0.Title

Australian Clinical Guidelines on HTLV-1 for Aboriginal Primary Health Care Settings

1. **Introduction and Background**

Overview	The Australian Clinical Guidelines on HTLV-1 for Aboriginal Primary Health Care Settings (the Guidelines) are a comprehensive, culturally safe and evidence-based guide to the prevention, testing, diagnosis, management and care of Human T-lymphotropic virus subtype 1 (HTLV-1).
Background to the Guidelines	These Guidelines were developed by the National Aboriginal Community Controlled Health Organisation (NACCHO), in partnership with the Australasian Society for HIV, Hepatitis and Sexual Health Medicine (ASHM) in response to community calls for action on HTLV-1. A governance group including NACCHO affiliates and ACCHO representatives and other experts provided oversight to the development of the Guidelines. While for many years the high prevalence of HTLV-1 in Central Australia has been known, these are the first Guidelines to be developed for primary health care services. These Guidelines are the result of advocacy from the ACCHO sector following a series of workshops, including a 2018 Collaborative Forum hosted by the Australian Government Department of Health and Aged Care. The forum recommended the development of clinical guidelines to promote a coordinated approach to HTLV-1 in Australia.
Who the Guidelines are for	These guidelines have been developed to support healthcare providers working in primary health care serving Aboriginal communities with advice for HTLV-1 testing, screening and management. This may include Aboriginal Health Workers and Practitioners, midwives, nurses and general practitioners.
What is the Purpose of the Guidelines	The purpose of the guidelines is to promote a coordinated, evidence-based, best-practice approach to prevention, testing and diagnosis, and clinical management for HTLV-1 in Australia.

Where is HTLV-1 Prevalent?	HTLV-1 occurs in clusters around the world and has been present in Australia for thousands of years. The prevalence of HTLV-1 across Australia varies, and consistent research has demonstrated high rates of HTLV-1 in some Aboriginal Communities in Central Australia. There is also some evidence that there is high prevalence in other areas including the Barkly and Katherine regions of the Northern Territory.
What the Guidelines do and do not Cover	These guidelines cover considerations for HTLV-1 for Aboriginal communities in the Central Australia, Barkly, and Katherine regions. They focus on epidemiology, prevention strategies, screening and diagnosis, and clinical management for HTLV-1. The guidelines also cover advice for people who are pregnant, or planning a pregnancy, as well as advice on breastfeeding, with the aim of minimising maternal-infant transmission. The Guidelines do not include information on the specialist management of HTLV-1 associated diseases such as Adult T-cell leukaemia/lymphoma (ATLL) and HTLV-1 associated acute myelopathy / tropical spastic paraparesis (HAM/TSP) as the management of these conditions should be determined and led by specialist services. These Guidelines do not include information on the prevention, testing or care of HTLV-1 among other population groups.

How the Guidelines Were Developed	In 2023 NACCHO established the HTLV-1 Clinical Guidelines Working Group, with membership including representatives from government and ACCHO sectors across NT, WA and South Australia, and expertise in general practice, obstetrics, public health, midwifery and Aboriginal health. NACCHO and ASHM thank the following for the expertise and experience they contributed to this group: Dawn Casey (Co-chair) – NACCHO Megan Campbell (Co-chair) – NACCHO

	Liz Moore – AMSANT Barb Molanus – AMSANT John Boffa - CAAC Sue Roth – CAAC Laura Caldwell – CRANAPlus Daniel Hunt – Derrbal Yerrigan Health Service Rosalie Schultz – Ngaanyatjarra Health Service Manoji Gunathilake – NT Health Karly Ahfat – Sunrise Health Service ACHSA ACHWA KAMS Jessica Michaels – ASHM Nathan Ryder – Clinical guideline writer Sally Nelson – Clinical guideline writer Lyn Byers – Clinical guideline writer
Consultation, Development and Endorsement Process	These Guidelines have been informed by a literature review that was undertaken in 2024, translations of international HTLV-1 guidelines and interviews with subject matter experts. The WHO evidence-to-decision framework was used to synthesise available evidence with ethical and contextual considerations; the quality and strength of the evidence was assessed for each recommendation. All evidence-to-decision frameworks and guideline sections were initially reviewed by the clinical guideline writing group (comprising three clinical guideline writers, the Working Group co-chair and ASHM representative) prior to review by the broader Clinical Guidelines Working Group, which served as a guideline panel. Key stakeholders were invited to review documents as identified by the Working Group, including other Central Australian primary health care services and specialist services. The Guidelines are up to date as of March 2025. The Guidelines will be reviewed and updated annually.
Endorsing Bodies	Endorsement from the following bodies has been received:

