

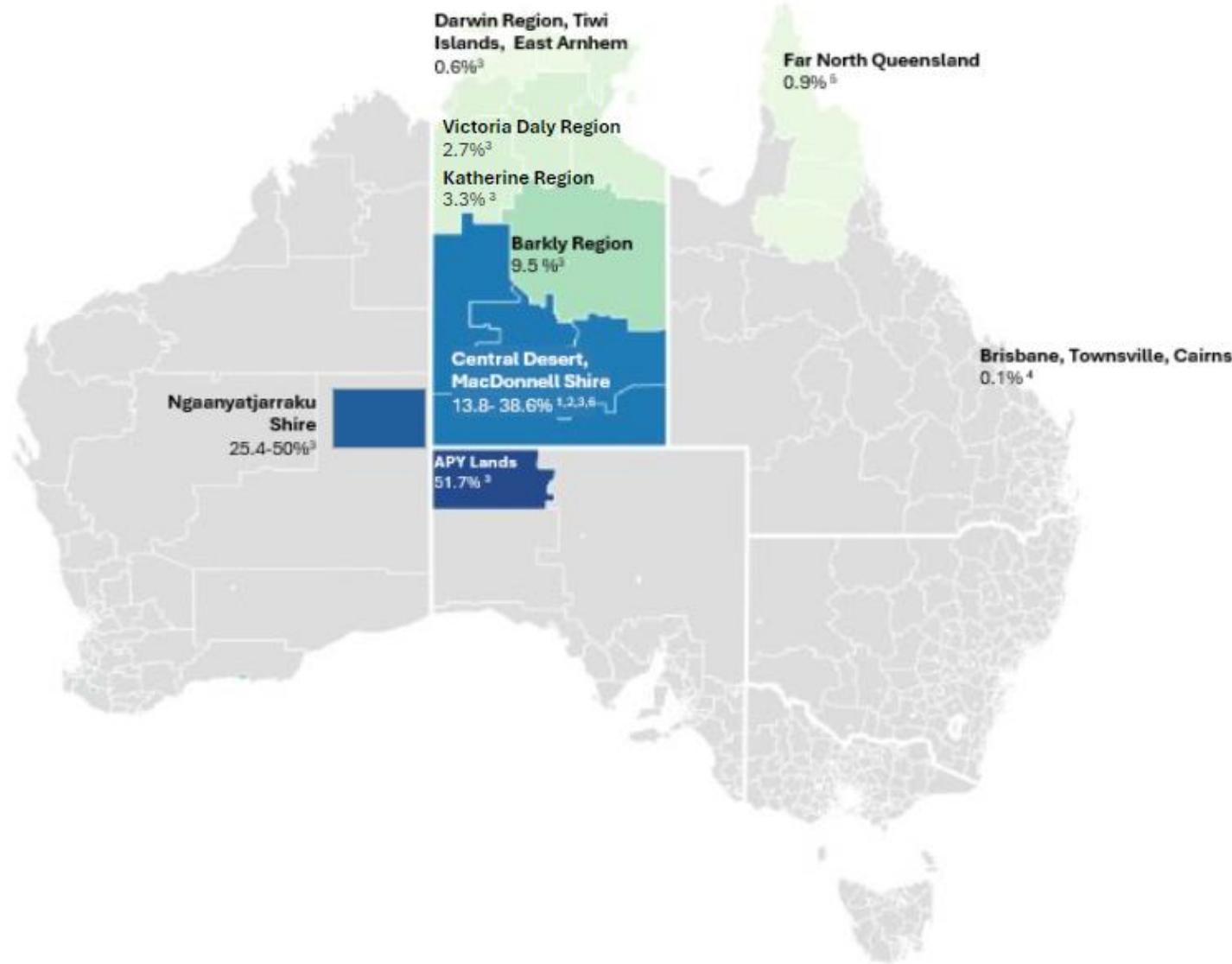
HTLV-1 guideline key recommendations

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Acknowledgement of Country Role of NACCHO and ASHM

Conflicts of Interests to
declare: None

Figure 1: HTLV-1 Prevalence in Aboriginal and Torres Strait Islander People



HTLV-1 Guidelines

Decision Making Tool

NACCHO | **ashm** | DECISION MAKING IN HTLV-1

1. What is HTLV-1?

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, Apangu Pitjantjatjara Yankunytjatjara (APY) lands in South Australia and the Nganayitjatjara (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-1 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 breast milk.

3. Health Impact of HTLV-1

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-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 Borned 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.



NACCHO | **ashm** | DECISION MAKING IN HTLV-1

4. Who to Test (continued)

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.

5. Management and Care

People living with HTLV-1 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-1 associated disease should be referred to a specialist for management.

