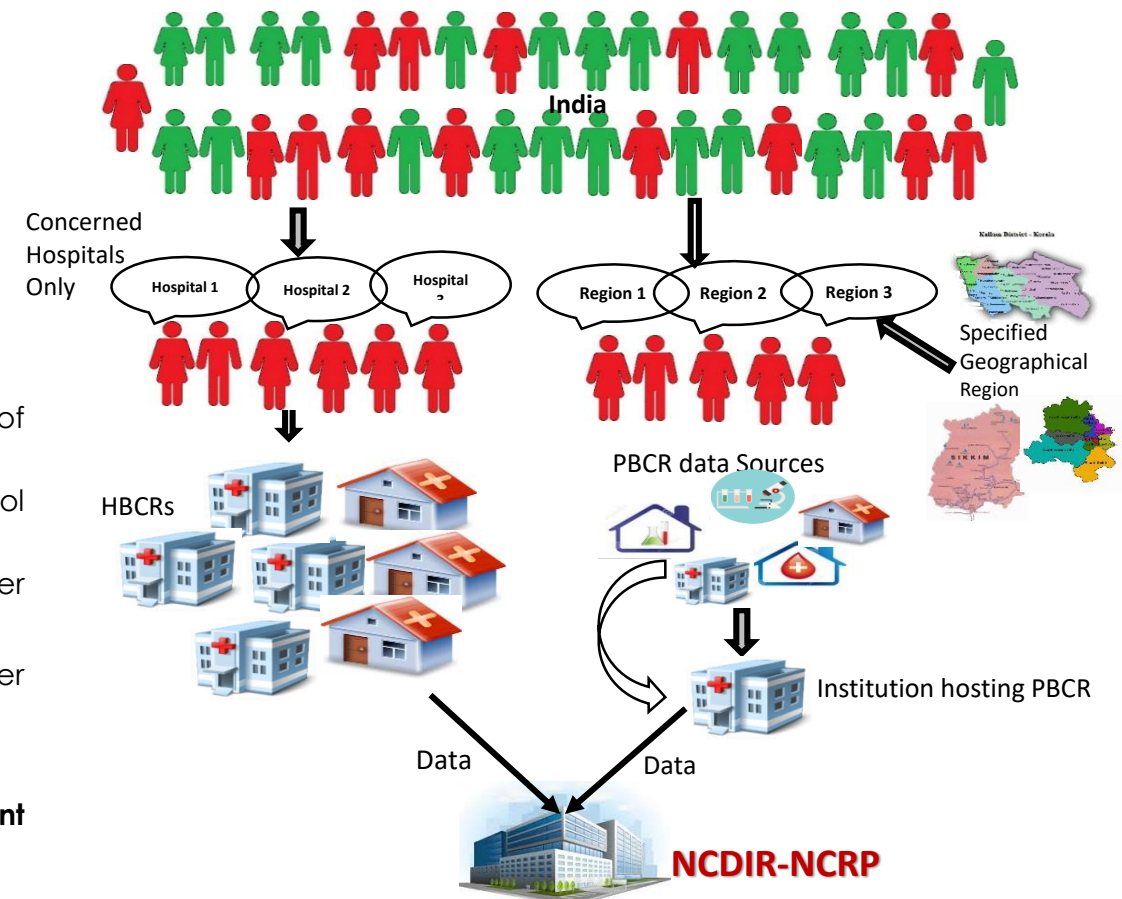
## Benefits of Cancer Registration

Cancer registration data can be used as:

- + Way of obtaining information on **burden and patterns** of cancer in developing countries.
- + **Monitoring and assessing** the effectiveness of cancer control activities.
- + HBCR focuses on research into **possible causes**, cancer prevention and control of cancer.
  - **Time trend studies** are possible from data on cancer registration
  - Data has great value for **International comparisons**
  - Cancer registry provides an **economical and efficient method** of ascertaining cancer occurrence

- **HBCR provides source of cases** for case-control and epidemiological studies, particularly useful in the conduct of case-control studies to investigate the carcinogenic effects
- Help assess quality of hospital care and cancer services in covered areas

## Cancer data Transmission by HBCRs and PBCRs



Cancer registration can provide the extent and nature of cancer burden in the community. Cancer Registration assists in establishment of public health priorities and management plans. The State Health authorities of the state where PBCR is located should be part of the coordination /advisory committee.