	BBVSS NATSIHP RACGP ACRRM CRANAPlus ASID

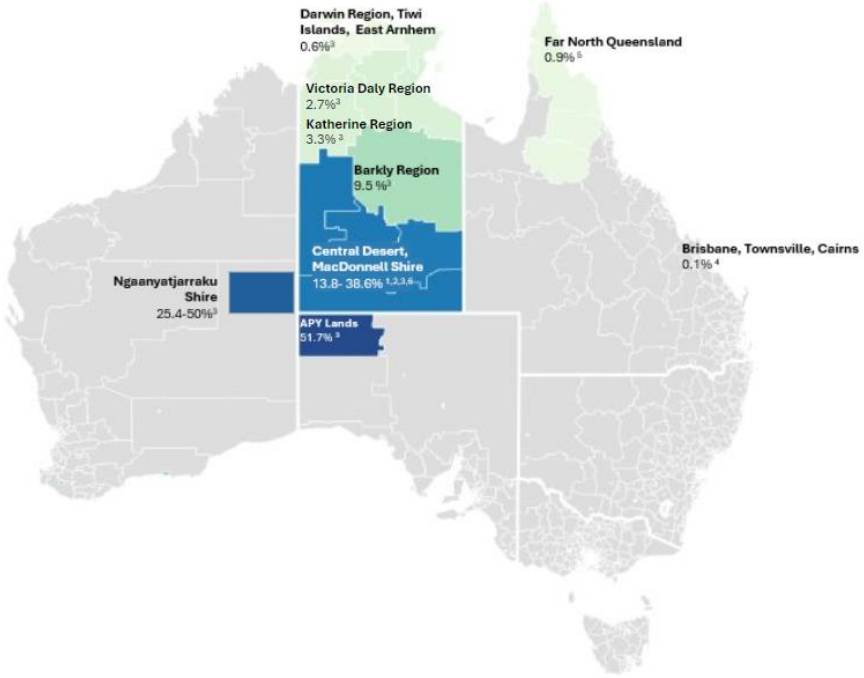
2. Definition of Terms

ACCHO	Aboriginal Community Controlled Health Organisation
AMSANT	Aboriginal Medical Services Alliance Northern Territory
ASHM	Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine
ATLL	Adult T-cell leukaemia/lymphoma
Breastfeeding	Also referred to as chest feeding or nursing
CAAC	Central Australian Aboriginal Congress
CMF	Commercial milk formula
Exclusive breastfeeding	When a baby receives only breast milk, with no other liquids or foods, except for vitamins, minerals and medications. This includes expressed milk or donor milk.
HAM/TSP	HTLV-1 associated acute myelopathy / tropical spastic paraparesis
HIV	Human immunodeficiency virus
HTLV-1	Human T-lymphotopic virus type 1
HAU	HTLV-1 associated uveitis
Mother or Maternal	A person born with a vagina/uterus/cervix
NACCHO	National Aboriginal Community Controlled Health Organisation
NATSIHP	National Aboriginal and Torres Strait Islander Health Protection sub-committee
PCR	Polymerase chain reaction, a type of test to identify different infections
PVL	Pro-viral load, a measure of the amount of virus circulating in the blood
STI	Sexually transmissible infection
Vertical transmission	The passing of an infection from a pregnant person to their infant during pregnancy, childbirth, or breastfeeding
WHO	World Health Organisation

3. What is HTLV-1

Overview	Human T-lymphotropic virus type 1 (HTLV-1) is an oncogenic retrovirus (a virus that can cause cancer), that causes a chronic infection affecting CD4+ T-cells. There is no cure currently. There are no proven associations between viral subtype and transmission patterns or health outcomes. There are very limited data about transmission patterns and health outcomes in Australia however research is currently being undertaken.
HTLV-1 Sub-Types	There are seven main subtypes (A to G) worldwide, the subtype A occurs globally, subtypes B, D, E, F and G are found in Africa and subtype C in Australia and Melanesia. Countries with HTLV-1c subtype include Papua New Guinea, Solomon Islands, French Territory of New Caledonia and Vanuatu. There is a significant lack of data that is specific to Central Australia or subtype C, this includes but is not limited to transmission routes and risk factors, impacts of breastfeeding and HTLV-1 infection, rates of HTLV-1 associated conditions and possible disease associations to HTLV-1 infection. While there is more data known about other subtypes and in other populations the technical report by WHO describes a global lack of systemically collected information around prevalence and particularly for HTLV-1-related diseases. These guidelines are written using what is known internationally and locally, recognising the paucity of knowledge as described.
Epidemiology	WHO estimates 5–12 million people are infected with HTLV-1 globally. HTLV-1 prevalence is poorly understood but is known to be extremely variable, often characterised by discrete geographical areas of higher prevalence. Countries and regions considered to have areas with endemic HTLV-1 include Japan, the Islamic Republic of Iran, Australia, Latin America, the Caribbean, Melanesia and West Africa. Prevalence generally increases with age and is higher in females than males. There is limited information about the Australia wide-prevalence of HTLV-1. Overall, the prevalence of HTLV-1 in the general population is extremely low. Blood donor surveillance data from 2013–2022 found a prevalence of 4.4 per 100,000 donations with no significant trend over the period. Most (85%) positive donors were born outside Australia.
HTLV-1 Epidemiology in Aboriginal Communities	In some remote Aboriginal communities, the prevalence of HTLV-1 is high (Figure 1). The prevalence of HTLV-1 is highly variable across geographic regions and populations in Central Australia. Two large community-based studies have been conducted in Aboriginal communities in the Alice Springs region. The first study assessed HTLV-1 prevalence and transmission risk factors, revealing infection rates of 3.5% in children under 15 and 36.8% in adults. Prevalence increased with age, reaching 49.3% in individuals over 45 in that cohort. The second study examined

	the association between HTLV-1 infection and noncommunicable diseases, finding a prevalence of 38.6%. There are no data specific to young children. However, one community-based study reported prevalence by age and sex. The prevalence in children aged under 15 years was 4.3%. Prevalence increased markedly with age suggesting transmission between adults account for the bulk of cases, consistent with other countries. The sex-distribution within Central Australian Aboriginal communities is markedly different from many other HTLV-1 affected populations, with higher rates observed among males. This atypical sex distribution may indicate non-sexual transmission, such as blood exposure, may play a role. The community-based studies have reported higher prevalence in Central Australia communities, particularly in areas to the South and West of Alice Springs. A laboratory-based study found relatively high prevalences in people living in areas adjacent to Central Australia including the Aṉangu Pitjantjatjara Yankunytjatjara (APY) lands of South Australia (51%), Barkly (9.5%), Katherine (3.3%) and Daly (2.7%) regions. There was a low prevalence in Darwin (0.6%), which is consistent with another study of children with bronchiectasis in Royal Darwin Hospital. An older community-based study from the West Kimberley found a prevalence of 15%, however methodological and reporting concerns limit the certainty of this evidence and further research is needed in this region to determine HTLV-1 prevalence. A large seroprevalence study in Queensland found HTLV-1 prevalence to be 0.1%.
Areas with High HTLV-1 Prevalence in Australia	There is no globally accepted definition of "high prevalence". The European Centre for Disease Prevention and Control consider above 1% in the general population to indicate high prevalence. The prevalence in pregnant women in the three countries recommending routine antenatal screening is 0.26-1.05%. These Guidelines define the following region as having high HTLV-1 prevalence, as demonstrated through multiple published studies: 1. Central Australian region including: a. Central Australian region in the Northern Territory b. Anangu Pitjantjatjara Yankunytjatjara (APY) lands in South Australia c. Ngaanyatjarra (Ng) lands in Western Australia These Guidelines also define the following regions as being likely to have high HTLV-1 prevalence, although the strength of this evidence is weaker: 2. Barkly region of the Northern Territory (based on 31 positive results) 3. Katherine region of the Northern Territory (based on six positive results)

