22nd International Conference on Human Retrovirology:
HTLV and Related Retroviruses
HTLV2026

June 3-6, 2026 | Philadelphia, Pennsylvania, USA

Workshop 1
Public Health, Transmission & Community Engagement

Moderators: *Leandro Sereno & Damian Purcell*

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A New Area of Advocacy and Research Toward the Global Elimination of HTLV

Fabiola Martin
Canberra Health Services/Canberra Sexual Health Centre, Australia

Canberra Health Services

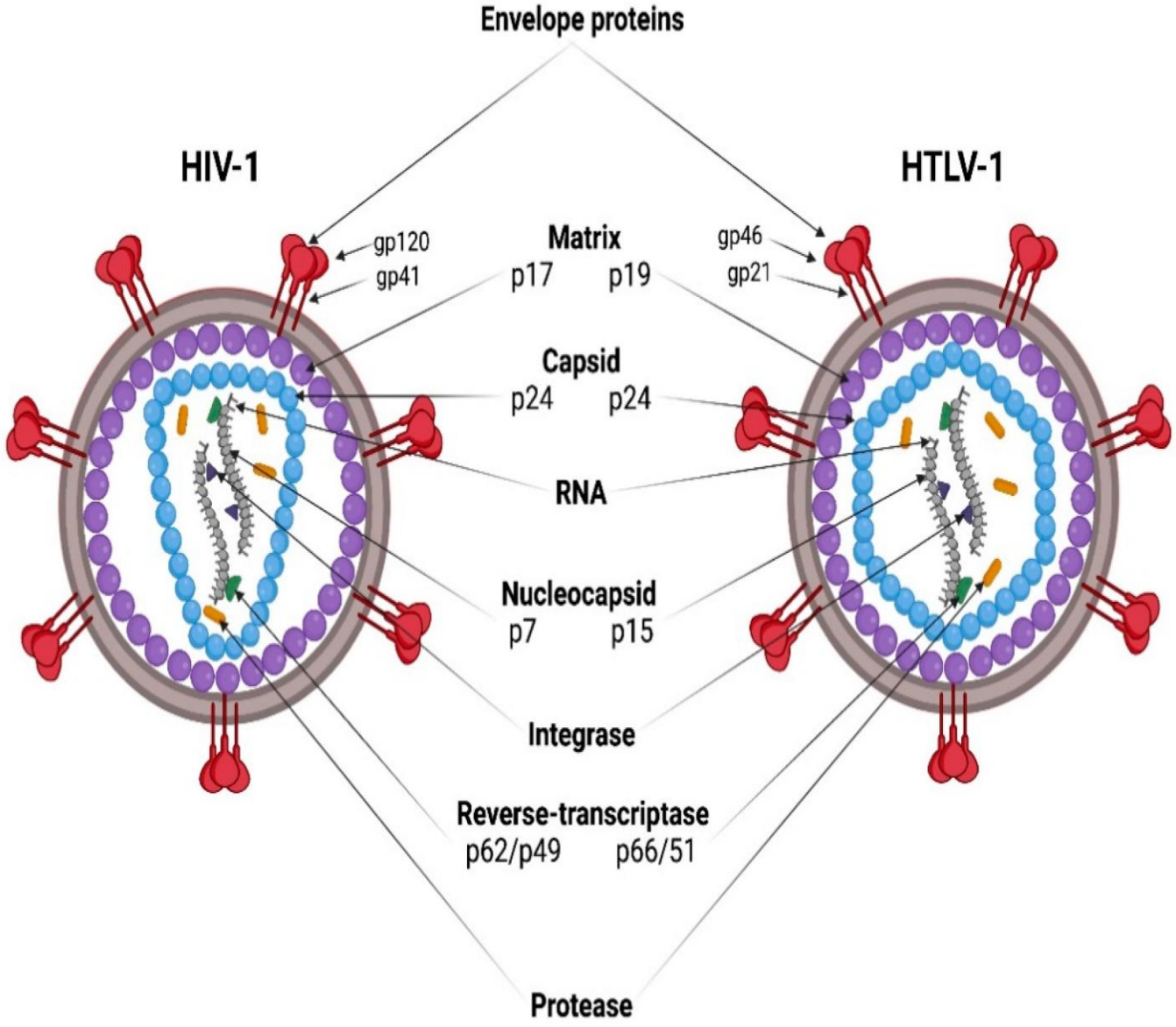
ACT Government

A New Area of Advocacy and Research Toward the Global Elimination of HTLV-1

HTLV-1 Pre-exposure Prophylaxis Drug Trials

Presented by Fabiola Martin, June 2026

fabiola.az.martin@gmail.com



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Kalinichenko, S.; Komkov, D.; Mazurov, D. HIV-1 and HTLV-1 Transmission Modes: Mechanisms and Importance for Virus Spread. Viruses ***2022****, 14, 152.*

Acknowledgement of Country

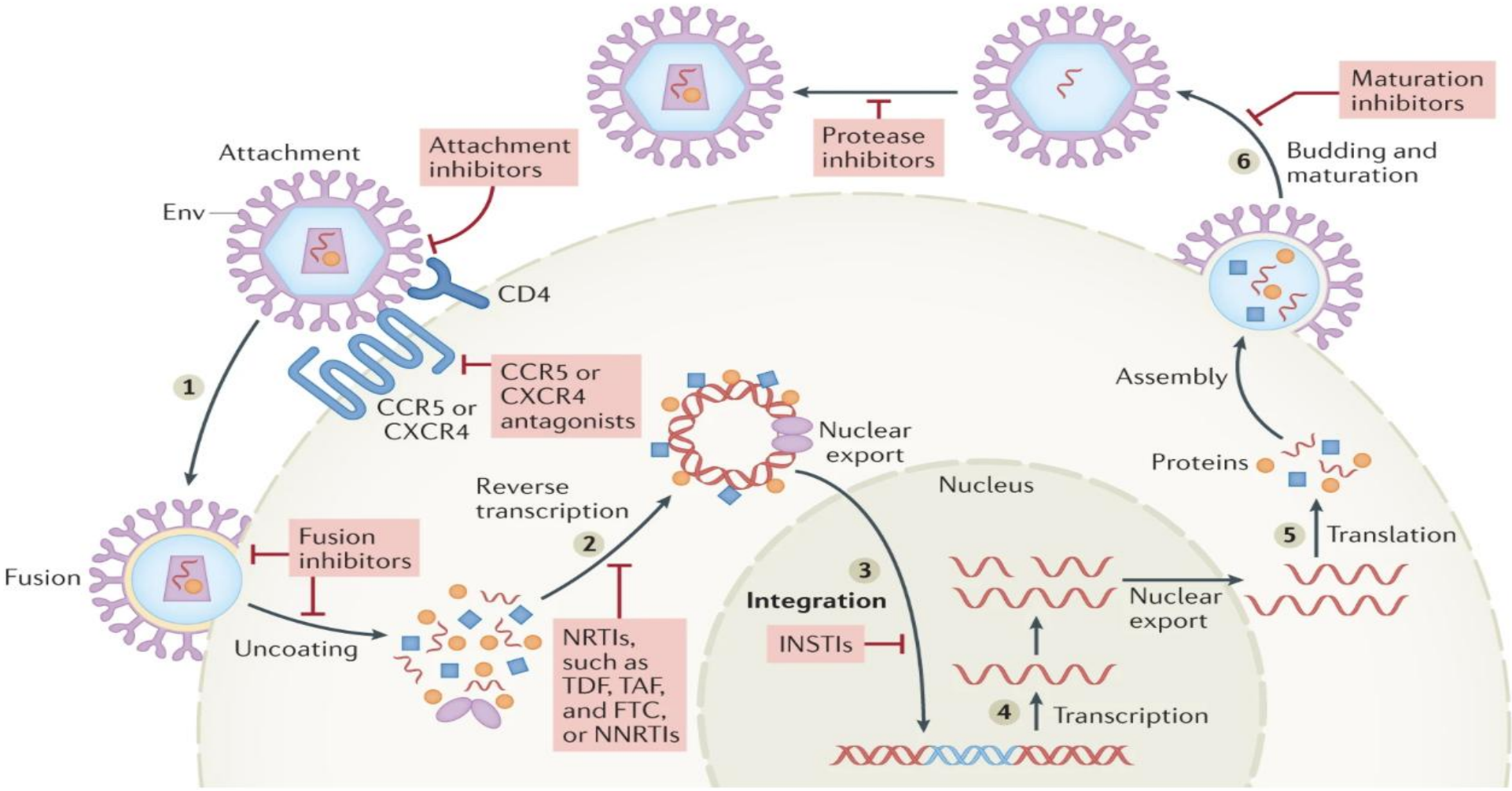
Canberra Health Services acknowledges the Ngunnawal people as traditional custodians of the ACT and recognises any other people or families with connection to the lands of the ACT and region. We acknowledge and respect their continuing culture and contribution to the life of this region.

Artwork credit:
Natalie Bateman (Walbanja-Yuin)
Monga Waratah 2021

What is antiretroviral pre and post exposure prophylaxis?

Antiretroviral medication that prevents the transmission of infection

From: HIV pre-exposure prophylaxis and sexually transmitted infections: intersection and opportunity



Stewart, J., Baeten, J.M. ***HIV pre-exposure prophylaxis and sexually transmitted infections: intersection and opportunity.*** *Nat Rev Urol* ***19****, 7–15 (2022)*

HIV-1 Pre-exposure Prophylaxis (PrEP)

Compare your options for PrEP

Prepared by the SAN FRANCISCO DEPARTMENT OF PUBLIC HEALTH
Find continually updated information: sf.gov/cityclinic-compare-prep
Print version last revised Dec. 15, 2025.

4 medications are FDA-approved for PrEP. They are all **safe** and are **highly effective** when taken as directed.

	TRUVADA® (emtricitabine and tenofovir DF) **Daily pill or 2-1-1 pill schedule**	**DESCOVY®** (emtricitabine and tenofovir AF) **Daily pill**	**APRETUDE®** (cabotegravir) **Shot given every 2 months**	**YEZTUGO®** (lenacapavir) **Shots given every 6 months**
Dosing	2 options: • **1 pill daily** • **2-1-1 pill schedule** - 2 pills 2 to 24 hours before sex - 1 pill 24 hours after that - 1 pill 24 hours after that If more encounters, continue daily pills until 48 hours after last sex.	**1 pill daily**	**Shot in the gluteal (butt) muscle** - 1 shot each time **When starting:** Get 2 shots given 1 month apart, then 1 shot every 2 months	**Shots in the fatty layer under the skin of the stomach or thigh** - 2 shots each time **When starting:** You will also take 2 pills on day 1 and 2 pills on day 2
When it protects against HIV	**1 pill daily** ✓ Any type of sex ✓ When injecting drugs **2-1-1 pill schedule** ✓ When using your penis or anus for sex ✗ **Not** when using your vagina/front-hole for sex ✗ **Not** when injecting drugs	✓ Any type of sex ? It is not yet known if it protects when injecting drugs	✓ Any type of sex ? It is not yet known if it protects when injecting drugs	✓ Any type of sex ? It is not yet known if it protects when injecting drugs (currently being studied)

What we know about preventing HTLV-1 transmission:

1. HTLV-1 and HIV-1 are both human retroviruses
2. HTLV-1 and HIV-1 infection use the similar transmission routes
3. HTLV-1 and HIV-1 use reverse transcriptase, integrase, and protease to infect new cells
4. HTLV-1 enzymes are structurally comparable to HIV-1 enzymes to allow for drug efficacy testing
5. HTLV-1 expression of these enzymes declines over time after infection
6. *In vitro* drug potency could reflect *in vivo* potential, during the acute phase of infection
7. There is a narrow but real window early after exposure to new HTLV-1 in which drugs could prevent infection like HIV-1 PrEP used routinely in clinics
8. HTLV-1 infection incidence is sufficiently high in some communities to allow for PrEP trials

