

Focus 5. Social inequalities and cancer in Indigenous populations

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There are approximately 370 million Indigenous people spread across 70 countries worldwide (UN, 2009). They represent as many as 5000 different cultures and account for much of the world's cultural diversity (UN, 2009). Indigenous people live in a wide variety of environments and circumstances (UN, 2009). Despite this diversity, many Indigenous people around the world, in both high-income countries and low- and middle-income countries, continue to face substantial economic, health, and social disadvantages as a result of an enduring legacy of colonization, an ongoing marginalization and disempowerment, and the social, structural, and political arrangements of the countries in which they live (UN, 2009; Paradies, 2016).

Gaining an accurate statistical picture of the health and well-being of Indigenous populations is challenging. In some countries, the national information infrastructure is inadequate for the whole population; in others, high-quality data exist for the total population, but Indigenous people are not always identified as such in the relevant data collections. In addition, some Indigenous populations live on lands that cross modern-day national boundaries (e.g. the Sami in northern Europe), and many countries group together several distinct Indigenous populations using a single umbrella term (e.g. Aboriginal in Australia, First Nations in Canada, and Native American in the USA).

Despite the data limitations arising from such challenges, it is increasingly clear that cancer is an important health priority for Indigenous populations throughout the world both in absolute terms, as a leading cause of illness and death, and in relative terms, based on disparities in the cancer burden between Indigenous and non-Indigenous populations within countries. Furthermore, in an era of major advances in reducing the impact of cancer, there is evidence that disparities between Indigenous and non-Indigenous populations may be widening (Fig. F5.1).

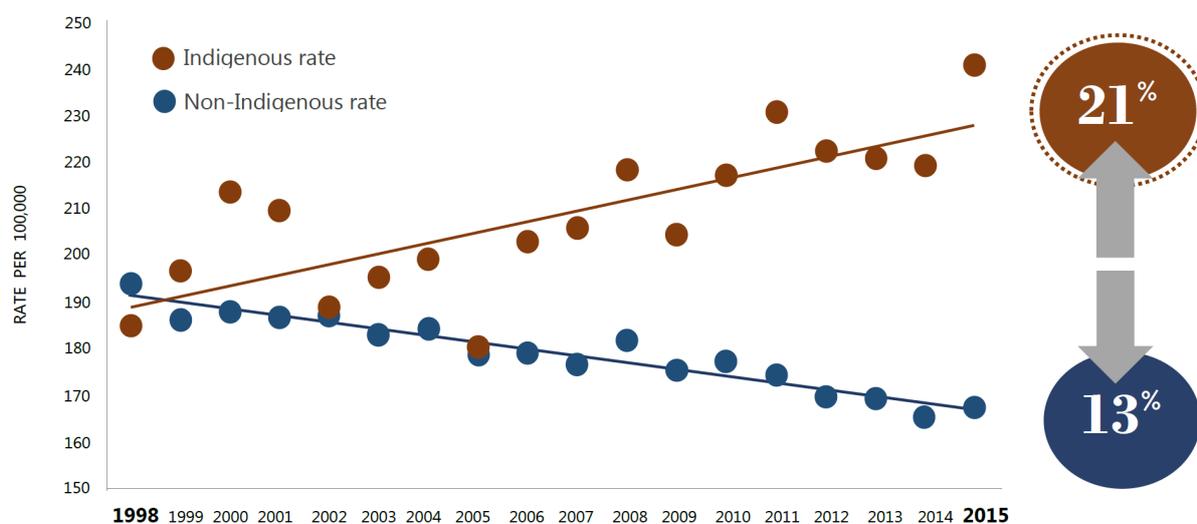


Fig. F5.1. Trends in age-standardized mortality rates of all cancers combined, by Australian Indigenous status, 1998–2015. Source: compiled from Australian Institute of Health and Welfare (2018). Cancer in Aboriginal and Torres Strait Islander people of Australia. Cat. No: CAN 109. Canberra, Australia: AIHW. <https://www.aihw.gov.au/reports/cancer-screening/cancer-in-Indigenous-australians/contents/mortality>.

Studies from around the world provide evidence that Indigenous populations experience significant disparities relative to the local non-Indigenous populations with respect to risk factor prevalence, cancer incidence, stage at diagnosis, care received, and disease outcomes (Moore et al., 2015; Ellison-Loschmann et al., 2017). Although variation exists between and within countries, Indigenous people are more likely to have cancers that are largely preventable, detectable by screening, and/or have a poor prognosis, such as lung, liver, and cervical cancers (Moore et al., 2015).