	4. Daly region of the Northern Territory (based on two positive results) These regions and documented prevalences are outlined in Figure 1: **Figure 1: HTLV-1 Prevalence in Aboriginal and Torres Strait Islander People**  Recommendations in these Guidelines relate to communities in all four regions. People residing in adjacent areas, or who have connections to high prevalence areas but are no longer residing there, may also have high pre-test probability and could be considered for testing if considered appropriate by treating clinicians.
	Transmission
Overview	HTLV-1 is thought to be almost entirely, although not exclusively, transmitted via direct contact between infected and uninfected cells. In practice this means transmission requires the transfer of cell-containing fluids such as blood, semen or breast milk.
Sexual Transmission	While sexual transmission is generally thought to account for most transmission globally, there are very few studies that can distinguish sexual from other modes of transmission. In prospective studies of serodiscordant couples, transmission has been shown to be greater from men to women than the reverse. Data from cross-sectional studies is generally consistent with this, with women having higher prevalence than men. A higher proviral load has been shown to be a risk factor for transmission. There are no epidemiological data demonstrating a

	protective effect of condoms, but condoms are highly likely to be protective based on biological plausibility.
Exposure to Blood and Blood Products	Several studies conducted outside of Australia have demonstrated transmission from blood products containing cellular components, and organ donations. In Australia all blood donations are tested for HTLV-1 and the risk of transmission is negligible. Injecting drug use has been found to be associated with HTLV-1 positivity. While there is no data demonstrating this, it is highly likely that avoiding receptive needle sharing would prevent acquisition of HTLV-1. Clusters of infection have been associated with cultural practices involving blood exposure, including one Australian study that looked at self-flagellation in non-Aboriginal people. Any form of blood exposure not involving a sterile single use sharp could potentially lead to transmission, including tattooing and traditional cutting practices.
Vertical Transmission	The reported rate of vertical transmission to child ranges from 3.9%-27%, with a consensus estimate of 20%. The primary mode of vertical transmission is through breastfeeding. As there is a residual transmission rate of about 5% in exclusively formula fed babies it is assumed that intrauterine and intrapartum transmission can occur. Systematic reviews have found breastfeeding for less than 3-months to be equal to commercial formula feeding. Breastfeeding for more than 6 months greatly increases the risk of HTLV-1 transmission. Two retrospective studies have shown a significant association between maternal proviral load (PVL) and the risk of vertical transmission. In one study the transmission rate increased from 5% to 15% for a PVL greater than 0.5%. There is no known PVL threshold below which transmission does not occur. In mothers with a high PVL some guidelines recommend caesarean section, immediate cord clamping and anti-retroviral drugs for both the mother and child based on laboratory data, however there are currently no published clinical data demonstrating a benefit from such interventions. For more information refer to **Prenatal and Postnatal Care for People who are Pregnant**

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4. HTLV-1 Testing and Diagnosis

Overview	Discussions about testing for HTLV-1 should emphasise informed shared decision making, and understanding the implications of a positive or negative test result. There are no currently available treatments for HTLV-1, and a diagnosis may carry stigma, shame and adverse mental health impacts.
Informed Consent and Shared Decision Making	The decision to test for HTLV-1 must be made by the person to be tested following a process of informed shared decision making, preferably using a culturally appropriate decision-aid. Where the clinician has insufficient knowledge to adequately explain the risks and benefits of testing, they should refer the person to another clinician or obtain sufficient support to gain informed consent. Shared decision making is more than informed consent. Shared decision making is a consultation process where a clinician and patient jointly participate in making a health decision, having discussed the options and their benefits and harms, and having considered the patient's values, preferences and circumstances. Shared decision making is especially valuable when there is uncertainty as to which option is superior, when each option has different inherent benefits and harms, or when the decision is likely to be strongly influenced by patients' preferences and values. Documentation of shared decision making is also important so that other services do not repeat the process, particularly for people who access care at several clinics, or who attend specialist antenatal clinics throughout pregnancy. For more information refer to **Prenatal and Postnatal Care for People who are Pregnant**
Pregnant People	All Aboriginal pregnant people, and other pregnant people whose baby will be identified as Aboriginal, who are living in or were born in high prevalence communities for HTLV-1 should be offered information

	about HTLV-1. This should include the availability of testing and the implications of a positive and negative test for their own and their baby's health. This discussion should occur with a clinician with knowledge of HTLV-1 as soon as safely possible in pregnancy. HTLV-1 testing should never be included in a predefined antenatal care test set. For more information refer to **Prenatal and Postnatal Care for People who are Pregnant**
People Requesting Testing, Including Partners and Sexual Contacts of People Living with HTLV-1	The potential benefits and harms of testing for all Aboriginal people, including partners of Aboriginal people, who are living in, or were born in, high prevalence communities should be discussed with people who request testing. This includes people who have had sexual contact with a person living with HTLV-1.
Children Birthed or Breastfed by a Person Living with HTLV-1	Do not routinely test children who may have been exposed to HTLV-1 during pregnancy, birth or breast feeding. There is currently no proven health benefit to diagnosing a child with HTLV-1 and testing may lead to harms, including stigma, shame and adverse mental health impacts. In the absence of a specific clinical indication, testing should be deferred until the child can understand the implications for themselves and make an informed shared decision about testing.
Children with Symptoms Consistent with HTLV-1	Testing of children presenting with symptoms consistent with HTLV-1 associated health conditions should be carefully considered as to the immediate clinical benefit of ascertaining HTLV-1 status versus the potential harms associated with diagnosis of an untreatable chronic infection. Testing should only be performed where the result will alter clinical management and the decision to test is made as a shared decision with the child's carers.
People Presenting with Symptoms Consistent with HTLV-1 Associated Disease	Recommend testing for HTLV-1 in all Aboriginal people who are living in, or were born in, high prevalence communities with clinical findings suggestive of ATLL,

