

Chapter 9

DATA QUALITY AND INDICES OF RELIABILITY

The objective of this chapter is to provide an assessment of the quality of the data and the completeness of coverage of cases in a given registry area.

Newer PBCRs

The data of the newer PBCRs that are being reported for the first time in this report are Nagaland, Meghalaya including Khasi Hills district, Tripura and Wardha. Care has been taken to ensure that these registries have complied with quality of data in terms of actual data collation from various sources of registration of their cases, duplicate elimination and the characteristics of the data submitted (Parkin et al, 1994). This has been doubly checked for the considerable high incident rates reported for certain sites of cancer in Meghalaya including East Khasi Hills district. The results are along the lines of the cancer atlas and North East cancer atlas report published earlier. Nonetheless, a certain degree of discretion may be used in interpreting and drawing conclusions.

Decline in AARs

The PBCRs at Mumbai, Pune, Aurangabad, Sikkim and Dibrugarh have shown a decline in the AARs of all sites of cancer (in both males and females) when compared with that of the 2006-2008 report. In Cachar District a decline in AARs in males and in Delhi and Bangalore PBCRs a decline in AARs in females (for all sites) is observed. Decline/fluctuation in the AARs of leading sites of cancer is also observed in several PBCRs. Such a decline reflects either incomplete coverage and/or changes in population dynamics. The 2011 census population was not used in estimating population and rates in this report as the populations by five year age group have not yet been published and only the total population figures of 2011 census are available. Five year age group populations are essential to calculate Age Adjusted Incidence/Mortality rates of cancer. Therefore while interpreting the data, this limitation may be kept in mind.

Checks on Quality of Data

The registry data undergoes several quality checks, both, at the time of data entry and subsequently. These include: Range, Consistency, Unlikely and Family checks as per the IARC norms. All the checks are built into the PBCRDM 2.1 application. The list of cases with possible errors is sent back to the respective registries for verification with the original medical records and the corrections received are updated in the registry data base. Tables 9.1 to 9.8 provide an insight into the quality of the data of 25 PBCRs after such corrections have been done on the data.

Age Unknown

The number and proportion of cancers with age being unknown in each of the 25 PBCRs is given in Table 9.1. Most of the PBCRs do not have any cases with age unknown. Nonetheless, all the PBCRs are unable to ascertain the date of birth in the vast majority of cases. This includes PBCRs that cover entirely an urban highly literate population.

Table 9.1: Age Unknown - Both Sexes*Number (#) and Relative Proportion (%)*

| Registry | Total | Age Unknown | | Registry | Total | Age Unknown | |
|-----------------------|-------|-------------|-----|--------------------|-------|-------------|-----|
| | # | # | % | | # | # | % |
| Pune | 5927 | 68 | 1.1 | Ahmedabad - Rural | 1721 | 0 | 0.0 |
| Nagpur | 4300 | 45 | 1.0 | Barshi Expanded | 1765 | 0 | 0.0 |
| Delhi | 29027 | 182 | 0.6 | Aurangabad | 1044 | 0 | 0.0 |
| Kollam | 6503 | 14 | 0.2 | Chennai | 5415 | 0 | 0.0 |
| Barshi Rural | 575 | 1 | 0.2 | Dibrugarh District | 2488 | 0 | 0.0 |
| Bangalore | 13415 | 13 | 0.1 | Manipur State | 2871 | 0 | 0.0 |
| Mumbai | 22864 | 21 | 0.1 | Meghalaya | 2379 | 0 | 0.0 |
| Ahmedabad - Urban | 7993 | 5 | 0.1 | Nagaland | 328 | 0 | 0.0 |
| Kolkata | 9913 | 4 | 0.0 | Sikkim State | 1212 | 0 | 0.0 |
| Mizoram State | 2483 | 1 | 0.0 | Thiruvananthapuram | 5132 | 0 | 0.0 |
| Cachar District | 2842 | 1 | 0.0 | Tripura State | 1836 | 0 | 0.0 |
| Bhopal | 2928 | 1 | 0.0 | Wardha | 1582 | 0 | 0.0 |
| Kamrup Urban District | 4416 | 1 | 0.0 | | | | |

Unspecified or Unknown Duration of Stay at Permanent Place of Residence

A cancer case is accepted as a case belonging to the concerned registry based on the area of living. However, only a personal interview (as opposed to abstraction from records) with the patient or the relative/accompanying person can provide information on the duration of stay at the permanent address. The number and proportion of cases where the duration of stay is unspecified by each registry is given in Table 9.2. More and more cases of cancer are being distributed across many centres in urban cities. Therefore, that much more effort and cooperation of other institutions is needed by the registries to get the desired information, that can only be obtained through personal interview (NCRP, 2006).

Table 9.2: Unspecified (Unsp) / Unknown (Unk) Duration of Stay (DOS) - Both Sexes*Number (#) and Relative Proportion (%)*

| Registry | Total | DOS Unsp / Unk | | Registry | Total | DOS Unsp / Unk | |
|-----------------------|-------|----------------|------|--------------------|-------|----------------|-----|
| | # | # | % | | # | # | % |
| Delhi | 29027 | 24782 | 85.4 | Aurangabad | 1044 | 7 | 0.7 |
| Barshi Expanded | 1765 | 881 | 49.9 | Cachar District | 2842 | 18 | 0.6 |
| Bangalore | 13415 | 5807 | 43.3 | Manipur State | 2871 | 18 | 0.6 |
| Chennai | 5415 | 2027 | 37.4 | Kolkata | 9913 | 36 | 0.4 |
| Bhopal | 2928 | 1096 | 37.4 | Kollam | 6503 | 18 | 0.3 |
| Mizoram State | 2483 | 649 | 26.1 | Dibrugarh District | 2488 | 4 | 0.2 |
| Pune | 5927 | 1335 | 22.5 | Ahmedabad - Urban | 7993 | 6 | 0.1 |
| Kamrup Urban District | 4416 | 892 | 20.2 | Ahmedabad - Rural | 1721 | 0 | 0.0 |
| Mumbai | 22864 | 3290 | 14.4 | Sikkim State | 1212 | 0 | 0.0 |
| Barshi Rural | 575 | 16 | 2.8 | Thiruvananthapuram | 5132 | 0 | 0.0 |
| Nagaland | 328 | 9 | 2.7 | Tripura State | 1836 | 0 | 0.0 |
| Nagpur | 4300 | 101 | 2.3 | Wardha | 1582 | 0 | 0.0 |
| Meghalaya | 2379 | 55 | 2.3 | | | | |

Microscopic Verification

The proportion of microscopically verified cases (Table 9.3) is an internationally accepted indicator of data quality. The higher the proportion of microscopically verified cases the more accurate is the confirmation as microscopic verification is the most valid basis of diagnosis of cancer. Still, a very high proportion (above 90-95%) of microscopic diagnosis suggests the likelihood that some cancers with a diagnosis based on imaging techniques and solely clinical diagnoses may be missed by the registry.

Table 9.3: Microscopic Verification (MV) - Both Sexes

Number (#) and Relative Proportion (%)

| Registry | Total | MV | | Registry | Total | MV | |
|--------------------------|-------|-------|-------|------------------------------|-------|-------|------|
| | # | # | % | | # | # | % |
| Nagaland | 328 | 328 | 100.0 | Cachar District | 2842 | 2493 | 87.7 |
| Ahmedabad - Urban | 7993 | 7752 | 97.0 | Barshi Rural | 575 | 500 | 87.0 |
| Tripura State | 1836 | 1779 | 96.9 | Delhi | 29027 | 25099 | 86.5 |
| Aurangabad | 1044 | 1006 | 96.4 | Meghalaya | 2379 | 2050 | 86.2 |
| Ahmedabad - Rural | 1721 | 1656 | 96.2 | Barshi Expanded | 1765 | 1518 | 86.0 |
| Bhopal | 2928 | 2773 | 94.7 | Kollam | 6503 | 5420 | 83.3 |
| Manipur State | 2871 | 2704 | 94.2 | Thiruvananthapuram | 5132 | 4075 | 79.4 |
| Wardha | 1582 | 1488 | 94.1 | Sikkim State | 1212 | 961 | 79.3 |
| Nagpur | 4300 | 4004 | 93.1 | Dibrugarh District | 2488 | 1965 | 79.0 |
| Mumbai | 22864 | 21265 | 93.0 | Kamrup Urban District | 4416 | 3448 | 78.1 |
| Kolkata | 9913 | 9003 | 90.8 | Chennai | 5415 | 3983 | 73.6 |
| Pune | 5927 | 5341 | 90.1 | Mizoram State | 2483 | 1607 | 64.7 |
| Bangalore | 13415 | 12044 | 89.8 | | | | |

Death Certificate 'Only' (DCO) cases

The relative proportion of DCO cases (Table 9.4) is another assessor of data quality. The relative proportion of DCOs should ideally be between 2-3% or at least, less than 5%. It was less than 5% in 13 of the 25 PBCRs. It was more than 10% in Dibrugarh and Mizoram. There is a need to follow-back on these cases to the last hospital attended and if necessary make home visits. Investigation into the details of diagnosis especially the date of diagnosis will help ascertain whether the case has been missed or is already present in the incident records but not picked up during the process of matching. To successfully achieve this in the majority of cases, scrutiny of current deaths mentioned as cancer in the death registers/certificates should be undertaken. This way the exact primary site of tumour would also be obtained in a good number of the cases. In the present data over 50% of DCO cases had no information on primary site of tumour in Barshi, Bhopal, Nagpur, Thiruvananthapuram, Kollam and Mizoram.

Table 9.4: Death Certificate 'Only' (DCO) Cases - Both Sexes*Number (#) and Relative Proportion (%)*

| Registry | Total | DCO | | Registry | Total | DCO | |
|-----------------------|-------|------|------|-------------------|-------|-----|-----|
| | # | # | % | | # | # | % |
| Dibrugarh District | 2488 | 368 | 14.8 | Chennai | 5415 | 181 | 3.3 |
| Mizoram State | 2483 | 360 | 14.5 | Aurangabad | 1044 | 34 | 3.3 |
| Kamrup Urban District | 4416 | 432 | 9.8 | Nagpur | 4300 | 109 | 2.5 |
| Thiruvananthapuram | 5132 | 455 | 8.9 | Bhopal | 2928 | 53 | 1.8 |
| Kolkata | 9913 | 787 | 7.9 | Ahmedabad - Urban | 7993 | 136 | 1.7 |
| Meghalaya | 2379 | 187 | 7.9 | Ahmedabad - Rural | 1721 | 24 | 1.4 |
| Cachar District | 2842 | 185 | 6.5 | Barshi Rural | 575 | 4 | 0.7 |
| Pune | 5927 | 383 | 6.5 | Tripura State | 1836 | 12 | 0.7 |
| Bangalore | 13415 | 847 | 6.3 | Delhi | 29027 | 165 | 0.6 |
| Sikkim State | 1212 | 76 | 6.3 | Manipur State | 2871 | 16 | 0.6 |
| Kollam | 6503 | 333 | 5.1 | Barshi Expanded | 1765 | 3 | 0.2 |
| Mumbai | 22864 | 1084 | 4.7 | Nagaland | 328 | 0 | 0.0 |
| Wardha | 1582 | 60 | 3.8 | | | | |

Mortality-Incident Ratio (MI Ratio)

The mortality-incident or MI ratio is an indicator of the completeness and accuracy of cancer mortality data. Table 9.5 provides registry-wise MI ratios. The system of registration of death and certification of cause of death are of major concern. In order to overcome this deficit in cancer mortality data, some PBCRs have used the all cause mortality data of their registry area to match with the incident cases and arrive at a more realistic figure of cancer mortality.

