

Abstract NO. 27 Challenges in Setting-up Special Registries and its functionality in India

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INTRODUCTION

Cancer registries are an essential component of the national effort to initiate cancer control activities by setting up Hospital based cancer registry (HBCR) and Population based cancer registry (PBCR).

OBJECTIVES

To elucidate and overcome the data accrual hurdles in the Nuclear Power Plant Locations, Special registry areas and obtain incidence and mortality rates in this area.

MATERIAL & METHODS

Four PBCRs were setup in NPP locations in India under Tata Memorial Centre (TMC), Mumbai since 2012. They are located in Palghar (Maharashtra), Kaiga (Karnataka), Kakrapara (Gujrat) and Rawatbhata (Rajasthan). Data collection: (i) Visit to hospitals, pathology laboratories, vital statistics department, primary health centres, Anganwadis etc. after due notifications and permissions. (ii) By telephone calls. Tools: (i) A pre-designed core proforma after pilot testing, that included demographics, diagnosis, site and histology, clinical extent of disease, staging and treatment details and follow up was used. (ii) Tablet-PC was utilized to capture data and record it in real time, besides a hard copy of proforma, helping in quick transmission of data to the central registry database in TMC, which is useful to check duplicates, incomplete cases etc. online.

RESULTS

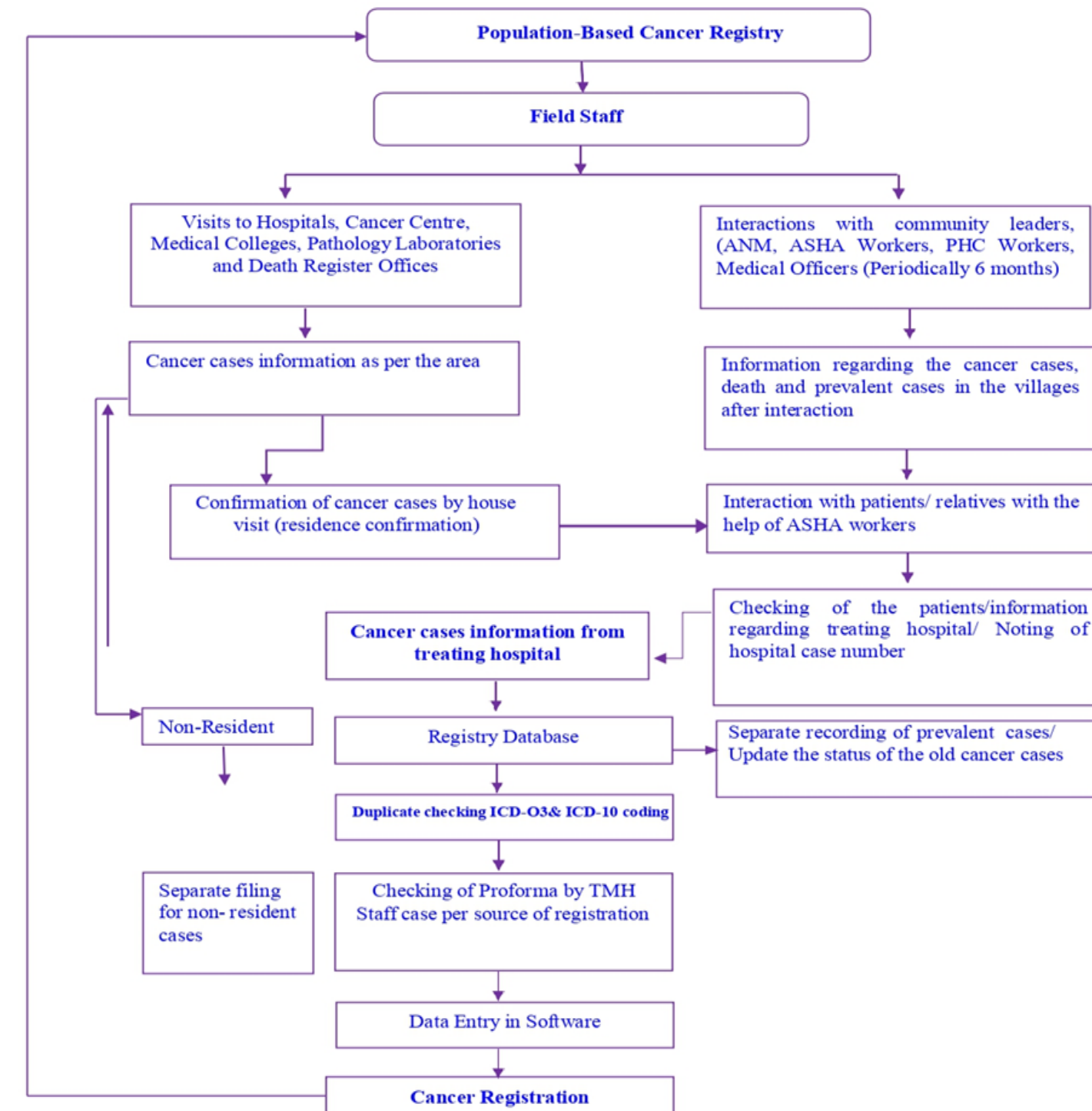
It was a challenge to collect data from NPP location population due to non compliance from source and patients etc. Operational cost was different for each registry. The cost per case in low volume registry ranged from 11,000/- in Palghar to 14,350/- in Kaiga. Till date in the last 8 years, the four registries have accrued more than 10,000 cases and coverage improved over the years due to counselling and better awareness.