	HAM/TSP, infective dermatitis or HTLV-associated uveitis. Consider testing for HTLV-1 in patients with diseases possibly associated with HTLV-1, including crusted scabies, bronchiectasis and tuberculosis, where knowing HTLV-1 status may alter management, or where the person wishes to know their status to prevent transmission.
How to Test for HTLV-1	Testing is performed by requesting HTLV-1 serology on a plasma or serum sample. Local laboratories will perform an initial HTLV-1 screening antibody test which, if reactive, is then sent to a reference laboratory for confirmation. Confirmation of a diagnosis is performed by repeating the serology testing in duplicate and if reactive, performing a Western Blot assay. The Western Blot result will be reported as positive, negative or indeterminate. Ideally, a PCR test for the presence/absence of viral DNA in white blood cells should then be performed on all Western Blot indeterminate results, with a positive result for viral DNA sufficient to confirm a diagnosis of HTLV-1 infection. However, as of March 2025 a PCR test is not currently funded under the Medicare Benefits Schedule. If unable to be resolved, an indeterminate result is reported with a request for submission of a follow-up specimen in 6 months.
Interpreting HTLV1 Test Results	Positive – person is HTLV-1 infected. Negative – person is not HTLV-1 infected. False negative results can occur so where the clinical suspicion is high repeat the test and seek expert advice. Indeterminant – requires additional testing with either a repeat serological test and/or proviral load assay to determine infection status. Seek expert advice.
Positive Results	Persons found to be HTLV-1 positive should be informed that they are infected with HTLV-1 and that HTLV-1 is a lifelong infection. People with HTLV-1 should be given information regarding modes and efficiency of transmission, and the probability of developing HTLV-1 associated conditions.

	All people found to be HTLV-1 positive should be provided with information regarding modes and efficiency of transmission, and how to minimise the risk of transmission by: ○ Not sharing needles or syringes or other injecting equipment ○ Using condoms to prevent sexual transmission ○ Not donating blood, semen, body organs, or other tissues ○ If undergoing cultural rituals where blood is involved, ensuring all equipment is single use and no blood to bloodstream contact occurs ○ Engaging in pre-conception counselling if they are planning to become pregnant
	People found to be HTLV-1 positive should also be provided with advice about general health, such as smoking cessation, diet and exercise. Referral to a mental health worker or psychologist should also be considered. For more information refer to **Management and Care**
	It is not currently recommended to perform pro-viral load testing for patients living with HTLV-1 who are not pregnant, planning pregnancy or considering breastfeeding.

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5. HTLV-1 Clinical Presentations

Overview	While most people with HTLV-1 infection will remain asymptomatic, HTLV-1 can cause specific medical conditions. There is also evidence that some conditions may be more likely in those living with HTLV-1. Further, there is strong evidence from populations outside Australia that HTLV-1 infection is associated with a 1.6 times increase in all-cause mortality not explained by these conditions known to be associated with HTLV-1. While there are limited Australian data on the health outcomes associated with HTLV-1 infection, research on this topic is currently underway. The HTLV-1 virus found in Australia has evolved separately from other HTLV genotypes over a long time period and therefore may have differing health impacts. There is some evidence that people with a higher proviral load have an increased risk of developing some HTLV-1-associated conditions. However, while research is currently underway to identify other indicative biomarkers, at present there is no method that can be applied in routine clinical practice to reliably determine which individual patients are at risk of developing HTLV-1-associated conditions.
Adult T Cell Leukemia-Lymphoma (ATLL)	
Overview	Adult T cell leukemia-lymphoma (ATLL) is a rare and aggressive lymphoid cancer that only occurs in people living with HTLV-1 infection. The exact mechanism that leads to ATLL developing in some people living with HTLV-1 infection is currently unknown. There are four subtypes of ATLL: acute, lymphoma, chronic and smouldering. Each subtype has different clinical presentations.
Incidence	Overall lifetime risk of ATLL in people living with HTLV-1 infection is estimated to be between 2% and 5%. The risk appears to increase with age, longer duration of infection, in people with higher proviral load, and in those with a family history of ATLL. Although a higher proviral load is associated with progression to ATLL there is no clear

	threshold that can be applied to an individual to reliably predict their risk.
Mortality	The prognosis of untreated ATLL is generally poor but varies considerably by type and between individuals. Four-year survival rates range from 52% for smouldering to 11% for acute type.
Symptoms and Clinical Findings	People with ATLL can present with a range of symptoms depending on the type. The key symptoms and signs include generalised lymphadenopathy, hepatosplenomegaly and skin lesions (nodules, plaques or rash). Blood tests may show elevated white blood cells, hypercalcaemia and elevated LDH. Patients can also present with opportunistic infections (e.g. Pneumocystis jirovecci, candida, cytomegalovirus, and Strongyloides stercoralis) secondary to ATLL induced immunosuppression.
Diagnosis	ATLL is diagnosed using a combination of clinical features and laboratory examination of malignant cells in a person with confirmed HTLV-1 infection.
Treatment	There are a variety of treatment options including chemotherapy with allogeneic hematopoietic stem cell transplantation, antiviral agents and monoclonal antibodies. Most patients do not achieve a cure with current treatment options.
Management and Care	Refer for specialist care including treatment and management of opportunistic infections.
HTLV-1 Associated Myelopathy/Tropical Spastic Paresis (HAM/TSP)	
Overview	HTLV-1-associated myelopathy/tropical spastic paresis (HAM/TSP) is a chronic inflammatory disease of the central nervous system that only occurs in people living with HTLV-1 infection.

Incidence	Lifetime prevalence is estimated to be approximately 2% among people with HTLV-1. There is significant variation in the reported prevalence, from 0.25% in Japan to 1.8% in Trinidad. There is evidence that HAM/TSP is associated with a higher pro-viral load.
Mortality	While HAM/TSP causes significant morbidity it is unclear whether there is a direct effect on mortality.
Symptoms	Initial presentation is often urinary symptoms or an impaired gait, as perceived by the patient. Clinical features generally include slowly progressive weakness and spasticity in one or both legs, back pain with or without radiation, bladder dysfunction (spastic or flaccid) and bowel dysfunction, normally constipation. Examination shows hyperreflexia, ankle clonus, extensor plantar responses and loss of vibration sense.
Diagnosis	Clinical diagnosis is based on the WHO consensus criteria of neurological signs and cerebrospinal fluid examination. Newer technologies developed after the WHO criteria including serum and cerebrospinal fluid proviral load and MRI may also be useful.
Treatment	There is no treatment proven to alter the natural history of HAM/TSP. However, systemic corticosteroids are recommended in patients with progressive disease as there is some evidence they may slow progression.
Management and Care	Support and management of the neurological deficits are an important component of care.
HTLV-1 Associated Uveitis (HAU)	
Overview	HAU is an inflammatory condition thought to be related to lymphocyte-driven inflammation mediated by infected CD4+ T cells in the aqueous humour of the eye.