Table 9.5: Mortality-Incident Ratio (M/I%) - Both Sexes*Number (#) and Relative Proportion (%)*

| Registry | Incidence | Mortality | M/I% | Registry | Incidence | Mortality | M/I% |
|--------------------|-----------|-----------|------|-----------------------|-----------|-----------|------|
| Barshi Rural | 575 | 399 | 69.4 | Meghalaya | 2379 | 728 | 30.6 |
| Mizoram State | 2483 | 1330 | 53.6 | Bangalore | 13415 | 4084 | 30.4 |
| Kollam | 6503 | 2920 | 44.9 | Dibrugarh District | 2488 | 677 | 27.2 |
| Kolkata | 9913 | 4389 | 44.3 | Chennai | 5415 | 1399 | 25.8 |
| Mumbai | 22864 | 10075 | 44.1 | Kamrup Urban District | 4416 | 1093 | 24.8 |
| Wardha | 1582 | 695 | 43.9 | Ahmedabad - Urban | 7993 | 1873 | 23.4 |
| Sikkim State | 1212 | 516 | 42.6 | Aurangabad | 1044 | 202 | 19.3 |
| Pune | 5927 | 2339 | 39.5 | Nagpur | 4300 | 758 | 17.6 |
| Ahmedabad - Rural | 1721 | 643 | 37.4 | Manipur State | 2871 | 457 | 15.9 |
| Tripura State | 1836 | 657 | 35.8 | Nagaland | 328 | 43 | 13.1 |
| Bhopal | 2928 | 983 | 33.6 | Delhi | 29027 | 3456 | 11.9 |
| Thiruvananthapuram | 5132 | 1720 | 33.5 | Cachar District | 2842 | 296 | 10.4 |
| Barshi Expanded | 1765 | 561 | 31.8 | | | | |

Other and Unspecified Site (O&U)

The sites of cancer that were categorised as “Other and Unspecified Sites (O&U)” were as per ICD-10 = C26, C39, C48, C75, C76, C77, C78, C79, C80, C97 (WHO 1994).

The relative proportion of cancers that fell into this group (Table 9.6) was more than 10% in the PBCRs at Cachar District, Thiruvananthapuram and Mizoram State. It was less than 5% in Chennai, Bhopal, Aurangabad, Kolkata, Bangalore, Pune, Wardha and Nagaland. Since several PBCRs had five or more than 5% of cases in this category (without exact primary site of tumour), we looked into whether such cases were mainly those obtained through death certificates or otherwise. The rationale is that, death certificates are generally incomplete and the chances of the primary site of tumour not mentioned or missing in the death certificate/register is not unexpected. On the other hand, in the setting of an equipped hospital there will be some patients whose primary site would remain unknown despite the battery of investigations but this proportion would be in the range of 1% or less. Apart from the three PBCRs at Kollam, Thiruvananthapuram and Mizoram all other PBCRs had more than 50% of the O&U cases abstracted from medical institutions including the base institution where the PBCR is located and not through death registration units. Further, the basis of diagnosis of these cases showed that a high proportion had microscopic verification and that too by primary histology. Thus there is a need for registry abstractors to diligently track these cases to the concerned physician/pathologist and find the information on the exact primary site of tumour. Timeliness is extremely important, and this should be done at initial abstraction itself which in turn should be as close as possible to the date of diagnosis.

Table 9.6: Other and Unspecified Site (O&U) - Both Sexes

Number (#) and Relative Proportion (%)

| Registry | Total | O&U | | Registry | Total | O&U | |
|--------------------|-------|-----|------|-----------------------|-------|------|-----|
| | # | # | % | | # | # | % |
| Cachar District | 2842 | 588 | 20.7 | Kamrup Urban District | 4416 | 264 | 6.0 |
| Thiruvananthapuram | 5132 | 640 | 12.5 | Mumbai | 22864 | 1167 | 5.1 |
| Mizoram State | 2483 | 295 | 11.9 | Manipur State | 2871 | 144 | 5.0 |
| Sikkim State | 1212 | 104 | 8.6 | Delhi | 29027 | 1450 | 5.0 |
| Nagpur | 4300 | 366 | 8.5 | Chennai | 5415 | 258 | 4.8 |
| Barshi Rural | 575 | 46 | 8.0 | Bhopal | 2928 | 134 | 4.6 |
| Ahmedabad - Rural | 1721 | 134 | 7.8 | Aurangabad | 1044 | 45 | 4.3 |
| Ahmedabad - Urban | 7993 | 611 | 7.6 | Kolkata | 9913 | 420 | 4.2 |
| Tripura State | 1836 | 138 | 7.5 | Bangalore | 13415 | 555 | 4.1 |
| Kollam | 6503 | 483 | 7.4 | Pune | 5927 | 229 | 3.9 |
| Meghalaya | 2379 | 171 | 7.2 | Wardha | 1582 | 32 | 2.0 |
| Barshi Expanded | 1765 | 125 | 7.1 | Nagaland | 328 | 2 | 0.6 |
| Dibrugarh District | 2488 | 165 | 6.6 | | | | |

Unspecified Sub-site

Anatomical sites of cancer are generally considered as one complete entity for overall expression of numbers for incidence/mortality rates. However, bearing in mind embryological development and in terms of identifying risk factors, there is a need for sub-site classification of at least some important pertinent sites of cancer such as tongue, oesophagus, stomach and colon. Sub-site identification is also an indicator of the meticulousness of the registry staff and the extent of detail of data availability vis-à-vis clinical-pathology records. The registry-wise proportion of unspecified sub-site for these four sites of cancer is given in Table 9.7. Suffice to state that sub-site categorisation is uniformly low across all PBCRs. Even those with small numbers are unable to obtain information on sub-site in a substantial proportion of cases. Like for “Other and Unspecified Sites” awareness by the abstractor on the need to collect such information where available and pursuing with the concerned clinician/pathologist where not available. Timeliness in both abstraction and pursuit is once again the key in getting such data.

Table 9.7(a): Unspecified (Unsp) Sub-Site - Tongue (ICD10: C01-C02) - Both Sexes*Number (#) and Relative Proportion (%)*

| Registry | Total | Unsp Sub-Site | | Registry | Total | Unsp Sub-Site | |
|-------------------|-------|---------------|------|-----------------------|-------|---------------|------|
| | # | # | % | | # | # | % |
| Pune | 191 | 170 | 89.0 | Thiruvananthapuram | 184 | 94 | 51.1 |
| Barshi Expanded | 84 | 74 | 88.1 | Mizoram State | 32 | 15 | 46.9 |
| Manipur State | 48 | 40 | 83.3 | Kollam | 215 | 99 | 46.0 |
| Aurangabad | 41 | 31 | 75.6 | Delhi | 1231 | 471 | 38.3 |
| Sikkim State | 16 | 11 | 68.8 | Nagaland | 8 | 3 | 37.5 |
| Kolkata | 297 | 196 | 66.0 | Chennai | 212 | 75 | 35.4 |
| Mumbai | 749 | 460 | 61.4 | Kamrup Urban District | 174 | 48 | 27.6 |
| Ahmedabad - Urban | 644 | 392 | 60.9 | Wardha | 67 | 16 | 23.9 |
| Bhopal | 171 | 102 | 59.6 | Meghalaya | 85 | 20 | 23.5 |
| Nagpur | 180 | 107 | 59.4 | Dibrugarh District | 81 | 18 | 22.2 |
| Barshi Rural | 18 | 10 | 55.6 | Tripura State | 97 | 14 | 14.4 |
| Bangalore | 334 | 181 | 54.2 | Cachar District | 122 | 15 | 12.3 |
| Ahmedabad - Rural | 163 | 84 | 51.5 | | | | |

Table 9.7(b): Unspecified (Unsp) Sub-Site - Oesophagus (ICD10: C15) - Both Sexes*Number (#) and Relative Proportion (%)*

| Registry | Total | Unsp Sub-Site | | Registry | Total | Unsp Sub-Site | |
|-----------------------|-------|---------------|------|--------------------|-------|---------------|------|
| | # | # | % | | # | # | % |
| Tripura State | 134 | 133 | 99.3 | Dibrugarh District | 316 | 208 | 65.8 |
| Aurangabad | 51 | 50 | 98.0 | Nagpur | 222 | 142 | 64.0 |
| Cachar District | 237 | 228 | 96.2 | Bangalore | 722 | 427 | 59.1 |
| Kolkata | 237 | 224 | 94.5 | Bhopal | 129 | 76 | 58.9 |
| Barshi Expanded | 89 | 83 | 93.3 | Ahmedabad - Urban | 390 | 227 | 58.2 |
| Pune | 281 | 260 | 92.5 | Manipur State | 105 | 61 | 58.1 |
| Delhi | 865 | 789 | 91.2 | Thiruvananthapuram | 98 | 55 | 56.1 |
| Kamrup Urban District | 562 | 494 | 87.9 | Wardha | 93 | 52 | 55.9 |
| Sikkim State | 88 | 74 | 84.1 | Meghalaya | 641 | 344 | 53.7 |
| Barshi Rural | 40 | 32 | 80.0 | Chennai | 227 | 121 | 53.3 |
| Mumbai | 756 | 563 | 74.5 | Mizoram State | 244 | 115 | 47.1 |
| Ahmedabad - Rural | 73 | 51 | 69.9 | Kollam | 192 | 86 | 44.8 |
| Nagaland | 39 | 26 | 66.7 | | | | |