World Scenario

Incidence Rate per 10⁵

| | India (ASR) | World (ASR) |
|--------|-------------|-------------|
| Male | 96 | 206.9 |
| Female | 99 | 178.1 |

TMH network of cancer registries in Nuclear Power Plant areas



The Challenges faced are :

- Unwillingness of Small Clinics, Hospitals for data sharing (concept behind is Migration of Patients to Large Oncology Centre like Tata Memorial Hospital)
- Non-maintained Records like address of patients, contact number etc.
- Rituals like destroying dead patient reports/records by relatives
- 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 may 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.

Challenges of PBCRs- specifics

Low Coverage

Coverage of areas based on geographical boundary is of primary importance.

In India there is only a 10% coverage (PBCR, 2018), and further 0.1% coverage of the rural population of India (Gajalakshmi et al., 2001).

The special registries, NPCIL-location registries, are rural-based and the common hardships of obtaining information remains.

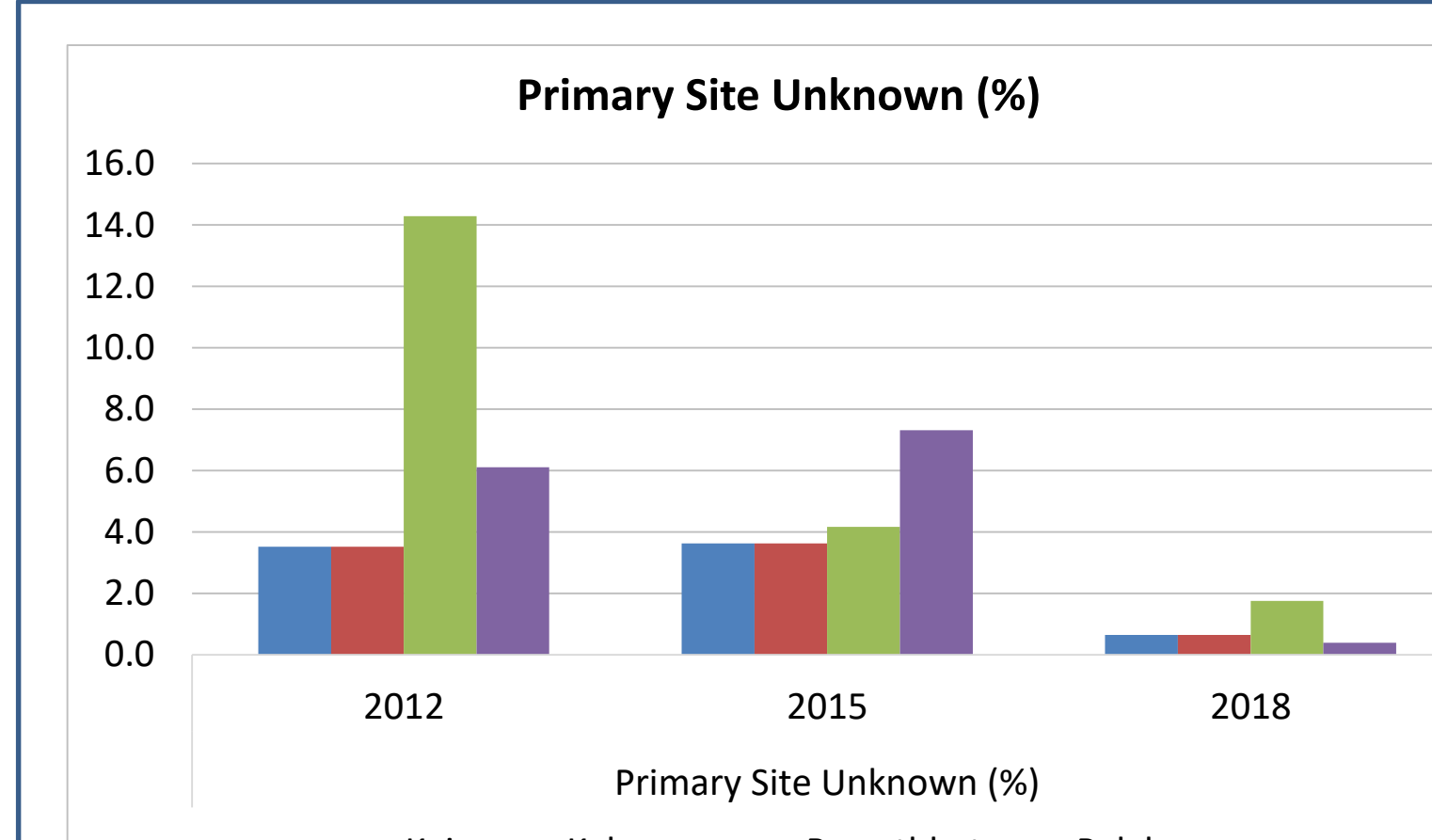
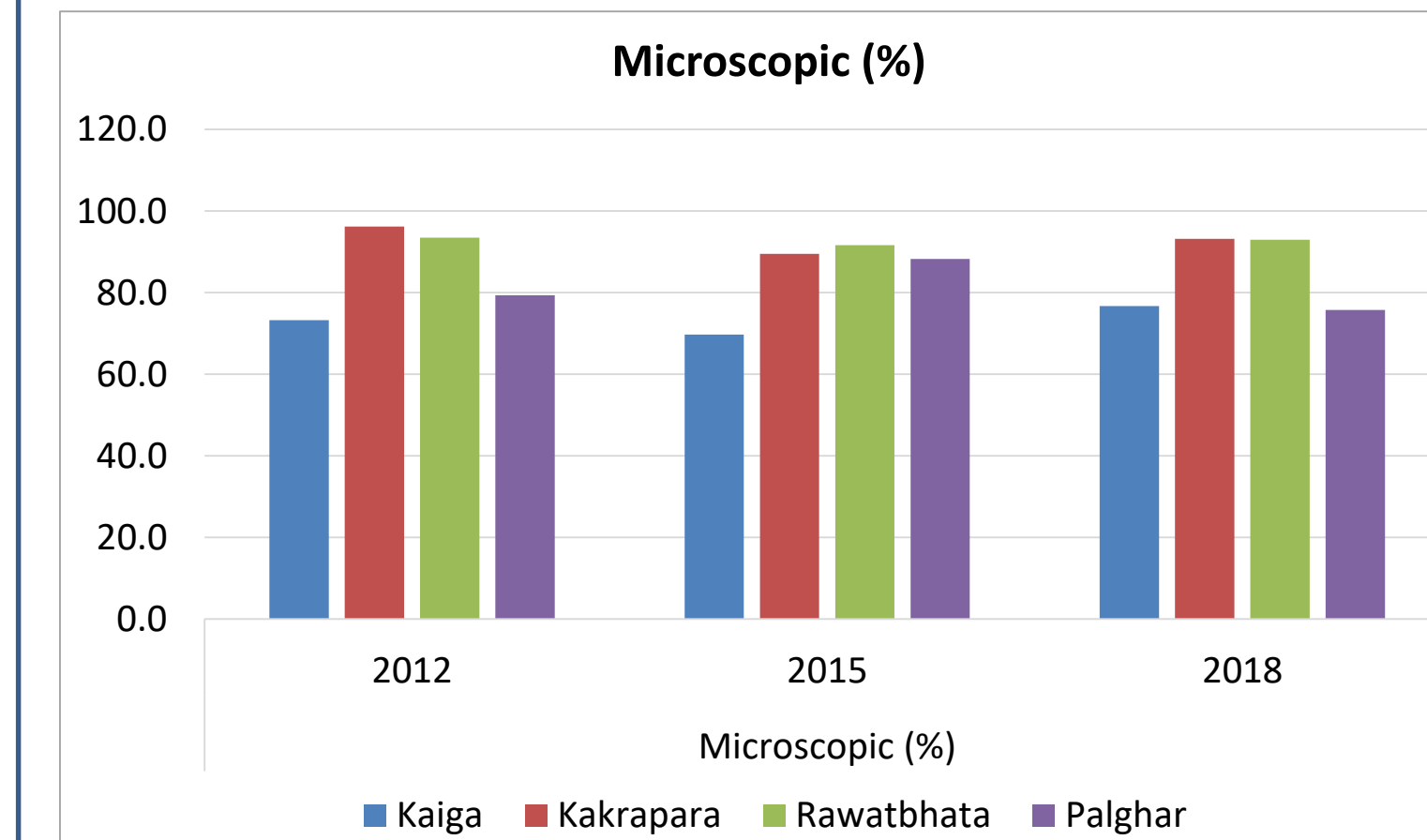
Thus it is seen that cancer data are missing from a large part of the country. However a continued effort and pursuance by the field investigators of registry have shown improvement in coverage over the years from the year 2012 onwards till date.