In vitro: Testing licensed HIV-1 antiretrovirals against HTLV-1

	HTLV-I		HIV-I
ANTI-RETROVIRAL	IC_{50} (nM)	EC_{50} (nM)	EC_{50} (nM)
INSTI:			
Raltegravir	530 ± 102[a]	6.42 ± 4.24[a]	9.4 ± 1.4[e]
Elvitegravir	100 ± 16[a]	9.57 ± 5.54[a]	2.4 ± 0.9[e]
✓ **Dolutegravir**	260 ± 59[a]	0.25 ± 0.42[d]	1.4 ± 0.3[e]
✓ **Bictegravir**	180 ± 29[a]	0.30 ± 0.17[a]	1.6 ± 0.4[e]
XZ450	120.2 ± 36.1[b]	1.67 ± 1.52[b]	NA
✓ **Cabotegravir**	78 ± 24[c]	0.56 ± 0.26[c]	1.5 ± 0.3[f]
NRTI:			
✓ **Tenofovir disproxil fumarate**	NR	17.78 ± 7.16[a]	50 ± 30[g]
✓ **Tenofovir alafenamide**	NR	15.10 ± 9.06[d]	5 ± 2[g]

[a]Barski, M.S. et al. Frontiers in Microbiology, 2019; [b]Barski, M.S. et al. Nat Comms, 2021; [c]Schneiderman B.S. et al. Frontiers in Medicine, 2022; [d]Kalemera M. D. and Maertens G.N., DOI: 10.20944/preprints202311.0045.v1; [e] Tsiang, M. et al. Antimicrobial Agents Chemother., 2016; [f] Smith, R.A. et al. Antimicrobial Agents Chemother, 2018; [g] Lee, W.A. et al. Antimicrobial Agents Chemother., 2005.

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In vivo: Which drugs should be considered as potential HTLV-1 PrEP?

HIV-1 antiretrovirals	Pros	Cons
Dolutegravir (DTG) ✓	Lowest EC50 Safety data incl. pregnancy, renal transplant	Oral - adherence issues Weight gain esp. women of African heritage Single agent less effective?
Dolutegravir + Tenofovir (TDF) + Lamivudine ✓	DTG lowest EC50 Added efficacy if combined with TDF Safety data incl. pregnancy	Oral -adherence issues Weight gain esp. women of African heritage TDF renal/bone toxicity TDF – avoid in renal transplantation
Bictegravir (BIC) + Tenofovir (TAF) + Emtricitabine ✓	BIC low EC50 Added efficacy if combined with TAF	Oral - adherence issues, May be worst for weight esp women of African heritage Conflicting recommendations on use in pregnancy
Cabotegravir ✓	Injectable = better adherence Higher effectiveness of IM PrEP for HIV	Feasibility of IM placebo injections Insufficient data for use in pregnancy Single agent less effective?

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BHIVA Treatment Guidelines 2025, EACS Guidelines 2023, IAS USA Guidelines 2024 and *HPTN083/084 **DISCOVER

IRVA HTLV-1 PrEP Working Group (2025- ongoing): PICO (S/T)

Aim: Develop recommendations on HTLV-1 PrEP clinical trial design

P = Population/patient/problem:

Which groups of people would benefit?

How large should the study group be?

I = Intervention: Which licensed and available HIV PrEP drugs could be tested?

C = Comparison: What is ethically and practically acceptable?

O = Outcomes: What outcomes should be tested for?

Safety? Tolerance? Acceptability? Incidence? Feasibility? Cost efficacy?

S = Study type

T = Time: During which time frames should these studies be conducted to be meaningful?

Message to People burdened with HTLV

- Inform & engage your Governments' Departments of Health of all the interventions that effectively prevent the transmission of HTLV-1
  - from pregnant/breastfeeding persons to babies
  - between sexual partners
  - through HTLV-1 positive blood/organ donations
- Lobby through your members of parliament and demand that HTLV-1 transmission prevention trials and clinical guidelines are developed urgently

Acknowledgments: IRVA and IRVA HTLV-1 PrEP Working Group

People with HTLV

Fatumata Djalo

Goedele Maertens

Daniel Bradshaw

Jake O’Donnell

Eisuke Inoue

Yoshihisa Yamano

Adam Williams

Fiona Fowler

Mirna Biglione

Eduardo Gatuzzo

Zahra Rezaei

Canberra Health Services

ACT Government

Thank you, any questions?

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Healthy Brazil (Brasil Saudável): A bold agenda to eliminate HTLV vertical transmission as a Public Health Problem

Pamela Gaspar
Ministry of Health, Brazil

Thomas Jefferson University | Drexel University | Drexel Medicine

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“Brasil Saudável”, a bold agenda to eliminate HTLV as a Public Health Problem

Pâmela Cristina Gaspar (Pharm., Ph.D)

General Coordinator for the Surveillance of Sexually Transmitted Infections - CGIST

Department of HIV, AIDS, Tuberculosis, Viral Hepatitis, and Sexually Transmitted Infections - Dathi

Secretariat for Health and Environmental Surveillance - SVSA

Ministry of Health of Brazil - MoH

Draurio Barreira
Director

SUS | MINISTÉRIO DA SAÚDE | GOVERNO DO BRASIL DO LADO DO POVO BRASILEIRO

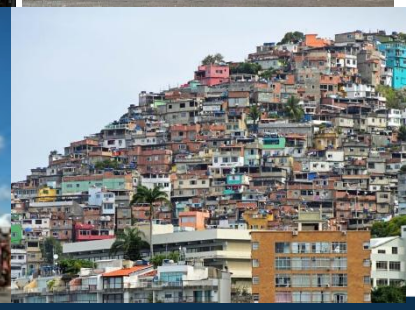
Conflicts of interest:

I have no conflicts of interest

Brazil

- **Area:** 8,514,877 km2: continental country (sixth largest)
- **Population:** 212,583,750 inhabitants (seventh most populous)
- Pregnant women/year: 2,500,000
- **Geographical regions:** 5 / **Federal Units:** 27
- **Municipalities:** 5,571

There are many Brazils within the same country



Regional differences in geography, income, population, and infrastructure.

OVERVIEW OF THE UNIFIED HEALTH SYSTEM (SUS)

Created by the 1988 Federal Constitution. Regulated by Laws No. 8,080/1990 and 8,142/1990.

Funded by domestic resources.

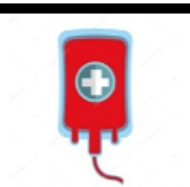
Principles: universality, completeness, and equity. Access guaranteed to all.

About **71.5%** of the Brazilian population relies exclusively on the public health network — approximately 150 million people (PNS/IBGE, 2020).

Coordinated response to communicable diseases, supported by national surveillance systems.

Centralized procurement of essential health commodities, ensuring access and scale.

National Public Policies addressing HTLV over the years

1993	1998	2003	2009	2013	2014	2016	2019	2021
Ministerial Ordinance No. 1376/93 establishing HTLV screening for blood product donors	Publication of the HTLV Technical Report for hemotherapy services and Public Health laboratories	Clinical Management Guide for Patients with HTLV – Ministry of Health, 1st edition.	Ministerial Ordinance No. 2600/09 establishing HTLV screening for tissue and cellular product donors.	Clinical Management Guide for Patients with HTLV – Ministry of Health, 2nd edition.	Ministerial Ordinance No. 371/14 establishing guidelines for newborn care.	Ministerial Ordinance establishing confirmatory tests for individuals with ATLL and regulating the use of AZT.	Ministry of Health – STI Coordination – and inclusion of HTLV within this coordination.	Clinical Management Guide for Patients with HTLV – Ministry of Health, 3rd edition.
							STI	

Bringing HTLV out of invisibility

Conducting workshops with civil society, scientists, professors, managers, and healthcare professionals to explain what HTLV is.

Campaign for National (23th March) and Internacional HTLV day (10th November)

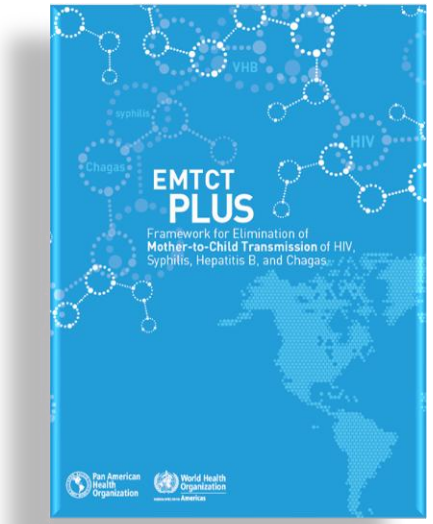
Guidelines, Courses, Informative Materials, Inclusion HTLV in STI and Public Health congress

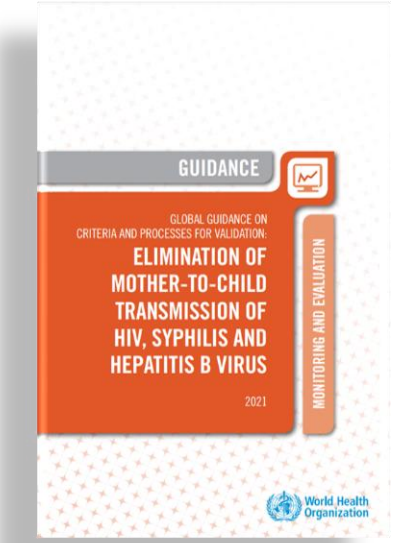
SUS MINISTÉRIO DA SAÚDE GOVERNO DO BRASIL DO LADO DO POVO BRASILEIRO

ELIMINATION OF VERTICAL TRANSMISSION

Pan American Health Organization

World Health Organization





Brazil is part of a group of countries, along with the **Pan American Health Organization (PAHO)** and the **World Health Organization (WHO)**, that are committed to eliminating the vertical transmission of HIV, syphilis, Hepatitis B, Chagas disease, and **HTLV** as a public health problem.

SUS MINISTÉRIO DA SAÚDE GOVERNO DO BRASIL DO LADO DO POVO BRASILEIRO

Prevention HTLV Vertical Transmission

Pregnant women/year ≈ 2.5 million

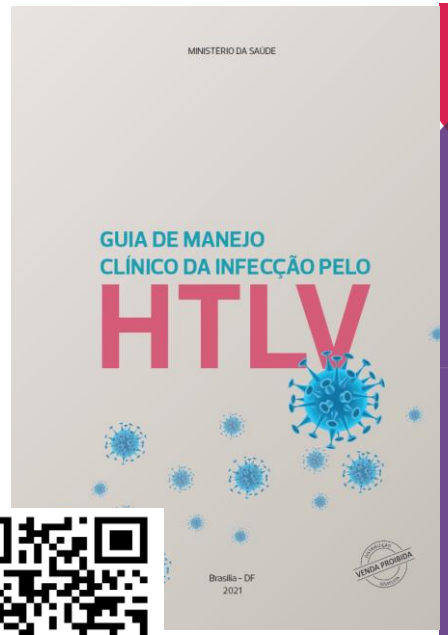
Condoms
(internal and external)

Antenatal screening for HTLV and counseling during antenatal care

Cabergoline
(lactation suppression)

Infant Formula
(6 months minimum)

Long-term follow-up in primary and specialized care and Serological testing for HTLV-1/2 (at 18 months)



SUS MINISTÉRIO DA SAÚDE GOVERNO DO BRASIL DO LADO DO POVO BRASILEIRO

HTLV-1 in Brazil

Estimation: 0.8 - 1.2 million individuals are living with HTLV-1

Establish HTLV as a Notifiable Disease (under implementation)

National surveillance data to better guide public policies and improve the quality of care.

