

# Challenges and Way Forward for Establishing Population Based Cancer Registry in Nepal

Ranjeeta Subedi,<sup>1</sup> Meghnath Dhimal,<sup>1</sup> Atul Budukh,<sup>2</sup> Pradeep Gyawali,<sup>1</sup> Anjani Kumar Jha<sup>1</sup>

<sup>1</sup>Nepal Health Research Council, Ramshahpath, Kathmandu, Nepal, <sup>2</sup>Homi Bhabha National Institute, Tata Memorial Centre, Mumbai, India.

## ABSTRACT

Population Based Cancer Registry plays a crucial role in cancer control through identifying cancer incidence, mortality, pattern and trends over time in a particular population. The registry is in a very infancy stage in Nepal. During the process of establishing Population Based Cancer Registry in Nepal, the major challenges include adequate coverage of the cases, high cost of registration, sustainability along with expansion of the registry to other regions and non-linkage of Hospital Based Cancer Registry with Population Based Cancer Registry. However, the approach of mobilization of field enumerators at the end of year once had increased coverage of the cases. Similarly, the linkage of Population Based Cancer Registry with the existing Health Management and Information System will help in developing sustainable Population Based Cancer Registry and also provides an opportunity to increase coverage and expand it to other districts as well.

**Keywords:** Challenges; Nepal; population based cancer registry; way forward

## INTRODUCTION

The burden of non-communicable diseases (NCDs) including cancer has increased in Nepal since few decades.<sup>1</sup> In Nepal, among the outpatients, the major NCDs include chronic obstructive pulmonary disease (43%), cardio vascular disease (40%), diabetes mellitus (12%) and cancer (5%).<sup>2</sup> According to the hospital based data the trend of cancer incidence has been increased from 2003 to 2012 and was predicted to rise steadily from 2013 to 2020. However, due to the lack of prior Population Based Cancer Registry (PBCR), it was difficult to precisely identify and predict the cancer incidence.<sup>3</sup>

Population Based Cancer Registry is the process of collecting, storing, analyzing and interpreting the data of cancer cases in a particular geographical region. The main aim of PBCR is to identify cancer incidence, mortality, patterns and trends in a defined population. It is one of the core components for identifying and developing cancer control strategies and monitoring cancer treatment, early detection and prevention programmes.<sup>4,5</sup> Cancer control strategies without reliable data will mislead priorities and incur unnecessary investment.<sup>4</sup> Hence, with the aim of providing evidence on cancer burden in Nepal and assisting the government of Nepal in developing evidence based cancer control

strategies, Nepal Health Research Council (NHRC) has started PBCR in 9 of total 77 districts since 2018, with three registries namely Kathmandu Valley PBCR representing urban areas, Siraha, Saptari, Dhanusha, Mohattari PBCR representing semi-urban areas and Rukum PBCR representing rural areas of Nepal.<sup>6</sup> The PBCR collects the data from the health facilities, hospice, ayurvedic center, community, social security and nursing division where the data of patient receiving treatment subsidy from Government of Nepal is stored and the community.

## CHALLENGES

Currently, there are more than 700 PBCRs throughout the world; however, the pace of development is much slower in low and middle income countries.<sup>4</sup> The population coverage by PBCR in Africa is only 1.4% and in Southeast Asia, only 2%.<sup>7</sup> In Nepalese context, the BP Koirala Memorial Cancer Hospital (BPKMCH) had piloted PBCR in 15 districts in 2013 covering 25% of the population<sup>8</sup> and the NHRC has initiated PBCR in 2018 at other 9 districts of the country covering 20.3% of the total population. The major challenges are to sustain the registry and to expand registry throughout the country to get the complete, accurate and unbiased picture of cancer burden in Nepal.

**Correspondence:** Ranjeeta Subedi, Nepal Health Research Council, Ramshahpath, Kathmandu, Nepal. Email: [knockranju2012@gmail.com](mailto:knockranju2012@gmail.com), Phone +9779868571255.

In Nepal, people use multiple locations/sources for the diagnosis and treatment of cancer. People also visit many cancer hospitals in various places of India as well as other countries for treatment challenging to obtain cancer data on regular basis. Some hospitals (government and private) do not wish to share detail information/data of cancer patients, and they are unlikely to make coordination to the registry. Similarly, in the semi urban and the rural areas lack of cancer diagnostic and treatment facilities resulted in more scattered data. Hence, it is hard to keep exact record of cancer cases within a certain territory.