Incidence	There is insufficient evidence to comment on the incidence of HAU in people with HTLV-1 infection or on the predictors of disease development either internationally or in Australia. The age of onset ranges from teens to over 60 years of age.
Morbidity	Prognosis is generally favourable however recurrence is common. Sight-threatening complications include retinochoroidal degeneration and glaucoma. Corticosteroid-induced cataracts can occur. Vision loss in the untreated also can occur. Due to recurrence rates (up to 52% in one study) follow up with optometry and ophthalmology services is recommended.
Symptoms	Symptoms include blurred vision, floaters, decline in vision, eye redness, eye pain and photophobia. This can occur suddenly in both eyes or in one eye. The main clinicopathological features are vitreous opacity and retinal vasculitis.
Diagnosis	The gold standard for diagnosis is detection of HTLV-1 proviral DNA or anti-HTLV-1 antibodies in aqueous humour. This is infrequently done, and diagnosis is usually made by exclusion of other causes of uveitis and the presence of HTLV-1 infection.
Treatment	Treatment involves either topical and/or systemic corticosteroids.
Management and Care	Management and care should be initiated by the ophthalmology service. Education should be provided to the patient to be aware of early presentation if vision changes or new visual symptoms develop after the acute episode has been treated.

Infective Dermatitis	
Overview	Infective dermatitis is a rare and severe chronic dermatitis which relapses. It promptly responds to therapy (antibiotics) and recurs on discontinuation.

Incidence	The incidence of infective dermatitis for people with HTLV-1 infection varies across geographical locations. Its incidence in Central Australia is unknown. It is a condition of childhood with incidence and severity decreasing into adolescence and adulthood.
Morbidity	Infective dermatitis responds well to antibiotics aimed at common pathogens Staphylococcus and B haemolytic Streptococcus.
Symptoms	Severe erythematous and exudative dermatitis with scaling and crusting primarily affecting the scalp, forehead, eyelids, paranasal area, neck, retroauricular areas, and to a lesser extent axilla and groin.
Diagnosis	Diagnostic criteria include: i. dermatitis of the scalp, axillae and groin, external ear and retroauricular areas, eyelid margins, paranasal skin, and/or neck; ii. chronic watery nasal discharge without other signs of rhinitis and/or crusting of the anterior nares; iii. early childhood-onset or chronic relapsing dermatitis with prompt response to appropriate therapy but prompt recurrence on withdrawal of use of antibiotics; and iv. HTLV-1 antibody seropositivity. Differentiating infective dermatitis from other skin conditions in a person living with HTLV-1 infection can be difficult and relies on clinical features, including the relapsing nature, and exclusion of alternative diagnoses such as atopic and seborrheic dermatitis.
Treatment	Infective dermatitis responds well to antibiotics aimed at common pathogens Staphylococcus and B haemolytic Streptococcus.
Management and Care	Treatment with continuous antibiotics until adolescence is recommended due to risk of relapse, and the risk of conditions associated with Streptococcal infection, i.e. post streptococcal glomerulonephritis (PSGN) and acute rheumatic fever. Infective dermatitis may serve as an indicator of increased risk of developing other HTLV-1 associated diseases, in particular HAM/TSP and ATTL. Clinical surveillance of patients after a diagnosis of infectious dermatitis is recommended.

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6. Other Conditions Associated with HTLV-1

Overview

HTLV-1 infection is associated with an increase in all-cause mortality. HTLV-1 infection may be associated with inflammatory and infective conditions resulting in either more significant disease or different disease characteristics or both. Conditions that are diagnosed more frequently in people infected with HTLV-1 include seborrheic dermatitis, tuberculosis, bronchitis, bronchiectasis and bronchiolitis, Sjogren's syndrome, Stronglyoides hyperinfection syndrome and symptomatic Strongyloidiasis, urinary tract infection, thyroid disease and liver cancer. The strength of association of these conditions and HTLV-1 found in the meta-analysis below, was either limited or very limited except for tuberculosis where the strength was moderate.

A full list of the possible disease associations examined by the meta-analysis is included in the table below.

Meta Analysis of HTLV-1 Associated Conditions

In addition to diseases that are designated as HTLV-1associated conditions, that is, where HLTV-1 infection is required for the diagnosis, a number of other conditions have been investigated for their association with HTLV-1.

The following table provided is an overall summary of a published meta-analysis of studies showing significant associations between HTLV-1 infection and either disease or death.

Table 1: HTLV-1 infection, all-cause mortality, and possible disease associations

Condition*	RR or OR (95% CI)	Total number of studies	Studies used for summary estimate	Strength of association GRADE‡
Mortality				
All-cause mortality	1.57 (1.37-1.80)	9	8	STRONG
Inflammatory conditions				

	Seborrheic dermatitis (adults)	3.95 (1.99-7.81)	2	2	LIMITED
	Seborrheic dermatitis (children)	4.70 (1.70-13.20)	1	1	LIMITED
	Eczema (children)	3.10 (1.20-7.90)	1	1	LIMITED
	Rheumatoid arthritis	2.8 (1.8-4.6)	1	1	LIMITED
	Arthritis	2.84 (1.51-5.33)	1	1	VERY LIMITED
	Sjogren's syndrome	3.25 (1.85-5.70)	2	2	LIMITED
	Fibromyalgia	9.14 (2.42-34.52)	1	1	VERY LIMITED
	Bronchiectasis, bronchitis, bronchiolitis†	2.90 (2.0-4.3)	3	1	LIMITED
	Asthma (males)	3.4 (1.2-3.3)	1	1	VERY LIMITED
	Cancer other than ATLL				
	Lymphoma other than ATLL	2.76 (1.36-5.62)	1	1	LIMITED
	Liver cancer	1.49 (0.97-2.30) 1.46 (0.85-2.51)	3 2	3 2	LIMITED
	Gastric cancer	0.45 (0.28-0.71)	3	3	VERY LIMITED
	Cervical cancer	8.30 (0.83-82.90)	1	1	VERY LIMITED

