

1. What is HTLV-I?

Human T-lymphotropic virus type 1 (HTLV-1) is an oncogenic retrovirus (a virus that can cause cancer).

The rate of HTLV-1 in the general population is extremely low, however in some Aboriginal communities in Central Australia, the prevalence is extremely high.

The following regions are considered as having high HTLV-1 prevalence, as demonstrated through multiple published studies:

Central Australia region in the Northern Territory, Anangu Pitjantjatjara Yankunytjatjara (APY) lands in South Australia and the Ngaanyatjarra (Ng) lands in Western Australia.

The following regions are also considered as likely to have high HTLV-1 prevalence, however the strength of this evidence is weaker:

LOW CERTAINTY

Barkly region of the Northern Territory (based on 31 positive results)

Katherine region of the Northern Territory (based on six positive results)

Daly region of the Northern Territory (based on two positive results)

2. HTLV-I Transmission

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 largely requires the transfer of cell-containing fluids such as blood, semen or breastmilk.

3. Health Impact of HTLV-I

Most people with HTLV-1 infection will remain asymptomatic. At present there is no method of determining which patients are at risk of developing HTLV-1 associated conditions that can be applied in routine clinical practice. There is a significant increase (1.6 x) in all-cause mortality.

The following conditions are caused by HTLV-1:

- Adult T cell leukemia-lymphoma (ATLL) is a rare and aggressive lymphoid cancer that only occurs in people living with HTLV-1 infection.
- 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.
- HTLV-1 associated Uveitis (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 that only occurs in people living with HTLV-1 infection.
- Infective dermatitis is a severe, chronic, relapsing dermatitis involving the scalp and pre-auricular areas which promptly responds to therapy (antibiotics) and recurs on discontinuation. It occurs in people living with HTLV-1 infection.

4. Who to Test

Decisions about whether or not to test for HTLV-1 should always be undertaken using a shared decision-making approach. The harms and benefits of testing and a subsequent result should also always be considered and discussed. Informed consent must always be obtained prior to HTLV-1 testing.

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.

People Requesting Testing, Including Partners and Sexual Contacts of People Living with HTLV-I

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-I

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.

4. Who to Test (continued)

Children with Symptoms Consistent with HTLV-I

Testing of children presenting with symptoms consistent with HTLV-I associated health conditions should be carefully considered as to the immediate clinical benefit of ascertaining HTLV-I 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-I Associated Disease

Recommend testing for HTLV-I 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-I in patients with diseases possibly associated with HTLV-I, including crusted scabies, bronchiectasis and tuberculosis, where knowing HTLV-I status may alter management, or where the person wishes to know their status to prevent transmission.

5. How to Test for HTLV-I

Testing purpose	Proviral Load	Pathology request text	Samples for collection
Determine a diagnosis of HTLV-I – not pregnant	No	"HTLV-I status"	1 x EDTA (purple) 1 x SST (gold)
Determine a diagnosis of HTLV-I – pregnant	Yes	"HTLV-I status + HTLV-I proviral load"	1 x EDTA (purple) 1 x SST (gold)
Pregnant person, known HTLV-I positive, requesting proviral load to inform decision making	Yes	"HTLV-I proviral load"	1 x EDTA (purple)

6. Management and Care

People living with HTLV-I should be seen at least annually for a Health Check and provided with advice and support for healthy lifestyle factors including smoking cessation, limiting alcohol consumption, and the importance of a healthy diet and regular exercise.

People with possible or confirmed HTLV-I associated diseases should be referred to a specialist for management.

Regular proviral load testing is not recommended outside of antenatal care.

7. Prenatal and Postnatal Care

HTLV-I 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-I diagnosis. There are also many uncertainties and risks in relation to not breastfeeding.

Informed shared decision making, where an individual feels they have the information they need to make decisions is a critical component of HTLV-I associated prenatal and postnatal care.

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-I should be offered information about HTLV-I. 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-I as soon as safely possible in pregnancy. HTLV-I testing should never be included in a predefined antenatal care test set.

All pregnant people diagnosed with HTLV-I should be offered a proviral 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-I about availability and costs.

All pregnant people diagnosed with HTLV-I should be provided with support to make an individual assessment of the risks and benefits of breastfeeding for both the pregnant person and the infant. This includes evaluating whether to breast or formula feed, the duration of breastfeeding, and what information and resources are required for safe infant feeding.

Mixed feeding (breastfeeding combined with formula feeding) is not recommended for people with HTLV-I, as it may increase the risk of transmission to the infant. Although specific studies on HTLV-I are lacking, evidence from HIV research indicates that mixed feeding increases the risk of vertical transmission.

All pregnant people with HTLV-I, 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.

Disclaimer: Guidance provided on this resource is based on guidelines and best-practices at the time of publication. For further information, refer to the Australian Clinical Guidelines on HTLV-I for Aboriginal Primary Health Care Settings www.htlv1.guidelines.org.au. The term breastfeeding is used in this tool however it is important to be aware that it may not be a preferred term by all people.