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

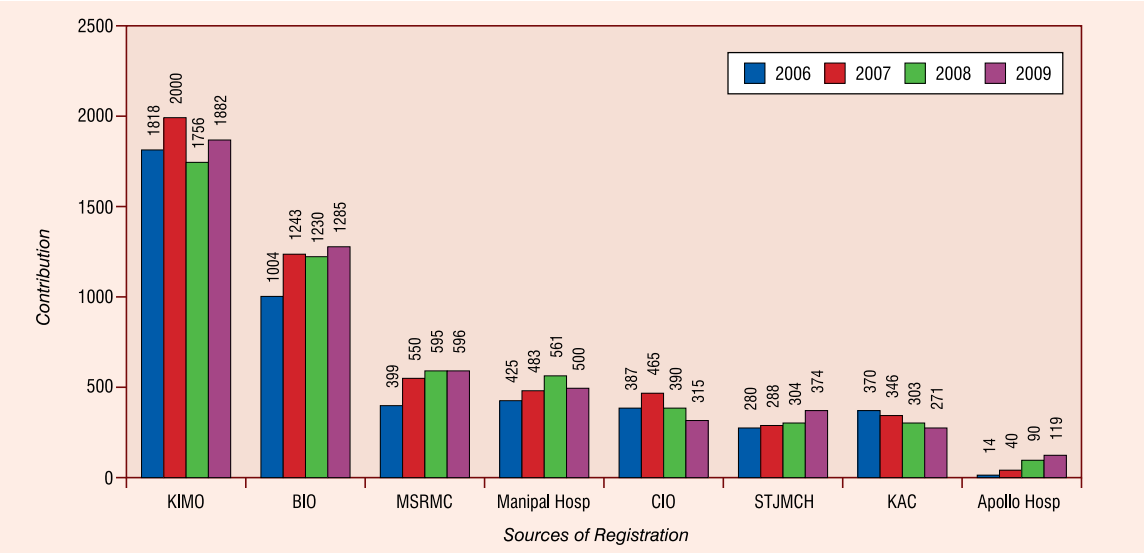


Fig. 9.2: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010 Barshi Rural

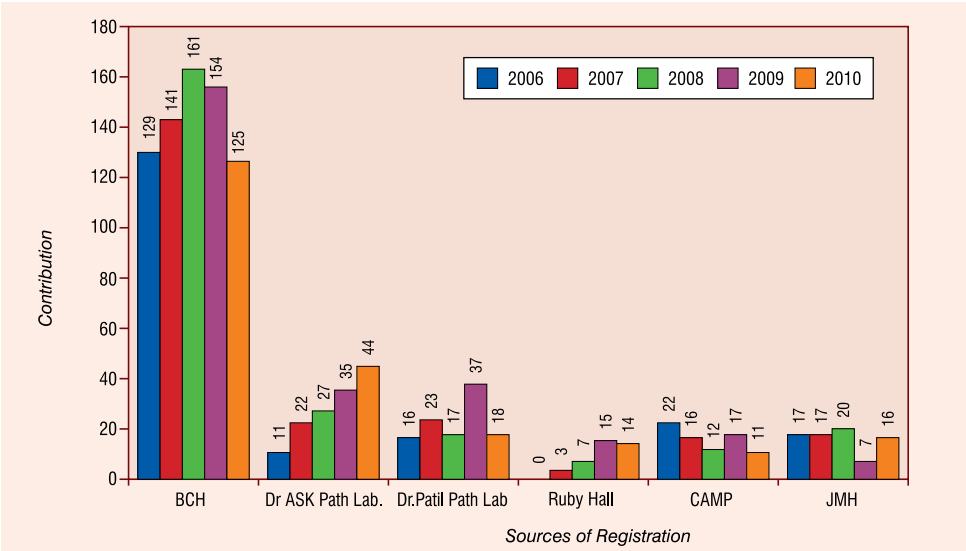


Fig. 9.3: Year-wise Comparison of Data Received from Main Sources of Registration: 2007-2009
Barshi Expanded