To date, published reports on cancer in Indigenous populations have come largely from Australia, Canada, New Zealand, and the USA; even in these countries, however, limitations in data quality and availability have generally precluded national-level reporting (with the exception of New Zealand) (Boyd et al., 2016). Data inadequacies have also limited the number of cross-country comparisons. Moore et al. (2015) reported higher incidence rates of preventable cancers for a range of Indigenous populations across Australia, Canada, New Zealand, and the USA, with some notable variations among groups (Moore et al., 2015). Systematic reviews of peer-reviewed literature have been used in some countries to overcome data inadequacies (Hassler et al., 2008; Moore et al., 2014). Moore et al. (2014) found higher incidence rates of cervical cancer in parts of Brazil, Ecuador, and Guyana for Indigenous women compared with non-Indigenous women; higher incidence rates of stomach cancer in

regions of Chile and of gallbladder cancer in Bolivia and Chile were also reported for Indigenous populations compared with non-Indigenous populations (Moore et al., 2014). Within countries, data linkage has been used to overcome deficiencies in population-level cancer surveillance programmes to enable reporting for Indigenous populations, for example in Australia (Whop et al., 2016), Canada (Sanchez-Ramirez et al., 2016), and the USA (Espey et al., 2008).

A broad range of factors may contribute to poorer cancer outcomes for Indigenous populations, including those relating to individual patients, health-care systems, and sociocultural and political contexts (Fig. F5.2). Although many of these interconnected and multifaceted factors are relevant for Indigenous populations globally, the relative importance of particular factors is likely to vary from place to place. In addition to the Indigenous-specific factors included in Fig. F5.2, patterns of cancer incidence and mortality in Indigenous populations are also strongly influenced by the prevalence of traditional risk factors such as tobacco use, excessive alcohol consumption, nutrition, and level of physical activity, as well as by social determinants such as education level, employment, income, and housing (more information about the social determinants of cancer is provided in Chapters 3 and 7).

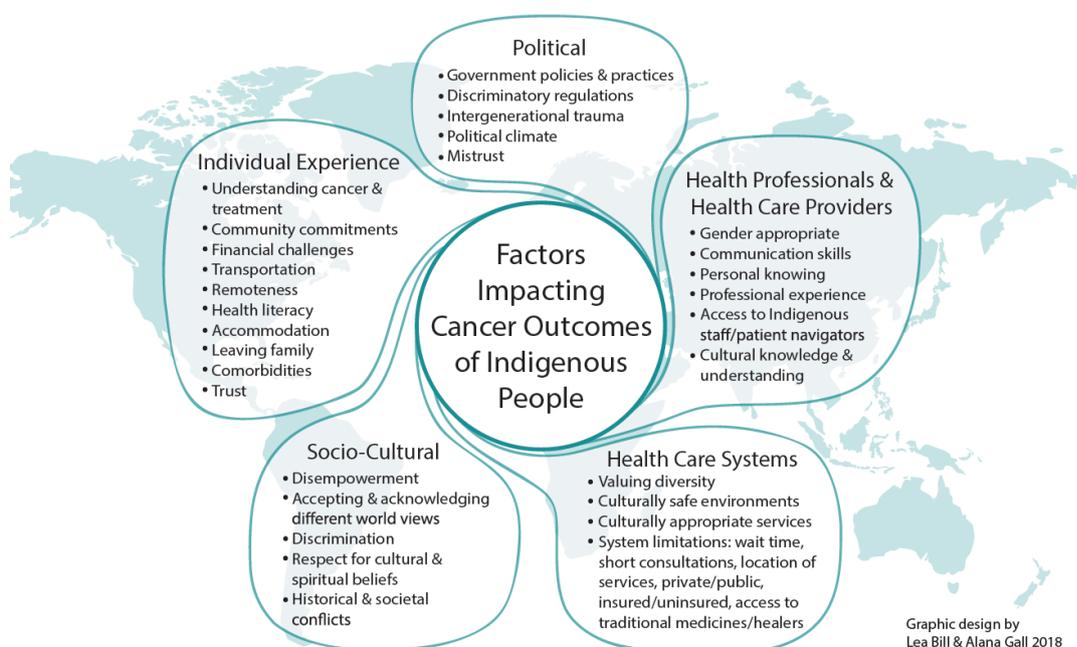


Fig. F5.2. Factors impacting cancer outcomes of Indigenous people. Design by Lea Bill and Alana Gall.