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

6. Prenatal and Postnatal Care

HTLV-1

HTLV-1 can be transmitted vertically through breastfeeding and possibly during pregnancy or at birth. Diagnosis in pregnant people may enable them to take 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.

All pregnant people diagnosed with HTLV-1

All pregnant people diagnosed with HTLV-1 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-1 about availability and costs.

All pregnant people diagnosed with HTLV-1

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 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.

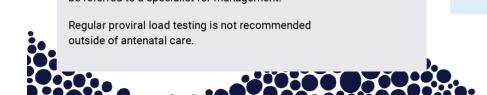
Mixed feeding (breastfeeding combined with formula feeding)

Mixed feeding (breastfeeding combined with formula feeding) is not recommended for people 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

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.

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-1 for Aboriginal Primary Health Care Settings www.hntl1guidelines.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.



1. What is HTLV-1?

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

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

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3. Health Impact of HTLV-1

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.

What regions are considered high prevalence?

High certainty

- Central Australian region (NT)
- Anangu Pitjanjatjara lands (SA)

- HTLV-1 associated uveitis (HAI) 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.

Children Borned 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.

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How is HTLV-1 transmitted?

- Sex
- Sharing needles or any other sharp
- Breastfeeding

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.
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Sharing Partners and Sexual Contacts with HTLV-1

Testing for all Aboriginal people, who are living in, or were born in, should be discussed with people who request had sexual contact with a person

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Who to test?

- Shared decision making for all testing

In some Aboriginal communities in Central Australia, the prevalence is extremely high.

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

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

not excreted in breast milk and uninfected cells. It does not transfer to breast milk.

3. Health Impact of HTLV-1

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.
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Pregnant People

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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 Born or Breastfed by a Person Living with HTLV-1

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What is shared decision making and why?

- Shared decision making is a process for making a clinical decision that involves discussing the risks and benefits of each option available. While it normally occurs between one person and their clinician, it can involve a clinical team, families and carers. It takes into consideration the person's values, preferences and circumstances.
- Shared decision making is particularly useful when the evidence doesn't clearly support one decision or another, it explores a patient's values and priorities as well as addresses components that influence how well they can manage their health.

Components of shared decision making

- The benefits and risks of different options (including doing nothing)
- The person's knowledge about treatment options
- Psychological issues or barriers
- The physical benefits and burdens of each option
- The person's capacity to access and afford healthcare
- The person's personal preferences, values and circumstances
- Cultural considerations, such as who should be in the room
- Whether families and communities need to be involved
- Two-way trust between the clinician and consumer

Who to test?

Pregnant people

- Provide information and offer testing to people who choose
- Do not add to routine test sets

demonstrated through multiple published studies:

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

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not exclusively, and uninfected cells. This increases the transfer of HTLV-1 to breast milk.

symptoms. These 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.
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- 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

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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-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 Borned 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.

Who to test?

People requesting testing

- Provide information and test people who choose
- This includes “contacts”

demonstrated through multiple published studies:

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not exclusively, and uninfected cells. It causes the transfer of HTLV-1 in breast milk.

symptomatic. At least 10% of patients are at risk

of developing HTLV-1 associated conditions that can be applied in routine clinical practice. There is a significant increase (1.5x) in all-cause mortality.

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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.

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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.

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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.

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3. Health Impact of HTLV-1

Most people with HTLV-1 infection will remain asymptomatic. Present there is no method of determining who will develop HTLV-1 associated conditions. In routine clinical practice. There is a significant risk of cause mortality.

The following conditions are caused by HTLV-1:

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4. Who to Test

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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

Do not test

Children birthed or breastfed by person living with HTLV-1 unless there is a clinical

The potential benefits and harms of testing for all Aboriginal people, including pregnant 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.

4. Who to Test (continued)

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.

5. Management and Care

People living with HTLV-1 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-1 associated disease should be referred to a specialist for management.

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

6. Prenatal and Postnatal Care

Recommend testing

HTLV-1 can be transmitted through breast feeding and possibly during pregnancy. Diagnosis in pregnancy is difficult. There are many uncertainties regarding the best measures to reduce transmission risk. There are also many uncertainties regarding the best values and preferences of mothers regarding breast feeding. There are also many uncertainties regarding the best values and preferences of mothers regarding breast feeding.

Information shared decision making, where an individual feels they have the information they need to make decisions is a critical component of HTLV-1 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-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.

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-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.

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-1 for Aboriginal Primary Health Care Settings www.hiv1guidelines.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.

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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.

5. Management and Care

People living with HTLV-1 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-1 associated disease should be referred to a specialist for management.