		3.59 (0.68-19.11)	1	1	
	Infectious diseases				
	Tuberculosis	2.30 (1.60-4.10) 2.04 (1.36-3.06)	1 6	1 6	MODERATE
	Kidney and bladder infections	2.32 (1.50-3.59) 1.80 (1.0-3.2)	2 1	1 1	LIMITED
	Dermatophyte infection	3.32 (1.5-7.35)	1	1	VERY LIMITED
	Community acquired pneumonia	1.36 (1.00-1.85)	1	1	VERY LIMITED
	Strongyloides hyperinfection syndrome	120 (11.43-1259)	1	1	VERY LIMITED
	Adapted from Schierhout et al (2) Overall summary of meta-analysis of studies showing significant associations between disease or death and HTLV-1 infection. *There were two further inflammatory conditions, Crohn's disease and ulcerative colitis and one other condition, renal disease, which reported statistically significant associations with HTLV-1 or substantially increased risk, but effects are not shown here on the basis of <5 participants with these conditions. †As determined by study authors ‡ Strength of association, based on modification of GRADE criteria. Colour corresponds with strength of association.				
HTLV-1 and Respiratory Diseases	There is very limited evidence for an association between HTLV-1 and bronchiectasis, bronchitis, bronchiolitis and asthma. International research has not found an association between respiratory diseases and HTLV-1 infection.				

	One non-Australian study found an association between self-reported diagnosis of asthma and HTLV-1 infection. Two case control studies in Central Australia within the same hospital population found statistically significant associations between HTLV-1 and radiologically confirmed bronchiectasis, bronchitis and bronchiolitis, and one cross-sectional study from Central Australia found a strong association between HTLV-1 and pulmonary disease. However, an analysis of children with bronchiectasis attending Royal Darwin Hospital (a population with a similarly high prevalence of bronchiectasis to Central Australia) found no cases of HTLV-1 in the 299 children tested. The proposed mechanism of persistent HTLV-1 mediated airways inflammation leading to progressive bronchial wall dilatation and bronchiectasis has similarities to the mechanism of inflammation which underlies HTLV-1 associated myelopathy (HAM). More research is needed to understand the role that HTLV-1 plays in respiratory diseases, especially considering the high prevalence and burden of bronchiectasis and pulmonary disease in Aboriginal People living across the Northern Territory and adjacent areas of South Australia and Western Australia. It is also acknowledged that the subtype of HTLV-1 prevalent in Australia is different to subtypes prevalent internationally, so it is possible and plausible that there could be an association.
HTLV-1 and Tuberculosis	The most studied HTLV-1 related condition identified in the meta-analysis was pulmonary tuberculosis, possibly because of the strong causative association between TB and HIV, and similarities between HTLV-1 and HIV. Analysis suggests that the risk of developing tuberculosis is higher in patients with HTLV-1: the pooled odds of developing tuberculosis is 2.04 times (95% CI 1.36-3.06) higher in people with HTLV-1, thought to be secondary to the immune response increasing susceptibility. The strength of the evidence connecting these two conditions is low to moderate.
HTLV-1 and Autoimmune Diseases	There may be an increased risk of rheumatoid arthritis (RA) and Sjogren's syndrome associated with HTLV-1 infection. Some research has suggested that there is attenuated effectiveness of TNF inhibitor medications (tumor necrosis factor) in HTLV-1-

	positive patients with RA. However, treatment recommendations are unchanged and at present testing for HTLV-1 prior to commencing treatment with DMARDs (disease modifying anti-rheumatic drugs) is not recommended. There is almost no data on systemic lupus erythematosus (SLE) in relation to HTLV-1.
HTLV-1 and Strongyloidiasis	There is very limited evidence for an association between either Strongyloidiasis hyper infection syndrome or symptomatic strongyloidiasis and HTLV-1 infection. Some research showed higher rates of Strongyloidiasis treatment failure for HTLV-1 positive patients. However, this does not appear to apply to the CAPRA-recommended treatment regime of ivermectin. Due to a high prevalence of Strongyloidiasis infection in Central Australia, the risk of symptomatic strongyloidiasis or Strongyloidiasis hyper infection should be considered in patients living with HTLV-1 despite the weak evidence for an association.
HTLV-1 and Scabies	There is some evidence that in areas that are endemic for scabies, individuals living with HTLV-1 are more susceptible for either recurrent scabies or crusted scabies. However, the strength of this evidence is low. There is significant morbidity associated with skin diseases in Central Australia, such as acute rheumatic fever and post-streptococcal glomerulonephritis. Regardless of an individual's HTLV-1 status, early detection and treatment, and ongoing monitoring of crusted scabies is important for reduction in spread and associated morbidity.
HTLV-1 and All Cause Mortality	In addition to these conditions that are statistically associated with HTLV1, HTLV-1 infection is associated with an increase in all-cause mortality, with a pooled relative risk of 1.57 (95% CI 1.37-1.80). The association appears to be slightly stronger among men. This increase is not explained by the impact that the HTLV-1 associated conditions, in particular ATLL, has on mortality. The mortality increase is consistent across different settings, in diverse geographical locations and across different subtypes, however there are no reported studies on mortality in Aboriginal people in Australia as yet.

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7. **HTLV-1 Management and Care**

Overview	Evidence indicates that a high proviral load, considered to be 4%* or above, appears to increase the risk of certain HTLV-1 associated conditions. Currently, the recommendations for management for this group (excluding the breastfeeding group) do not differ to those for patients with a low viral load, due to a lack of evidence that outcomes are impacted by differences in management. While there are low levels of evidence across HTLV-1, this area in particular lacks evidence.
Recommendations	Caring for patients living with HTLV-1 should focus on health promotion, including promoting cancer screening and cardiovascular risk reduction. The focus should include lifestyle advice, which normally forms part of the annual health check. This includes advice on diet, regular exercise, adequate sleep, and alcohol and tobacco consumption.
	During annual health checks, people living with HTLV-1 should be assessed for HTLV-1-associated conditions and provided with education to reduce the morbidity that HTLV-1 associated conditions can have. This care plan could include: a. Taking a screening history for HAM/TSP; asking about new urinary symptoms or a self-identified deterioration in gait. Further history and examination using the WHO diagnostic criteria should be guided by the screening history. b. Coupling the annual vision assessment with an opportunity to educate the patient that they are at risk of developing HAU, including the advice to present urgently if new vision symptoms develop or there is a change in vision. If the patient has a history of previous HAU, this is an opportunity to acknowledge that it can reoccur and the importance of treating urgently if it does. c. Annual skin examination looking for signs of infective dermatitis in the child, adolescent and young adult population (see infective dermatitis section for diagnostic criteria).