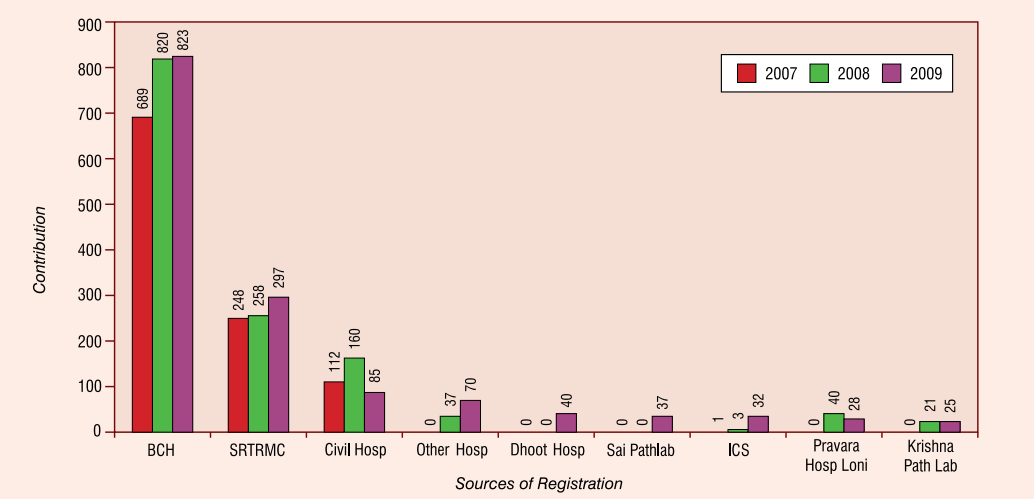


Fig. 9.4: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010
Bhopal

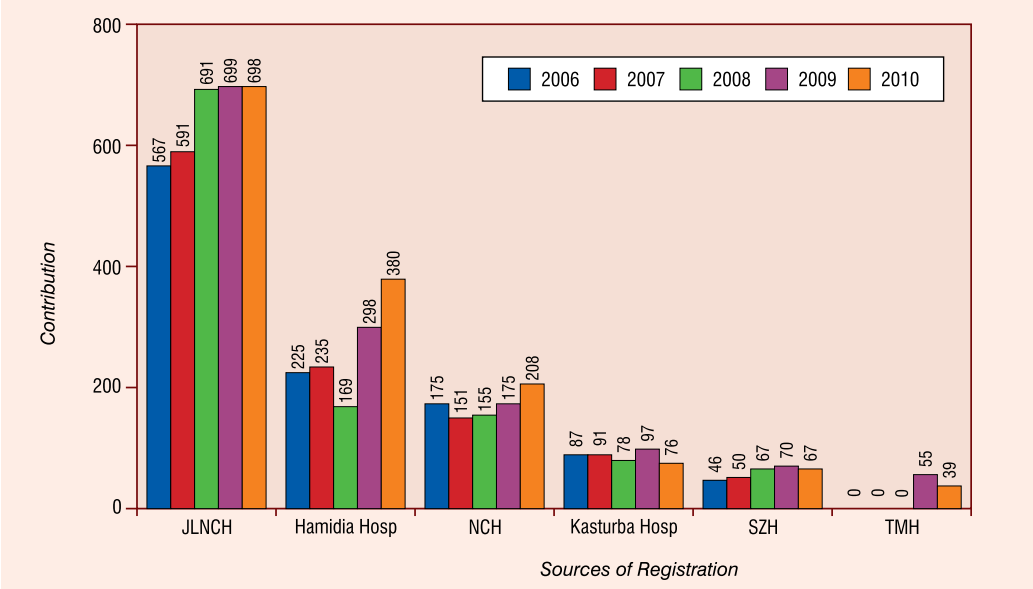


Fig. 9.5: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2009
Chennai

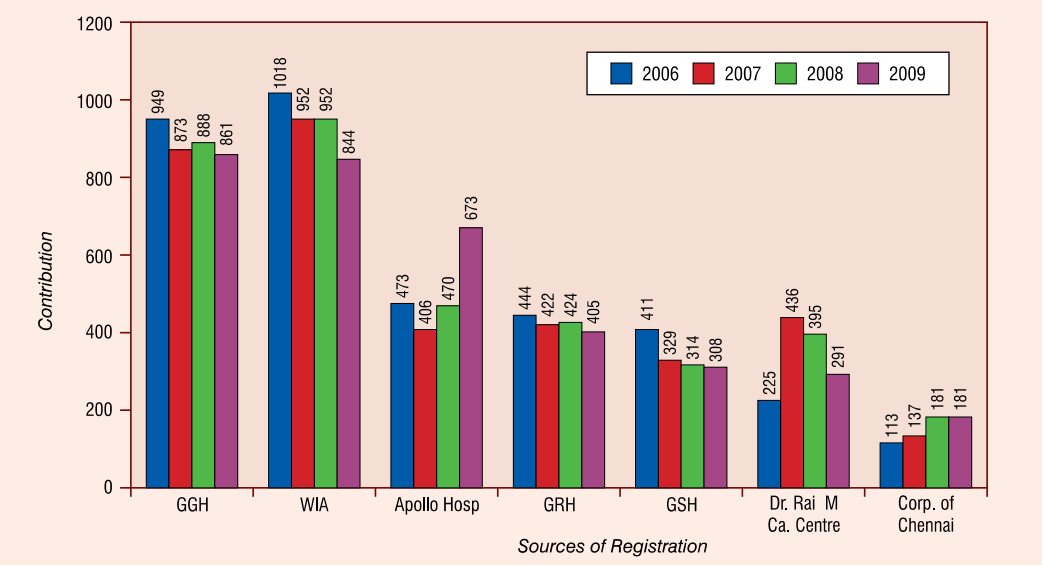


Fig. 9.6: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2009 - Delhi

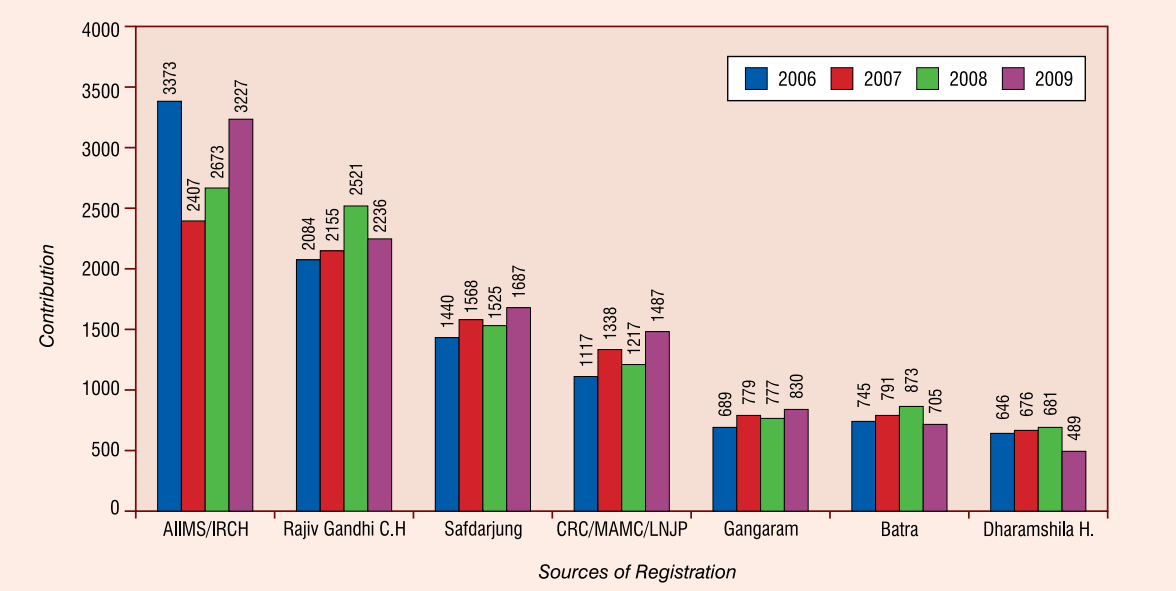


