

Initiation of Population-based Cancer Registry in Nepal

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Cancer ranks second globally and third leading cause of death for Nepal, accounting for an estimated 18,314 deaths in 2017.¹ This shows that cancer remains a major public health issue in Nepal. However, the estimation of the burden of disease, trends and the effectiveness of interventions carried out, depends unexceptionally on the continuous availability of robust surveillance data. Registries have been shown to be a vital component of any logical cancer control programs.² Population based cancer registry (PBCR) data provides information on the scale and profile of cancer that enables informed planning and monitoring.

In Nepal, hospital-based cancer registry (HBCR) program was initiated in 2003, which incorporates 12 hospitals.³ There is no routine cancer surveillance or national PBCR in the country. Estimates on the incidence and prevalence of cancer cases are being done on the basis of small scale data from neighboring countries and GLOBOCAN. Although HBCR has generated some basic evidence on incidence of cancer cases by site, sex and age it cannot provide measures of occurrence of cancer in a defined population and alone cannot be used to generate national estimates. Moreover, not all the hospitals have initiated hospital-based registry which necessitates the establishment of PBCR in Nepal.

The existing HBCR in Nepal is not inclusive to the whole population, hence of limited significance in formulating long term cancer control plan and policies. Thus, a PBCR is crucial as it gives a systematic ascertainment of cancer incidence from multiple sources like health facilities, laboratories, cancer centers, hospice and so on which can provide an unbiased profile of the cancer burden in the defined population and its trend over time. Population registries in turn, can have a different role in planning and evaluating cancer control programs thus proving more useful information than hospital or laboratory-based registries. According to the World Health Organization (WHO), PBCR is a core component of

a national cancer control strategy.^{4,5} In Nepal, although HBCR, has generated some basic evidence but it cannot be used to estimate cancer rates as it is not population-based.

In view of all these felt needs, Nepal Health Research Council (NHRC) with the support of Ministry of Health and Population (MoHP) initiated PBCR in 2018. An advisory/steering committee with representation from NHRC, MoHP, WHO, and other stakeholders such as hospital directors and clinical oncologists was formed so as to guide the entire process of PBCR in close coordination with the MoHP. Alongside a technical working group (TWG) was formed under the steering committee to manage operational task. The TWG is responsible for the development of the data collection form for the registry and implementation of cancer registry software based on the registry data collection form.

At that moment we only knew that we need PBCR but were unaware of the process on how to move further. As evident, PBCR is one of the important data sources for burden of disease (BoD) estimates, and Nepal has made some initiation in terms of refining its BoD estimates in collaboration with the Institute for Health Metrics and Evaluation (IHME). The IHME supported us to get in touch with the International Agency for Research on Cancer (IARC) team in Lyon, France. Through multiple skype meetings and mails we developed a proposal which was further refined collaboratively with IARC. After series of meetings, IARC connected us with the experts in IARC Regional Hub, Tata Memorial Centre, Mumbai. Experts from Mumbai hub were very much co-operative and were instantly ready to provide us the required technical support.

In 2017, we received the first training of PBCR at Mumbai. A team of five persons comprising oncologist, research officer, record keeper and IT people attended a week long training which was very personnel and eyeopener for all

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of us as we all have minimal knowledge about PBCR. With this ground work, we initiated PBCR formally. Concerned officials from IARC, France and the Mumbai Hub visited us in Nepal for the launching of the PBCR and was formally launched in 17th January 2018. At the moment, we have three registries namely, Kathmandu valley PBCR; Siraha, Saptari, Dhanusa and Mahottari Registry and Rukum Registry. Our registry staff are continuously working with the data collection. The interim analysis of the data has been completed and is now on the process of releasing annual PBCR report which will be ready by December 2019. Data collection from the multiple sources is very tedious and troublesome task, which needs continuous support and co-operation from the stakeholders at various data source. At the same time, we need to have a sincere commitment from the governing body for the sustainability of PBCR. During a year journey of PBCR, we have experienced various hurdles, witnessed several challenges and have been discovering the solutions too. We feel that the team work is the key and patience and persistence are the accessories needed to be worn by the individuals working with PBCR.

Data from the PBCR are precious and every nation have the right and should own it for setting their own standard cancer control strategies. This will be valuable for the policy makers and the program managers to develop and/ or modify the cancer control strategies. The process has set in and needs to be a continuous one.

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