## PBCRs

PBCR collects data on all cases of cancer occurring in a well-defined population. The population is that which is resident in a particular geographical region for **one year or more**.

The main objectives of PBCRs are to:

- ✚ Produce statistics on the occurrence and outcome of cancer in a geographically defined population
- ✚ Provide frame work for assessing and controlling the impact of cancer in the community

## PBCRs & NCDIR-NCRP

- ✚ 32 PBCRs across the country
- ✚ PBCRs are corner stone of NCDIR-NCRP especially from public health point of view
- ✚ Source which provides authentic data on incidence and mortality of cancer in the country
- ✚ Provide an unbiased profile of the cancer burden in population and time trends from multiple sources.
- ✚ Provide a unique role in planning and evaluation of cancer control programmes

## Pre-requisites for Initiating Population Based Cancer Registries in Urban Agglomeration / Rural Setup

The key requirements for establishment of Population Based Cancer Registries in urban agglomeration or rural setup are

1. A **nodal officer** with knowledge of epidemiology and of **cancer epidemiology in particular** should be identified by

the head of Reporting Institution (RI) for carrying out activities of cancer registry.

2. The nodal officer should be able to give **dedicated time and effort** for commencing and sustaining the activity of cancer registration.
3. The institute as well as the nodal officer along with cancer registry team should have **good networking with sources of registration**
4. **Dedicated space** should be assigned in the RI for the staff to work in, for storing the core forms of cancer registration. The room should have adequate furniture, computer systems and other wherewithal to have a comfortable working environment.
5. An **advisory/coordination committee** should be constituted with members from all **major sources of registration**. The departments of the RI who have **major contribution** towards cancer cases should be part of this committee.
6. The cancer registry team along with nodal officer should **maintain full secrecy, confidentiality and follow good ethical practices** for the data collected. The team should maintain **professional conduct** as required when dealing with such confidential data.
7. If the hospital or RI has functioning **Hospital Management Information System (HMIS)**, efforts should be made to incorporate the cancer registry core form into the system for ease of data collection

## List of Activities for commencement of Population Based Cancer Registries (PBCRs)

1. **Area and population covered** and brief geography of the place, its population (as per 2011 census) number of

districts etc. A map of the region / state / districts should be available.

2. List of major sources of registration of cancer cases and details thereof, should be readily available. Over and above:

- + Name the source which will be the **Reporting Institution** (RI) and approximate proportion of cancers in registry area that are likely to be registered here. Advantages in completing core items of information in each of these sources should be explained to key person.

- + **Methods to be adopted for collection of information from major sources**

- + Whether **direct interview with patient/relative is possible** and if so in what proportion

- + Sources of registration that have no objection for registry staff to visit and collect information, but have **incomplete information** (like Incomplete or No residential address or duration of stay or no details of primary site of cancer)

- + The **time interval** between the diagnosis of cancer and completing the items of core information

- + Whether centre(s) could refuse to provide information on cancer, and if so the number and estimated number of cancers reported per year in each of such center(s); **provide list of Institutions/ Clinicians who are likely to refuse or are not likely to cooperate** with the PBCR

- + List all sources that have **facility for radiotherapy** and/or other cancer treatment and estimated number of cancer cases registered per year in each such centre

3. **When patient /relative/contact is not interviewed** -Methods that could be adopted to get complete information on permanent address and other identifying details like name of father, mother etc.
4. Whether **periodic meetings of the hospitals, pathologists, oncologists, clinicians in the registry area** can be convened and their co-operation elicited. Whether constitution of Core Committee/ Advisory Committee is possible.
5. The **rural hinterland covered under PBCR area** (depending on administrative constitution of the district) should be taken into account.

### Mortality Data Collection

1. Detailed account of the **System of Registration of Death** in the area to be covered by the registry;
2. Account of the **Certification of Cause of Death** given by medical institutions/physicians in the registry area with case ascertainment methods.
3. **Sources of Mortality Data Collection**- Corporation or 'Other' Units, Hospitals, Crematoria / Burial Ground, Statistical Department etc. and their possible cooperation

Cancer registration by PBCRs is a long term activity which carries on for several decades, because limited information can be abstracted on cancer with short term information (scientific or otherwise).