Table 9.7(c): Unspecified (Unsp) Sub-Site - Stomach (ICD10: C16) - Both Sexes*Number (#) and Relative Proportion (%)*

| Registry | Total | Unsp Sub-Site | | Registry | Total | Unsp Sub-Site | |
|-----------------------|-------|---------------|-------|--------------------|-------|---------------|------|
| | # | # | % | | # | # | % |
| Barshi Rural | 21 | 21 | 100.0 | Thiruvananthapuram | 132 | 110 | 83.3 |
| Ahmedabad - Rural | 25 | 24 | 96.0 | Delhi | 575 | 474 | 82.4 |
| Kolkata | 361 | 341 | 94.5 | Dibrugarh District | 165 | 134 | 81.2 |
| Tripura State | 116 | 108 | 93.1 | Mumbai | 716 | 581 | 81.1 |
| Barshi Expanded | 41 | 38 | 92.7 | Manipur State | 175 | 137 | 78.3 |
| Bhopal | 47 | 43 | 91.5 | Cachar District | 83 | 62 | 74.7 |
| Nagaland | 54 | 49 | 90.7 | Sikkim State | 144 | 106 | 73.6 |
| Nagpur | 119 | 107 | 89.9 | Aurangabad | 22 | 16 | 72.7 |
| Wardha | 38 | 34 | 89.5 | Kollam | 241 | 175 | 72.6 |
| Bangalore | 761 | 663 | 87.1 | Chennai | 394 | 279 | 72.1 |
| Pune | 196 | 169 | 86.2 | Mizoram State | 476 | 290 | 60.9 |
| Ahmedabad - Urban | 114 | 98 | 86.0 | Meghalaya | 169 | 68 | 40.2 |
| Kamrup Urban District | 255 | 218 | 85.5 | | | | |

Table 9.7(d): Unspecified (Unsp) Sub-Site - Colon (ICD10: C18) - Both Sexes*Number (#) and Relative Proportion (%)*

| Registry | Total | Unsp Sub-Site | | Registry | Total | Unsp Sub-Site | |
|-----------------------|-------|---------------|------|--------------------|-------|---------------|------|
| | # | # | % | | # | # | % |
| Nagaland | 12 | 11 | 91.7 | Mizoram State | 34 | 18 | 52.9 |
| Barshi Expanded | 38 | 31 | 81.6 | Ahmedabad - Urban | 161 | 82 | 50.9 |
| Kolkata | 298 | 227 | 76.2 | Bangalore | 364 | 180 | 49.5 |
| Kamrup Urban District | 85 | 63 | 74.1 | Ahmedabad - Rural | 29 | 14 | 48.3 |
| Pune | 180 | 131 | 72.8 | Mumbai | 724 | 349 | 48.2 |
| Manipur State | 62 | 43 | 69.4 | Thiruvananthapuram | 140 | 65 | 46.4 |
| Delhi | 581 | 383 | 65.9 | Aurangabad | 16 | 7 | 43.8 |
| Cachar District | 33 | 21 | 63.6 | Wardha | 28 | 12 | 42.9 |
| Nagpur | 99 | 61 | 61.6 | Kollam | 149 | 61 | 40.9 |
| Barshi Rural | 12 | 7 | 58.3 | Sikkim State | 28 | 11 | 39.3 |
| Bhopal | 53 | 30 | 56.6 | Chennai | 148 | 56 | 37.8 |
| Dibrugarh District | 59 | 33 | 55.9 | Meghalaya | 32 | 12 | 37.5 |
| Tripura State | 31 | 17 | 54.8 | | | | |

Unspecified Histology*

While cancers of different anatomical sites have certain distinctions due to their location, the histological type of cancer in the same site has its own identity in terms of aetiology, prognosis and treatment thereof. Hence, it is important to get information in at least cases where a microscopic diagnosis of cancer is available. Table 9.8 gives the proportion of cancers of selected sites where histology was "Not Otherwise Specified". * see page 89.

Table 9.8(a): Unspecified (Unsp) Histology - Stomach (ICD10: C16) - Both Sexes*Number (#) and Relative Proportion (%)*

| Registry | Total | Unsp Histology | | Registry | Total | Unsp Histology | |
|--------------------|-------|----------------|------|-----------------------|-------|----------------|-----|
| | # | # | % | | # | # | % |
| Delhi | 583 | 247 | 42.4 | Bhopal | 48 | 4 | 8.3 |
| Cachar District | 83 | 18 | 21.7 | Ahmedabad - Rural | 25 | 2 | 8.0 |
| Bangalore | 778 | 155 | 19.9 | Nagpur | 119 | 9 | 7.6 |
| Barshi Expanded | 42 | 7 | 16.7 | Kamrup Urban District | 256 | 17 | 6.6 |
| Tripura State | 116 | 18 | 15.5 | Pune | 196 | 12 | 6.1 |
| Manipur State | 176 | 27 | 15.3 | Chennai | 394 | 22 | 5.6 |
| Ahmedabad - Urban | 118 | 18 | 15.3 | Kolkata | 363 | 19 | 5.2 |
| Barshi Rural | 23 | 3 | 13.0 | Dibrugarh District | 165 | 7 | 4.2 |
| Kollam | 268 | 32 | 11.9 | Sikkim State | 144 | 6 | 4.2 |
| Mumbai | 716 | 82 | 11.5 | Mizoram State | 477 | 16 | 3.4 |
| Thiruvananthapuram | 134 | 14 | 10.4 | Aurangabad | 22 | 0 | 0.0 |
| Meghalaya | 169 | 16 | 9.5 | Wardha | 38 | 0 | 0.0 |
| Nagaland | 54 | 5 | 9.3 | | | | |

Table 9.8(b): Unspecified (Unsp) Histology - Lung (ICD10: C33-C34) - Both Sexes*Number (#) and Relative Proportion (%)*

| Registry | Total | Unsp Histology | | Registry | Total | Unsp Histology | |
|-----------------------|-------|----------------|------|--------------------|-------|----------------|-----|
| | # | # | % | | # | # | % |
| Barshi Rural | 19 | 8 | 42.1 | Mizoram State | 379 | 20 | 5.3 |
| Aurangabad | 56 | 23 | 41.1 | Dibrugarh District | 80 | 3 | 3.8 |
| Bhopal | 203 | 69 | 34.0 | Tripura State | 230 | 7 | 3.0 |
| Kollam | 646 | 213 | 33.0 | Ahmedabad - Urban | 457 | 12 | 2.6 |
| Thiruvananthapuram | 356 | 102 | 28.7 | Kolkata | 1160 | 29 | 2.5 |
| Barshi Expanded | 46 | 13 | 28.3 | Meghalaya | 117 | 2 | 1.7 |
| Manipur State | 461 | 121 | 26.2 | Ahmedabad - Rural | 119 | 2 | 1.7 |
| Mumbai | 1289 | 175 | 13.6 | Cachar District | 163 | 2 | 1.2 |
| Pune | 290 | 39 | 13.4 | Sikkim State | 91 | 1 | 1.1 |
| Bangalore | 777 | 88 | 11.3 | Delhi | 1921 | 2 | 0.1 |
| Nagpur | 156 | 15 | 9.6 | Nagaland | 6 | 0 | 0.0 |
| Chennai | 369 | 26 | 7.0 | Wardha | 72 | 0 | 0.0 |
| Kamrup Urban District | 266 | 17 | 6.4 | | | | |

Table 9.8(c): Unspecified (Unsp) Histology - Ovary (ICD10: C56) - Females*Number (#) and Relative Proportion (%)*

| Registry | Total | | Unsp Histology | | Registry | Total | | Unsp Histology | |
|--------------------|-------|------|----------------|------|-----------------------|-------|-----|----------------|-----|
| | # | % | # | % | | # | % | # | % |
| Delhi | 941 | 44.7 | 421 | 44.7 | Ahmedabad - Rural | 41 | 7.3 | 3 | 7.3 |
| Cachar District | 46 | 41.3 | 19 | 41.3 | Pune | 201 | 6.5 | 13 | 6.5 |
| Bangalore | 419 | 30.0 | 126 | 30.0 | Dibrugarh District | 85 | 5.9 | 5 | 5.9 |
| Bhopal | 116 | 28.5 | 33 | 28.5 | Ahmedabad - Urban | 177 | 5.6 | 10 | 5.6 |
| Barshi Expanded | 48 | 25.0 | 12 | 25.0 | Meghalaya | 22 | 4.5 | 1 | 4.5 |
| Kollam | 48 | 24.3 | 41 | 24.3 | Kolkata | 328 | 4.2 | 14 | 4.2 |
| Barshi Rural | 20 | 20.0 | 4 | 20.0 | Kamrup Urban District | 151 | 0.7 | 1 | 0.7 |
| Mumbai | 808 | 19.2 | 155 | 19.2 | Aurangabad | 27 | 0.0 | 0 | 0.0 |
| Chennai | 189 | 18.0 | 34 | 18.0 | Nagaland | 6 | 0.0 | 0 | 0.0 |
| Manipur State | 78 | 15.4 | 12 | 15.4 | Sikkim State | 21 | 0.0 | 0 | 0.0 |
| Nagpur | 110 | 15.4 | 17 | 15.4 | Tripura State | 169 | 0.0 | 0 | 0.0 |
| Mizoram State | 28 | 14.3 | 4 | 14.3 | Wardha | 52 | 0.0 | 0 | 0.0 |
| Thiruvananthapuram | 138 | 12.3 | 17 | 12.3 | | | | | |

Comparability of Certain Parameters with Previous Report

Some of these tables are given below. Others are available in the web version of the report.