- HTLV
- HTLV in pregnant women
- Exposed children to HTLV

DIÁRIO OFICIAL DA UNIÃO

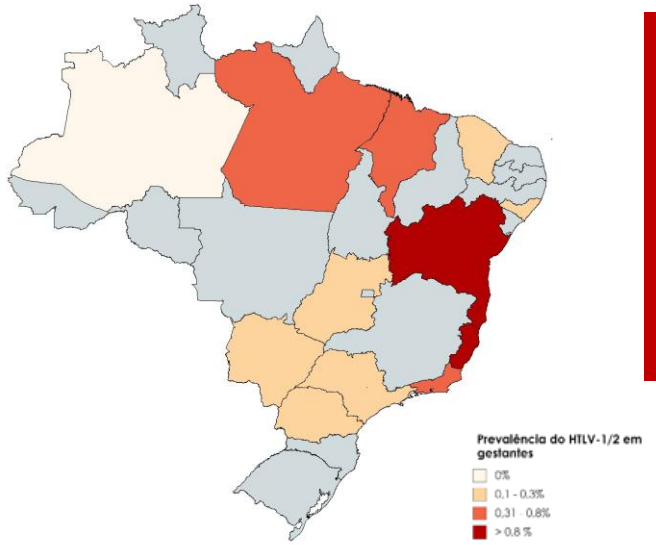
Publicado em: 15/02/2024 | Edição: 31 | Seção: 1 | Página: 87

Órgão: Ministério da Saúde/Gabinete da Ministra

PORTARIA GM/MS Nº 3.148, DE 6 DE FEVEREIRO DE 2024

Altera o Anexo 1 do Anexo V à Portaria de Consolidação GM/MS nº 4, de 2017, para incluir a infecção pelo vírus Linfotrópico de Células T Humanas -HTLV, da Infecção pelo HTLV em gestante, parturiente ou puérpera e da criança exposta ao risco de transmissão vertical do HTLV na lista nacional de notificação compulsória de doenças, agravos e eventos de Saúde Pública, nos serviços de saúde públicos e privados em todo o território nacional.

The prevalence of HTLV-1/2 infection among pregnant women ranges from 0% to 1.05%, depending on the region and vulnerability. (Around 16,000 pregnant women with HTLV per year)



Higher prevalence among:

- Women
- Black and mixed-race populations
- People with lower levels of education

Brasil, 2021; Assone & Casseb,2024; Rosadas et al 2018, Rosadas & Taylor 2023, Ishak et al 2024

National HTLV prevalence study involving 40,000 pregnant women is ongoing and is expected to conclude by the end of 2026.

Health alone is not enough. Eliminating socially determined diseases demands intersectoral solutions.

Brasil Saudável (Healthy Brazil):

- Cross governmental initiative that brings together **14 ministries to eliminate 11 diseases and 5 vertical transmission infections** as public health problems by 2030;
- Explicitly linked to the **Sustainable Development Goals**.
- Grounded in **multisectoral action** on the social determinants of health.

Foreign affairs

Secretariat of the Presidency

Secretariat for Institutional relations

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HEALTHY BRAZIL
Together to care

Diseases **expected to be eliminated as a public health problem by 2030**

- Malaria
- Geohelminthiasis
- Trachoma
- Lymphatic Filariasis
- Onchocerciasis
- Chagas Disease
- Schistosomiasis

Vertical Transmission

- Chagas Disease
- Syphilis
- Hepatitis B
- HIV
- HTLV

Diseases expected to reach the WHO and MoH **operational targets** by 2030

Tuberculosis

Incidence ≤ 10 cases per 100,000 inhabitants

Leprosy

Prevalence < 1 case per 10,000 inhabitants*

Hepatitis

Diagnose 90% of people

Treat 80% of people diagnosed

Reduce new infections by 90%

Reduce mortality by 65%

HIV

95% of people living with HIV diagnosed

95% of the people living with HIV on antiretroviral treatment

95% of people living with HIV with suppressed viral load

SUS MINISTÉRIO DA SAÚDE GOVERNO DO BRASIL DO LADO DO POVO BRASILEIRO

Launch of the Healthy Brazil Program

Luciana Santos, Tedros Adhanom, Adijeane Oliveira de Jesus, Nísia Trindade, Jarbas Barbosa and Budi Gunadi Sadikin (07th February 20234)

"Adijiane Oliveira gave us an emotional testimony about living with HTLV. It was great to have her with us, and she and everybody from HTLVida are great partners in this fight."

HTLVida
GRUPO DE APOIO AOS PORTADORES DO VÍRUS HTLV

Degrees of intersectorality

At the beginning → During → The goal

Information

Each sector must understand the diseases, recognize one another's roles and responsibilities, and identify how to work together to address them.

Cooperation

Each sector do their own work, in their own field, with their own methods, but in a synergy where resources and results can be optimized, or one sector ends up facilitating things to another.

Integration

Policies being designed and implemented collectively by different sectors towards people and their needs.

Examples of strategic actions and projects supported by

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Implementation of the National Agenda for Addressing HIV, AIDS, Tuberculosis, Viral Hepatitis, HTLV, Syphilis, and Other Sexually Transmitted Infections in Vulnerable Women

"Women living with HIV and/or AIDS and/or STIs and/or viral hepatitis and/or tuberculosis; girls and women born with HIV through vertical transmission; sex workers; women experiencing homelessness; trans women and travestis; lesbian, bisexual, and intersex women; women who use alcohol and other drugs or whose partners use such substances; women deprived of liberty, formerly incarcerated women, or those serving socio-educational measures; Black women; quilombola women; Indigenous women and women belonging to other Indigenous and traditional peoples; rural, forest, and waterside women; riverine women; Roma women and women belonging to other traditional peoples and communities; pregnant women; adolescents; older women; women living in extreme poverty or facing food insecurity; women victims of violence; migrants, refugees, expatriates, and stateless women; women affected by environmental disasters; women experiencing severe psychological distress; women with disabilities (physical or intellectual), rare diseases, debilitating chronic conditions, and reduced work capacity; women with albinism; women living in peripheral or hard-to-reach communities; as well as other women identified within each territory."

https://www.gov.br/aids/pt-br/central-de-conteudo/publicacoes/2025/agenda_mulheres.pdf

Ongoing Projects

- Project to promote (and empower) **Nursing leadership** in territorial intersectoral action to advance access to prevention and healthcare.

ENFERMAGEM
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- Supporting the Project designed to evaluate whether the combination of **Tenofovir and Dolutegravir** produces better outcomes on **HTLV treatment** than **Dolutegravir** alone.

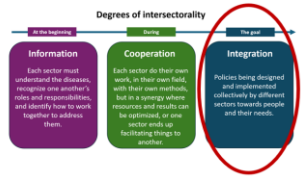
Prof. Dr. Carlos Brites (UFBA/Brazil)

- Supporting the **PrevINIr HTLV-TV** Project to evaluate the use of **Dolutegravir (DTG)** for the **prevention of vertical transmission** of HTLV-1.

Prof. Dra. Maria Fernanda R. Grassi (Fiocruz Bahia/Brazil)

Future perspectives of Projects

- Financial support **program to promote adherence to care for pregnant women** in situations of high socioeconomic vulnerability identified by the **health/social assistance team**, with HIV, syphilis, hepatitis B, HTLV and/or Chagas disease infection.



The Brazil Saudável Program also provides political support and visibility to existing actions, strengthening ongoing efforts and creating stronger momentum to do more, better and TOGETHER.

CERTIFICATION OF ELIMINATION OF VERTICAL TRANSMISSION FOR STATES AND MUNICIPALITIES

CERTIFICAÇÃO DA ELIMINAÇÃO DA TRANSMISSÃO VERTICAL DO HIV, SÍFILIS, HEPATITE B, DOENÇAS DE CHAGAS E HTLV E SELOS DE BOAS PRÁTICAS

Brazil adapted the PAHO/WHO framework (impact and process targets) and implemented the **Certification Strategy for states and municipalities (≥100,000 inhabitants)** for the **Elimination of the Vertical Transmission** or or awarded **progressive tiers** (bronze, silver of gold) of good practices, encouraging continuous improvement.

180 municipalities and 10 federal units until 2025 with certification (territories may hold multiple certifications across different infections - HIV, syphilis, Hepatitis B and/or Chagas Disease)

Certification for HTLV Vertical Transmission elimination under implementation (2025-2026)

Certification of Brazil by PAHO/WHO for the Vertical Transmission Elimination of of HIV as a Public Health Problem (Cerimony 18th December 2026)

Brazil eliminates lymphatic filariasis as a public health problem

1 October 2024 | News release |Reading time: 3 min (761 words)

The World Health Organization (WHO) congratulates Brazil for having eliminated lymphatic filariasis as a public health problem.

"Eliminating a disease is a momentous accomplishment that takes unwavering commitment," said Dr Tedros Adhanom Ghebreyesus, WHO Director-General. "I congratulate Brazil for its efforts to free its people of the scourge of this painful, disfiguring, disabling and stigmatizing disease. This is another example of the incredible progress we have made against neglected tropical diseases and gives hope to many other nations still fighting against lymphatic filariasis that they too can eliminate this disease."

October 2024

WHO validates Brazil for eliminating mother-to-child transmission of HIV

18 December 2025 | News release |Reading time: 3 min (679 words)

The World Health Organization (WHO) has validated Brazil for the elimination of mother-to-child transmission (EMTCT) of HIV, making it the most populous country in the Americas to achieve this historic milestone. This accomplishment reflects Brazil's long-standing commitment to universal and free access to health services through its Unified Health System (SUS), anchored in a strong primary health-care system and respect for human rights.

"Eliminating mother-to-child transmission of HIV is a major public health achievement for any country, especially for a country as large and complex as Brazil," said Dr Tedros Adhanom Ghebreyesus, WHO Director-General. "Brazil has shown that with sustained political commitment and equitable access to quality health services, every country can ensure that every child is born free of HIV and every mother receives the care she deserves."

The milestone was marked during a ceremony in Brasília, attended by President Luiz Inácio Lula da Silva, Brazil's Minister of Health Alexandre Padilha, and the Director of the Pan American Health Organization (PAHO) Dr Jarbas Barbosa, along with representatives from UNAIDS.

December 2025

HEALTHY BRAZIL
Together to care

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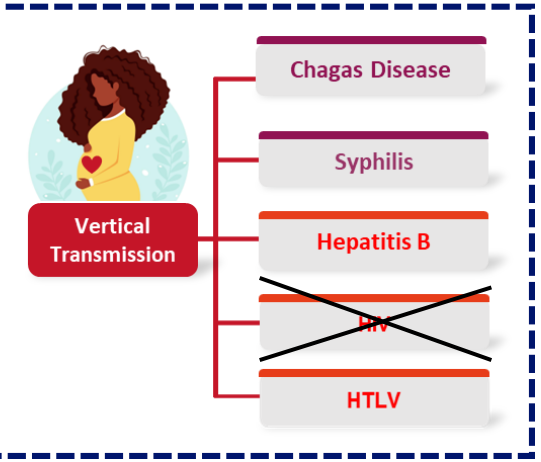
And no stopping...