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

6. Prenatal and Postnatal Care

HTLV-1 can be transmitted via breastmilk, during birth, through breastfeeding and postnatally. Diagnosis in pregnancy is important to allow measures to reduce transmission. There are many uncertainties regarding the best clinical values and preferences for Aboriginal people.

There are also many Aboriginal people who do not breastfeed.

Information and shared decision making is important. Aboriginal people who feel they have the information they need to make informed decisions is a critical component of HTLV-1 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-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.

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-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.

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-1 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.

4. Who to Test (continued)

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 in, or were born in, high prevalence communities for HTLV-1, suggestive of ATLL, HAM/TSP, infective dermatitis or HTLV-1 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.

5. Management and Care

People living with HTLV-1 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-1 associated disease should be referred to a specialist for management.

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

6. Prenatal and Postnatal Care

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.

All pregnant people diagnosed with HTLV-1 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-1 about availability and costs.

All pregnant people diagnosed with HTLV-1 should be provided with support to make an individual assessment of the benefits of breastfeeding for both the person and the infant. This includes evaluating breast or formula feed, the duration of feeding, and what information and resources are available for safe infant feeding.

Mixed feeding (breastfeeding combined with formula feeding) is not recommended for people 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.

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4. Who to Test (continued)

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.

5. Management and Care

People living with HTLV-1 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-1 associated disease should be referred to a specialist for management.

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

6. Prenatal and Postnatal Care

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.

Informed shared decision making, where an individual feels they have the information they need to make decisions is a critical component of HTLV-1 associated prenatal and postnatal care.

All Aboriginal people whose babies are born in or were born in high prevalence communities with clinical findings suggestive of ATLL, HAM/TSP, infective dermatitis or HTLV-associated uveitis should be offered a proviral load test. This should include information on the implications of a positive result and their baby's future care. A clinician who is able to provide this information in a culturally safe and appropriate manner should be included in the care team.

Disclaimer: Gu...

All pregnant people diagnosed with HTLV-1 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-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 pregnant person and the infant. This includes evaluating whether to breast or formula feed, the duration of breastfeeding, and what information and resources are available.

Caring for people with a positive result

- Annual health check with healthy lifestyle advice
- Support people to inform sexual partners should they wish to do so

For further information, refer to the Australian Clinical Guidelines on HTLV-1 for Aboriginal Primary Health Care Settings www.htlv1.guidelines.org.au

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4. Who to Test (continued)**Children with Symptoms Consistent with HTLV-1**

Pregnant people living with HTLV-1

- Offer HTLV-1 proviral load

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.

5. Management and Care

People living with HTLV-1 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-1 associated disease should be referred to a specialist for management.

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

6. Prenatal and Postnatal Care

HTLV-1 can be transmitted vertically through breastfeeding and possibly during pregnancy or at birth. Pregnant people may enable them to take steps to reduce transmission. However, there are many uncertainties relating to HTLV-1 and in personal preferences related to a HTLV-1 diagnosis. There are also many uncertainties and risks in relation to breastfeeding.

Shared decision making, where an individual can receive the information they need to make decisions is a critical component of HTLV-1 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-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.

All pregnant people diagnosed with HTLV-1 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-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 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-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.

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4. Who to Test (continued)

Children with Symptoms Consistent with HTLV-1

Pregnant people living with HTLV-1

- Offer HTLV-1 proviral load

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.

5. Management and Care

People living with HTLV-1 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-1 associated disease should be referred to a specialist for management.

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

Table 1: Breastfeeding scenarios and risk of transmission

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

Mothers who are 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.

Mixed feeding (breastfeeding combined with formula feeding) is not recommended for people 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

"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."

4. Who to Test (continued)**Children with Symptoms Consistent with HTLV-1**

Pregnant people living with HTLV-1

- Offer HTLV-1 proviral load
- Support to decide whether to breastfeed and/or duration of breastfeeding
- Recommend against mixed feeding

5. Management and Care

People living with HTLV-1 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-1 associated disease should be referred to a specialist for management.

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

6. Prenatal and Postnatal Care

HTLV-1 can be transmitted vertically through breastmilk feeding and possibly during pregnancy or at birth. Breastfeeding may enable pregnant people to take steps to reduce transmission. However, there are many uncertainties relating to evidence, and in personal preferences related to a HTLV-1 diagnosis. There are also many uncertainties and risks in relation to breastfeeding.

Shared decision making, where an individual can access the information they need to make an informed choice, is a critical component of HTLV-1 associated postnatal care.

All pregnant people, and other pregnant people who will be identified as Aboriginal, who are living in high prevalence communities for HTLV-1 should be offered information about HTLV-1. This should include the availability of testing and the choice of a positive and negative result for their own and their baby's health. This discussion should occur 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.

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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 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-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.

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