	Identification of HTLV-1-associated conditions should result in referral to a specialist service.
	It is not currently recommended to perform pro-viral load testing for patients living with HTLV-1 who are not pregnant, planning pregnancy or considering breastfeeding.
	For clients who are known to have a high pro-viral load but are not pregnant, these guidelines do not currently recommend any additional care beyond the routine recommended primary care health activities for people living with HTLV-1.
What is HTLV-1 Associated Stigma?	HTLV-1 infection has the potential to be associated with stigma. Health-related stigma is a social process where people devalue or exclude others based on a perceived health condition or characteristics associated with that health condition. Stigma is a barrier to health-seeking behaviour, engagement in care and adherence to treatment across a range of health conditions. It enables discrimination that denies the individual or group full social acceptance, reduces individuals' opportunities, and fuels social inequalities. Stigma influences population health outcomes by worsening stress and psychological and behavioural responses, undermining social relationships, and exacerbating poor health. Health care providers' actions can either reinforce or reduce stigma. The experience of stigma for Aboriginal and Torres Strait Islander people is complex, often entwined with experiences of racism and discrimination. HTLV-1 infection may be associated with stigma due to certain characteristics, such as transmission causes (sexual contact, blood exposure) and a lack of public awareness and understanding.

	HTLV-1 related stigma could potentially be driven by fear of infection, or anxiety related to knowledge of a life-long, untreatable disease with potentially serious outcomes. Given that social norms and accepted best practice promote breastfeeding, women who choose not to breastfeed, or to limit breastfeeding, irrespective of HTLV-1 status, may experience stigma related to their choice of infant feeding.
Reducing HTLV-1 Associated Stigma	Reducing stigma related to HIV requires both systemic and individual level interventions and it is likely that similar multi-focussed approaches are needed for HTLV-1. Population-wide public health messages about safe sex and injecting drug use need to be tailored to local contexts. At an individual level, developing an understanding of HTLV-1 will allow clinicians to work with patients to develop a shared approach to management and avoid contributing to HTLV-1 associated stigma and discrimination. Other strategies to reduce stigma include the use of appropriate language for HTLV-1, prioritising lived experience and establishing therapeutic relationships between health professionals and patients. For more information refer to **Prenatal and Postnatal Care for People who are Pregnant**

**This figure varies depending on the literature. The figure of 4% has been chosen to be consistent with UK guidelines.*

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8. HTLV-1 Prevention for Adults and Adolescents

Overview	HTLV-1 is transmitted through direct contact between infected and uninfected target cells, a process facilitated by cell-containing bodily fluids, including blood, breast milk and semen. Globally, the main mechanism of HTLV-1 transmission among adults is thought to be through sexual contact. Evidence for this is the typical age associated prevalence increases, and increased prevalence in populations with greater rates of sexually transmissible infections. There is no vaccine for HTLV-1.
HTLV-1 Transmission	Refer to **What is HTLV-1**
HTLV-1 Prevention	HTLV-1 transmission can be prevented by: • Using condoms to prevent sexual transmission • Not sharing needles, syringes or other injecting equipment • When undergoing cultural rituals where blood is involved, ensuring all equipment is single use and no blood-to-bloodstream contact occurs • Not donating blood, semen, body organs, or other tissues
Prevention of Vertical Transmission	Refer to **Prenatal and Postnatal Care for People Who Are Pregnant**

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9. HTLV-1 Contact Tracing

Overview	Contact tracing for people diagnosed with HTLV-1 is not recommended as there is insufficient evidence of individual or public health benefits. However, people should be provided with information about HTLV-1 transmission and prevention and supported to inform sexual partners should they wish to do so.
Testing Partners of People Diagnosed with HTLV-1	Diagnosis in a sexual partner would enable this person to take steps to limit sexual transmission by using condoms with new or other partners. There is insufficient evidence of individual or public health benefits to recommend contact tracing.
Recommendations	People with long-term sexual partners should be provided with information about HTLV-1 transmission and prevention and supported to inform their long-term sexual partners. Individuals can also be provided with access to condoms.
	People with casual sexual partners should be provided with information about HTLV-1 transmission and prevention and supported to inform their casual sexual partners should they wish to do so. Individuals can also be provided with access to condoms.

10. HTLV-1 Prenatal and Postnatal Care for People who are Pregnant

Overview	HTLV-1 can be transmitted vertically through breastfeeding and possibly during pregnancy or at birth. Diagnosis in pregnant people may enable them to take measures to reduce transmission. However, there are many uncertainties relating to evidence, and in personal values and preferences related to a HTLV-1 diagnosis. There are also many uncertainties and risks in relation to not breastfeeding.
Testing	Testing is requested on a serum sample. Local laboratories will perform an initial HTLV-1 screening antibody test, which is then sent to a reference laboratory for confirmation. Confirmation is usually performed with Western Blot. Ideally a PCR test is also used to aid confirmation, however as of March 2025, this test is not funded by the Medicare Benefits Schedule. The result will be reported as positive, negative or indeterminant. Indeterminant results can usually be resolved with repeat testing after a 1-month interval.
When to Test	At the first antenatal visit, determine whether the pregnant person's HTLV-1 status is known. For pregnant people known to be living with HTLV-1 infection refer to the recommendations section below. For pregnant people of unknown status, or where their previous test was HTLV-1 negative, a discussion about the risks and benefits of HTLV-1 testing should begin as soon as possible in the pregnancy. This is to try and ensure sufficient time to receive their test results and if needed make a shared decision about feeding their baby and discuss breastfeeding duration. Discussion about testing should be deferred if the practitioner does not have sufficient knowledge to adequately inform the person of the implications of testing. Ideally, testing will occur early in pregnancy to allow the person time to consider feeding options prior to the baby's birth. However, as the greatest risk of transmission is associated with breastfeeding after 6 months of age there is still potential benefit to testing at any stage of pregnancy and into the breastfeeding period.