Table 9.9: Comparison of Age Adjusted Incidence Rates (AARs) between Previous (2006-2008) and Present (2009-2011) Report - All Sites**Males**

| Registry | AARs | | % Change | Registry | AARs | | % Change |
|-----------------------|-----------|-----------|----------|--------------------|-----------|-----------|----------|
| | 2006-2008 | 2009-2011 | | | 2006-2008 | 2009-2011 | |
| Ahmedabad - Urban | 94.4 | 117.5 | 24.5 | Delhi | 124.3 | 125.2 | 0.7 |
| Kamrup Urban District | 161.6 | 185.2 | 14.6 | Barshi Rural | 51.5 | 51.8 | 0.6 |
| Thiruvananthapuram | 121.7 | 132.6 | 9.0 | Bangalore | 113.4 | 113.7 | 0.3 |
| Kolkata | 86.0 | 92.8 | 7.9 | Barshi Expanded | 40.8 | 40.9 | 0.2 |
| Mizoram State | 176.5 | 189.5 | 7.4 | Mumbai | 99.1 | 98.4 | -0.7 |
| Nagpur | 91.2 | 96.4 | 5.7 | Cachar District | 133.5 | 129.0 | -3.4 |
| Kollam | 113.6 | 118.5 | 4.3 | Pune | 78.8 | 74.3 | -5.7 |
| Ahmedabad - Rural | 71.7 | 74.2 | 3.5 | Sikkim State | 89.0 | 82.6 | -7.2 |
| Manipur State | 72.5 | 74.7 | 3.0 | Aurangabad | 64.9 | 59.6 | -8.2 |
| Chennai | 115.2 | 118 | 2.4 | Dibrugarh District | 109.6 | 99.4 | -9.3 |
| Bhopal | 104.6 | 105.9 | 1.2 | | | | |

Females

| Registry | AARs | | % Change | Registry | AARs | | % Change |
|-----------------------|-----------|-----------|----------|--------------------|-----------|-----------|----------|
| | 2006-2008 | 2009-2011 | | | 2006-2008 | 2009-2011 | |
| Kamrup Urban District | 122.5 | 156.3 | 27.6 | Mizoram State | 152.8 | 153.7 | 0.6 |
| Cachar District | 78.4 | 98.0 | 25.0 | Bhopal | 105.5 | 105.6 | 0.1 |
| Ahmedabad - Urban | 75.4 | 87.1 | 15.5 | Delhi | 121.2 | 120.6 | -0.5 |
| Thiruvananthapuram | 108.3 | 123.2 | 13.8 | Bangalore | 139.1 | 137.2 | -1.4 |
| Barshi Rural | 55.1 | 62.6 | 13.6 | Barshi Expanded | 54.3 | 52.8 | -2.8 |
| Nagpur | 91.2 | 103.0 | 12.9 | Mumbai | 110.4 | 105.5 | -4.4 |
| Ahmedabad - Rural | 49.0 | 51.6 | 5.3 | Aurangabad | 65.0 | 62.1 | -4.5 |
| Kolkata | 95.3 | 99.4 | 4.3 | Sikkim State | 99.8 | 94.2 | -5.6 |
| Chennai | 121.1 | 123.8 | 2.2 | Dibrugarh District | 78.5 | 71.8 | -8.5 |
| Kollam | 89.7 | 91.6 | 2.1 | Pune | 85.5 | 75.7 | -11.5 |
| Manipur State | 72.5 | 73.9 | 1.9 | | | | |

Table 9.10: Comparison of Microscopic Verification (MV%) between Previous (2006-2008) and Present (2009-2011) Report - Both Sexes

| Registry | MV% | | % Change | Registry | MV% | | % Change |
|-------------------|-----------|-----------|----------|-----------------------|-----------|-----------|----------|
| | 2006-2008 | 2009-2011 | | | 2006-2008 | 2009-2011 | |
| Cachar District | 69.8 | 87.7 | 25.6 | Pune | 86.7 | 90.1 | 3.9 |
| Bhopal | 82.1 | 94.7 | 15.3 | Nagpur | 89.7 | 93.1 | 3.8 |
| Barshi Rural | 76.2 | 87.0 | 14.2 | Kamrup Urban District | 75.4 | 78.1 | 3.6 |
| Delhi | 76.9 | 86.5 | 12.5 | Mizoram State | 62.5 | 64.7 | 3.5 |
| Ahmedabad - Urban | 90.2 | 97.0 | 7.5 | Bangalore | 88.5 | 89.8 | 1.5 |
| Mumbai | 87.4 | 93.0 | 6.4 | Manipur State | 93.8 | 94.2 | 0.4 |
| Kollam | 78.7 | 83.3 | 5.8 | Kolkata | 90.8 | 90.8 | 0.0 |
| Sikkim State | 74.9 | 79.3 | 5.9 | Thiruvananthapuram | 79.5 | 79.4 | -0.1 |
| Barshi Expanded | 81.5 | 86.0 | 5.5 | Dibrugarh District | 83.6 | 79.0 | -5.5 |
| Aurangabad | 91.5 | 96.4 | 5.4 | Chennai | 79.9 | 73.6 | -7.9 |
| Ahmedabad - Rural | 91.7 | 96.2 | 4.9 | | | | |

Table 9.11: Comparison of Death Certificates Only (DCO%) between Previous (2006-2008) and Present (2009-2011) Report - Both Sexes

| Registry | DCO% | | % Change | Registry | DCO% | | % Change |
|-----------------------|-----------|-----------|----------|-------------------|-----------|-----------|----------|
| | 2006-2008 | 2009-2011 | | | 2006-2008 | 2009-2011 | |
| Barshi Rural | 0.4 | 0.7 | 75.0 | Manipur State | 0.8 | 0.6 | -25.0 |
| Dibrugarh District | 12.3 | 14.8 | 20.3 | Sikkim State | 8.5 | 6.3 | -25.9 |
| Delhi | 0.5 | 0.6 | 20.0 | Cachar District | 9.5 | 6.5 | -31.6 |
| Chennai | 2.8 | 3.3 | 17.9 | Mizoram State | 22.6 | 14.5 | -35.8 |
| Thiruvananthapuram | 8.1 | 8.9 | 9.9 | Ahmedabad - Rural | 2.4 | 1.4 | -41.7 |
| Pune | 6.0 | 6.5 | 8.3 | Kollam | 8.9 | 5.1 | -42.7 |
| Kolkata | 8.2 | 7.9 | -3.7 | Ahmedabad - Urban | 3.0 | 1.7 | -43.3 |
| Nagpur | 2.8 | 2.5 | -10.7 | Barshi Expanded | 0.2 | 0.1 | -50.0 |
| Bangalore | 7.2 | 6.3 | -12.5 | Bhopal | 3.8 | 1.8 | -52.6 |
| Mumbai | 5.6 | 4.7 | -16.1 | Aurangabad | 7.4 | 3.3 | -55.4 |
| Kamrup Urban District | 12.8 | 9.8 | -23.4 | | | | |

Identification of Duplicate Registrations

This is a major exercise for PBCRs and is compounded by the fact that more diagnostic and treatment centres are being opened on a regular basis in most of the cities and towns of India where PBCRs are in operation. The PBCRDM 2.1 application has taken up this as a major challenge in evolving tools to identify potential duplicates.

A software application, PHONETICS has been developed to identify duplicate names that are spelt differently but sound phonetically the same. A dictionary of such names has been created by perusing through 3.2 lakh records to make zonal/regional dictionary of duplicate names covering all the four zones of the country. The dictionary is also capable to include any new found duplicate name at any point of time.

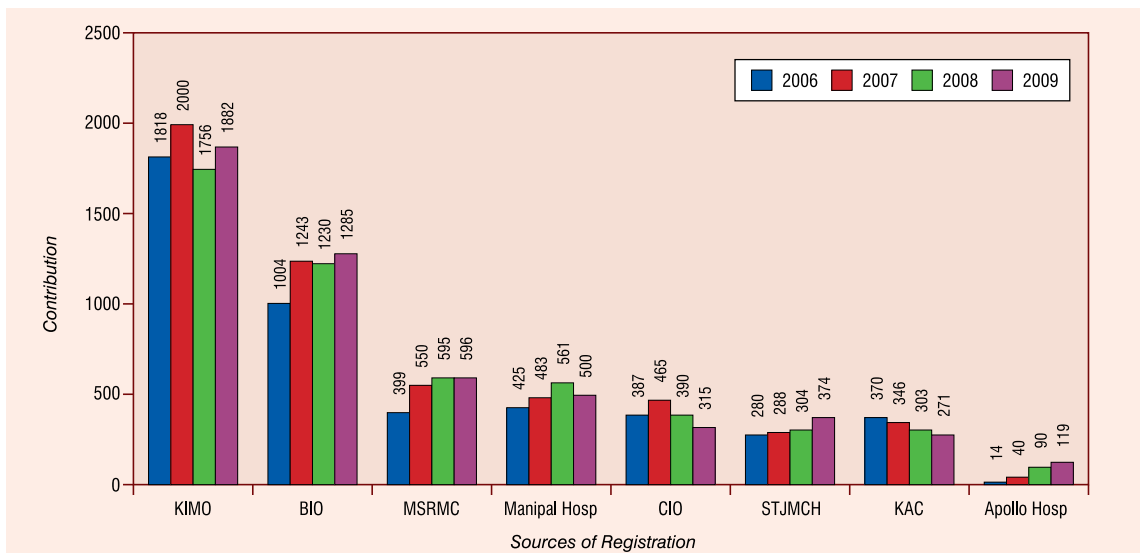
Coverage of Cancer Cases

This includes: (a) Variation in Contribution of Major Sources of Registration; (b) Resident Unknown

(a) Variation in Contribution of Major Sources of Registration

Every PBCR aspires to achieve completeness of registration. The proportion of all incident cases in the registry population that have been included in the registry database is an indicator of completeness. While each registry may try to collect 100% of the cases belonging to the registry area, some cases may be missed. Figure 9.1 gives comparison of the contributions made by the main sources of registrations in the previous and present report. Sources that have shown a decreasing or fluctuating contribution over the years would require special attention by the registries. The reasons could either be actual decline in the cancers (belonging to the registry area) diagnosed/treated by these institutions or inadequate collection of cases by the registry staff. The latter would also include cases that could be missed because of late visits to these institutions when details of residential status will not be available. The registry can take up specific measures to ensure better collection and coverage in such sources. The year-wise contributions of cases can be generated from the PBCRDM 2.1 application.

