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Proposed IPVS Policy Statement addressing the burden of HPV disease for Indigenous peoples

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TITLE

IPVS Policy Statement

Addressing the Burden of HPV Disease for Indigenous peoples

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Proposed IPVS Policy Statement**Addressing the Burden of HPV Disease for Indigenous peoples**

The International Papillomavirus Society (IPVS) supports best practice and evidence-based research, strategies, and policies to prevent HPV-related diseases worldwide.

With the recent call from the World Health Organization (WHO) to global entities to work towards the elimination of cervical cancer globally as a public health problem, a call supported by IPVS (1), it is vital that principles of equity are central to activity in all countries developing strategies to eliminate cervical cancer as a public health problem. This call for equity is outlined in the related IPVS Policy Statement 'Equity in cervical cancer prevention for all women'.

This statement recognises the unequal burden from cervical cancer and other HPV-related diseases that Indigenous peoples face in many areas of the world. With an estimated 370 million Indigenous peoples in 90 countries globally (2), it is paramount that the HPV research and practice community supports culturally appropriate best practices in research and policy to reduce this burden of disease. This statement outlines the origins of this burden, the fundamental requirement to work with Indigenous peoples to reduce this burden, and makes recommendations for actions.

An inequitable disease burden

Health inequities for Indigenous peoples, including disparities in cervical cancer and other HPV-related diseases, are rooted in systemic disadvantage including reduced access to health care, culturally inappropriate models of health care, lack of support for Indigenous workforce capacity building, and, in many countries, trauma and disenfranchisement due to colonisation and ongoing dispossession from traditional land and practices (2-8).

Cervical cancer, the most common HPV-related cancer, disproportionately affects Indigenous women who often have higher incidence and mortality rates than other women in their regions. In high-income countries such as Australia, New Zealand, Canada, and some regions of the USA, cervical cancer incidence rates are 2 to 3.5 times greater, and mortality rates 2.5 to 4 times greater among Indigenous populations than non-Indigenous populations (9-12).¹

The true extent of the burden of HPV-related cancers among Indigenous peoples, especially in less-resourced regions such as Latin America, is largely unknown and may be substantially underestimated due to insufficient data collection (2, 13). To answer the WHO call to eliminate cervical cancer, these inequities must be addressed (14).

Best practice and principles in reducing Indigenous health inequities

To achieve equitable health outcomes for Indigenous peoples, strategies are required that consider co-creation of methods and tools, that acknowledge the importance of shared data ownership, and include Indigenous "ways of being, doing, and knowing", i.e., Indigenous beliefs, practices and knowledge systems; and determinants of 'responsibility', 'relationships' and 'respect' (15).

¹ Australia (incidence 2.5X, mortality 4X); New Zealand (incidence 2X, mortality 2.5X); Canada (incidence <3.5X, mortality 4X); USA (incidence <2X, mortality <4X)

Indigenous leadership is key to developing prioritisation of research focus and methods leading to solutions that are acceptable, appropriate and sustainable, incorporating the WHO health rights platform and best practice principles (16-19).

Recommendations for action to reduce Indigenous HPV-related health burden

IPVS supports action by IPVS members and stakeholders (healthcare and research communities, research funding bodies, governments and policy makers) to:

- Acknowledge the fundamental right of Indigenous peoples to equal protection against, and treatment of, HPV-related diseases consistent with the United Nations Declaration on the Rights of Indigenous Peoples (18);
- Develop meaningful respectful partnerships with Indigenous researchers, leaders and communities to conduct work addressing data quality, policy, program and research development in relation to HPV-related disease and HPV Indigenous workforce capacity development;
- Ensure that HPV related issues affecting Indigenous people are presented at relevant forums.

