

Chapter - 1 Introduction

1.1 Burden of cancer

Cancer is a prominent cause of morbidity and mortality worldwide and in India as well. In 2020, the estimated number of cancer cases globally was 19.3 million, with 10 million reported deaths [1]. Cancer cases were higher in males (10.06 million) than females (9.22 million). Cancer is also ranked the second leading cause of death globally, following deaths due to cardiovascular reasons [2]. India reported an estimated 1.39 million new cancer cases in 2020 [3]. In 2016, cancer contributed to 8.3% of deaths and 5.0% of Disability Adjusted Life Years (DALYs) in India in 2016, which was twice its contribution in 1990 [4]. Among these, stomach cancer contributed to the highest proportion of DALYs (9%), followed by breast cancer (8.2%) and lung cancer (7.5%). The incidence, mortality, and cumulative risk of developing cancer has been consistently high in the Northeastern Region of India.

The region has a unique cancer profile compared to the other areas of the country. Aizawl district in Mizoram recorded the highest Age-Adjusted Incidence Rate (269.4 per 100,000) in males, and Papumpare district in Arunachal Pradesh recorded the most elevated AAR (219.8 per 100,000) in females for all cancer sites [3],[5]. Likewise, the crude mortality rate of cancer was highest in males (115.0 per 100,000) and females (69.6 per 100,000) in Aizawl district of Mizoram state. Pooled analysis of cancer data in all eight states of the NER showed that the leading sites in males included cancer of the oesophagus (13.6%) followed by lung (10.9%). At the same time, in females, the breast was the top site (14.5%), followed by the cervix uteri (12.2%). The probability of developing cancer in any target organ over a lifetime was highest for both the genders in Kamrup urban in Assam (1 in 4 males and 1 in 6 females). Close to half of the cancers (49.3%) among males in the NER were cancers in sites associated with tobacco use.

1.2 Risk factors of cancer

A risk factor is any attribute, characteristic or exposure of an individual which increases the likelihood of developing a disease. Cancers share several common risk factors, and comparable health system needs with other significant NCDs (cardiovascular

diseases, diabetes, stroke, chronic obstructive pulmonary disease and chronic kidney disease) for prevention, early detection and control. These include major behavioural and metabolic risk factors such as tobacco use, unhealthy diet, inadequate physical activity, alcohol use, raised blood glucose and overweight/obesity. There is sufficient evidence that besides lung cancer, smoked tobacco is causally associated with cancer of the mouth, gastrointestinal tract, urinary bladder and pancreas [6],[7]. Smokeless tobacco has been linked with a high chance of oral potentially malignant diseases (OPMD) and cancers of the head and neck and oesophagus [8],[9]. The International Agency for Research on Cancer (IARC) has identified the following sites of cancer that are causally associated with alcohol use: cancers of the oral cavity, pharynx, larynx, oesophagus, liver and female breast [10]. Similarly, for obesity, cancers with convincing scientific evidence of a causal link with obesity and overweight; include oesophageal adenocarcinoma and cancers of the colon, rectum, kidney, pancreas, gallbladder, postmenopausal breast, corpus uteri, and ovary [11].

India state-level disease burden report (2017) indicates that behavioural risk factors account for a significant proportion of DALYs [4]. In the Northeast states, the prevalence rates of smoking and drinking were estimated to be 11.4% and 9.1%, while almost two-thirds of the population consumed a diet low in fruits [4]. Similarly, the summary exposure value for metabolic risk factors such as high body mass index and fasting glucose has increased by 105.9% and 19.9% from 1990 to 2016. A consensus is that about 60 per cent of cancer deaths can be averted with adequate preventive measures and early detection by screening [12].

1.3 Health system preparedness for cancer care

Apart from behavioural and environmental risk factors, the challenges to tackle NCDs are compounded by the state of the health care system. The burden of cancer in India is linked to inequities in health care access and uneven distribution of infrastructure and human resources across the country. Report of the World Cancer Initiative on 'Cancer preparedness index' places India on a much lower rank on the 19th position among the 28 countries that were part of the study [13]. A public health approach for the continuum of care for cancer ranges from prevention to treatment, including palliative care. Treatment seeking behaviour and delay in diagnosis pose a significant impact on survivorship and mortality. Even factors such as attitude towards cancer

prevention practices that include Human Papilloma Virus (HPV) vaccination, screening and lifestyle modification could decrease cancer risk. There is a shortage of quality cancer-related healthcare facilities. The proportion of cancer patients seeking treatment outside NER is highest for Sikkim (95.3%), followed by Nagaland (58.1%) [5]. Less than one-third of cancers of the breast, cervix, head and neck, stomach and lung cancer detected in the region were localised at the time of getting diagnosed.

