J Nepal Health Res Counc 2026 Jan-March; 24 (70):iv-v

Ethical Issues in Establishing a Registry in Nepal: Experiences from the Population-Based Cancer Registry

Namita Ghimire,[1] Dilip KC,[1] Bishnu P. Marasini,[1] Hari Dhakal,[1] Pramod Joshi,[1] Meghnath Dhimal,[1] Bikash Devkota[2] Aarati Shah[1]

[1]Nepal Health Research Council, Ramshah Path, Kathmandu, Nepal, [2]Ministry of Health and Food Safety, Singhadurbar, Kathmandu, Nepal.

A registry is a database or information system created to gather, store, and manage data from specific populations, presenting its users with an overview of the actual disease burden. Specifically, a population based cancer registry is the process which collects information continuously and systematically on all reportable malignancies occurring in a geographically-defined population from the multiple sources.[1] Low- and middle- income countries (LMICs) face a significant burden of the global cancer epidemic, representing the majority of both cancer cases and mortality, with accounting for 75% of the global entirety. According to GLOBOCAN (2022), Nepal recorded 22,008 cancer cases and 14,704 cancers- associated deaths,[2] an increase that have nearly doubled since 1990. So, the population-based cancer registries (PBCRs) are essential for evidence-based policies, strategic investment, and evaluating interventions.[3]

To provide more information on the cancer burden in Nepal and aid the Nepalese government in developing effective cancer control strategies, the Nepal Health Research Council (NHRC) established population-based cancer registries (PBCR) in 2018. These registries currently represent nine of Nepal's seventy-seven districts. They include the Kathmandu Valley (Kathmandu, Bhaktapur and Lalitpur districts) PBCR which focuses on urban areas; the Siraha, Saptari, Dhanusha, and Mohattari (SSDM) PBCR, which covers semi-urban regions; and the Rukum (Rukum East and West districts) PBCR, representing the country's rural areas.[4] The data were collected from many sources that included public and private hospitals, pathological laboratories, hospices, Ayurvedic centers, the Social Security and Nursing Division and community.[5]

During the establishment and operation of population-based cancer registries in LMICs like Nepal, numerous ethical and operational challenges arise; identifying and addressing these challenges can strengthen the ethical governance, implementation, and sustainability of PBCRs in Nepal and other LMICs.

Population-based cancer registries play a crucial role for evaluating a nation's cancer burden by providing reliable data on incidence, survival, trends, patterns and mortality. However, the establishment and operation of PBCR raise several ethical concerns, particularly regarding patient participation, data privacy, confidentiality and equitable representation.[6] Confidentiality has become a major concern for both new and long-established cancer registries. The increasing use of paper-based and electronic databases containing identifiable patient medical information which can be link to other databases for research purposes creates a significant potential risk of unauthorized access and potential breaches of patient confidentiality.[7]

Similarly, activities such as residence verification and follow-up telephone calls for updating survival status of patients may cause emotional and psychological distress to patients and their families. Administrative requirements for cancer notification, such as obtaining written or verbal consent before recording patient information in the cancer registry, may also introduce substantial bias leading to incomplete case biased incidence estimates. Such bias can significantly compromise the completeness, representativeness and overall value of registry data for public health planning and research. Furthermore, ensuring data safety and security issues remains a major challenges include protecting registry data from unauthorized physical and electronic access, maintaining data integrity, and preventing information securely over extended periods to ensure its long-terms usability for policy and planning.

To address these ethical challenges, particularly in LMICs, robust ethical and legal frameworks are needed

Correspondence: **Dilip KC, Nepal Health Research Council, Ramshah Path, Kathmandu, Nepal. Email: k.cdilip049@gmail.com, Phone: +9779811541167.**

to govern the collection, storage, use, sharing, and protection of registry data. Ethical approval should be obtained prior to the collection or processing of identifiable patient data, with continuing ethical oversight throughout the registry's lifecycle to ensure compliance with evolving ethical and legal standards.[8] Strengthening data confidentiality and security, implementing effective data governance mechanisms, promoting collaboration among government agencies, healthcare institutions, researchers, and international partners, and minimizing potential harm during active patient follow-up are essential to safeguarding participants' privacy, autonomy, and confidentiality while enhancing public trust and community engagement. Sustainable financing and investment in secure digital infrastructure, including information technology and artificial intelligence, are equally important to ensure the long-term sustainability of registry systems. However, many registries face financial constraints, shortages of skilled personnel, high staff turnover, and limited capacity in data management, cybersecurity, and registry operations. Addressing these governance, collaboration, financial, infrastructural, and workforce challenges is critical to ensuring the ethical, secure, high-quality, and sustainable operation of population-based cancer registries.

REFERENCES

1. Tiangco B, Daguit SEJ, Astrologo NC, Flores L, Parma RN, Celi LA. Challenges in the maintenance of an open hospital-based cancer registry system in a low-to-middle-income country (LMIC): 2017–2022 experience. Armengol De La Hoz MÁ, editor. PLOS Digit Health. 2024 Jan 24;3(1):e0000328.[PubMed]

2. HERD International. Status of Cancer in Nepal. Lalitpur, Nepal: HERD International; 2024.Available from: https://herdint.com/resources/status-of-cancer-in-nepal/

3. Dahal UK, Khadka K, Neupane K, Acharya SC, Jha AK, Gyanwali P, et al. Cancer Risk in Nepal: An Analysis from Population-Based Cancer Registry of Urban, Suburban, and Rural Regions. Kane E, editor. J Cancer Epidemiol. 2024 Jan;2024(1):4687221. doi: 10.1155/2024/4687221

4. Subedi R, Dhimal M, Budukh A, Gyawali P, Jha AK. Challenges and Way Forward for Establishing Population Based Cancer Registry in Nepal. J Nepal Health Res Counc. 2020 Nov 14;18(3):544-6. [PubMed]

5. Subedi R, Budukh A, Chapagain S, Gyanwali P, Gyawali B, Khadka K, et al. Differences in cancer incidence and pattern between urban and rural Nepal: one-year experience from two population-based cancer registries. ecancermedicalscience [Internet]. 2021 May 11 [cited 2026 Jan 12];15. [PMC8183641]

6. Mohapatra PR. Ethical challenges in cancer registries: public benefits and patient rights. The Lancet. 2025 Mar;405(10484):1051–2. Available from: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(25)00458-1/fulltext?rss=yes

7. Coleman M, Muir C, Ménégoz F. Confidentiality in the cancer registry. Br J Cancer. 1992 Dec;66(6):1138-49.[PMC1978023]

8. Ghimire N, Adhikari S, Sharma S, Basnet R, Acharya R, Verma S, et al. Knowledge, Attitude and Practice of Research Ethics among Researchers in Nepal. J Nepal Med Assoc. 2024 Feb 29;62(271):174–9. doi: 10.31729/jnma.8492