Fig. 9.7: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010

Mumbai

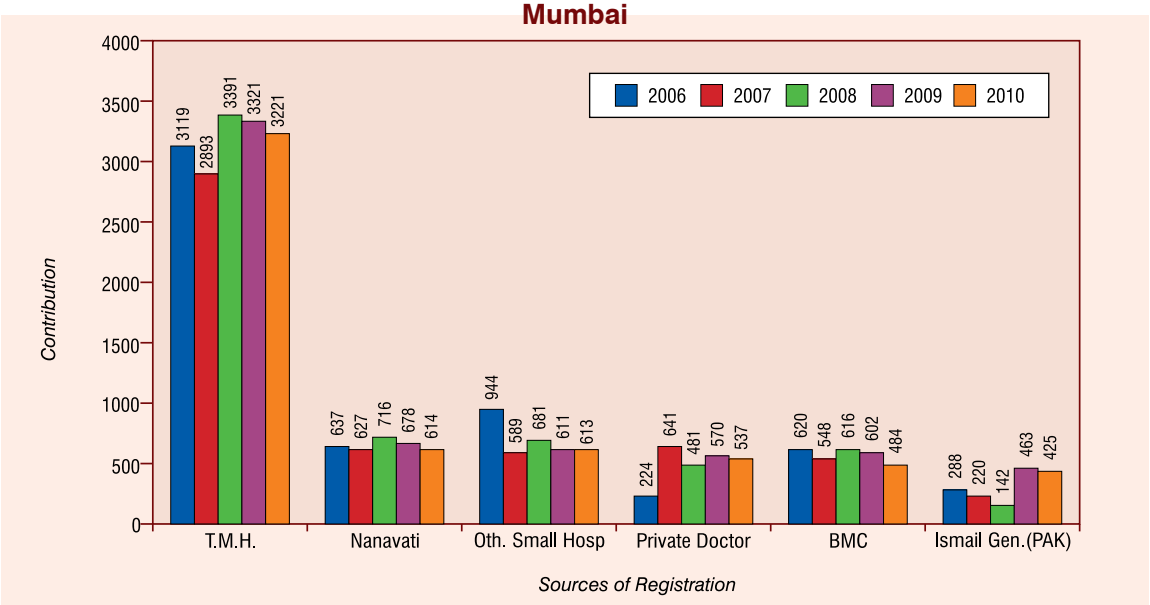


Fig. 9.8: Year-wise Comparison of Data Received from Main Sources of Registration: 2007-2010

Cachar District

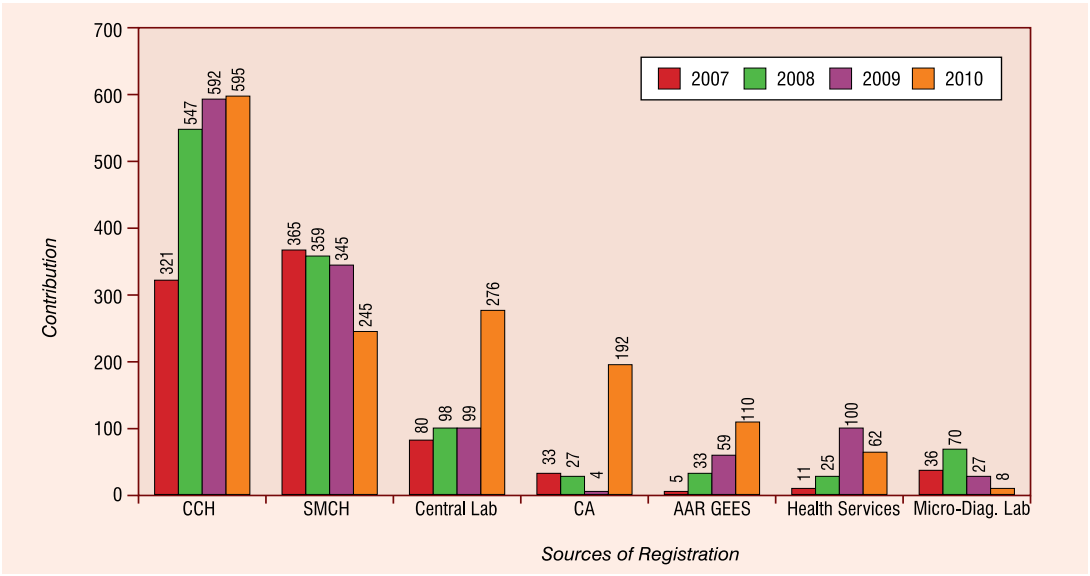


Fig. 9.9: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2011
Dibrugarh District