Developed by the International Indigenous HPV Alliance (IIHpvA) members:

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References

1. Garland SM, Giuliano A, Brotherton JML, Moscicki AB, Stanley M, Kaufmann AM, et al. 2018. IPVS Statement Moving towards Elimination of Cervical Cancer as a Public Health Problem. *Papillomavirus Research*;5: 87-8. <https://doi.org/10.1016/j.pvr.2018.02.003>
2. Sarfati D, Garvey G, Robson B, Moore S, Cunningham R, Withrow D, et al. 2018. Measuring cancer in Indigenous populations. *Annals of epidemiology*; 28(5):335-42.
3. Ahmed S, Shahid RK, Episkenew JA. 2015. Disparity in cancer prevention and screening in Aboriginal populations: recommendations for action. *Current Oncology*. Dec;22(6):417.
4. Robson B, Cormack D, Purdie G. 2010. *Unequal Impact II: Māori and Non-Māori Cancer Statistics by Deprivation and Rural-Urban Status 2002-2006*. Te Rōpū Rangahu Hauora a Eru Pōmare, University of Otago, Wellington.
5. Pihama L, Reynolds P, Smith C, Reid J, Smith LT, Nana RT. 2014. Positioning historical trauma theory within Aotearoa New Zealand. *AlterNative: An International Journal of Indigenous Peoples*. Sep;10 (3):248-62.
6. Maar M, Burchell A, Little J, Ogilvie G, Severini A, Yang JM, Zehbe I. 2013. A qualitative study of provider perspectives of structural barriers to cervical cancer screening among first nations women. *Women's Health Issues*. Sep 1;23(5): e319-25.

7. Wakewich P, Wood B, Davey C, Laframboise A, Zehbe I, ACCSS group. 2016. Colonial legacy and the experience of First Nations women in cervical cancer screening: a Canadian multi-community study. *Critical Public Health*. Aug 7;26(4):368-80
8. Hutchinson, P, Tobin, P, Muirhead, A & Robinson, N 2018, 'Closing the gaps in cancer screening with First Nations, Inuit, and Métis populations: A narrative literature review', *Journal of Indigenous Wellbeing*, Vol.1, Iss. 1.pp. 3-17.
9. Australian Institute of Health and Welfare 2018. *Cancer in Aboriginal and Torres Strait Islander people of Australia*. Available from: <https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians/contents/cancer-type/cervical-cancer-c53> [accessed March 2019]
10. New Zealand Ministry of Health 2018. *Tatau Kahukura Māori health statistics*. Available from: <https://www.health.govt.nz/our-work/populations/maori-health/tatau-kahukura-maori-health-statistics/nga-mana-hauora-tutohu-health-status-indicators/cancer> [accessed March 2019]
11. Demers AA, Kliewer EV, Remes O, Onysko J, Dinner K, Wong T, Jayaraman GC. 2012 Cervical cancer among Aboriginal women in Canada. *CMAJ*. Apr 17;184(7):743-4.
12. Watson M¹, Benard V, Thomas C, Brayboy A, Paisano R, Becker T. Cervical cancer incidence and mortality among American Indian and Alaska Native women, 1999-2009. *American Journal of Public Health*. Jun;104(S3): S415-22. doi: 10.2105/AJPH.2013.301681. Epub 2014 Apr 22.
13. Goss PE, Lee BL, Badovinac-Crnjevic T, Strasser-Weippl K, Chavarri-Guerra Y, St Louis J, Villarreal-Garza C, Unger-Saldaña K, Ferreyra M, Debiasi M, Liedke PE. 2013. Planning cancer control in Latin America and the Caribbean. *The Lancet Oncology*. Apr 1;14(5):391-436.
14. Whop LJ, Cunningham J, Garvey G, Condon JR. Towards global elimination of cervical cancer in all groups of women. *Lancet Oncology* 2019;20:e238.
15. Bainbridge R, Whiteside M, McCalman J. 2013. Being, knowing, and doing: a phronetic approach to constructing grounded theory with Aboriginal Australian partners. *Qualitative Health Research*;23(2):275-88.
16. Cochran, P. A., Marshall, C. A., Garcia-Downing, C., Kendall, E., Cook, D., McCubbin, L., & Gover, R. M. 2008. Indigenous ways of knowing: implications for participatory research and community. *American journal of public health*, 98(1), 22-7.
17. National Health and Medical Research Council 2018. *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*, Commonwealth of Australia: Canberra. Available at: <https://nhmrc.gov.au/about-us/publications/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities#block-views-block-file-attachments-content-block-1> [accessed March 2019]
18. Whitehead M, Dahlgren G. 2006. Concepts and principles for tackling social inequities in health: Levelling up Part 1. *World Health Organization: Studies on social and economic determinants of population health*;2.
19. United Nations 2007. United Nations Declaration on the Rights of Indigenous Peoples. Geneva: *United Nations*.