Diseases **expected to be eliminated as a public health problem by 2030**

- Malaria
- Geohelminthiasis
- Trachoma
- ~~Lymphatic Filariasis~~
- Onchocerciasis
- Chagas Disease
- Schistosomiasis



Diseases expected to reach the WHO and MoH **operational targets** by 2030

Tuberculosis
Incidence ≤ 10 cases per 100,000 inhabitants

Leprosy
Prevalence < 1 case per 10,000 inhabitants*

Hepatitis
Diagnose 90% of people

Treat 80% of people diagnosed

Reduce new infections by 90%

Reduce mortality by 65%

HIV
95% of people living with HIV diagnosed

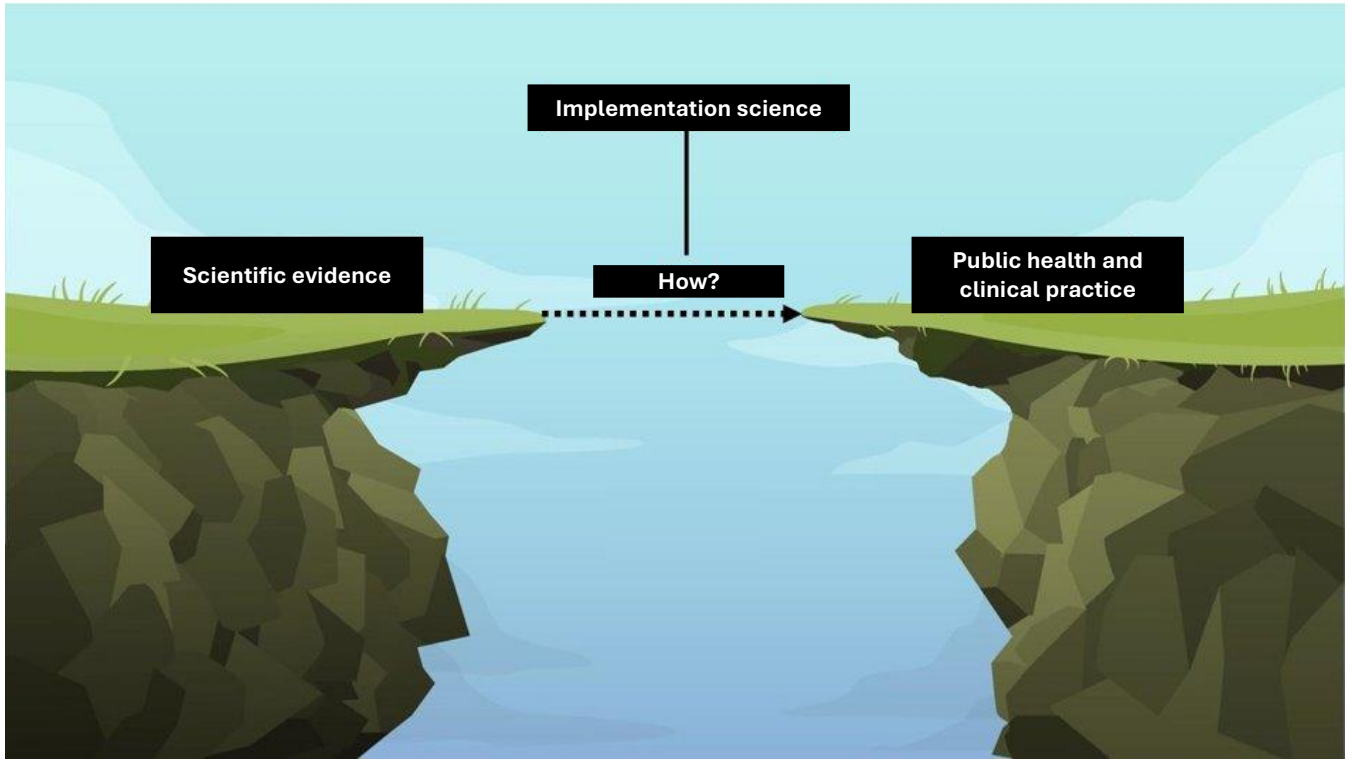
95% of the people living with HIV on antiretroviral treatment

95% of people living with HIV with suppressed viral load

... until all diseases are eliminated by 2030.

"In all implementation efforts, there is a need for someone somewhere to do something differently."

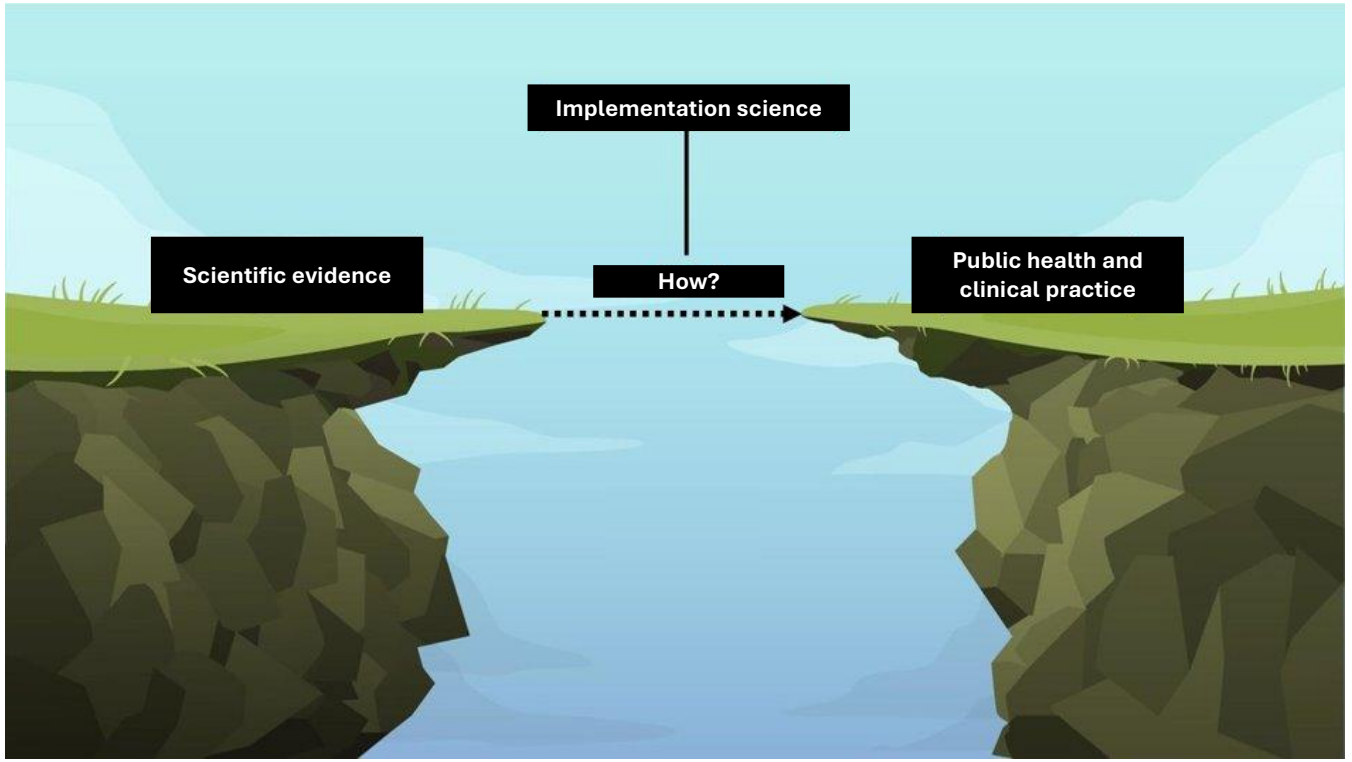
Presseau et al., 2019



Presseau J, McCleary N, Lorencatto F, et al. Action, actor, context, target, time (AACTT): a framework for specifying behaviour. Implement Sci 2019; 14: 102.

"In all implementation efforts, there is a need for someone somewhere to do something differently."

Presseau et al., 2019



HTLV community (governments, healthcare professionals, institutions, scientists, and civil society)

Someone is about us!

Presseau J, McCleary N, Lorencatto F, et al. Action, actor, context, target, time (AACTT): a framework for specifying behaviour. Implement Sci 2019; 14: 102.

OBRIGADA! THANK YOU!

General Coordination of Sexually Transmitted Infection (CGIST)
MoH BRAZIL

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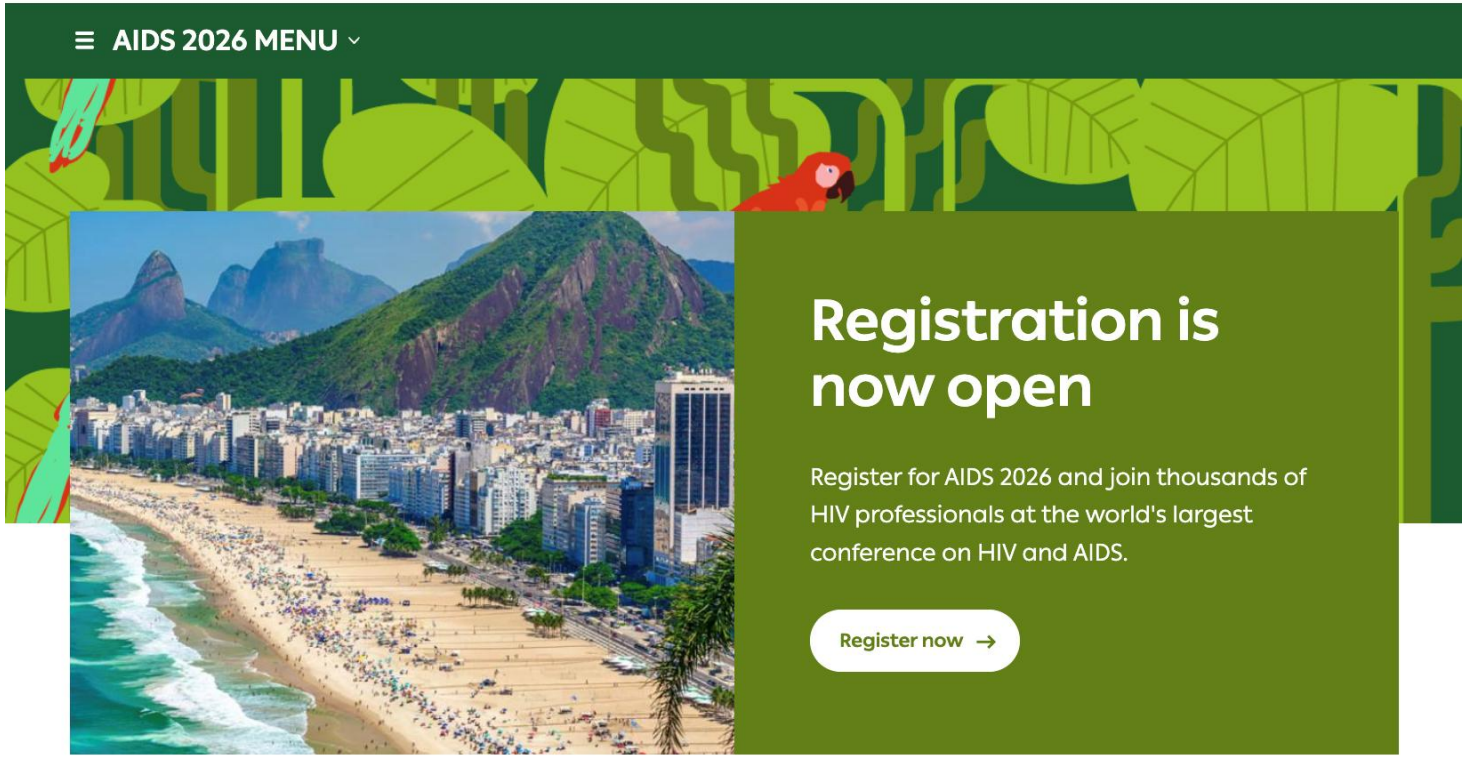
cgist@aids.gov.br

www.gov.br/saude/pt-br/assuntos/brasil-saudavel
https://www.gov.br/saude/pt-br/assuntos/saude-de-a-a-z/h/htlv

