

Abstract No. 284 CHALLENGES (AND SOLUTIONS) TO CANCER REGISTRATION

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Introduction

Cancer registries are an essential component of the national effort to initiate cancer control activities. The ultimate aim is to reduce morbidity and mortality due to cancer and this can be done by aggressive and widespread application of the state-of-art methods for prevention, early detection and treatment. It requires the use of cancer registries to focus programs and monitor progress. A network-of cancer registries like in India, has evolved over the years. Population and hospital registries continue to provide information.

Objectives

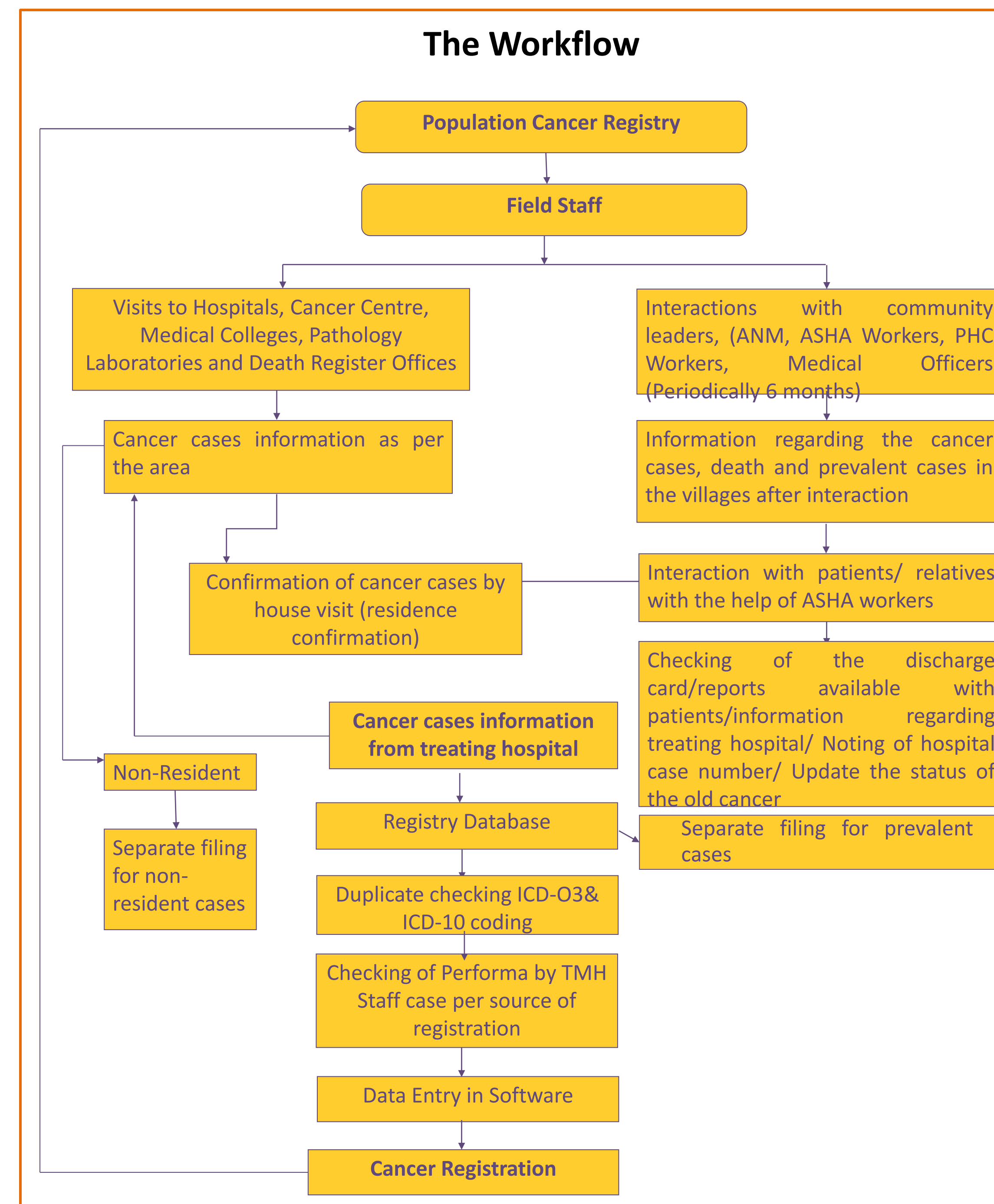
To elucidate the problems and challenges in setting up a rural cancer registry.