Key international bodies, including the Seventieth World Health Assembly and the Union for International Cancer Control, have recognized the need for specific, targeted cancer control strategies for population groups experiencing an inequitable cancer burden. Understandings of health and well-being are culturally bound (Petersen et al., 2004), and this needs to be considered in improving the performance of the cancer system with and for Indigenous people. For example, Cancer Care Ontario’s Aboriginal Cancer Strategy aims to do this by honouring the Aboriginal Path of Well-being (Fig. F5.3) (Kewayosh et al., 2015). The development of shared principles and priorities to guide efforts to improve cancer outcomes for Indigenous populations is also critical. For example, Cancer Australia, the Australian government’s key cancer control agency, undertook extensive stakeholder consultation with a wide range of key Indigenous organizations and individuals, as well as with health service providers, governments, nongovernmental organizations, and researchers, to develop the National Aboriginal and Torres Strait Islander Cancer Framework (Cancer Australia, 2015). This framework is underpinned by four key principles: Indigenous engagement, Indigenous information and empowerment, working together, and evidence-informed practice. The key priorities address issues such as cancer-related health literacy, prevention and early detection, optimal treatment, supportive care, and service development, with a range of enablers highlighted (Cancer Australia, 2015).

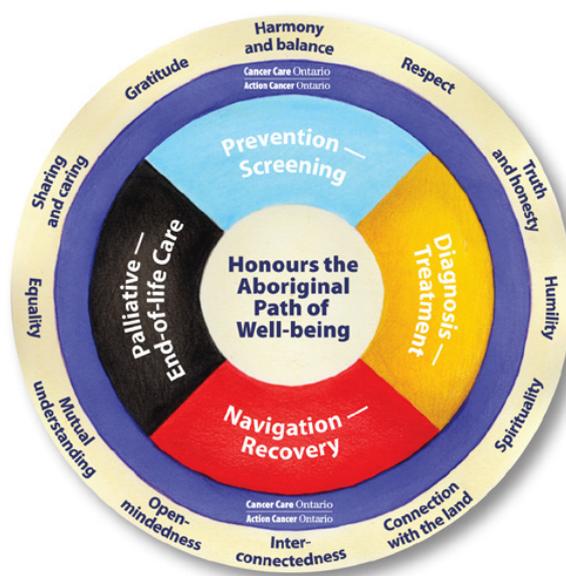


Fig. F5.3. An example of incorporating Indigenous understandings of health and well-being into a jurisdictional cancer strategy: Cancer Ontario’s Aboriginal Cancer Strategy II. Source: reproduced with permission from Kewayosh et al. (2015).

Addressing the excess cancer burden for Indigenous populations requires culturally appropriate public health interventions that are developed, implemented, and evaluated in partnership with Indigenous communities. Such community partnerships can have a positive impact in addressing cancer disparities providing they are built on trust, a shared commitment, agreement of the outcomes, and mutual benefit, and that Indigenous people are involved at all levels. An example of a successful collaborative partnership is the cancer prevention and screening practices project among Alberta First Nations communities (Voyageur et al., 2018). Providing patient navigators and conducting community education workshops can also play an important role in improving cancer screening rates and empowering Indigenous populations (Burhansstipanov et al., 2017).

Conclusions

Measuring the cancer burden of Indigenous populations is critically important, but gaps and challenges remain. In particular, reliable and accurate data are needed to develop appropriate cancer policy, priority setting, and service responses, and to monitor cancer outcomes over time. In addition to measuring traditional end-points such as morbidity and mortality, better information is also needed about quality of life, well-being, and the psychosocial impacts of cancer for Indigenous people. Sarfati et al. (2018) have described key issues relating to cancer surveillance among Indigenous populations and suggested a range of solutions to strengthen their visibility. In particular, it is critical to ensure that Indigenous people are centrally involved in determining appropriate data governance structures, including data ownership and access.

Improved measurement is necessary but by no means sufficient to reduce the cancer burden for Indigenous populations. Indigenous leadership, empowering Indigenous communities, and establishing authentic partnerships across the continuum of cancer care are vital to eliminating cancer inequalities. The development of a culturally competent health-care workforce and of culturally appropriate systems, services, and programmes is also needed. Research is required to identify and evaluate innovative approaches to cancer control across the cancer continuum.