## HBCRs

HBCRs are concerned with the recording of information on the cancer patients seen in a particular hospital.

Data are mainly used for

- + administrative purpose and for reviewing the clinical performance
- + epidemiological purpose to a limited extent

Statistics on occurrence of cancer cannot be measured since it is an undefined catchment population.

### HBCRs & NCDIR-NCRP

- + More than 100 HBCRs across the country
- + Major concern is over recording of information on the cancer patients in a hospital set-up
- + Data collection in standardized common core form for all registries

Core form consists of mainly

- Patient identifying and demographic information
- Details of diagnosis
- Clinical stage of disease
- Broad type of treatment

Purpose of HBCRs is to contribute to patient care by providing readily accessible information on the subjects with cancer, the treatment they received and its result.

## Objectives of HBCRs are:

### General

1. Assess patient care
2. Participate in Clinical Research
3. Provide profile of the patterns of cancer in the area and their description

### Specific

1. Contribute to **active follow-up** of the cancer patient
2. Describe **length and quality of survival** in relation to anatomical sites, clinical stage and treatment
3. **Contribute to the PBCRs** in a given area.
4. Undertake epidemiological research through short term case control studies.
5. Show time trends in proportion of early to late stages at the time of diagnoses

## Pre-requisites for initiating Hospital Based Cancer Registry

1. The **clinician- nodal officer (later may be Principal Investigator-PI)** who is interested in research with knowledge of cancer registration should initiate the process via head of the institution.
2. The nodal officer should conduct a **sensitization meeting** to start the cancer registry process in the institute.
3. The nodal officer should get **cooperation from all the departments** in which cancer patients being diagnosed/ treated in the institution
4. A dedicated staff and **exclusive space** for functioning of registry.
5. The computer with good internet connectivity

6. The patient identifying information should be gathered **at the registration desk itself**
7. Make sure that the pathologist should mention clearly about the primary site of cancer with ICD codes for topography as well as morphology and TNM stage
8. Purchase of the International Classification of Disease for Oncology, TNM books for registry

### List of Activities for commencement of Hospital Based Cancer Registries (HBCRs)

1. The hospital should be a cancer hospital/ tertiary care centre/general hospital **with oncology unit**
2. The Director / Head of the Institution has to give a decision regarding **suitable Principal Investigator(PI)** and Co-PIs for this project
3. The prospective HBCR has to complete Registration form which is available on website [www.ncdirindia.org](http://www.ncdirindia.org)
4. An **agreement** (MoU) between collaborative hospital and NCDIR would then be finalized.
5. After receiving registration form and MoU, NCDIR would **provide credentials** to access and transmit data using online HBCRDM software free of cost
6. Materials such as **hardcopy core form, procedure manual** will be provided by NCDIR
7. Systematic continuous collation of all malignant neoplasms that are registered in the hospital
8. An inter-departmental meeting should be held at periodic intervals as collection of cases from all the departments in the hospital, hence inter department co-operation is essential.
9. The primary departments concerned (as shown in figure) are:

- a. Oncology Departments (Surgical, Radiation, Medical oncology, etc.,)
  - b. Non-Oncology Departments (Paediatrics, General Surgery, Medicine, etc.,)
10. **Dedicated staff** for visiting departments and collection of data along with computer and internet connectivity to transmit the data