**Fig. 9.1: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2009
Bangalore**



**Fig. 9.2: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010
Barshi Rural**

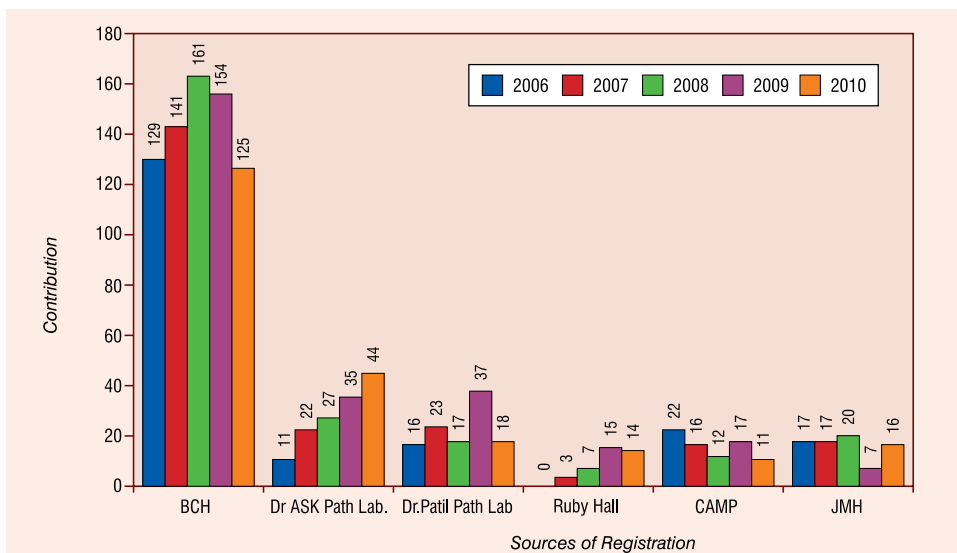


Fig. 9.3: Year-wise Comparison of Data Received from Main Sources of Registration: 2007-2009
Barshi Expanded

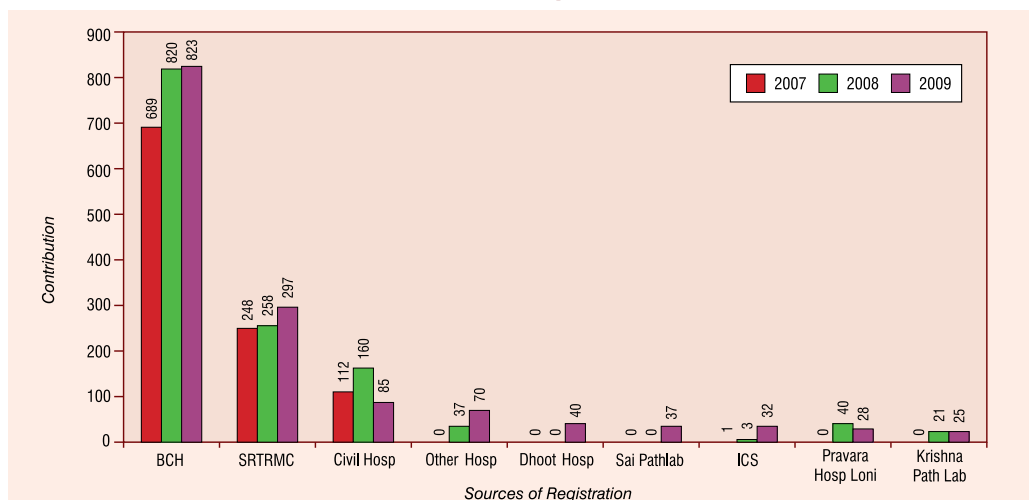


Fig. 9.4: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010
Bhopal

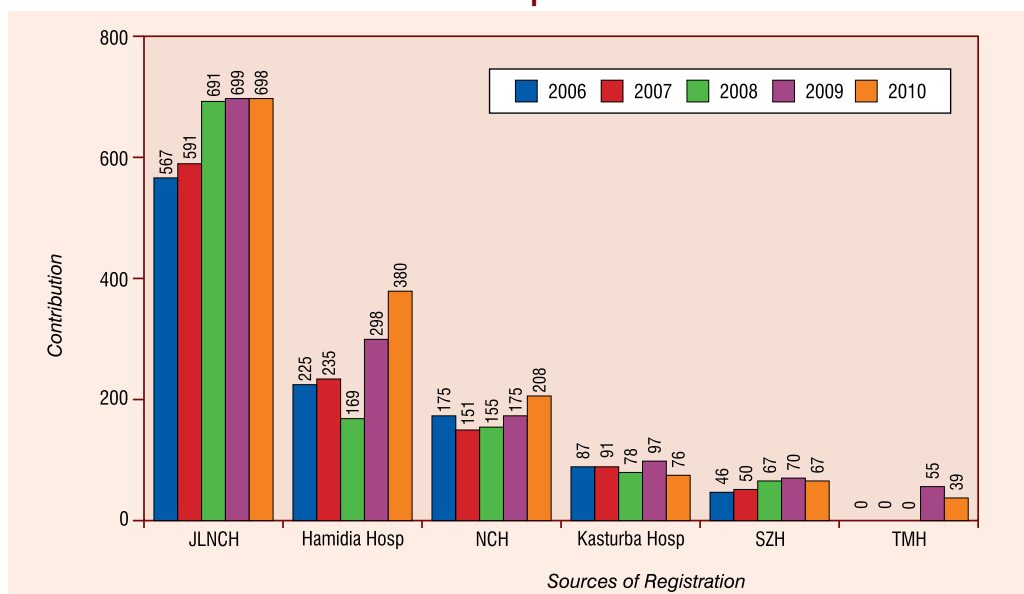


Fig. 9.5: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2009
Chennai

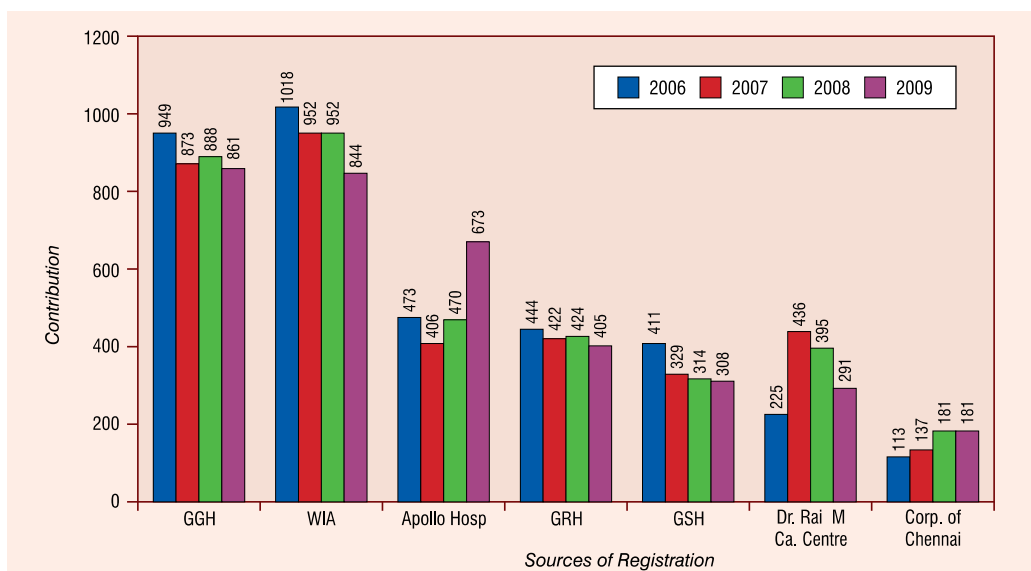


Fig. 9.6: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2009 - Delhi

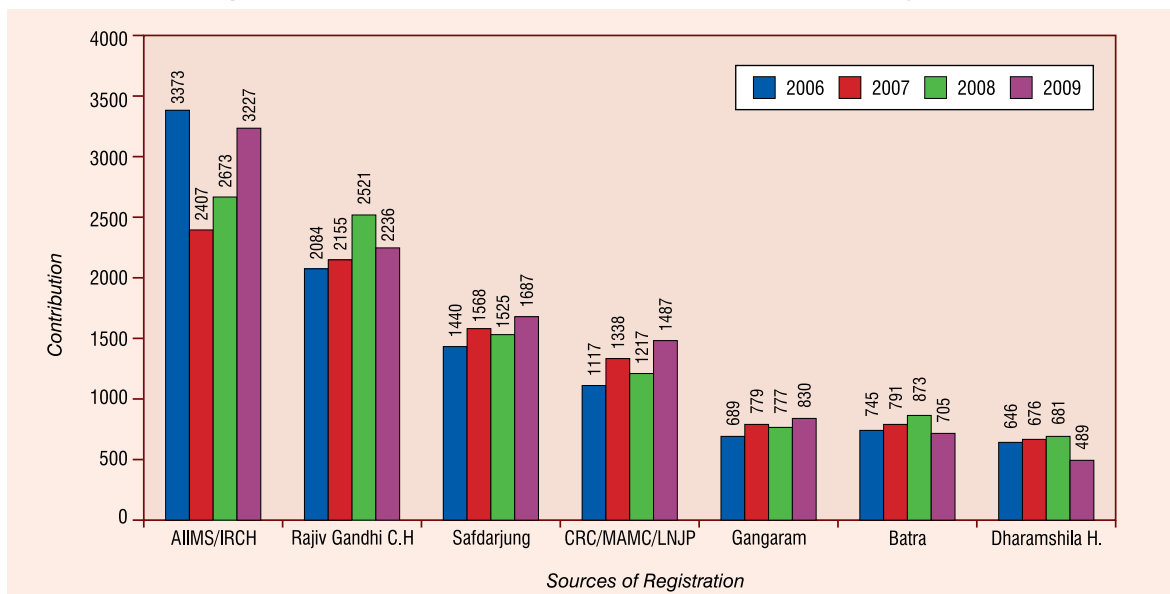


Fig. 9.7: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010

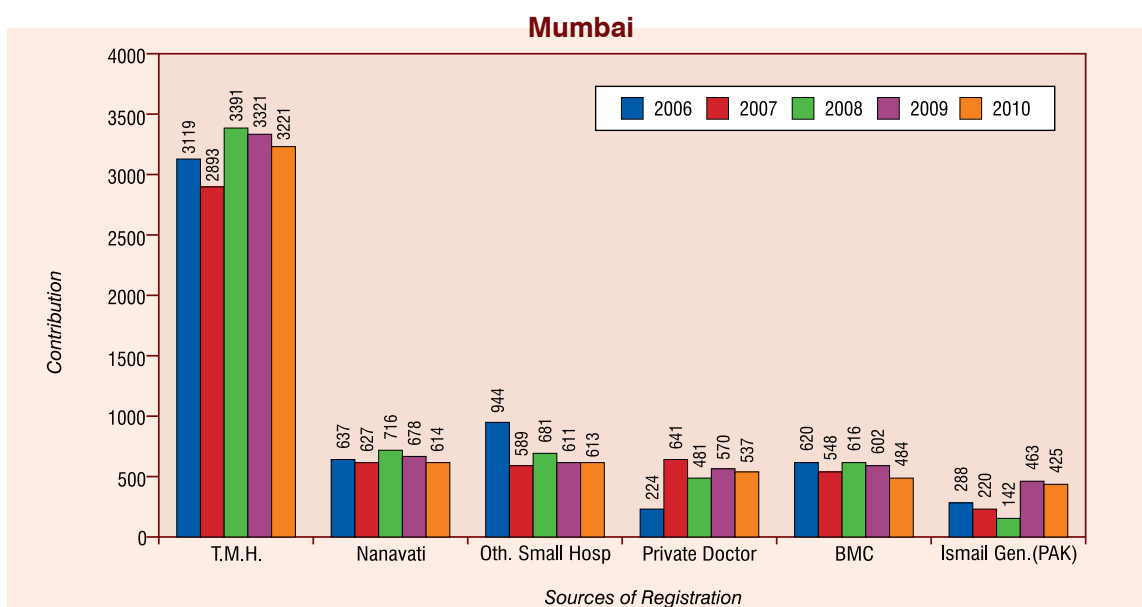


Fig. 9.8: Year-wise Comparison of Data Received from Main Sources of Registration: 2007-2010