Material and Methods

Tata Memorial Hospital Rural Cancer Registries data. However setting up a rural cancer registry in developing countries has many limitations and challenges mainly due to limited resources, infrastructure in health sector. The Tata Memorial Hospital (TMH) has recently set up 9 rural registries, mostly in the nuclear power plant areas, where access to information is a big challenge. Active Registration through visits to Hospitals, Path labs, village Panchayats, Clinics, Municipal death records, PHCs, Local Aanganwadi(Health workers) and House visits. Introduction of Real-Time Data Capture in various registries has been implemented by us.

Results

Preliminary data suggests that the incidence rate are between 30 –60 per 100,000.



Challenges: Tata Memorial Hospital has two types of registries: Near Nuclear Power Plant (NPP) and Other Rural Cancer Registries

The Common Challenges faced by both are :

- Unwillingness of Small Clinics, Hospitals for data sharing (concept behind is Migration of Patients to Large Oncology Centre like Tata Memorial Hospital)
- Rituals like destroying dead patient reports/records by relatives
- Non-maintained Records like address of patients, contact number etc.
- Non-cooperation from patients/relatives (concept behind is social stigma)
- Illiteracy and unawareness about disease and the treatment methods.
- Patients do not go for diagnosis and disease management (concept behind is Cancer as a terminal disease and do not wish to invest in elaborate medical treatment)

The Challenges faced by Registries in NPP Areas are:

- Death due to reasons other than cancer is also reported as a 'Cancer Death' for claiming compensation from NPP
- Population in NPP areas have a Myth that they are at greater risk due to exposure of radiation from NPP and do not wish to communicate with any cancer registry personnel as they see no benefit from it.

Solutions: The Registries were started from 2009 onwards. There has been a continued efforts to develop rapport with the villagers, the health authorities and various medical facilities (nursing homes, laboratories etc)

- Address the community on various health hazards due to Tobacco use, Alcohol Consumption, Unhealthy Dietary practices and Hygiene.
- Conduct Workshops for Continuing Medical Education for Medical Practitioners
- Conduct Cancer Awareness Programmes for the Community and Health Authorities.
- Elucidate the Community on benefits of Health Outcomes in initiating and Setting up Cancer Control Programmes
- Educate the population about the Health Schemes available from Government/ NGOs for Free/ Minimal Cost Treatments
- To obtain the cause of death in cases where no documentation is available by the Verbal Autopsy Method.

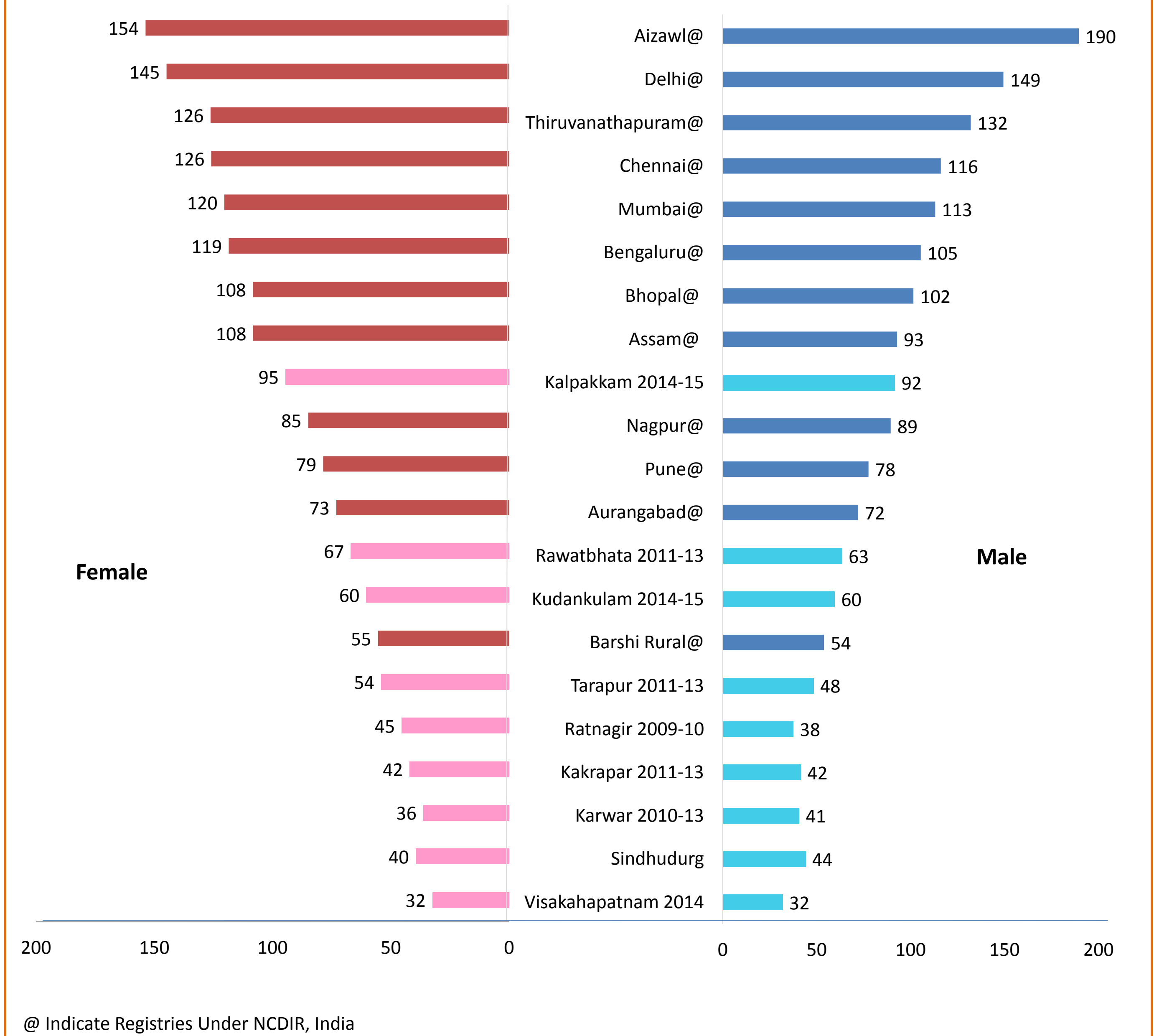
Population, Cancer Numbers and Incidence in Cancer Registries under Tata Memorial Hospital