Welcome to Rio de Janeiro/RJ - Brazil

AIDS 2026
26–31 July

AIDS 2026, the 26th International AIDS Conference



Welcome to Belo Horizonte/MG - Brazil

22nd International Conference on Human Retrovirology:
HTLV and Related Retroviruses
HTLV2026

June 3-6, 2026 | Philadelphia, Pennsylvania, USA

Impact of HTLV in vulnerable population in Peru

Eduardo Gotuzzo
Universidad peruana cayetano heredia, Peru

HTLV-1 Infection Impact on the Peruvian Population

Prof. Eduardo Gotuzzo, MD FACP FIDSA FESCMID

Emeritus Professor

Instituto de Medicina Tropical “Alexander von Humboldt”

Universidad Peruana Cayetano Heredia

Estimated HTLV-1 Infection in Peru

360,000 – 500,000

Peruvians infected

National seroprevalence:

1.2% – 1.6%

Why it matters

- One of the highest HTLV-1 endemic countries in Latin America
- Significant under-diagnosis and lack of systematic national screening
- Wide geographic variation across ethnic and regional groups
- Major public health burden with multi-system complications

Meta-analysis (40 studies):

General population: 2.9% (95% CI: 1.2–5.3%)
Blood donors: 1.2%–1.7% across regions

Ramos-Rincón JM et al. Pathogens 2021;10(3):260. DOI: 10.3390/pathogens10030260

Regional Seroprevalence

Seroprevalence varies significantly by geography and ethnicity

Quechua Communities

Highland zones

1.8% – 2.3%

Afro-Peruvian Population

Southern coastal zones

1.7% – 2.2%

Northern Coastal Zone

Urban / semi-urban areas

0.6% – 1.0%

Amazonian Communities

Jungle / indigenous groups

2.0% – 4.0%

Estimated HTLV-1 Infection in Peru

Table 3. Pooled prevalence of HTLV infection in different population groups.

Population Group	Pooled Prevalence	95% CI	I^2%
Pregnant women	0.025	0.012–0.040	90.7
Sex workers	0.093	0.056–0.137	92.9
HIV infection	0.104	0.013–0.64	94.8
Men who have sex with men	0.033	0.009–0.069	97.1
Relatives/descendants of HTLV patients	0.225	0.155–0.304	94.7
Strongyloides infections	0.300	0.003–0.792	96
Tuberculosis	0.065	0.045–0.088	0
Blood donors	0.021	0.005–0.048	96.8
General population	0.029	0.012–0.053	95.4

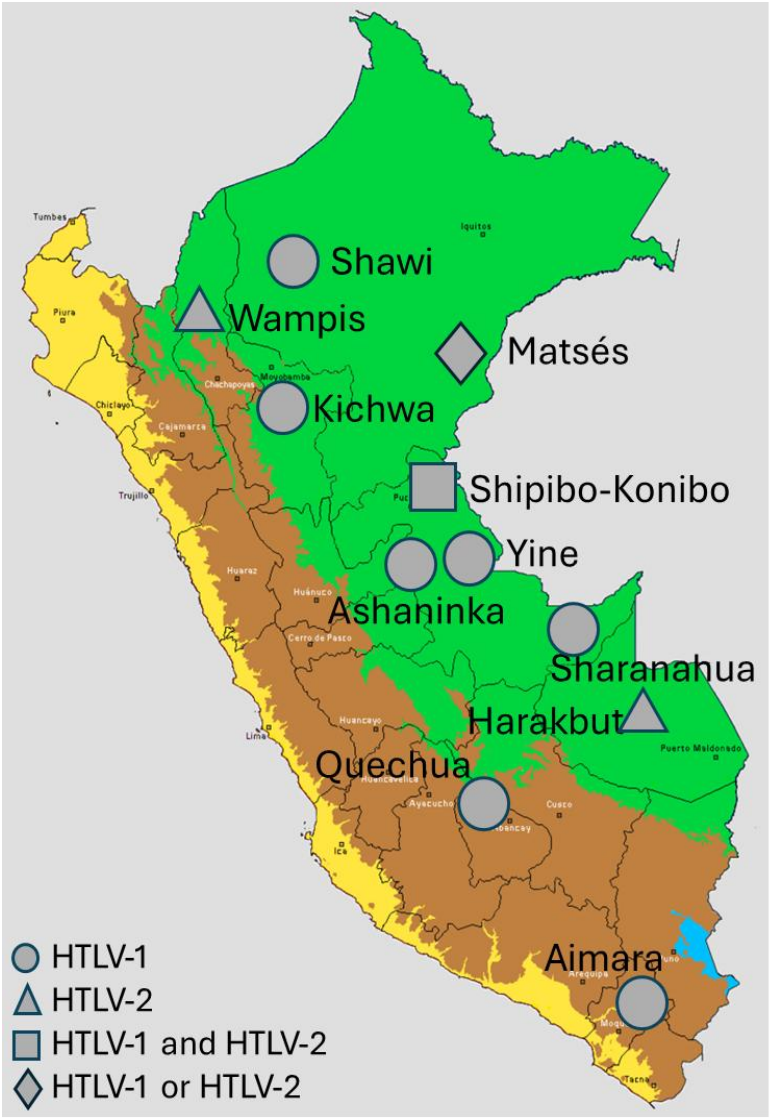
Subgroup differences: total $Chi^2 = 2.44$ | Chi | = 49.68 (8 degrees of freedom) $p < 0.001$.

Ramos-Rincón JM et al. Pathogens 2021;10(3):260. DOI: 10.3390/pathogens10030260

Shipibo-Konibo and HTLV

The Shipibo-Konibo people are the only indigenous population with **coexistence of HTLV-1 (6%) and HTLV-2 (4%)** infections in Peru. It is also the best studied indigenous population with this coexistence in the Americas.

Estimated population: 50 000.



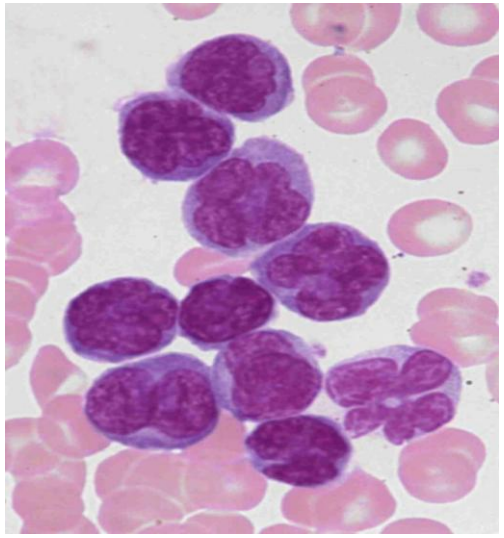
Alva IE et al. Am J Trop Med Hyg. 2012 Nov;87(5):954-6.

Blas et al. PLoS One. 2013 Sep 5;8(9):e73978

Paiva et al. Rev Inst Med Trop Sao Paulo. 2015 Jan-Feb; 57(1): 1–14.

Human T-lymphotropic virus type 1 (HTLV-1)

Cell proliferation and transformation	• Adult T-Cell Leukemia/Lymphoma (ATL)
Inflammatory response	• **HTLV-1-associated myelopathy/Tropical Spastic Paraparesis (HAM/TSP)** • Uveitis • Thyroiditis • Sjogren's syndrome
Selective immune dysfunction	• Strongyloides stercoralis hyperinfection • Crusted scabies • **Infective dermatitis** • Tuberculosis

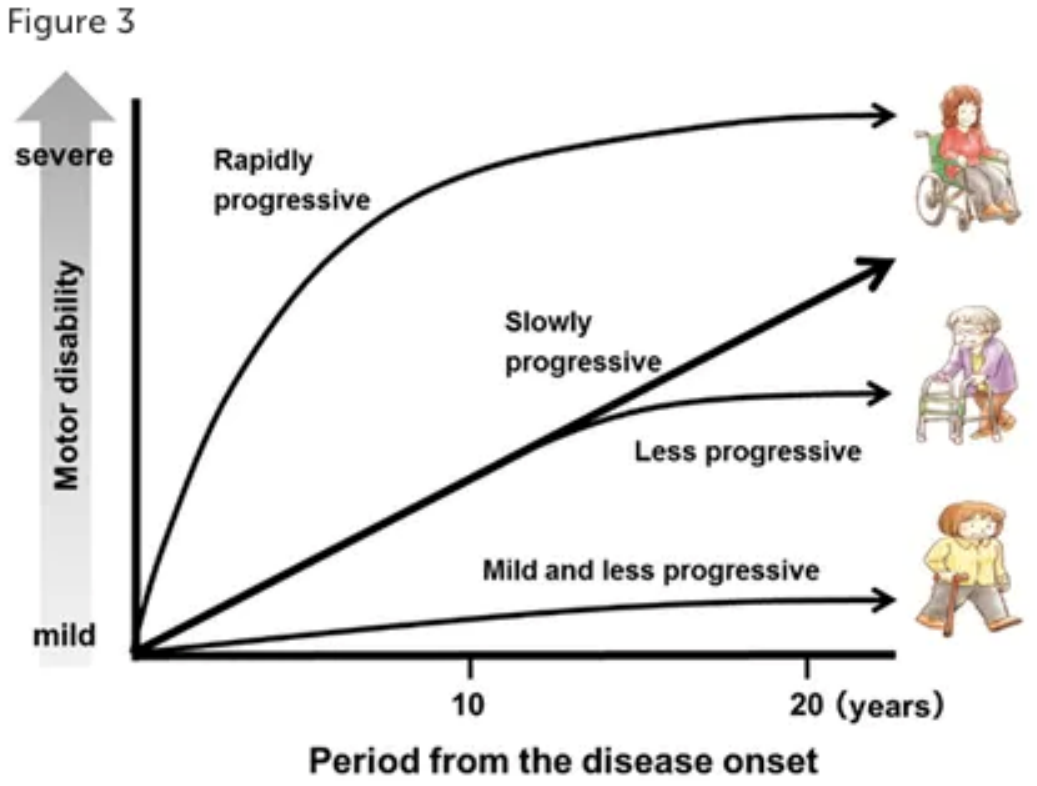


Flower cells in Adult T-cell Leukemia/Lymphoma.
Author: Isao Miyoshi

Verdonck et al. Lancet Infect Dis 2007, 7:266-81.