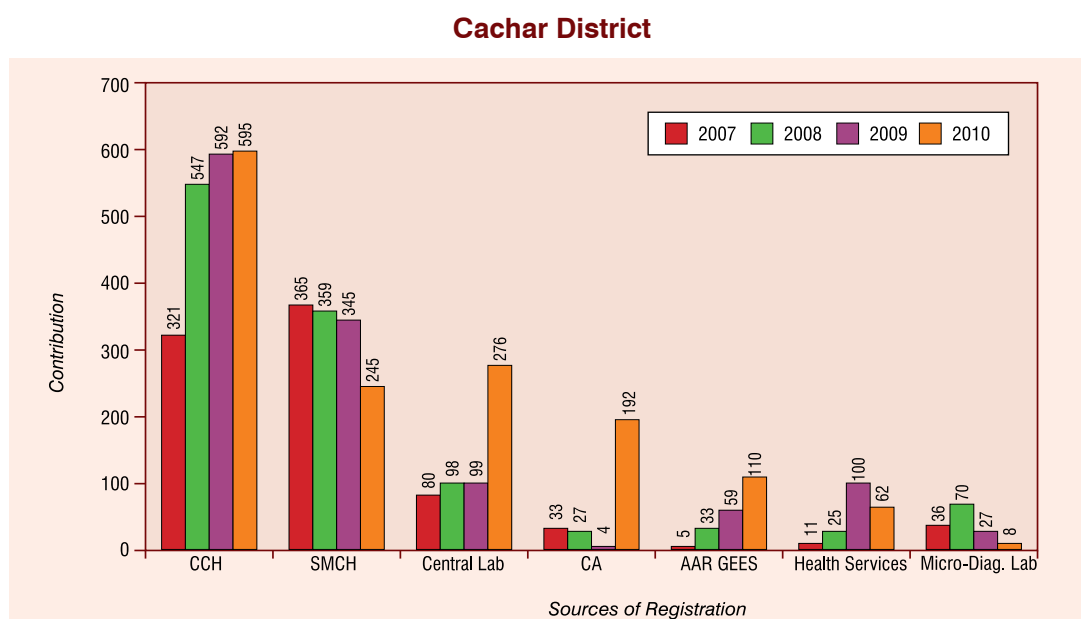


Fig. 9.9: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2011

Dibrugarh District

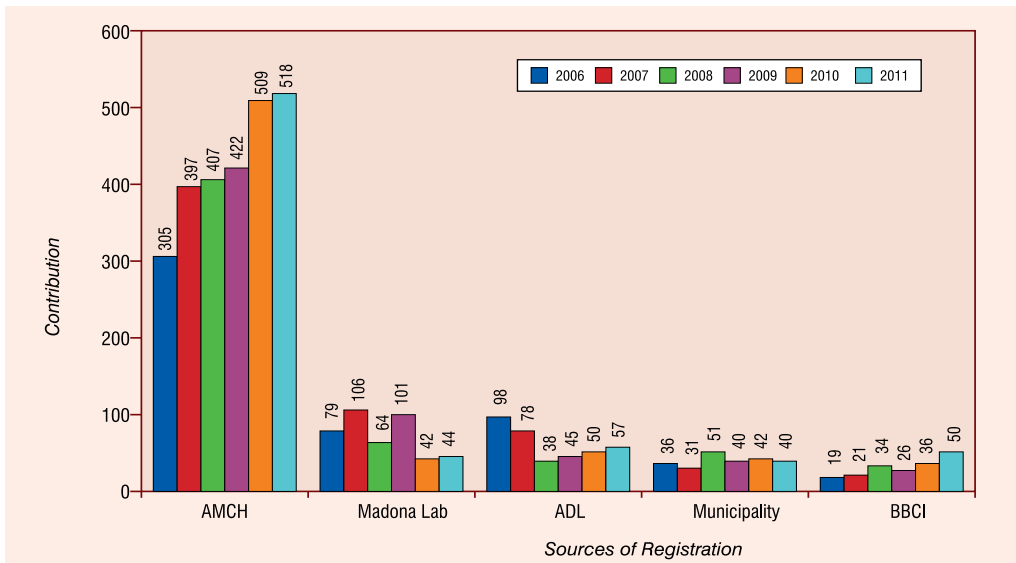


Fig. 9.10: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2011

Kamrup Urban District

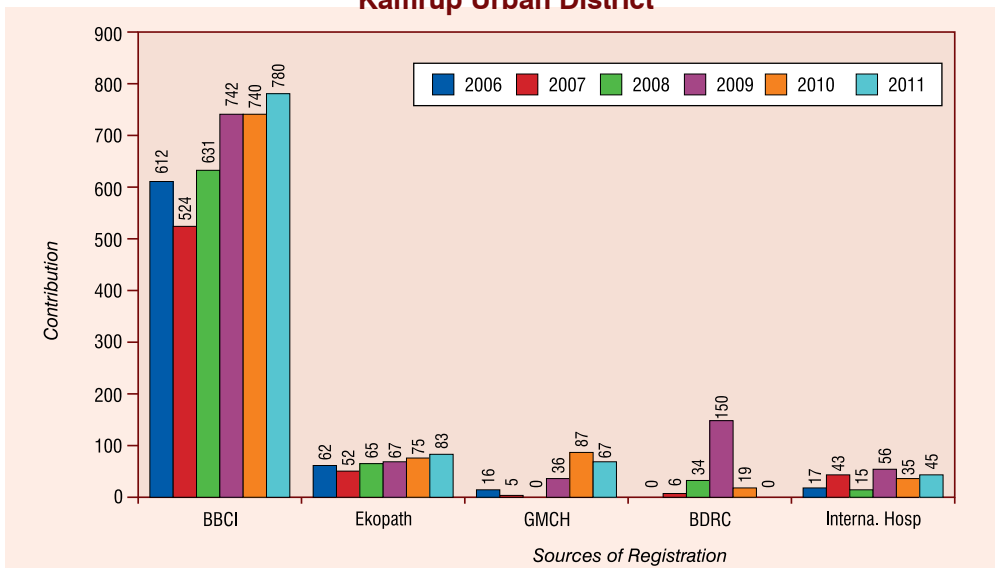


Fig. 9.11: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010

Manipur State

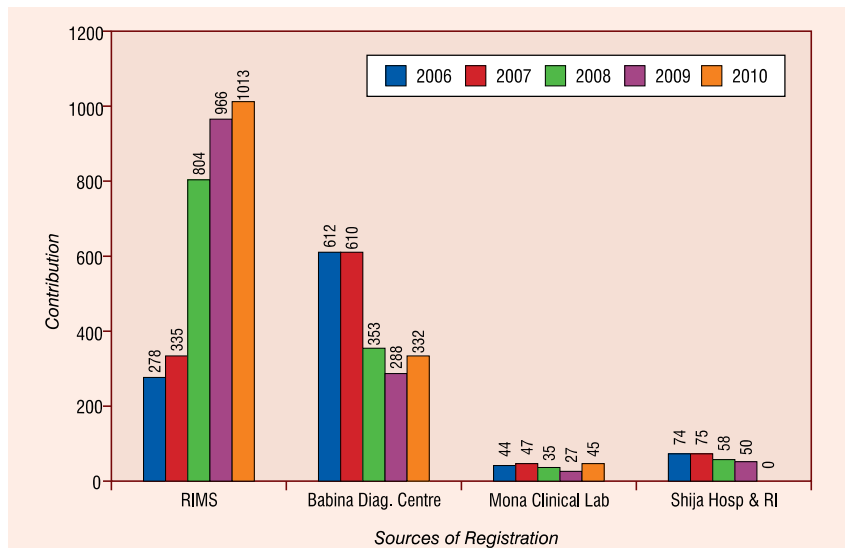


Fig. 9.12: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010

Mizoram State

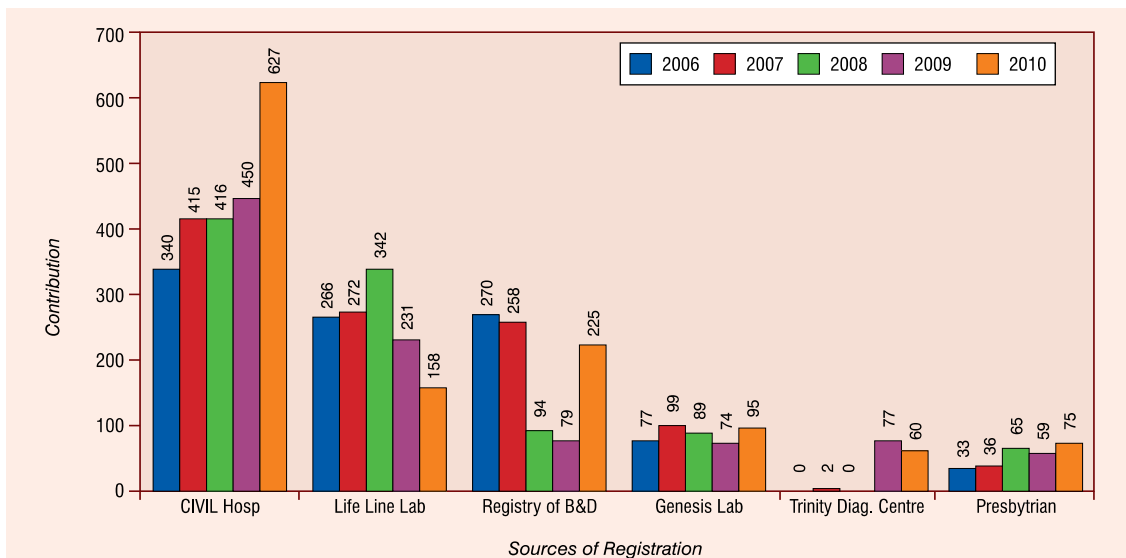


Fig. 9.13: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2011

Sikkim State

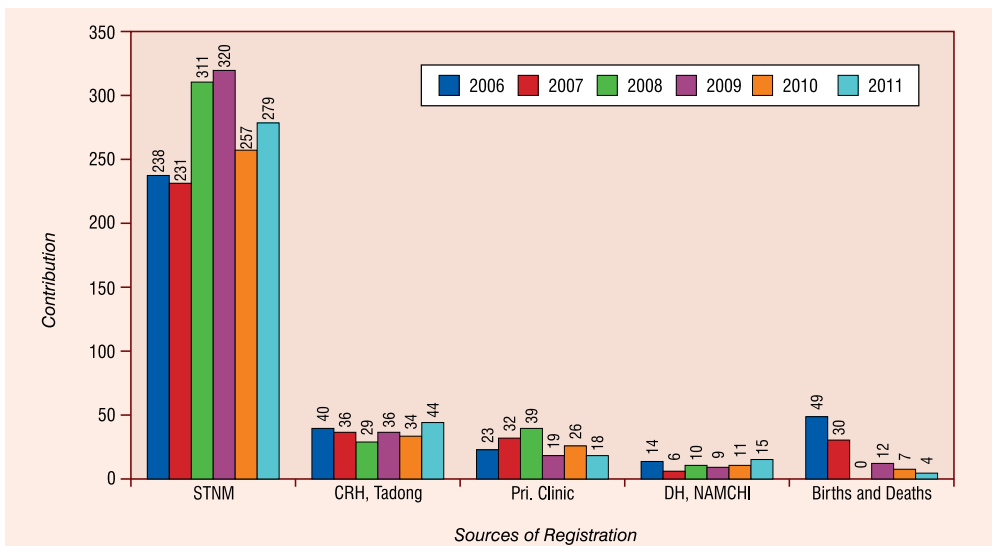