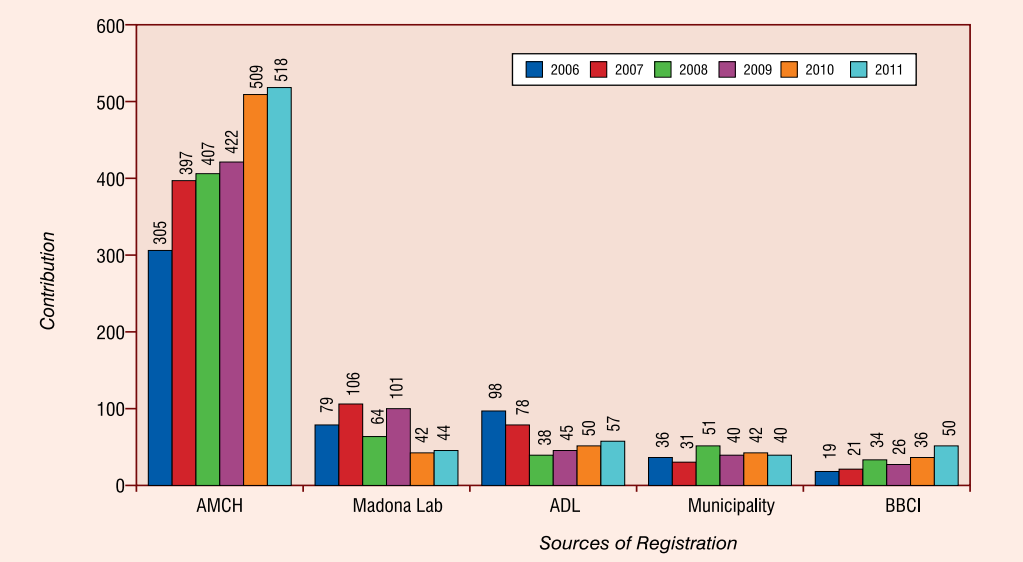


Fig. 9.10: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2011
Kamrup Urban District