Goal 3 of the Sustainable Development Goals focuses on good health and well-being [14]. One of the critical targets is reducing premature mortality due to Noncommunicable Diseases (NCDs) by one third through prevention and treatment, promoting mental health and well-being by 2030. In response to the rising NCD epidemic, the Government of India initiated the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (NPCDCS) in 2010. Concerning cancer control, the program emphasises risk reduction and promotes organised screening for the three common cancers-oral, breast and cervix. According to NFHS-5, the proportion of those who reported having undergone screening for breast, cervical or oral cancer was very low in many states in the NE region [15]

The Tertiary Care Cancer Centers (TCCC) scheme was also initiated to provide comprehensive and robust cancer care by setting up State Cancer Institutes (SCIs) and TCCCs'. Presently, there are two State Cancer Institutes and seven TCCCs' in the region [16]. The number of health facilities under the public health delivery system is shown in the table below:

Healthcare Facilities of NER states*							
S. No	States	HWCs-Subcentres	Number of Subcentres	HWCs-PHCs	Number of PHCs	HWCs-UPHCs	Number of CHCs
1.	Arunachal Pradesh	78	363	38	124	4	60
2.	Assam	765	4680	379	1002	52	192
3.	Manipur	85	418	29	93	1	17
4.	Meghalaya	67	443	35	143	19	28
5.	Mizoram	42	370	54	65	8	9
6.	Nagaland	103	415	46	137	7	21
7.	Sikkim	27	153	13	25	0	2
8.	Tripura	233	1001	32	112	5	22

*As of 31st March 2020. Source [17]

The National Tobacco Control Program (NTCP) has been pivotal for preventing and controlling tobacco use [18]. Rigorous policy implementation is crucial for ensuring primordial and primary prevention of NCDs, including cancer, through managing risk factors. The Cigarette and Other Tobacco Product Act (COTPA), 2003 prohibits smoking in public places, promotion of branded tobacco products, sale of tobacco products by or to minor and pictorial warning labels on tobacco products. However, the actual implementation of the Act could be a matter of concern. Indian alcohol policies appear to fluctuate with imposing and removing prohibitions for consumption and sales from time to time and revising the legal age of consuming alcohol. In 2020, the Food Safety and Standards Authority of India (FSSAI) brought out regulations to curb junk food consumption by restricting the availability of foods that are high in added sugars, saturated and trans fats or sodium in or within a fifty-metre of schools [19].