Fig. 9.14: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010

Ahmedabad Rural

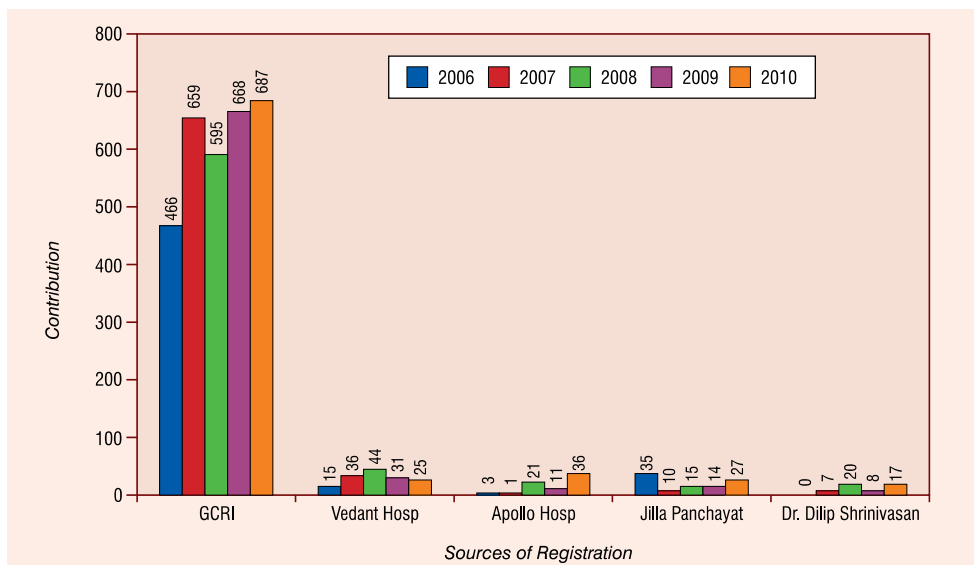


Fig. 9.15: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010

Ahmedabad Urban

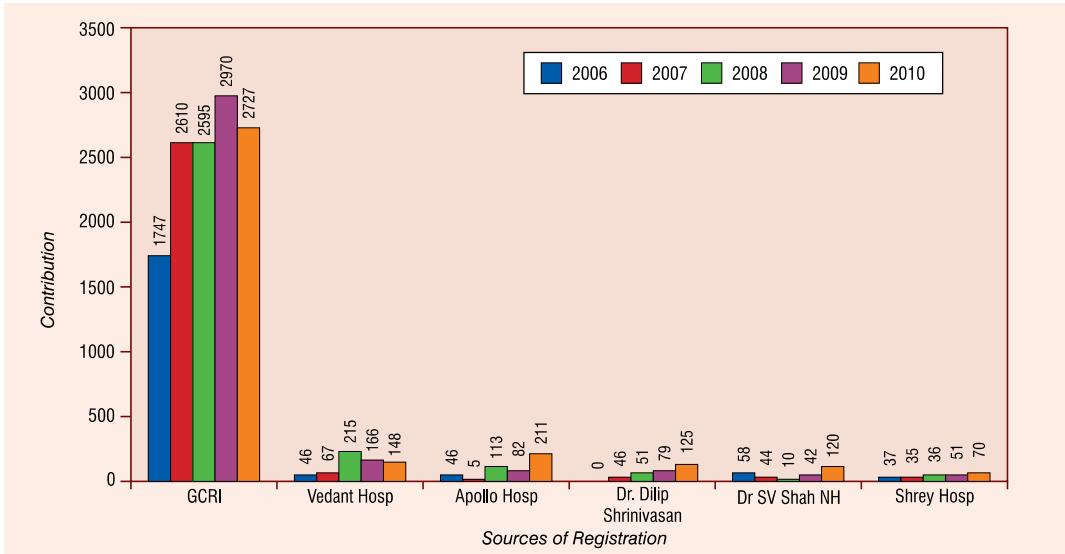


Fig. 9.16: Year-wise Comparison of Data Received from Main Sources of Registration: 2005-2010

Aurangabad

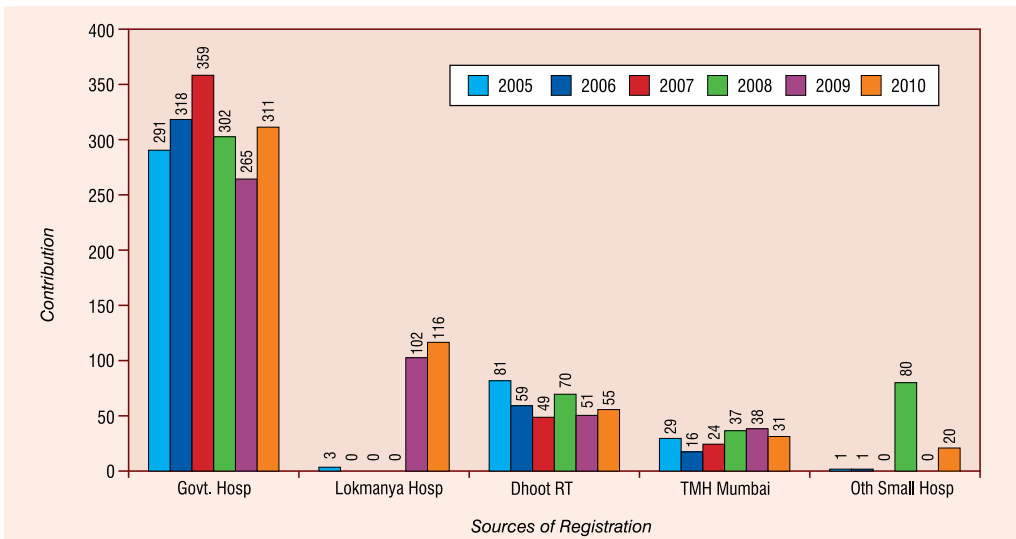


Fig. 9.17: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2009

Kolkata

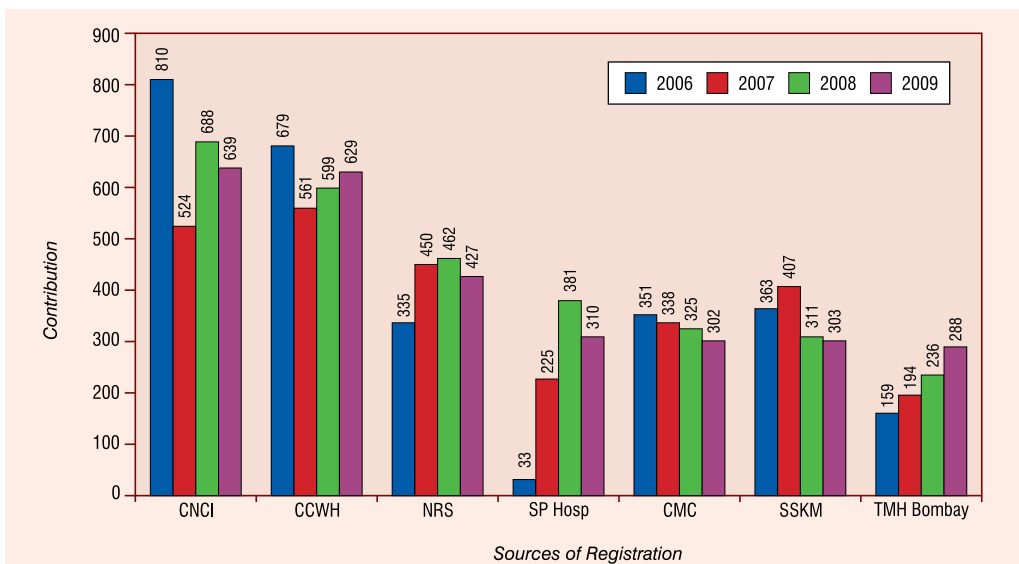


Fig. 9.18: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010

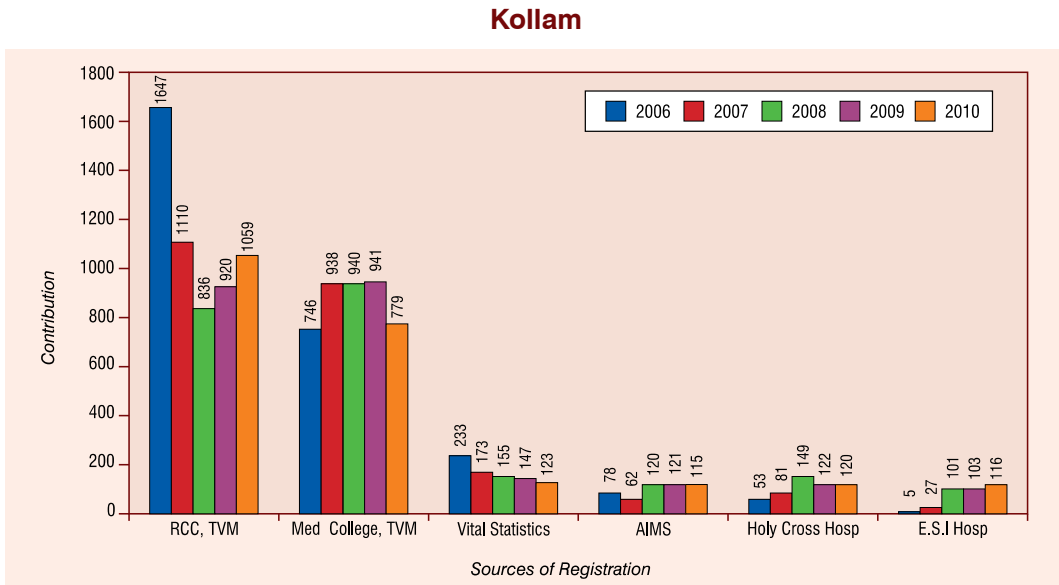


Fig. 9.19: Year-wise Comparison of Data Received from Main Sources of Registration: 2005-2009