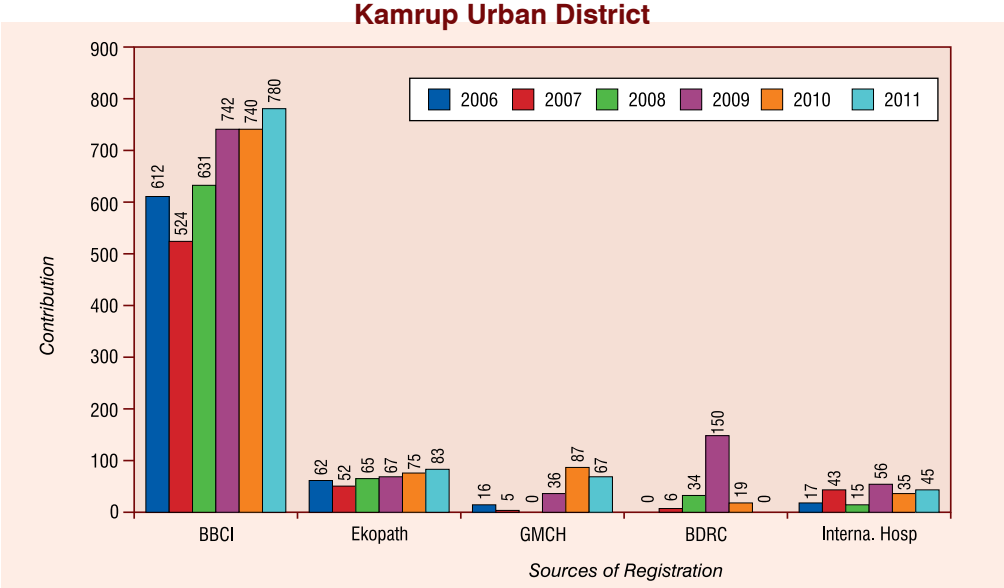


Fig. 9.11: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010
Manipur State

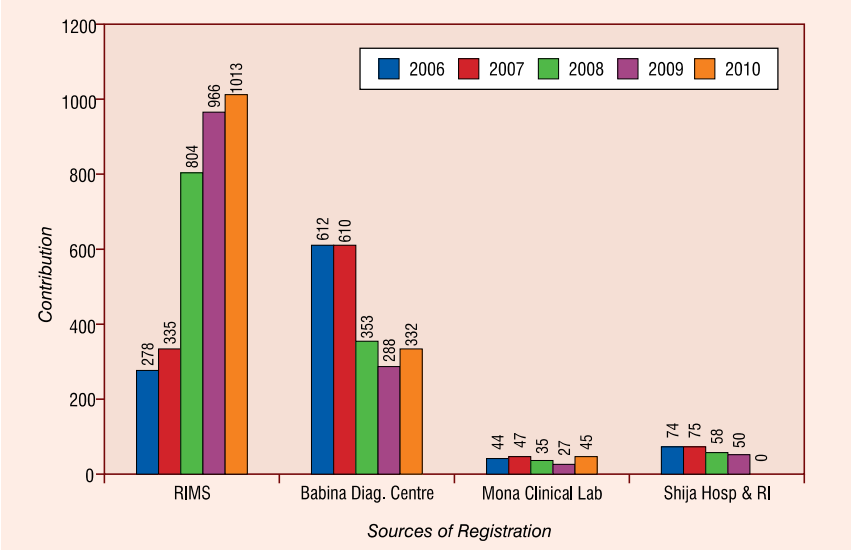


Fig. 9.12: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010

Mizoram State

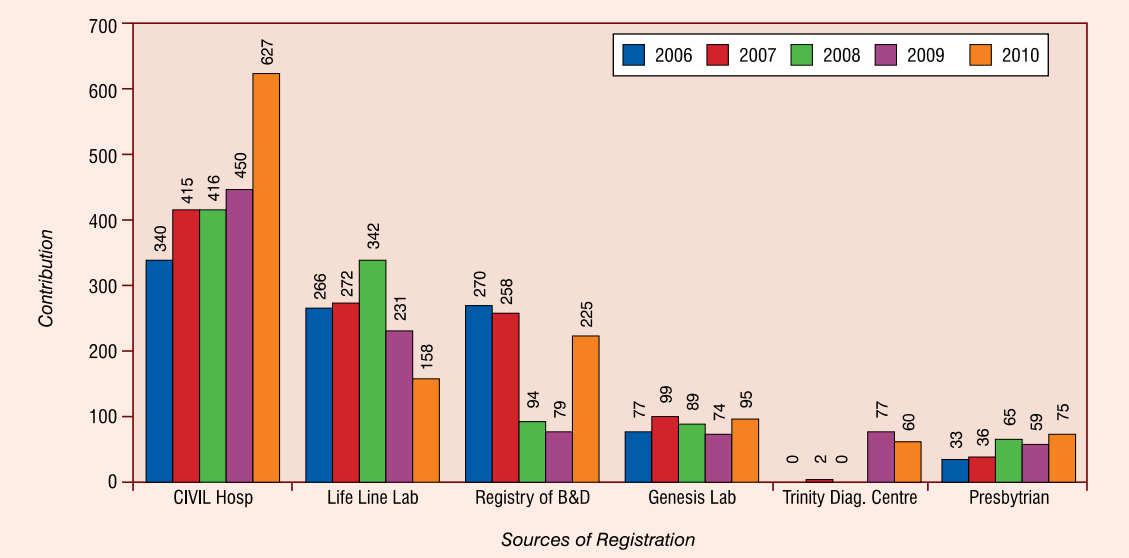


Fig. 9.13: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2011

Sikkim State