Urban Dominance

- Rural India constitutes approximately 68% of population (more than 2/3 rd) (World Bank, 2015).
- Most of the PBCRs in India are urban-based and only 2 are rural-based, under NCDIR. In India, there are only two PBCRs which are currently covering only rural population and 11 PBCRs which cover both urban and rural populations (PBCR, 2018).
- In 2012, TMC set up six NPCIL-location rural-based cancer registries, all covering the rural area population. So there is a urban-dominance of registries in India and representation of cancer burden in India is urban-based, and not necessarily true representation of cancer burden in India, as whole.
- NPCIL-location registries, being primarily rural has problems with different dimensions; availability of information, non-co-operation from some sources of data/ compliance etc, myth of radiation-exposure due to NPCIL plants etc add more woe to collection of complete information.

Low awareness among rural population of India

Most of the Indian population live in rural areas. There is lack of awareness in these areas, since access to health care facilities is also less and they have to travel to urban areas for health care. Further the literacy in rural areas is also very less compared to urban India. Summarily, there are low socio-economic class people in these rural areas, and what they seek is basic need, food etc., for survival. Many may be dying due to cancer without being diagnosed. Like in any other rural areas, NPCIL-location registries have similar problems; inadequate health care access and facilities.



| Summary- NPP-location Registries Outcome | | | | |
|------------------------------------------|---------|--------------------------------|-------------------|--------|
| Registry Name | Year | Estimated Population (in lacs) | ASR (per 100,000) | |
| | | | Male | Female |
| Palghar | 2017-18 | 5 | 57.9 | 56.9 |
| Rawatbhata | 2017-18 | 1.6 | 48.6 | 47.8 |
| Uttara Kannada | 2017-18 | 4 | 68.1 | 62.3 |
| Kakrapar | 2017-18 | 5.02 | 67.1 | 28.7 |

| Leading Sites | | | | |
|---------------|--------|-------------------------|--------|-------------------------|
| Registry Name | Site | Male | Site | Female |
| | | ASR (/10 ⁵) | | ASR (/10 ⁵) |
| Tarapur | Mouth | 12.6 | Breast | 16.6 |
| | Rectum | 3.9 | Ovary | 6.3 |
| Karwar | Mouth | 16 | Breast | 17.5 |
| | Tongue | 6.1 | Cervix | 6.1 |
| Rawatbhata | Lung | 10.8 | Breast | 16.5 |
| | Mouth | 7 | Cervix | 5.3 |
| Kakrapara | Mouth | 27.2 | Cervix | 8.2 |
| | Tongue | 17.4 | Breast | 5.2 |

| Registry coverage | | | |
|-------------------|----------------|------------------|-------------------------|
| Registry Name | Area (Sq. km) | Total Population | Sources of Registration |
| Palghar | 9558 | 603379 | 29 |
| Kakrapar | 731 | 480229 | 28 |
| Karwar | 732 | 405122 | 36 |
| Rawatbhata | 1643 | 151327 | 29 |

Cost per case for Various Registries

| Registry | No. of Cases | Cost/Case (in Rs) |
|----------------------|--------------|-------------------|
| Kaiga, Karnataka | 300 | 11000 |
| Kakrapara, Gujrat | 205 | 10732 |
| Rawatbhata, Rajstan | 70 | 15860 |
| Tarapur, Maharashtra | 260 | 10769 |

| Country Income Category * | | | | |
|----------------------------------------|-------------------------|----------------------------|-------------------------|-------------------------------------|
| Registry | Low Income | | Lower-Middle Income | High Income |
| | Kampala Cancer Registry | Zimbabwe National Registry | Nairobi Cancer Registry | Seychelles National Cancer Registry |
| Total cost per case in US Dollars (\$) | 8.62 \$ = Rs.690 | 10.45\$ = Rs. 836 | 33.19\$ = Rs 2655 | 95.63\$ = Rs. 7650 |

* J Registry Manag. 2019 Winter; 46(4): 114–119.

DISCUSSION & CONCLUSION

Some cost differences by volume is explained by the large fixed cost required for administering and performing registration activities due to difficult geographical terrains and automation will improve data collection potentially and reduce overall costs. 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.