
Introduction

The Indian Council of Medical Research initiated a network of cancer registries across the country under the National Cancer Registry Programme (NCRP) in December 1981. This move followed the recognition that there was an urgent need for strengthening the existing cancer registries and organization of new cancer registries in different regions of the country.

The programme was commenced with the following objectives:

1. To generate reliable data on the magnitude and patterns of cancer – this would be based on morbidity and mortality rates including incidence rates according to gender, age and residence of the patient, anatomical site of cancer and proportion of histological type or microscopic confirmation for each site; pattern of different types of cancer according to relative proportions or ratios in various population sub-groups such as religion, language spoken, educational status; clinical stage of disease when patients come to hospital for treatment and where possible the nature of treatment received and outcome;
2. To undertake epidemiologic studies in the form of case control or cohort studies based on observations of registry data;
3. Provide research base for developing appropriate strategies to aid in National Cancer Control Programme; this would be in the form of planning, monitoring and evaluation of activities under this programme;
4. Develop human resource in cancer registration and epidemiology.

Objectives of NCRP:

- Generate reliable data on magnitude and patterns of cancer
- Undertake epidemiologic studies
- Aid in Cancer Control Programmes
- Develop human resource in cancer registration and epidemiology.

Founder Members of NCRP:

- Dr. Usha K. Luthra
- Dr. L.D. Sanghvi

Cancer Registration is Active:

Cancer Registration in India is active in that staff of registries visit hospitals/pathology laboratories to collect information on cancer cases.

Completeness of Coverage:

Efforts made to ensure completeness of data collection on all cancer cases in geographic area.

Data collection commenced from 1 January 1982 in the Population Based Cancer Registries (PBCRs) at Bangalore, Chennai and Mumbai, and also in the Hospital Based Cancer Registries (HBCRs) at Chandigarh, Dibrugarh and Thiruvananthapuram. From 1986 two more urban population based cancer registries were started in Delhi and Bhopal. For the first time a population based rural cancer registry was also started by the ICMR during the subsequent year (1987) in Barshi in the state of Maharashtra. In order to extend the assessment of cancer patient care, HBCRs were also started at Bangalore, Chennai and Mumbai in 1984.

The NCRP is a long-term activity of the Indian Council of Medical Research. The programme is one of the many major activities of the Division of Non-Communicable Diseases. The Chief of the Division is the Director of the Programme with a Project Officer who coordinates the activities through the Coordinating Unit. Dr Usha K. Luthra who was the then Chief of the Division and Dr L.D. Sanghvi who was the first Project Officer were the founder members. The Programme is assisted by a Steering Committee that meets periodically to oversee and guide its functioning. A review meeting is held annually where the Principal Investigators and staff of the registries, under the NCRP, present data and participate in the discussions.

Cancer registration is active in that staff of registries visit hospitals on a routine basis and scrutinise the records in various departments that include pathology, radiology, radiotherapy, in-patient wards and out-patient clinics to elicit the desired information on reported cancer cases. The hospitals include the main cancer hospitals and other general hospitals in both the government and private sector. Besides pathology laboratories that periodically report cancer cases are also visited. Death certificates are also verified from the municipal corporation units. Every attempt is made by registries to register all cancer patients in the registration area who are resident (at least one year) in the area in all hospitals and copy all death certificates in which cancer is mentioned.

Cancer registries collect information on cancers reported in a prescribed format with specified guidelines and the data so collected is entered on a computer. All registries are required to register all malignant neoplasms coded as per the International Classification of Diseases for Oncology (ICD-O) with a behaviour code /3 (WHO, 1975,76). Besides identifying information and duration of stay at the permanent place of residence they also collect information on educational status, religion, language spoken, method of arriving at a final diagnosis of cancer, extent of disease at the time of diagnosis and mode of treatment(s) given up to six months of diagnosis.

Certain basic checks of data especially those related to duplicate verification and matching with mortality records are carried out by the individual registries. After this, the data is sent to the Coordinating Unit for subjecting the data to various range, consistency and unlikely combinations including a further round of possible duplicate listing. The list of cases with the items of patient information, that require verification are sent back to the respective registries. Individual registries go through the records/reports of such cases and wherever necessary discuss with the concerned clinician or the pathologist. On receiving the clarifications the Coordinating Unit prepares the detailed tabulations by five-year age group, site and sex including rates. The individual registries use these tables to prepare the registry's annual report. The Coordinating Unit collates the data and tables to prepare the consolidated report of that year.

A workshop is held annually, with the objectives of discussing the various aspects of working of the registry, problematic cases, use of coding and discussion on medical terminology, statistical and epidemiologic methods. About 2-3 senior and junior staff of all the registries under the NCRP, participate in the workshop.

Coding:

Coding of Malignant Neoplasms done according to the International Classification of Diseases for Oncology.

Meeting and Workshop:

Review Meeting and Workshop held annually.