In the community, the process of data collection was passive where the health coordinator, health post in-charge and female community health volunteers (FCHVs) were provided orientation about PBCR and were required to find cancer cases or cancer death in their locality and report to the registry. Thus, the success of PBCR also depends on reporting and dedication of these staffs. Due to absence of fully or partially dedicated staffs available at data source locations, it is difficult to obtain data regularly from these locations. Similarly, there was no separate budgetary provision to the FCHVs for collecting the data and the FCHVs have already their pre-determined roles and responsibilities in the communities. In such cases, they might be overburdened and de-motivated to collect data on cancer cases and submit on timely basis. Initiating the cancer registry requires a huge budget for maintaining sufficient human resources of its own as well as their capacity building and other logistic arrangements. Besides this, poor recording system in the facilities have increased the cost of the registry, as for the residence of the cancer cases, we are not able to rely on the resident address provided by them. Hence, each individual patient/relative should be contacted to confirm the residence, which incurs extra cost/ burden in terms of man, money and material.

Similarly, the approach of orienting health coordinators, health in-charges and FCHVs has been costly as well as less efficient. During the orientation, it has been found that though the FCHVs have knowledge about the cancer patient in their locality, the information has not reach to the registry office. This is caused by either they do not collect the information, or even if they collect the information and report to the health in-charges, the in-charges have not send the information to the health coordinators. Hence, the allowances provided during the orientation at the community level are extremely high as compared to the number of cancer cases obtained through them.

BPKMCH has initiated hospital based cancer registry

(HBCR) and currently there are 12 HBCRs existing in the country.<sup>8</sup> Linking HBCR and PBCR could have been the way for quality and coverage assurance of the cases and efforts have been made for the linkage however, obtaining data to PBCR from HBCR has not been possible since the existing HBCR is lagging behind the time i.e. currently working on the data of 2017.

## WAY FORWARD

PBCR is a central nervous system for cancer control. It has a huge implication in the formulation of cancer control strategy by the government because of its unbiased profile regarding cancer in a particular area. Hence, the ultimate goal of PBCR is of sustainability of the existing registries and their expansion throughout the country. Since the establishment and expansion of new cancer registries require huge amount of resources, incorporating cancer data in the regular health management information system (HMIS) could be a way for regular flow of data of cancer cases from the community as well as facilities with a minimum cost. Though at the initial phase, investment might be high for orientation and software development for HMIS, the huge amount of extra cost can be reduced by reducing the active visit of the registry personnel in the facilities. It requires recognition of the importance of data and commitment from the federal, provincial and local level and at the same time robust monitoring and evaluation for the data quality should be continued by the PBCR unit at NHRC.

A new approach has been adopted to collect the information from the community, , where the trained data enumerators were mobilized in the community; they first meet the health coordinators, health in-charges, FCHVs and/or community leaders to identify the cancer cases and cancer death and then visit the particular household of the cases for data collection. The process takes place only once a year at the end. Through this approach, the quality and coverage of the cases are ensured well.

In order to link PBCR with HBCR, memorandum of agreement (MoU) has been signed with BPKMCH, responsible for HBCR and NHRC, responsible for PBCR for the collaboration to strengthen registry in the country. This collaboration will help in the coverage and quality of cancer data in near future.

Government of Nepal is investing huge amount of money in the treatment of cancer cases along with the provision of NPR 100,000 support to its underprivileged citizens. Through the PBCR data, targeted strategies according

to geographical region on cancer prevention need to be initiated for cancer control. In this regard, linking the information generated by PBCR at policy formulation is one of the ways forward for successful PBCR in the country. In Nepal, most of the cases are diagnosed at the advanced stage resulting in high mortality. Besides, the diagnosis and treatment facilities are concentrated at the urban areas only. So, it's crucial to support with health education and infrastructure development based on the data from PBCR for cancer management.

## CONCLUSIONS

In conclusion, population based cancer registry is necessary for cancer epidemiology in Nepal. Strengthening the existing registries by addressing the challenges and moving forward will provide quality data regarding cancer incidence and mortality in Nepal and guide for the development of cancer control programs effectively in the context of Nepal.

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