

# POPULATION BASED CANCER REGISTRY, PASIGHAT

## General Hospital, Pasighat

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### **Arunachal Pradesh**

Arunachal Pradesh is located in the far northeast of India with 83,743 sq. kms in area. It borders the states of Assam and Nagaland to the south and shares international borders with Myanmar in the east (440 km), Bhutan in the west (160 km) and the People's Republic of China in the north (1,080 km). It is situated between latitude 26°30' N and 29°30' N and longitude 91°30' E and 97°30' E. Itanagar is the capital of the state. Most of the people native to and/or living in Arunachal Pradesh are of Tibeto-Burman origin.

It has mostly mountainous terrain with sparse population of 13,82,611 (7,20,232 were male & 6,62,379 were female) with the density of 17 persons per sq. km. and literacy rate of 66.95 as per 2011 census. The state is politically divided into 16 districts. The state is culturally and linguistically varied with over 26 major tribes and 120 Sub tribes and speaking over 100 dialects. The food habits and social system also varies from tribe to tribe.

### **Food Habits in Arunachal Pradesh**

The staple diet in Arunachal Pradesh comprise of rice, meat, green leafy vegetables, rice beer etc.

*Drinks:* Rice Beer (Apong) prepared from Rice and burnt out ash of Paddy husk is the most common drink in the district. Rice Beer (Apong) is used in many social occasion such as local festival, social gathering, marriage ceremony and even in social interaction. Nowadays foreign liquors are also used abundantly.

*Meat:* The forest cover of Arunachal Pradesh is vast and hence birds and wild animals are also found in abundance. They hunt these animals in jungle especially the squirrels and rats. They are hunted and kept for many years after smoking in the fire place. They use them as bride price in some of the tribes like Adi, Padam, Pasi etc. The Mithun is the precious domestic animal which is used for bride price in some tribes and they are sacrificed during festivals and social gatherings. The meat is preserved for many years by smoking in the fire place.

### **Registry Area**

East PBCR in Arunachal Pradesh covers whole of six districts namely East Siang, Upper Siang, Changlang, Lohit, Lower Dibang Valley and Tirap. These six districts cover an area of 26731 sq. km. with average population density of 26 per sq. km.

| District            | Male          | Female        | Total         |
|---------------------|---------------|---------------|---------------|
| Changlang           | 77289         | 70662         | 147951        |
| East Siang          | 50467         | 48552         | 99019         |
| Lohit               | 76544         | 68994         | 145538        |
| Lower Dibang Valley | 28127         | 25859         | 53986         |
| Tirap               | 57992         | 54005         | 111997        |
| Upper Siang         | 18657         | 16632         | 35289         |
| <b>Total</b>        | <b>309076</b> | <b>284704</b> | <b>593780</b> |

### Sources of Registration of Incident Cases of Cancer in Arunachal Pradesh - 2011

| EAST SIANG                          | UPPER SIANG                 | LOHIT                           | LOWER DIBANG VALLEY                |
|-------------------------------------|-----------------------------|---------------------------------|------------------------------------|
| General Hospital Pasighat           | District Hospital Yingkiong | District Hospital tezu          | District Hospital Roing            |
| Assa Nursing Home                   | Mariyang PHC                | Namsai CHC                      | Parbuk CHC                         |
| Doctor's Diagnostic Centre Pasighat | Geku CHC                    | Hayuliang PHC                   | Dambuk CHC                         |
| Pane Clinic                         | Katan PHC                   | Chowkam PHC                     | Hunli PHC                          |
| Other Clinic in Pasighat            | Jengging PHC                | Sunpura PHC                     | Desali PHC                         |
| Boleng CHC                          | Tuting PHC                  | Lekang PHC                      | Koronu PHC                         |
| Ruksin CHC                          |                             | Wakro PHC                       | Anpum PHC                          |
| Bilat PHC                           |                             | Piyong PHC                      | Bolung PHC                         |
| Koyu PHC                            |                             | Lathau PHC                      | Management diagnostic centre Roing |
| Nari PHC                            |                             |                                 |                                    |
| Riga PHC                            |                             |                                 |                                    |
| Pangin CHC                          |                             |                                 |                                    |
| Mebo PHC                            |                             |                                 |                                    |
| Sille PHC                           |                             |                                 |                                    |
| CHANGLANG                           | TIRAP                       | REFERRING CENTRE                |                                    |
| District Hospital Changlang         | District Hospital Konsa     | Dibrugarh AMC                   |                                    |
| Mehao CHC                           | Longding CHC                | Dr. B. Borooah Cancer Institute |                                    |
| Kimyang PHC                         | Kambari CHC                 | Others                          |                                    |
| Namtok PHC                          | Deomali CHC                 |                                 |                                    |
| Manmow PHC                          | Laju PHC                    |                                 |                                    |
| Bordumsa PHC                        | Pangchua PHC                |                                 |                                    |
| Joirampur PHC                       | Dadam PHC                   |                                 |                                    |
| Karsang PHC                         | Pumao PHC                   |                                 |                                    |
| Bijohnagar PHC                      | Soha PHC                    |                                 |                                    |
| Namong PHC                          | Wakka PHC                   |                                 |                                    |
| Diyun PHC                           |                             |                                 |                                    |