1.4 About the survey

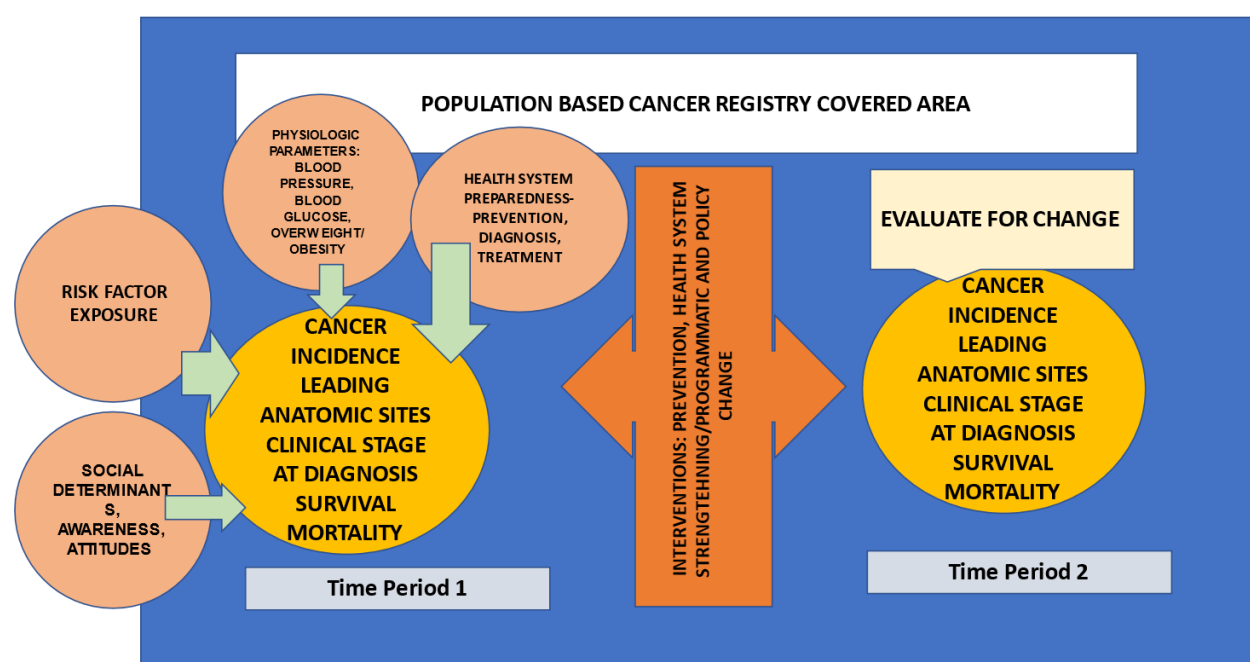
The National Cancer Registry Programme (NCRP) was commenced in 1981 by the Indian Council of Medical Research (ICMR) and is presently implemented at the National Centre for Disease Informatics and Research (ICMR - NCDIR) at Bengaluru through a network of cancer registries across the country. Population Based Cancer Registries (PBCRs') collect data on the incidence, profile, mortality and trends of cancer in a defined geographical area, while Hospital Based Cancer Registries (HBCRs') collect detailed clinical and disease outcome details of patients availing cancer care at specific hospital sites. There are 38 PBCRs under NCRP, of which twelve PBCRs' are situated in the northeastern region (NER). The data from the cancer registries have paved the way for cancer prevention and control activities in India.

While the Population Based Cancer Registries have been instrumental in providing the much-needed cancer data for the geographic area covered by a registry, it is vital to understand the likely reasons for the reported cancer incidence and its outcomes. The determinants of cancer burden could be explained in terms of the lifestyle and behavioural risk factors, comorbidities, social environment and preparedness of the health system (as shown on next page). Various surveys like the National NCD Monitoring Survey (NNMS), National Family Health Survey (NFHS) and Global Adult Tobacco Survey (GATS) have given either national or state-level estimates of behavioural risk factors, especially regarding tobacco use, alcohol consumption and

diet, which would not be sufficient to explain the reasons behind cancer occurring in a limited geographical area.

This survey was conducted as a part of Cancer Research in North East Region (CaRes-NER), a multidisciplinary programme for preventing and controlling cancer in the northeastern states. The survey aimed to form a baseline of risk factors for comparison in subsequent surveys. This would aid in establishing a cancer risk factor surveillance program comprising of a regular collection, analysis and dissemination of risk factor related data. As cancer registration is an integral part of cancer surveillance, ongoing surveillance of risk factors will help correlate trends in cancer incidence and risk factors. Moreover, with the set time-bound National NCD targets (10) and indicators (21) by 2025 adapted by the Ministry of Health and Family Welfare (MoHFW), Government of India (GoI) in 2012 and attempts to achieve Universal Health Coverage (UHC), an ongoing surveillance would determine outcomes of NCD control initiatives including comprehensive primary health care be delivered by the Health & Wellness Centres (HWCs) set up under 'Ayushman Bharat' scheme [19]. Therefore, establishing a cancer risk factor surveillance system within a cancer registry is essential to track changes, implement suitable interventions and evaluate their impact, which would be reflected in the magnitude of cancer that is periodically reported from the registry.

Cancer Prevention and Control through PBCRs



1.4.1 Objectives of the survey

1. Primary objective
To generate prevalence of key cancer and other NCD related risk factors and estimate health system response in all the 12 PBCRs of the eight states in Northeastern region of India.
2. Secondary objectives
To set a baseline to monitor and track trends in the prevalence of risk factors associated with cancer and other NCDs in the 12 PBCRs of the eight states in Northeastern region of India.
To link or correlate risk factors with cancer incidence and burden collected by the 12 PBCRs in the NER.