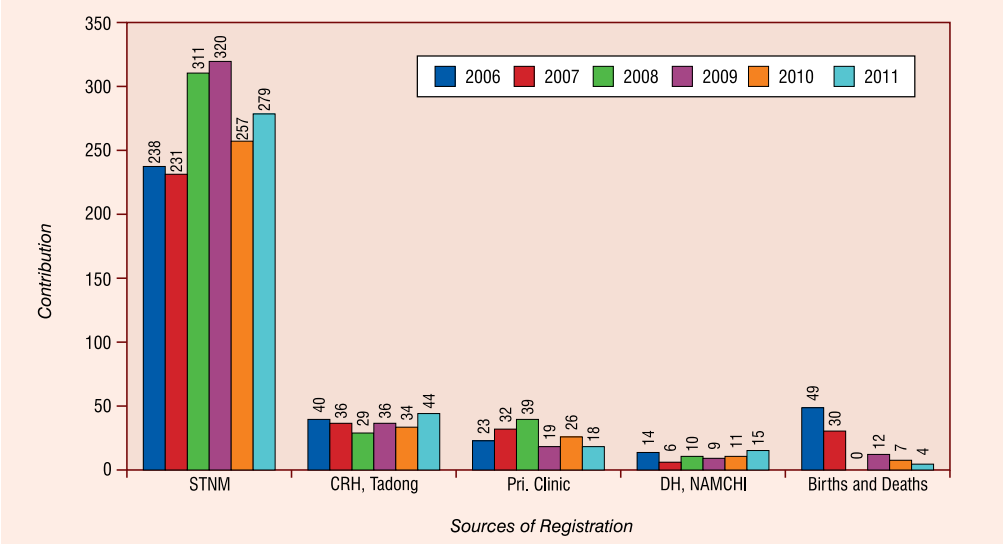


Fig. 9.14: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010

Ahmedabad Rural

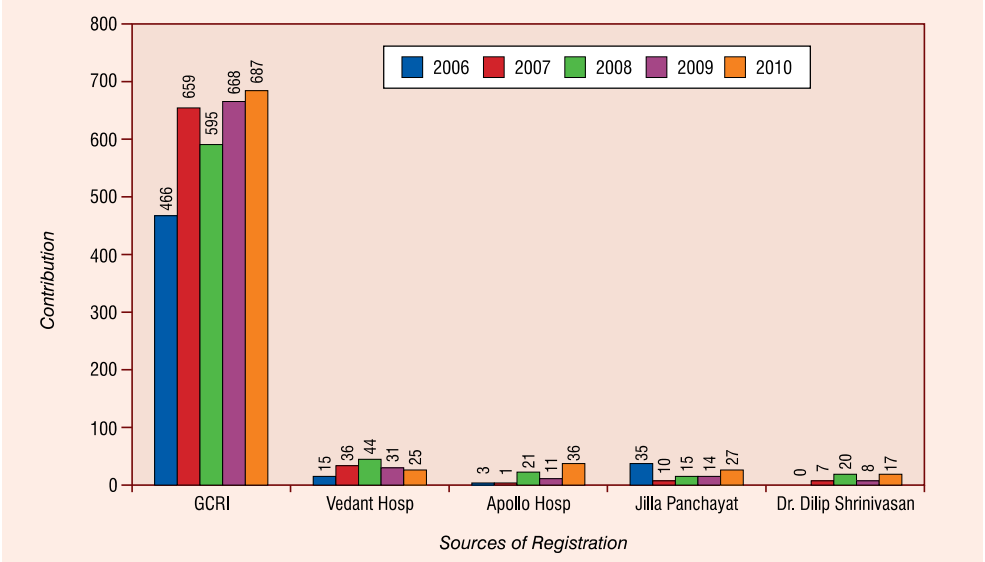


Fig. 9.15: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010
Ahmedabad Urban

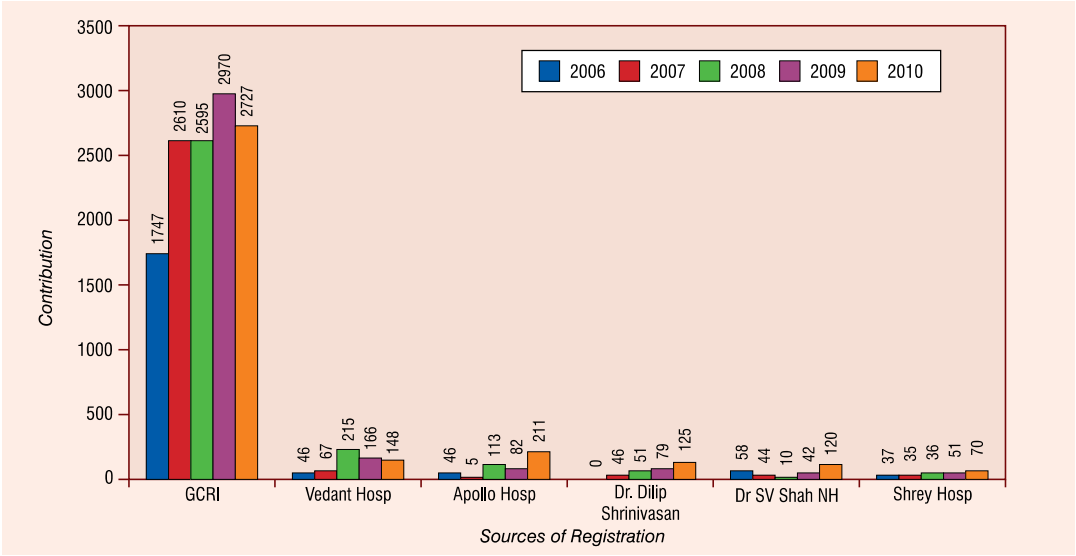


Fig. 9.16: Year-wise Comparison of Data Received from Main Sources of Registration: 2005-2010
Aurangabad