HTLV-1-associated myelopathy/tropical spastic paraparesis (HAM/TSP)

- **Slowly progressive**: Using walking-stick or walking without help after two years of symptom onset (80%)
- **Rapidly progressive**: Using walking-stick or wheel chair within 2 years (20%)

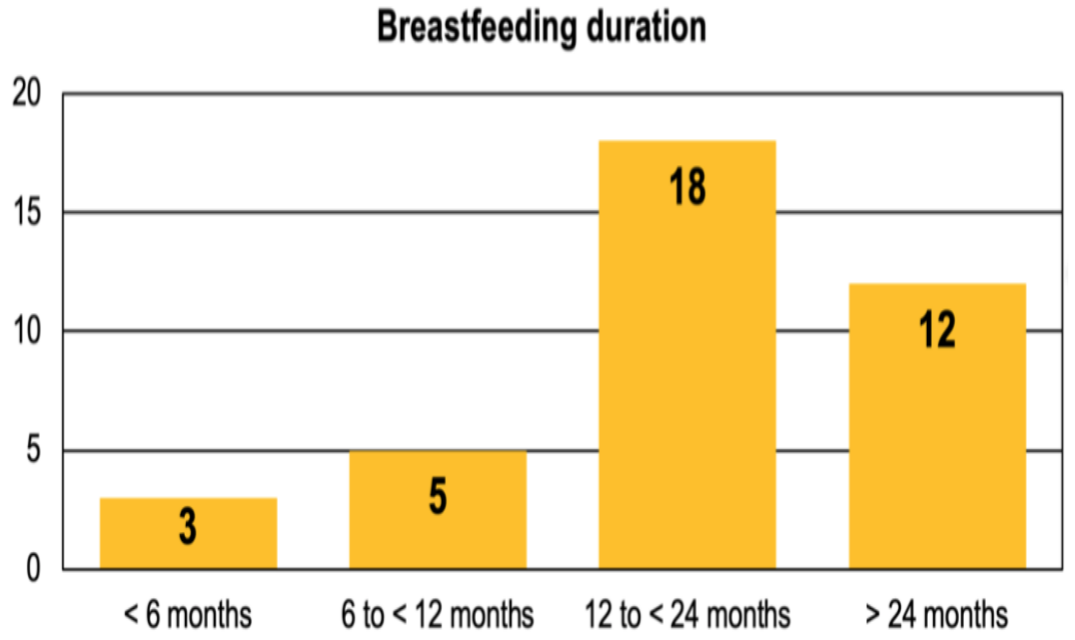


Gotuzzo et al. Clin Inf Dis 2004;39:939-944
Yamano, Sato. Front Microbiol 2012;3:389

UNIVERSIDAD PERUANA
CAYETANO HEREDIA
INSTITUTO DE MEDICINA TROPICAL
ALEXANDER VON HUMBOLDT

Early-Onset HTLV-1 Associated Myelopathy/Tropical Spastic Paraparesis

Median age at symptom onset = 14 years



HAM/TSP: Clinical & Epidemiological Profile

Paraparesia Espástica Tropical (PET)

Classical Profile (n=61)

- Female:male ratio 1.91:1
- Mean age at diagnosis: 51.7 yrs (21–76)
- 54% born in Andean regions
- 23% prior blood transfusion

De Las Casas C et al.
Rev Med Hered 1996;7:68-74

Early-Onset HAM/TSP (n=38)

- 66% female; median onset age: 14 yrs (earliest: 6 yrs)
- 79% breastfed >1 year
- 88% of tested mothers were HTLV-1 positive
- 47% eventually required mobility aids
- Median 6 yrs delay to diagnosis

Schwalb A et al.
Pathogens 2020;9:450

HAM/TSP & Pregnancy (n=15)

- 15/333 women: onset or worsening after delivery
- 10 women: new onset postpartum
- 5 women: worsening of prior symptoms
- Symptoms worsened after successive pregnancies
- Pregnancy proposed as immunological trigger

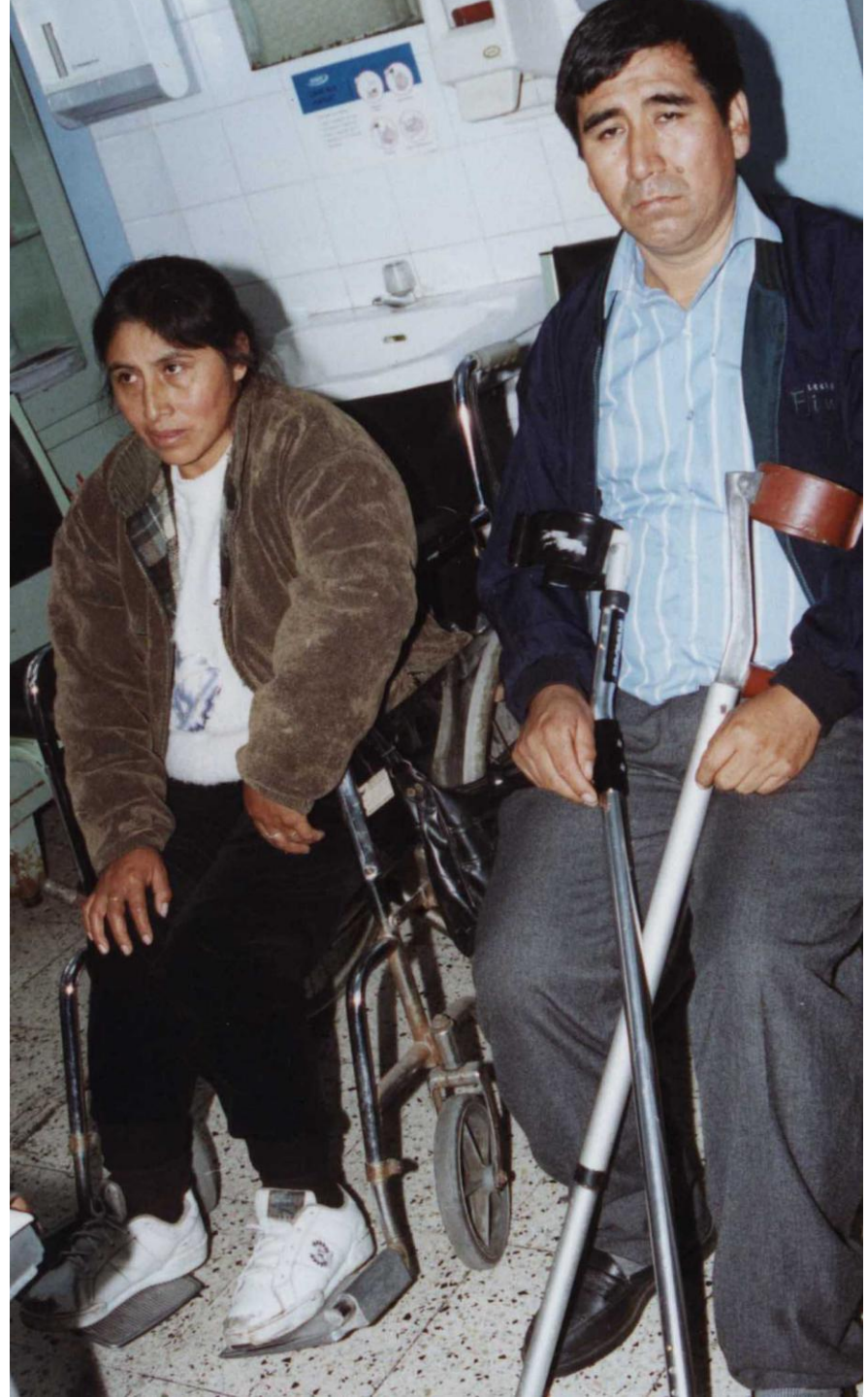
Jacquerioz FA et al.
Pathogens 2024;13:731

0.25–4%
lifetime HAM/TSP risk per carrier

3×
higher risk in women

≥50%
wheelchair by 10 yrs disease

14 yrs
median onset early-onset HAM



Fractures in HTLV-1 Patients

Musculoskeletal complications secondary to spastic myelopathy

Major Article

Impact of fractures and orthopedic surgeries in patients with HTLV-1 associated myelopathy/tropical spastic paraparesis

Pablo Julca-Copello[1], Alvaro Schwalb[2], Rodrigo Cachay[2], Martín Tipismana[1],[2],[3], Carolina Alvarez[2], Fernando Mejía[1],[2], Elsa González-Lagos[1],[2] and Eduardo Gotuzzo[1],[2]

[1]. Universidad Peruana Cayetano Heredia, School of Medicine, Lima, Perú.
[2]. Universidad Peruana Cayetano Heredia, Instituto de Medicina Tropical Alexander von Humboldt, Lima, Perú.
[3]. Hospital Cayetano Heredia, Neurology Department, Lima, Perú.

TABLE 1: Characteristics of patients with fractures associated with HAM/TSP.

Characteristics	n = 24	
	n	%
Sex (n = 23)		
Female	16	70
Male	7	30
Age of fracture (years)	60*	
Place of fracture		
Hip/coccyx	10	42
Lower extremities	7	29
Upper extremities	4	17
Others	3	13
Corrective orthopedic surgery (n = 23)	8	35
Gait problems (n = 23)	22	96
Lower back pain (n = 16)	14	88
Falls (n = 20)	14	70

*Median, interquartile range: 45-69. **HAM/TSP:** HTLV-1 associated myelopathy/tropical spastic paraparesis.

23
patients with fractures

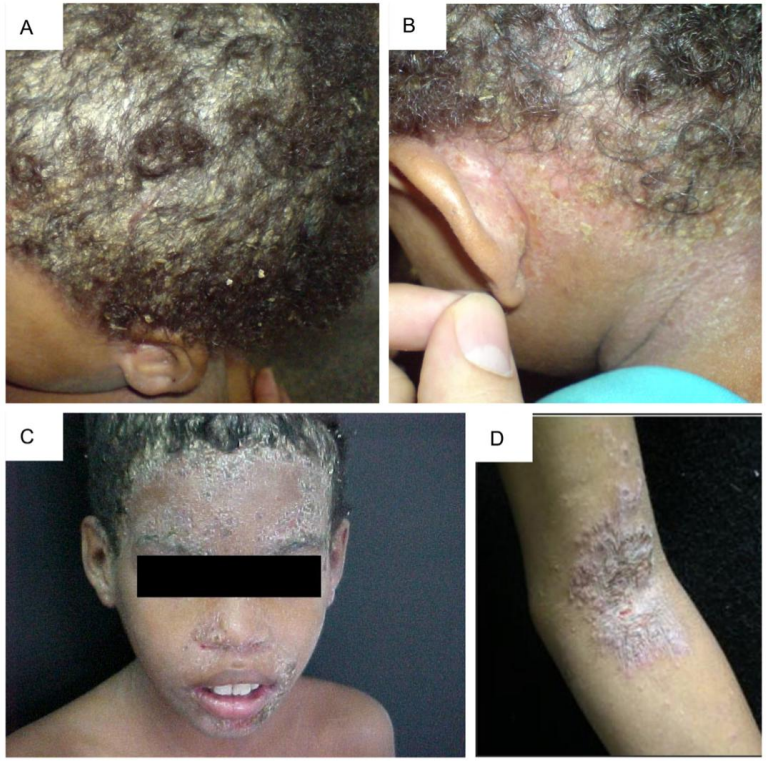
70%
female

42%
hip / coccyx fractures

35%
required corrective orthopedic surgery

Infective dermatitis associated with HTLV-1 (IDH)

- Severe form of chronically infected eczema occurring in **early childhood,** less frequently in adults
- Always involves the **scalp and retroauricular areas**
- Always associated with refractory *Staphylococcus aureus* **or beta-hemolytic Streptococcus infection.**
- Represents a risk factor for developing other severe HTLV-1-associated diseases



Adult-onset infective dermatitis → marker of recent infection?

Bittencourt et al. Int J Infect Dis. 2024:145:107058..

Strongyloidiasis as an early endemic marker for malignancy in HTLV-1

Eduardo Gotuzzo[1,2], Carolina Alvarez[1,3], Angélica Terashima[1], Kristien Verdonck[1,4], Martín Montes[1], Miro Rodríguez[2], Yéssica Ramos[1], Ruben Porudominsky[1], Elsa González[1]

Manuscrito en preparación

[1] Instituto de Medicina Tropical "Alexander von Humboldt", Universidad Peruana Cayetano Heredia, Lima, Peru

[2] Hospital Cayetano Heredia, Lima, Peru

[3] KU-Leuven – University of Leuven, Department of Microbiology and Immunology, Rega Institute for Medical Research, Clinical and Epidemiological Virology, Leuven, Belgium

[4] Department of Public Health, Institute of Tropical Medicine Antwerp, Antwerp, Belgium

Results

In the period 1989-2015, we identified 85 cases of HTLV-1 and severe strongyloidiasis.