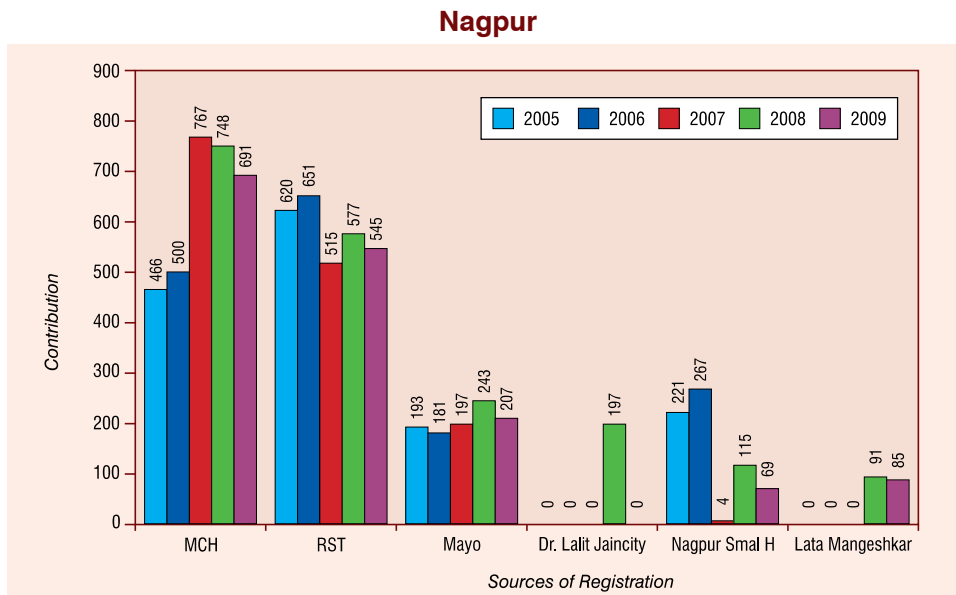


Fig. 9.20: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010 - Pune

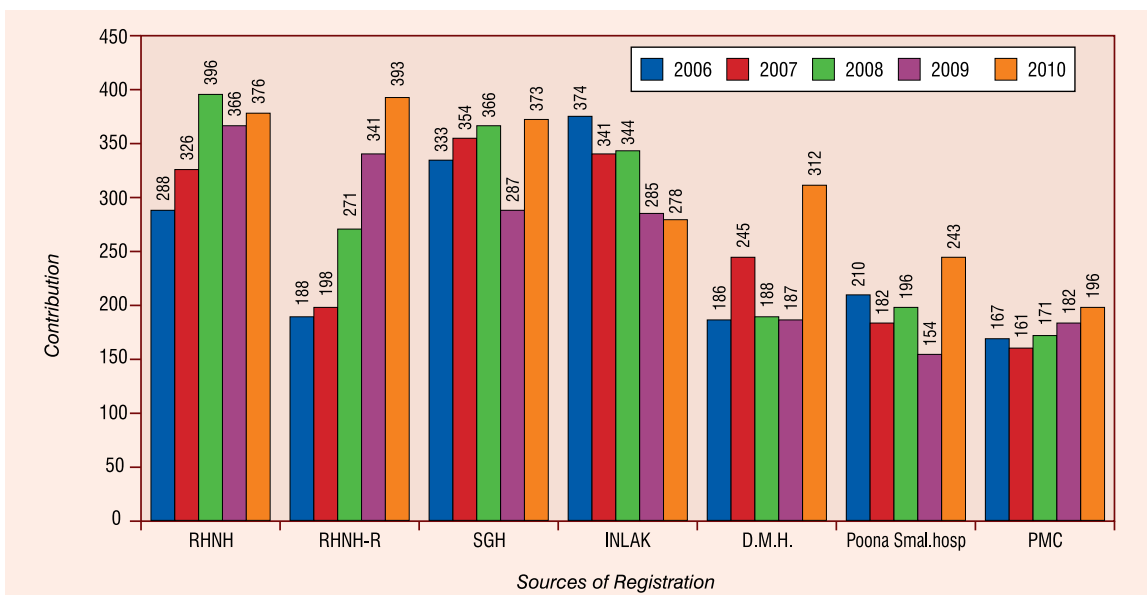
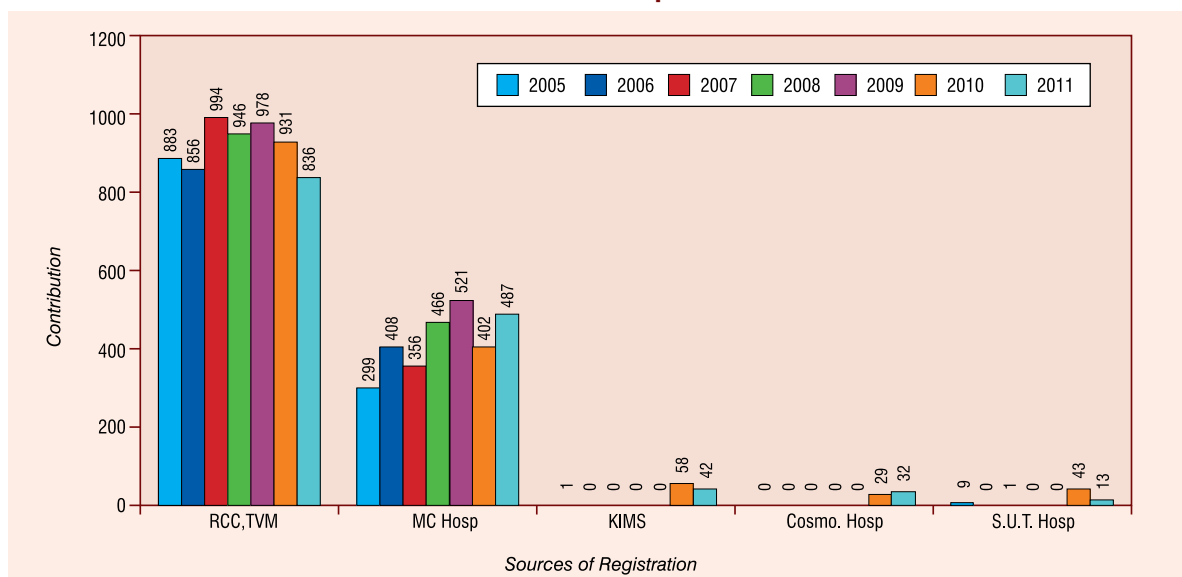


Fig. 9.21: Year-wise Comparison of Data Received from Main Sources of Registration: 2005-2011 Thiruvananthapuram



(b) Resident Unknown

All PBCRs in the Indian setting encounter cancer cases with confirmed microscopic diagnosis but with few other details beyond name, age and sex. Quite a few of these could be cases belonging to the registry area. Such cases if not picked (with residential details) from another source could be “missed”. PBCRs should have the number and records of these cases to estimate the proportion of cases that are likely to be missed.

Attention by the PBCRs to completeness of coverage of cases by a slew of measures as recommended in the XXVIII Annual Review Meeting is essential.

All PBCRs should continue to evolve an action plan for enlisting the cooperation of sources of registration to ensure and consolidate complete coverage of cases in the PBCR area. This includes:

- a) Writing to the respective state governments to make cancer a notifiable disease and following it up till such a legislation is brought about;
- b) Constituting advisory/panel of pathologists/any other committee/groups that would facilitate continued and sustained cooperation of the concerned institutions;
- c) Arranging annual meetings for personnel of at least major sources at different levels:
 - i) Medical records, technical and allied staff;
 - ii) Senior faculty in the critical departments in clinical oncology and pathology;
 - iii) Administrative heads of these institutions;
 - iv) Staff and concerned persons at birth and death registration/state statistical units;
 - v) In PBCRs that cover districts/state, the District Medical Officer/Civil Surgeon and NRHM Chief of the district etc.

Each PBCR should periodically check the data on number of cases received versus the expected cases (based on previous years) from each major source. This could also be calculated month-wise or

on a weekly basis. Besides this, PBCRs in the metros of Delhi, Mumbai, Kolkata, Chennai, Bangalore, Thiruvananthapuram or any other should encourage the major sources including histopathology laboratories to use the HBCR-DM software.

Further Use of PBCRDM Software

Over the years the NCRP and now the NCDIR has evolved (and is still refining) a PBCR software application programme. It has incorporated all the foregoing indices of quality and data coverage outlined in this chapter. However, its full potential would be appreciated and realised if PBCRs quickly get into abstracting and entering the data on to the software of currently diagnosed cases (say within 1-2 weeks of diagnosis). Likewise all deaths with cancer mentioned on the death certificate should also be abstracted and entered within a week of death. Such 'real time' activity by the PBCR using this software would greatly enhance the quality of data and coverage of cancer cases in the registry area. Two critical factors that come into play in the above improvements are (a) Immediate awareness of whether the data abstracted and entered is "correct" in all respects or whether there are any "deficiencies" in the same. (b) Timely action in re-accessing the records and / or consulting with the concerned physician/pathologist in obtaining further details to rectify the "defects". The more the delay in awareness (about the incompleteness and/or inconsistencies) and action taken to go back to the records/physician, the greater the chance of such information not being available at all. So all PBCRs are well advised to rapidly get into current data collection and entry mode. There are several other advantages, the most important being the almost negligible gap between calendar year of data and year of report publication.

** Since morphology is available only through ICD-O-3 (WHO, 2000), the same coding and not ICD-10 has been used to obtain the totals and relative proportions of unspecified histology. Since tumours of the Lymphoid and Haemopoietic system, especially extra-nodal lymphomas would be included under the specific topographic site of ICD-O-3 the numbers could be a few cases more than what has been analysed for other tables based on ICD-10.*

This chapter along with Chapter 5 that addresses the most valid basis of diagnosis of cancer and Chapter 6 dealing with mortality data show the challenges and limitations of cancer registration in the Indian context vis-à-vis International comparisons. Every effort is made by both the individual PBCRs and the coordinators at NCDIR to ensure that the data reported is as correct and as complete as possible. In more recent years the PBCR software applications programme has greatly helped in enhancing the speed of data submission and its quality.