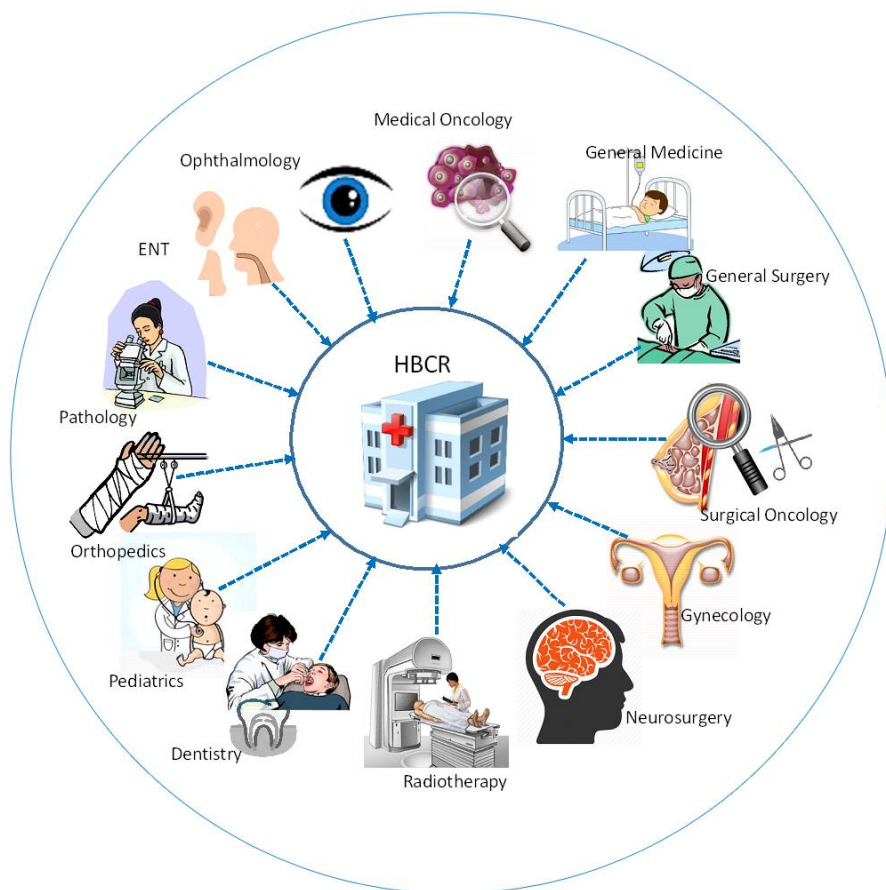
- + The registry will register cases of cancer in residents treated outside the area.
- + A de-duplication software at NCDIR would avoid registering the same case twice (which implies personal information including names).
- + Training of staff of PBCR/HBCR is undertaken periodically by NCDIR keeping them updated with software entries, cancer terminologies and coding as per the international classification of diseases.

Hospital administrative authorities should provide the following baseline books for coding and cancer staging (may be kept in hospital library)

International Classification of Diseases for Oncology - Third Edition (ICD-O-3)

Relevant books providing information on Clinical extent and staging of cancer i.e. TNM

## Inter-departmental cooperation required for HBCR



## Financing for Registries and Estimates

The costs of cancer registration depend on the size and population of the registration area, the number and type of different data sources, the number of data items collected (more or less standard), and the data collection methods. These will determine the number of staff required and the costs incurred in data collection, which will be major budget items. NCDIR –NCRP as an ICMR institute involved in Cancer Registration activities would provide technical support in the form of provision of software and subsequent maintenance for seamless transmission of data to central repository i.e. NCDIR. It may be noted that there are no financial assistance provisions available with ICMR –NCDIR for the activity undertaken.

The estimate can be relative according to the resources available within the hosting institution, physical and political environment of the registration area. Eg: North eastern states and rest of India. On an average the number of social investigators employed by the registry varies depending on the population. Other staff i.e. Data Entry operator and statistician are employed as singular staff.

The aim is to aggregate cost for each registry activity based on staff salaries, consultancies, infrastructure, travel, and training. The cost per case can then be calculated for core and advanced activities, and factors that affect cost can be further explored. The elements that need to be considered when planning the budget for a cancer registry are shown in Box. When planning a longer-term budget, it should be considered that the costs of the cancer registration process may increase over time as the registry expands its range of activities (e.g. to include follow-up of registered cases).

### **1. Capital costs (Non-recurring)**

- Office space and equipment/furnishings
- IT equipment (computers, printers, Internet link, etc.)

### **2. Recurring costs**

- Salaries
- Direct: registry staff (full-time or part-time)
- Indirect: allowances for part-time/contract work
- Contingencies
- Overhead charges
- Travel expenses (in particular for active data collection)
- Maintenance (including postage, internet charges, etc.)
- Consumables (office material)
- Publishing reports and/or establishing and maintaining the registry website

### **3. Training/workshops**

- To involve the sources of registration.

### **Disclaimer**

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