State	Registry	Year	Population	Male		Female	
				Cases	ASR (/10 ⁵)	Cases	ASR (/10 ⁵)
Maharashtra	Tarapur	2011-14	557721	216	48.3	206	45.4
Karnataka	Karwar	2010-13	156974	129	40.6	187	55.4
Rajasthan	Rawatbhata	2011-13	143477	122	63.4	82	42.0
Gujarat	Kakrapara	2011-13	468183	260	41.5	225	32.4
Tamil Nadu	Kudankulam	2013-14	3067428	1881	59.5	2322	66.9
Tamil Nadu	Kalpakkam	2013-14	4157956	3556	91.6	4452	108.2
Maharashtra	Ratnagiri	2009-12	1621083	672	46.7	811	46.4
Maharashtra	Sindhudurg	2010-11	849651	375	44.1	348	36.3
Andhra Pradesh	Visakhapatnam	2014	2238961	333	31.8	615	54.1

Leading Sites of Cancer in Various Locations

Registry	Site	Male		Female		
		Number	ASR (/10 ⁵)	Number	ASR (/10 ⁵)	
Tarapur	Mouth	31	6.2	Breast	49	10.2
	Tongue	21	4.5	Cervix	24	5.2
Karwar	Lung	16	5.2	Breast	67	19.6
	Mouth	13	3.8	Cervix	18	5.5
Rawatbhata	Lung	17	8.9	Cervix	14	7.7
	Mouth	17	8.4	Breast	14	7.0
Kakrapara	Tongue	62	8.9	Cervix	65	9.7
	Mouth	54	7.9	Breast	58	8.0
Kalpakkam	Stomach	395	10.1	Breast	1256	29.9
	Lung	308	8.1	Cervix	874	21.5
Kudankulam	Stomach	268	8.4	Breast	694	19.7
	Lung	181	5.8	Cervix	460	13.2
Ratnagiri	Mouth	134	9.6	Breast	227	13.4
	Tongue	56	4.0	Cervix	99	5.6
Sindhudurg	Mouth	79	9.5	Breast	106	11.4
	Tongue	37	4.5	Mouth	36	3.6
Visakhapatnam	Lung	38	11.4	Breast	203	33.0
	Stomach	36	10.8	Cervix	118	19.2

Cancer Incidence Rates (ASR per 10⁵) in Indian Registries



Conclusion

Problems in Cancer Registration in developing countries are well-known; nonetheless, due to the continued efforts and pursuance and hard work of the registry personnel, we could overcome many of the problems/hurdles during the past years. Results of these registries are presented along with the challenges faced during it operations and this efforts have given lessons and methods on how to overcome the problems faced in the rural areas of India. Results suggest that the compliance of medical facilities personnel, district authorities have improved and the outcomes are a proof of the cooperation given by the various authorities. In just a few years time, the registry data has given a leads on the cancer burden in the community. Results of these registries are comparable with those of the Indian Rural Cancer Registry in Barshi.