What is Shared Decision Making?	Shared decision making is a consultation process where a clinician and person jointly participate in making a health decision, having discussed the options and their benefits and harms, and having considered the patient's values, preferences and circumstances. Shared decision making is especially valuable when there is uncertainty as to which option is superior, when each option has different inherent benefits and harms, or when the decision is likely to be strongly influenced by patients' preferences and values. Documentation of shared decision making is also important so that other services do not repeat the process, particularly for pregnant people who access primary care at several clinics, or who attend specialist antenatal clinics throughout pregnancy. Additional information on shared decision making can be found here: Shared decision making | Australian Commission on Safety and Quality in Health Care
Shared Decision Making and Pregnancy	Encouraging open conversations and trust with pregnant people and their families is essential to minimise stigma and support information sharing. A positive result can have negative social and emotional wellbeing impacts including stress and anxiety. However, with adequate support and counselling it also allows the pregnant person to make an informed decision about breastfeeding when it suits them. It is never appropriate for a health care provider to inform a pregnant or breastfeeding person living with HTLV-1 that they are not able to breastfeed their infant. Decisions regarding method of feeding require informed discussion between the person and their care team, with consideration of the risks and benefits of breastfeeding given the pregnant or breastfeeding persons situation. Suitable decision-making aids should be used to guide a discussion between the pregnant person and their care givers. People should understand the implications of a positive HTLV-1 result for them and their babies and be supported to consider the impact of their individual values and preferences before undergoing testing. This includes the following: • On average overall about 1 in 5 pregnant persons will pass HTLV-1 on to their babies during pregnancy, birth or breastfeeding, with breastfeeding accounting for most transmission. • If breastfeeding is completely avoided there is still a risk of about 1 in 20 of passing on HTLV-1.

- There is uncertainty about the level of risk for short-term limited breast feeding, the following estimates are mainly based on Japanese data (Table 1).
- Breastfeeding for less than 3-months does not increase the risk of transmission above the residual 1 in 20 risk (Table 1).
- Breastfeeding beyond 6-months greatly increases the risk of transmission to about 1 in 5 (Table 1).

Scenario	Risk of Transmission Mother to Child	Degree of certainty
Baseline risk of transmission (birth, all events)	1/20	High certainty
Exclusive Breastfeeding (0-3 months)	1/20	Low certainty
Exclusive Breastfeeding (3-6 months)	1/10	Low certainty
Exclusive Breastfeeding (>6 months)	1/5	High certainty

Table 1: Exclusive breastfeeding scenarios and risk of transmission

- People with HTLV-1 and a higher proviral load are most at risk of transmitting HTLV-1 to their babies and may be more important to limit the duration of breastfeeding to 3-months or less. A proviral load of more than 0.5% tripled the rate of transmission in one study. It is not known whether there is a viral load threshold below which transmission does not occur.
- Breastfeeding has many health, social and emotional benefits for the person and their baby. For breastfeeding parents this includes supporting a healthy weight and reducing the risk of a range of diseases including diabetes, breast cancer, ovarian cancer, endometrial cancer, high blood pressure and cardiovascular disease. For babies this includes healthy growth and development and reducing risk of infections and conditions such as gastroenteritis, respiratory infections, ear infections, type 1 and 2 diabetes, obesity and some cancers. In communities with a high disease burden, and high levels of food insecurity and poverty, the benefits and risks of breastfeeding need to be carefully considered based on the person's personal circumstances.
- Breastfeeding is most important in the first 6 months of life although there is clear evidence of

	the benefit of breast feeding for two years and beyond, which is the WHO recommendation. • Commercial milk formula (CMF) feeding is expensive and is associated with safety risks, such as serious infections, if appropriate preparation and sterilisation can't be achieved. Safely using CMF may be more difficult for parents living with poverty, energy insecurity, and in transient, overcrowded or poorly maintained housing. • Given that social norms and accepted best practice promote breastfeeding, parents who choose not to breastfeed, or to limit breastfeeding, irrespective of HTLV-1 status, may experience stigma related to their choice of infant feeding**.** • Becoming infected with HTLV-1 as an infant may affect their health later in life. Based on information from overseas HTLV-1 causes ATLL in about 1 in 20 people, and HAM/TSP in about 1 in 50. HTLV-1 is also associated with some other diseases and with an overall reduced life expectancy. For more information refer to **Clinical Presentation.** • If a person is diagnosed with HTLV-1 in pregnancy, there are significant implications for their own health and there are no specific treatments available for the infection. For more information refer to **Management and Care.**
Postnatal Care	After the birth of their baby, people with a diagnosis of HTLV-1 should be offered further support to implement the feeding method that they have chosen. A specific review appointment may be required, for example when the infant is 3 or 6 months of age, particularly if a limited duration of breastfeeding is intended.
Recommendations	All people who are giving birth to an Aboriginal baby, are living in or were born in high prevalence communities for HTLV-1 should be provided with information about HTLV-1. This should include the availability of HTLV-1 testing and the implications of a positive and negative test for their own and their baby's health and wellbeing, to enable them to make an informed shared decision about testing for HTLV-1. This discussion should occur as soon as possible, with a person knowledgeable about HTLV-1.

	HTLV-1 testing should never be included in a predefined antenatal care test set. All pregnant people diagnosed with HTLV-1 should be offered a pro-viral load test during each pregnancy to help ascertain their individual risk of transmission. As of March 2025, this test is not funded by Medicare and clinicians should seek local advice from their laboratory or an expert in HTLV-1 about availability and costs. All pregnant people diagnosed with HTLV-1 should be provided with support to make an individual assessment of the risks and benefits of breastfeeding for both the mother and the infant. This includes evaluating whether to breast or formula feed, the duration of breastfeeding, what information and resources are required for safe infant feeding. Mixed feeding (breastfeeding combined with formula feeding) is not recommended for mothers with HTLV-1, as it may increase the risk of transmission to the infant. Although specific studies on HTLV-1 are lacking, evidence from HIV research indicates that mixed feeding increases the risk of vertical transmission. All pregnant people with HTLV-1, regardless of proviral load, should be provided with lactation and feeding advice and resources to provide CMF to their baby safely and reliably if they choose to use CMF. No recommendation is made about the mode of delivery.

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