

Decolonising the human T cell leukaemia virus type 1: Resisting neglect through local story

An Abstract of the Thesis by
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The human T cell leukaemia virus type 1 (HTLV-1) is a neglected retrovirus that is endemic to Aboriginal populations in Central Australia. This thesis presents the findings of a two-pronged qualitative study in which a decolonising lens was applied to explore perceptions toward HTLV-1. Critical archival methods were used to document the history of HTLV-1 in Australia, followed by the primary collection of HTLV-1 experiences via semi- and unstructured interviews with health professionals and Aboriginal people. The data points to a range of systemic factors determining the invisibility of HTLV-1, including the role of dominant actors in upholding these systems and perpetuating HTLV-1 inaction. A major finding was the collective belief of Aboriginal participants that they should be informed of, and can hold, knowledges pertaining to HTLV-1. Drawing on participant responses, a twin approach of clinical care and community-driven health promotion is suggested for the development of a future public health initiative.