## Method of Data Collection

### A) Incident Data Collection at General Hospital Pasighat

The patients in the hospital are identified at OPD, Pathology Laboratories, Ultrasound room and X-ray room. The Social Investigator identifies the cases by themselves or the doctor concerned acknowledges the SI. The SI then directly interviews either the patient or their family members or friends who can provide correct information. The data mostly collected after interviewing the patient or accompanying person includes information of the patient, residential address with postal pin code, duration of stay at permanent address, diagnosis status, date of first diagnosis and other personal information like religion, marital status, cultural background etc as per the core proforma. The other information is collected from their medical

reports with the assistance of consultant doctors. Follow up of every patient is done through telephonic conversation or through observation and direct interview during their treatment procedure. To overcome the problem of incomplete cases, the doctors, workers at ward and laboratories are requested to jot down the name, sex, age, address, diagnosis and contact number of the patient. This filled in proforma are divided into 2 files:

1. Complete files: With the completion of information from the patients and medical records, the data is entered into the core proforma followed by ICD Coding by the PI and Research Scientist. This is entered into the computer through PBCRDM 2.1 software. Duplicate cases are checked and if found are eliminated from the database.
2. Incomplete files: Here the cases are usually incomplete as direct interview may not have been possible or the medical records may be missing. The consultant doctor, wards and registration counter is visited to seek further information. These incomplete files when completed are sent to the complete files for further processing.
3. Missing files. The SI is intimated about some cases by laypersons that come in contact during group interview or discussions. When the address or contact number is collected for these missing cases they go into the incomplete files and follow the same process until they are completed and entered into the software.

## **B) Incident Data Collection from Other Sources**

The other sources are divided into 2 categories:

1. Cancer Diagnosis Source
2. Unavailable Cancer Diagnosis Source.
  - The Cancer Diagnosis Sources are the sources where cancer diagnosis can be done like AMC and BCCI. The SI collects data from the case files and medical records maintained by the respective PBCR. This data go through the same procedure as given in complete and incomplete files.
  - The Unavailable Cancer Diagnosis sources are the sources where cancer cannot be diagnosed due to unavailability of equipment and facilities like the CHC and PHC. The cases are usually suspected cases or could be cases that are under treatment hence under observation by a consultant doctor geographically far away and out of reach. The under treatment cases are interviewed through telephonic or face-to-face meeting with the assistance of CHC's doctors. The core proforma is filled up and then categorised as complete or incomplete files. The suspected cases are identified and the SI influences and tries to convince for further diagnosis and treatment.

There had also been some cases identified in Mother Teresa Home Borduria, Tirap District where the patient was said to be suffering from cancer and was under herbal treatment but the diagnosis had not been done medically. Thus, many cases are also being identified in this method by field visits to NGOs and Welfare Institutions.

*Mortality Data Collection:* Mortality data are collected from medical records from district hospitals, birth and death registry at district offices and verbal information of death from the relatives of the deceased.

#### *Difficulties in Data Collection*

- Since there is no department of Oncology or Radiotherapy in our registry area, the cancer cases are referred to other parts of India. This creates high dependency on outside sources.
- Absence of municipal bodies for proper certification of death and lack of awareness for certification among the people.
- Villages in Arunachal Pradesh are scattered so identification of patient at village level is hard and locating their exact house address is difficult.
- Physical-geographical barrier in this part of Registry with mountainous region and extreme climate.
- Lack of awareness of the disease - most of the time people are unaware that they have cancer and diagnosis is done at the last stage.
- People's apprehension to disclose information regarding their illness.

#### **Staff**

|                      |   |   |
|----------------------|---|---|
| Research Scientist   | : | <b>Dr Doli Geiyi, MBBS</b>  |
| Computer Programmer  | : | <b>Ms Maloti Tamin, BE (Computer Science)</b>                               |
| Social Investigators | : | <b>Ms T. Miti Boko, MA (Anthropology)</b><br><b>Ms Chaphiak Lowang, MSW</b> |
| Data Entry Operator  | : | <b>Mr Ogom Lego, ITI, COPA</b>  |
| Statistician         | : | <b>Mrs Moti Megu, MA (Hindi)</b>  |