Clinical follow-up information was obtained for 70 of the 85 patients with severe strongyloidiasis:

- 13/70 (18.6%) developed ATLL.
- 3/70 (4.3%) developed other unrelated neoplasms (breast cancer and gastric cancer).
- 20/70 (28.6%) died (the cause of death for five of them was non-malignant conditions).
- The median time between the diagnosis of severe strongyloidiasis and the diagnosis of malignancy was 5.7 years (range: 0.5 to 10 years).

:HTLV AND ST. ST.

More transmission mother -child

- More susceptibility to acquire *St.st*
- More susceptibility to have high parasitic load
- More risk to develop severe forms
- More risk to die by *St.st.*
- More risk to develop malignancy

HTLV-1 AND TUBERCULOSIS (PERU)
History of TB among HTLV-1-positive index cases and their relatives

	Patients	Relatives	Relatives
HTLV-1	positive	positive	negative
Number	638	397	847
TB history	89 (13.9%)	45 (11.3%)	36 (4.3%)

P<0.0001

K. Verdonck et al : Epidemiol Infect. 2008 Aug;136(8):1076-83.

Disability Burden in HTLV-1

Progressive, multi-system disability profoundly affects quality of life

Motor Disability:

Progressive spastic paraparesis — 50% wheelchair by 10 yrs; rapid progressors (30%) wheelchair within 2 yrs (De Las Casas et al. 1996)

Neurogenic Bladder:

Urinary retention and incontinence secondary to myelopathy; leads to recurrent UTIs and hospitalization

Falls & Fractures:

96% of HAM/TSP patients have gait disturbances; 70% fall; hip/coccyx fractures most common — can escalate cane users to wheelchair dependency (Julca-Copello et al. 2020)

Sexual Dysfunction:

Erectile and ejaculatory dysfunction; significant impact on patient relationships and quality of life

Reactive Depression:

Psychological burden of progressive chronic disease; early-onset HAM/TSP severely disrupts education and social development (Schwalb et al. 2020)

Other Major Manifestations of HTLV-1

Uveitis & Visual Disability

- HTLV-1-associated uveitis leads to significant visual impairment and blindness
- Vogt-Koyanagi-Harada syndrome (non-granulomatous uveitis) observed in pediatric HTLV-1 patients (Mejía-Mertel J et al., Infectio 2021;25:28-32)

Autoimmune & Endocrine Disorders

- ~20% of HTLV-1-infected patients develop autoimmune thyroiditis
- Autoimmune thrombocytopenic purpura and Crohn's disease also observed in pediatric HTLV-1 patients (Mejía-Mertel J et al., Infectio 2021;25:28-32)

Pulmonary Complications

- Adults — Cachay R et al. (Pathogens 2021;10:895): 9/14 HTLV-1 patients without prior TB had bronchiectasis (5 bilateral); 5 had pulmonary fibrosis; lower lobe predominance; HTLV-1 hyperinflammatory cascade mimics post-TB sequelae
- Pediatric — Mejía-Mertel J et al. (Infectio 2021;25:28-32): 8/12 juvenile HTLV-1 patients had structural lung disease on CT; 4 with pulmonary aspergillosis (galactomannan+); 2 with positive PCR for TB
- Pulmonary workup (CT chest) recommended in all symptomatic HTLV-1 patients regardless of TB history

Malignancy associated with oncogenic microorganisms

Infectious organism	Global burden (% in population)	Lifetime risk of malignancy
H. pylori	5.5	3%
HPV	5.2	0.29
HBV + HVC	4.9	< 3%
HHV-8	25	Minimally oncogenic by itself
EBV	> 90	0.3 ~0.4%
HTLV-1	**0.3**	**5 -10%**
MCV	0.06	??

Up to date, HTLV-1 is the most oncogenic virus

Front Microbiol. 2017;8:1425. doi: 10.3389/fmicb.2017.01425. eCollection 2017.

Epidemiology of Lymphomas in Latin America (ELLA)

Luis Malpica, MD & Christopher Flowers, MD, MS, FASCO
Department of Lymphoma and Myeloma
The University of Texas MD Anderson Cancer Center

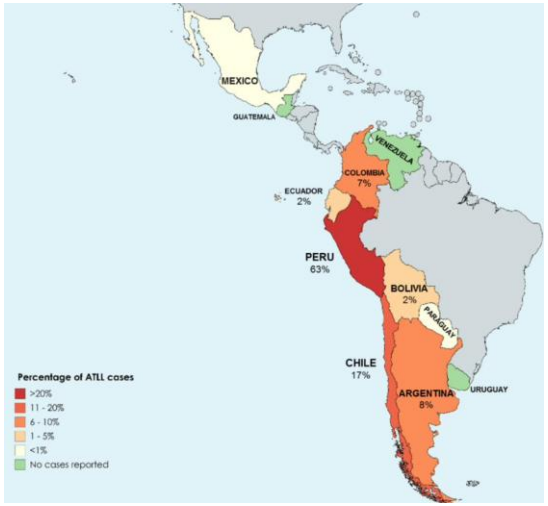
Aim 2: Improve prognostic models in LA

Prevalence HTLV-1 infection:

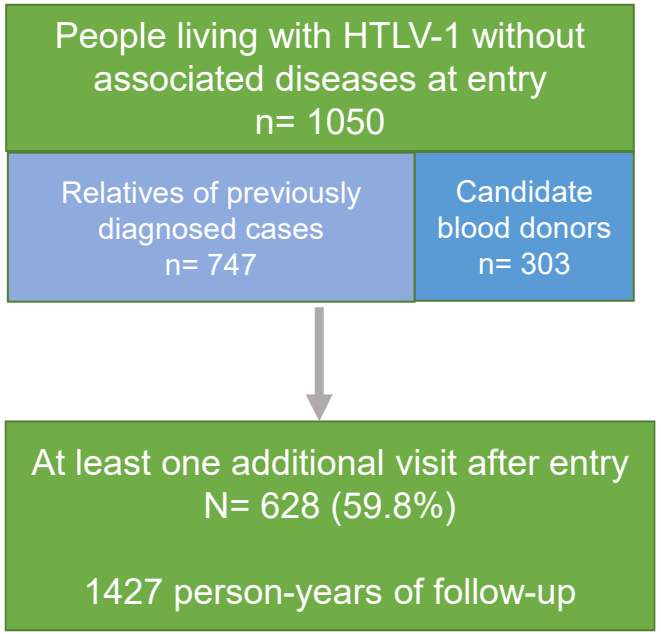
- US: 1.3 per 100,000.
- Latin America: 5-15 per 1,000.

ATLL cases per year:

- US: 10-20
- LA: 250-300



Incidence of ATLL in a sample of Peruvian HTLV-1 carriers



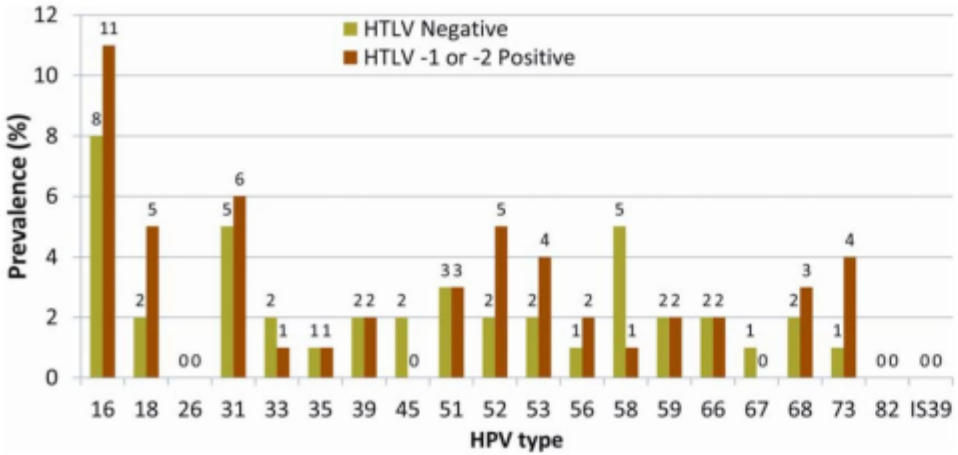
Median age: 42.1 years old (IQR: 32.0-52.9); 604 (57.5%) were women.

Incidence rate of ATL (per 1000 person-years): 17.52 (IC 95%: 11.83-25.93)

Family history of ATL ($p < 0.001$, log-rank test) and prior episodes of *Strongyloides stercoralis* ($p < 0.0001$, log-rank test) were associated with a higher incidence of ATL.

HTLV-1 and HPV infections

	HTLV Negative (n0 = 205)	HTLV-1 Positive (n = 62)	HTLV-1 infection PR (95%CI)	
			Crude	Adjusted*
HPV infection with any type	60 (29.3%)	27 (43.6%)	1.60 (1.09–2.35)	2.10 (1.53–2.87)
High-risk HPV infection	46 (22.4%)	20 (32.3%)	1.45 (0.75–2.80)	1.93 (1.04–3.59)
Abnormal Papanicolaou †	24 (11.8%)	11 (18.0%)	1.44 (0.69–2.99)	1.39 (0.65–2.97)
LSIL or higher cytological abnormalities ‡	14 (6.9%)	7 (11.5%)	1.50 (0.68–3.33)	1.73 (0.68–4.44)

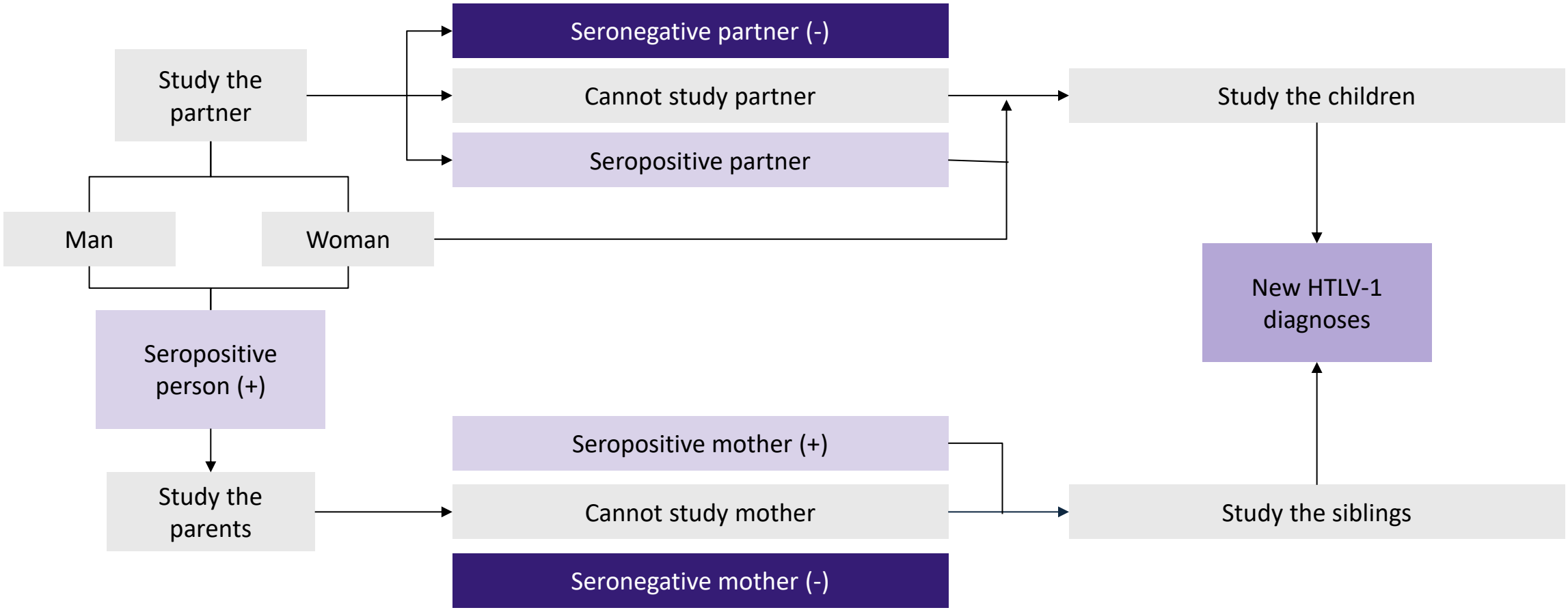


HTLV-1 infection was strongly associated with:

- HPV infection of any type (Prevalence Ratio (PR): 2.10, 95% CI: 1.53-2.87)
- High-risk HPV infection (PR: 1.93, 95% CI: 1.04-3.59).

