

HTLV-1 guideline key recommendations

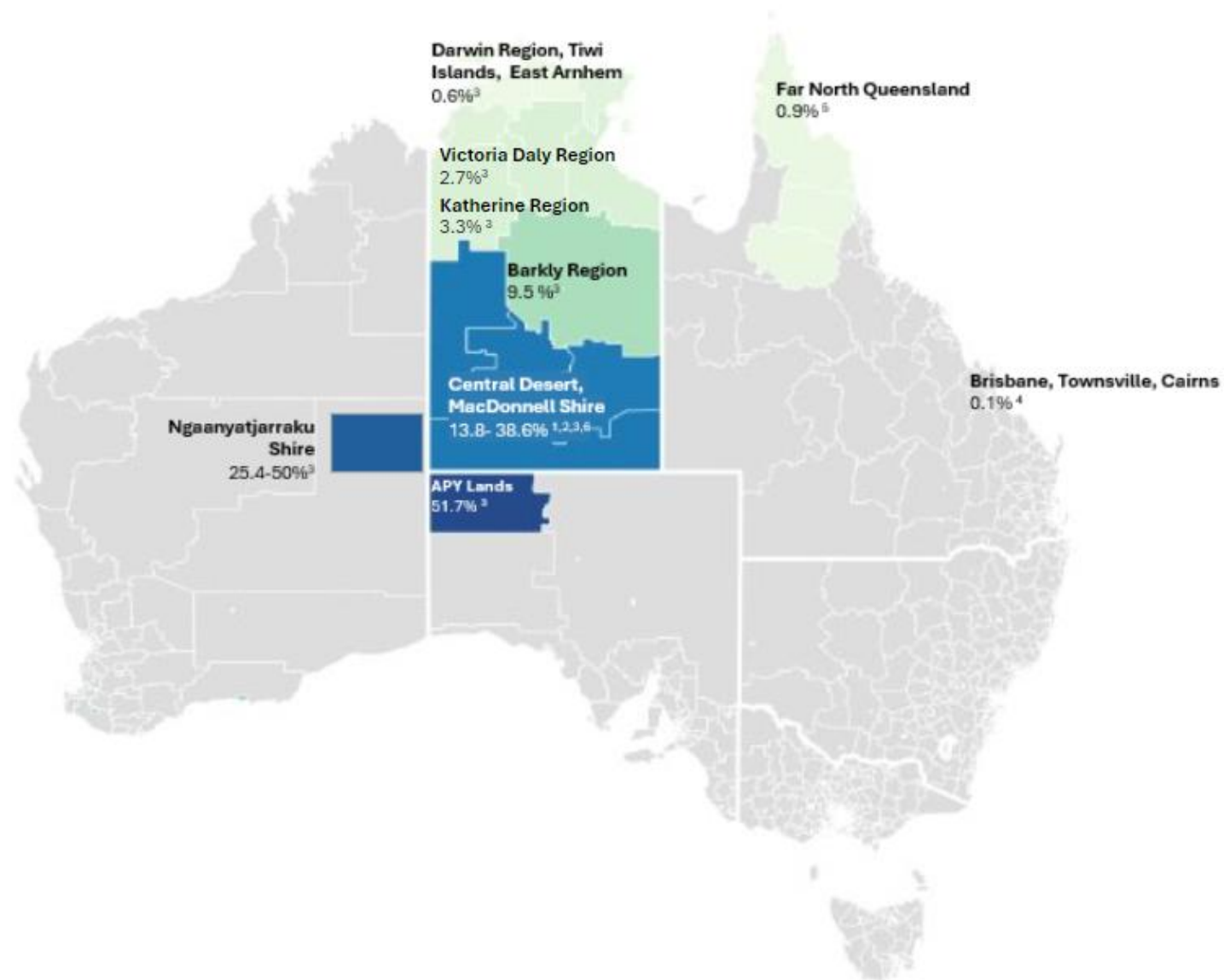
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Acknowledgement of Country Role of NACCHO and ASHM


Conflicts of Interests to
declare: None

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



HTLV-1 Guidelines

Decision Making Tool

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, 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-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 Born 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.

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-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.

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 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.

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.

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- Adult T cell leukaemia/lymphoma (ATLL) is a cancer of the lymphoid cells.
- HTLV-1-associated myelopathy (HAM/TSP) is a chronic neurological condition.
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Pregnant People

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What regions are considered high prevalence?

High certainty

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

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How is HTLV-1 transmitted?

- Sex
- Sharing needles or any other sharp
- Breastfeeding

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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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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:

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People Requesting Testing, Including Partners and Sexual Contacts of People Living with HTLV-1

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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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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.

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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 breastfeeding and postnatal contact. Diagnosis in pregnancy allows for measures to reduce transmission, many uncertainties remain and preferences vary. There are also many cultural considerations not breastfeeding.

Infants whose shared decision-making feels they have the information 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.

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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.

Consider testing

Children and adults with diseases that may be associated with HTLV-1

- Consider whether result is likely to change their management

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.

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 living in, or were born in, high prevalence communities where there are 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.

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 the person's ability to breastfeed, the duration of breastfeeding, and what information and resources are available to support 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.

Not recommended to include in a sexual health check-up

For people 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 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 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.

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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

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

Disclaimer: Gu

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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 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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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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Do not perform routine viral load monitoring

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

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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 uncertainties relating to HTLV-1 in personal preferences related to a HTLV-1 diagnosis. There are so many uncertainties and risks in relation to breastfeeding.

Shared decision making, where an individual has 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.

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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

These people 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 load, should be offered information about HTLV-1.

"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.

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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 uncertainties relating to evidence, and in personal preferences related to a HTLV-1 diagnosis. There are so many uncertainties and risks in relation to breastfeeding.

Shared decision making, where an individual has the information they need to make 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 includes the availability of testing and the implications 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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