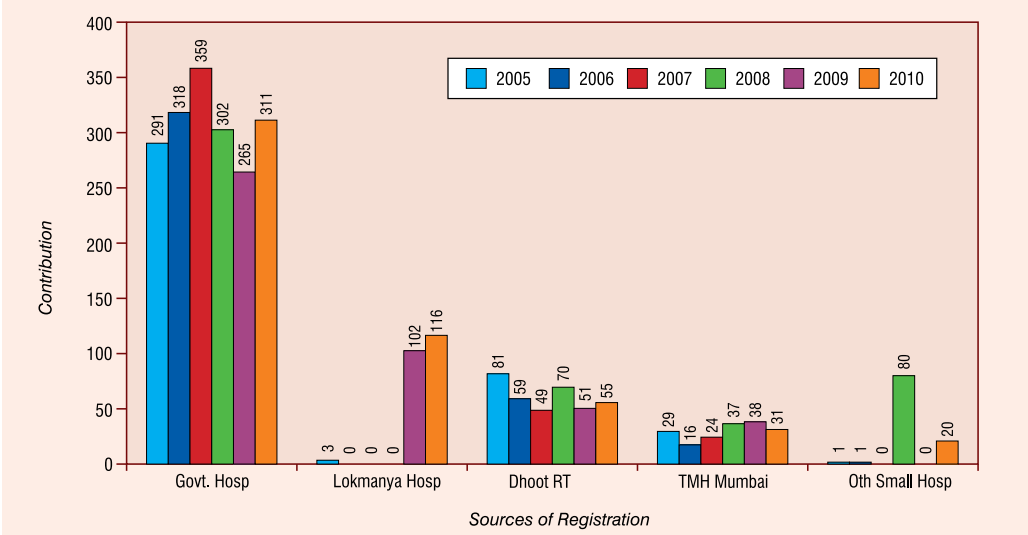


Fig. 9.17: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2009
Kolkata

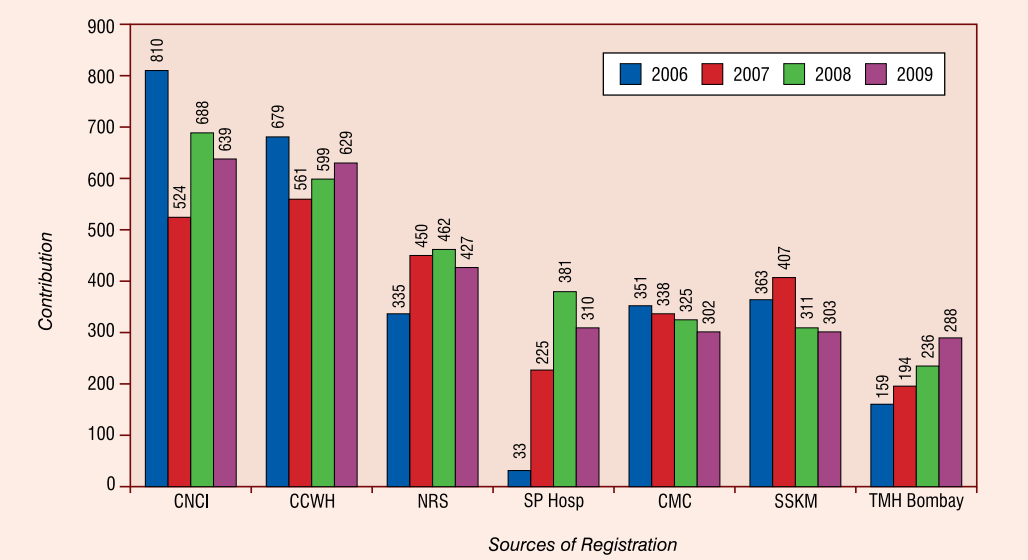


Fig. 9.18: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010 Kollam

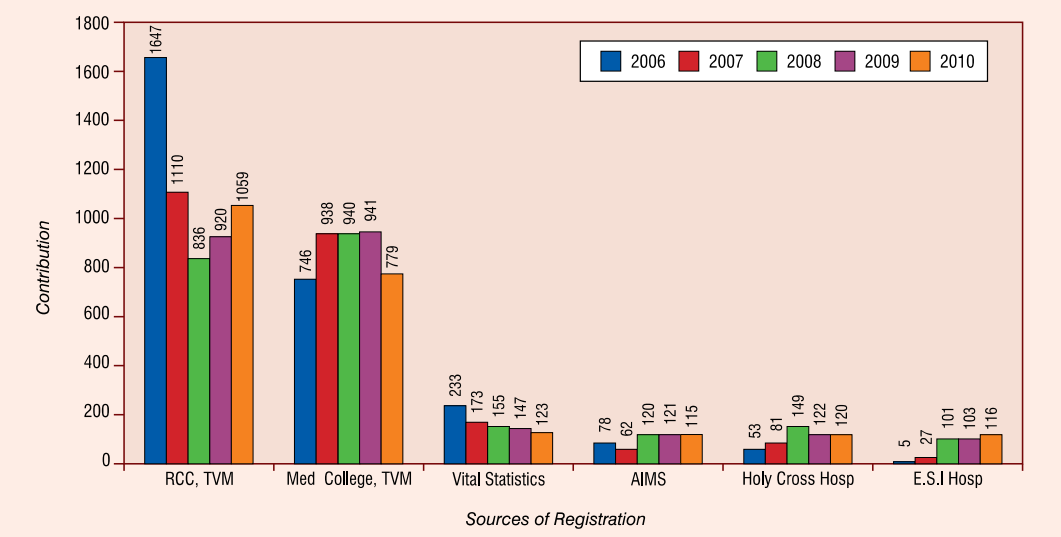


Fig. 9.19: Year-wise Comparison of Data Received from Main Sources of Registration: 2005-2009 Nagpur

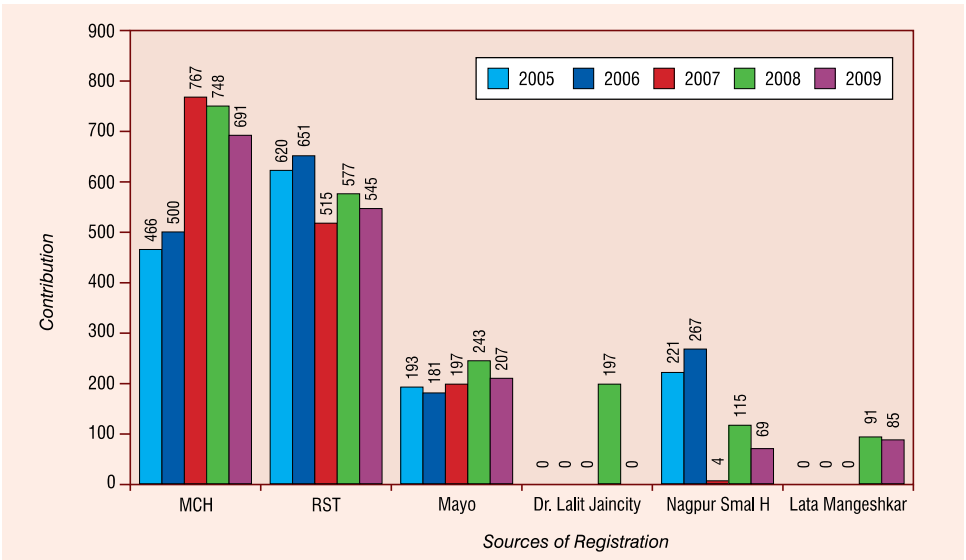


Fig. 9.20: Year-wise Comparison of Data Received from Main Sources of Registration: 2006-2010 - Pune