References

- Boyd M, Blakely T, Atkinson J (2016). Ethnic counts on mortality, New Zealand Cancer Registry and census data: 2006-2011. *N Z Med J.* 129(1429):22–39. [PMID:26914296](#)
- Burhansstipanov L, Harjo L, Kaur JS (2017). How can an education workshop serve as an intervention for American Indian screening participation. *J Cancer Educ.* <https://doi.org/10.1007/s13187-017-1289-1> [PMID:29159787](#)
- Cancer Australia (2015). National Aboriginal and Torres Strait Islander Cancer Framework 2015. Surry Hills, New South Wales. Australia: Cancer Australia. Available from: https://canceraustralia.gov.au/sites/default/files/publications/national-aboriginal-and-torres-strait-islander-cancer-framework/pdf/2015_atsi_framework_1.pdf.
- Ellison-Loschmann L, Sporle A, Corbin M, Cheng S, Harawira P, Gray M, et al. (2017). Risk of stomach cancer in Aotearoa/New Zealand: a Māori population based case-control study. *PLoS One.* 12(7):e0181581. <https://doi.org/10.1371/journal.pone.0181581> [PMID:28732086](#)
- Espey DK, Wiggins CL, Jim MA, Miller BA, Johnson CJ, Becker TM (2008). Methods for improving cancer surveillance data in American Indian and Alaska native populations. *Cancer.* 113(5) Suppl:1120–30. <https://doi.org/10.1002/cncr.23724> [PMID:18720372](#)
- Hassler S, Soininen L, Sjölander P, Eero P (2008). Cancer among the Sami—a review on the Norwegian, Swedish and Finnish Sami populations. *Int J Circumpolar Health.* 67(5):421–32. <https://doi.org/10.3402/ijch.v67i5.18351> [PMID:19186763](#)
- Kewayosh A, Marrett L, Aslam U, Steiner R, Moy Lum-Kwong M, Imre J, et al. (2015). Improving health equity for First Nations, Inuit and Métis people: Ontario's Aboriginal Cancer Strategy II. *Healthc Q.* 17(Spec No):33–40. [PMID:25562132](#)
- Moore SP, Antoni S, Colquhoun A, Healy B, Ellison-Loschmann L, Potter JD, et al. (2015). Cancer incidence in indigenous people in Australia, New Zealand, Canada, and the USA: a comparative population-based study. *Lancet Oncol.* 16(15):1483–92. [https://doi.org/10.1016/S1470-2045\(15\)00232-6](https://doi.org/10.1016/S1470-2045(15)00232-6) [PMID:26476758](#)
- Moore SP, Forman D, Piñeros M, Fernández SM, de Oliveira Santos M, Bray F (2014). Cancer in indigenous people in Latin America and the Caribbean: a review. *Cancer Med.* 3(1):70–80. <https://doi.org/10.1002/cam4.134> [PMID:24403278](#)
- Paradies Y (2016). Colonisation, racism and indigenous health. *J Popul Res (Canberra).* 33(1):83–96. <https://doi.org/10.1007/s12546-016-9159-y>
- Petersen S, Soucar B, Sherman-Slate E, Luna L (2004). The social construction of beliefs about cancer: A critical discourse analysis of racial differences in the popular press. *J Appl Biobehav Res.* 9(4):201–29. <https://doi.org/10.1111/j.1751-9861.2004.tb00101.x>
- Sanchez-Ramirez DC, Colquhoun A, Parker S, Randall J, Svenson LW, Voaklander D (2016). Cancer incidence and mortality among the Métis population of Alberta, Canada. *Int J Circumpolar Health.* 75(1):30059. <https://doi.org/10.3402/ijch.v75.30059> [PMID:26837668](#)
- Sarfati D, Garvey G, Robson B, Moore S, Cunningham R, Withrow D, et al. (2018). Measuring cancer in indigenous populations. *Ann Epidemiol.* 28(5):335–42. <https://doi.org/10.1016/j.annepidem.2018.02.005> [PMID:29503062](#)
- UN (2009). State of the world's indigenous peoples. New York (NY), USA: United Nations Department of Economic and Social Affairs, Division for Social Policy and Development, Secretariat of the Permanent Forum on Indigenous Issues. ST/ESA/328. Available from: <https://www.un.org/development/desa/indigenouspeoples/publications/state-of-the-worlds-indigenous-peoples.html>.
- Voyageur C, Letendre A, Healy B (2018). Alberta Baseline Services Report. The Alberta First Nations Information Governance Centre. Available from: <http://www.afnigc.ca/main/includes/media/pdf/digital%20reports/Alberta%20Baseline%20Assessment%20Report.pdf>.
- Whop LJ, Garvey G, Baade P, Cunningham J, Lokuge K, Brotherton JM, et al. (2016). The first comprehensive report on Indigenous Australian women's inequalities in cervical screening: a retrospective registry cohort study in Queensland, Australia (2000-2011). *Cancer.* 122(10):1560–9. <https://doi.org/10.1002/cncr.29954> [PMID:27149550](#)