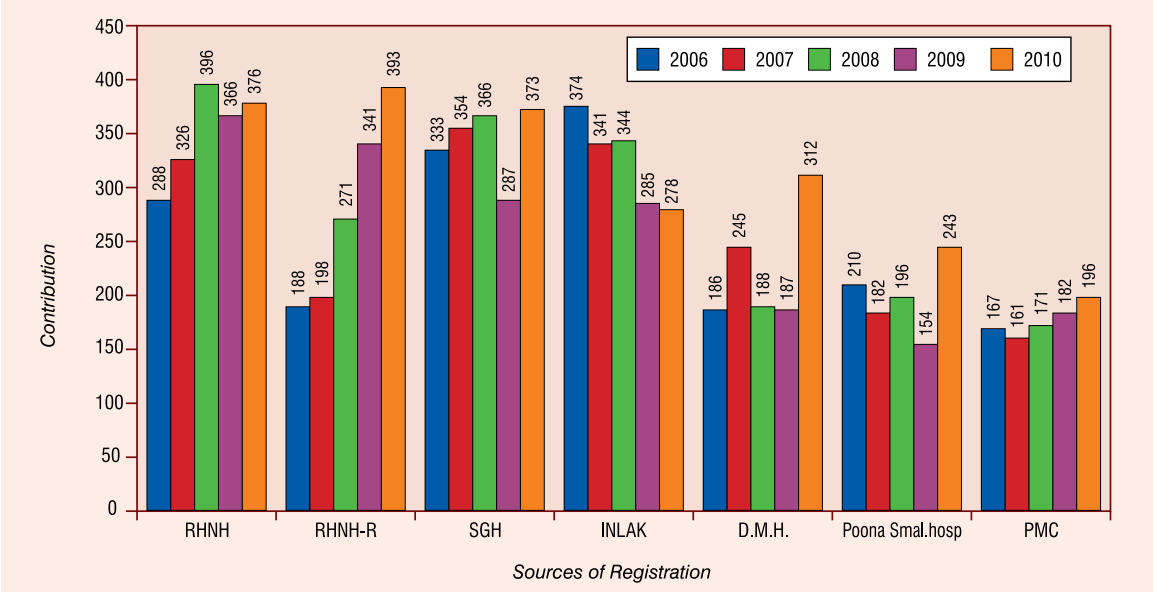
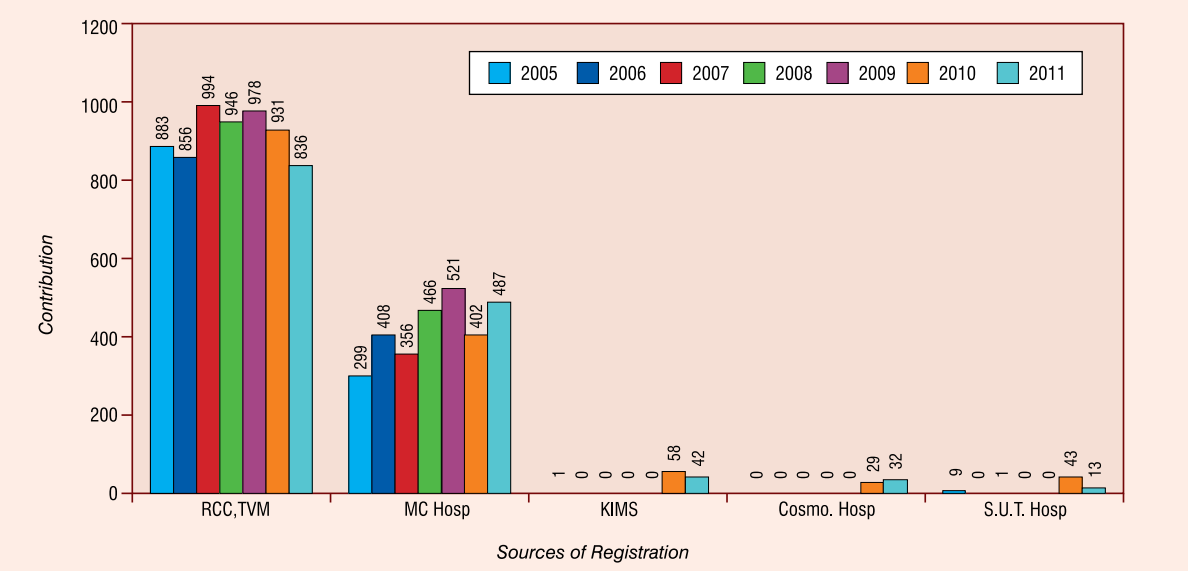


Fig. 9.21: Year-wise Comparison of Data Received from Main Sources of Registration: 2005-2011 Thiruvananthapuram



(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.