PLoS One. 2012;7(8):e44240. doi: 10.1371/journal.pone.0044240.

Family screening



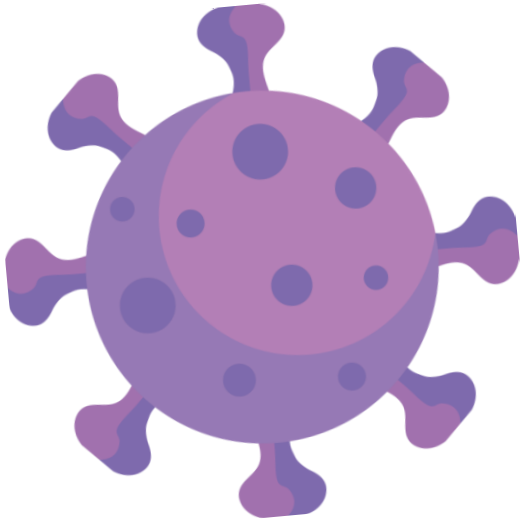
Gotuzzo E, Gonzáles El, Verdonck K, Mayer E, Ita F, Clark D. Veinte años de investigación sobre HTLV-1 y sus complicaciones médicas en el Perú: Perspectivas generales. Acta médica peruana. 2010;27(3):196–203 (Adaptation)

Family prevalence of HTLV-1 infection based on an index case from 1997-2022 in a cohort of HTLV patients in Peru

Thesis to obtain the degree of Medical Doctor

Authors:
Maria Pía Bobadilla Chuquiure
Estephany Lorena Quiliche Arévalo

Advisors:
Dr. Eduardo Gotuzzo Herencia
Dr. Fernando Mejía



Seroprevalence among family members

- 30.3% screened family members
- Seroprevalence among screening family members: 36.43%

Mothers	63,30%
Fathers	52,33%
Siblings	32,65%
Offspring	22,84%
Sexual partners	57,19%

Bobadilla MP, Quiliche L. Prevalencia familiar de infección por HTLV 1 a partir de un caso índice desde el año 1997-2022 en una cohorte de pacientes con HTLV de Perú. Tesis para optar por el título de médico cirujano (2024).

How and why do HTLV-1-associated diseases run in families?

frontiers in Microbiology

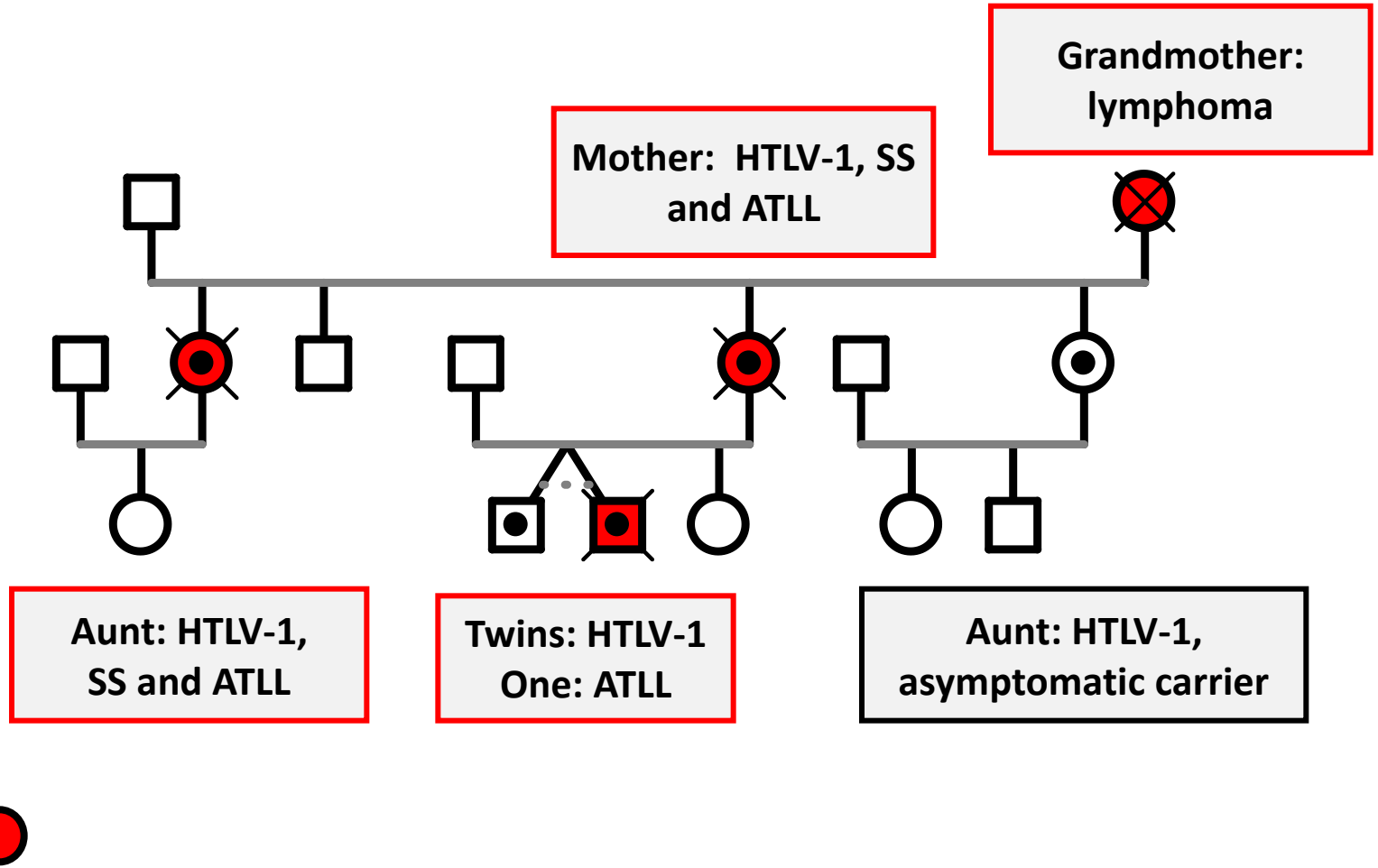
REVIEW
published: 28 October 2016
doi: 10.3389/fmicb.2016.01674

Family Aggregation of Human T-Lymphotropic Virus 1-Associated Diseases: A Systematic Review

Carolina Alvarez[1,2*], *Eduardo Gotuzzo*[1,3], *Anne-Mieke Vandamme*[2,4] and *Kristien Verdonck*[1,5]

[1] *Instituto de Medicina Tropical Alexander von Humboldt, Universidad Peruana Cayetano Heredia, Lima, Peru,* [2] *Department of Microbiology and Immunology, Clinical and Epidemiological Virology, Rega Institute for Medical Research, KU Leuven—University of Leuven, Leuven, Belgium,* [3] *Departamento de Enfermedades Infecciosas, Tropicales y Dermatológicas, Hospital Cayetano Heredia, Lima, Peru,* [4] *Center for Global Health and Tropical Medicine, Unidade de Microbiologia, Instituto de Higiene e Medicina Tropical, Universidade Nova de Lisboa, Lisbon, Portugal,* [5] *Department of Public Health, Institute of Tropical Medicine Antwerp, Antwerp, Belgium*

Familial presentation of ATLL



Mortality Associated with HTLV-1

Am. J. Trop. Med. Hyg., 00(00), 2025, pp. 1–3
doi:10.4269/ajtmh.25-0082

Human T Cell Lymphotropic Virus Type 1 and Human T Cell Lymphotropic Virus Type 2 Mortality in the Shipibo-Konibo People

Isaac E. Alva,[1,2*] Magaly M. Blas,[2] Nicanor Mori,[3] Victor Sal y Rosas,[4] Alex de la Cruz,[4] Joseph R. Zunt,[5,6,7,8] and Eduardo Gotuzzo[1]

[1]*Alexander von Humboldt Tropical Medicine Institute, Universidad Peruana Cayetano Heredia, Lima, Peru;* [2]*Intercultural Citizenship and Indigenous Health Unit, School of Public Health and Administration, Universidad Peruana Cayetano Heredia, Lima, Peru;* [3]*Department of Neurology, Daniel Alcides Carrion National Hospital, Callao, Peru;* [4]*Pontificia Universidad Católica del Perú, Lima, Peru;* [5]*Department of Neurology, University of Washington, Seattle, Washington;* [6]*Department of Global Health, University of Washington, Seattle, Washington;* [7]*Department of Medicine, University of Washington, Seattle, Washington;* [8]*Department of Epidemiology, University of Washington, Seattle, Washington*

Key Findings (n = 2,020 Shipibo-Konibo individuals)

3.11×

higher risk of death
HTLV-1 vs. negative
(HR 3.106; 95% CI 1.58–6.1)

HTLV-2

No significant increase
in mortality risk
(HR 1.11; 95% CI 0.34–3.61)

+4.5%

risk per additional year of age
(HR 1.045; 95% CI 1.02–1.07)

First study to assess HTLV-1 and HTLV-2 mortality in Amazonian indigenous people in Latin America

In Summary:

1. HTLV-1 is endemic in several Latin American countries.
2. In endemic areas, breastfeeding is an important factor, but it is also a frequent STi in these areas.

3. Some American Indian population groups, mainly of Quechua origin, and African-Latin American groups are commonly affected.

4. TSP in association with HTLV-1 is a common condition.
5. ATL in association with HTLV-1 is common in Non-Hodgkin Lymphoma and ATL.

In Summary(Cont)

. Some unusual conditions, such as *Strongyloides* hyperinfestation, Norwegian Scabies and a high mortality in TB have been associated with HTLV-1 in the region.

7. HTLV-1 screening in blood donors is recommended.

8. When a case of HTLV-1 is detected, it is necessary to check the whole family.

9. HTLV-1 is an emerging disease in Latin America, with complex clinical patterns.several discapacities and increase mortality

HTLV-1

- NTD[3]
  - Affects poor people, increasing Poverty
  - It is not in research priority lists.Also is not in the list of Neglected tropical diseases NTD
  - The impact in Mortality, Morbility,Disability and immunosuppression is not recognized

22nd International Conference on Human Retrovirology:
HTLV and Related Retroviruses
HTLV2026

June 3-6, 2026 | Philadelphia, Pennsylvania, USA

HTLV challenges and opportunities in the international public health agenda

Josh Anzinger
The University Of The West Indies, Jamaica

HTLV Challenges and Opportunities in the International Public Health Agenda

Joshua Anzinger
Head of Department
Director, Global Virus Network Jamaica Affiliate
Department of Microbiology
The University of the West Indies, Mona

HTLV is Mainly in LMIC

Challenge

Prevalence High HDI: 0.41%

Prevalence Low HDI: 1.18%

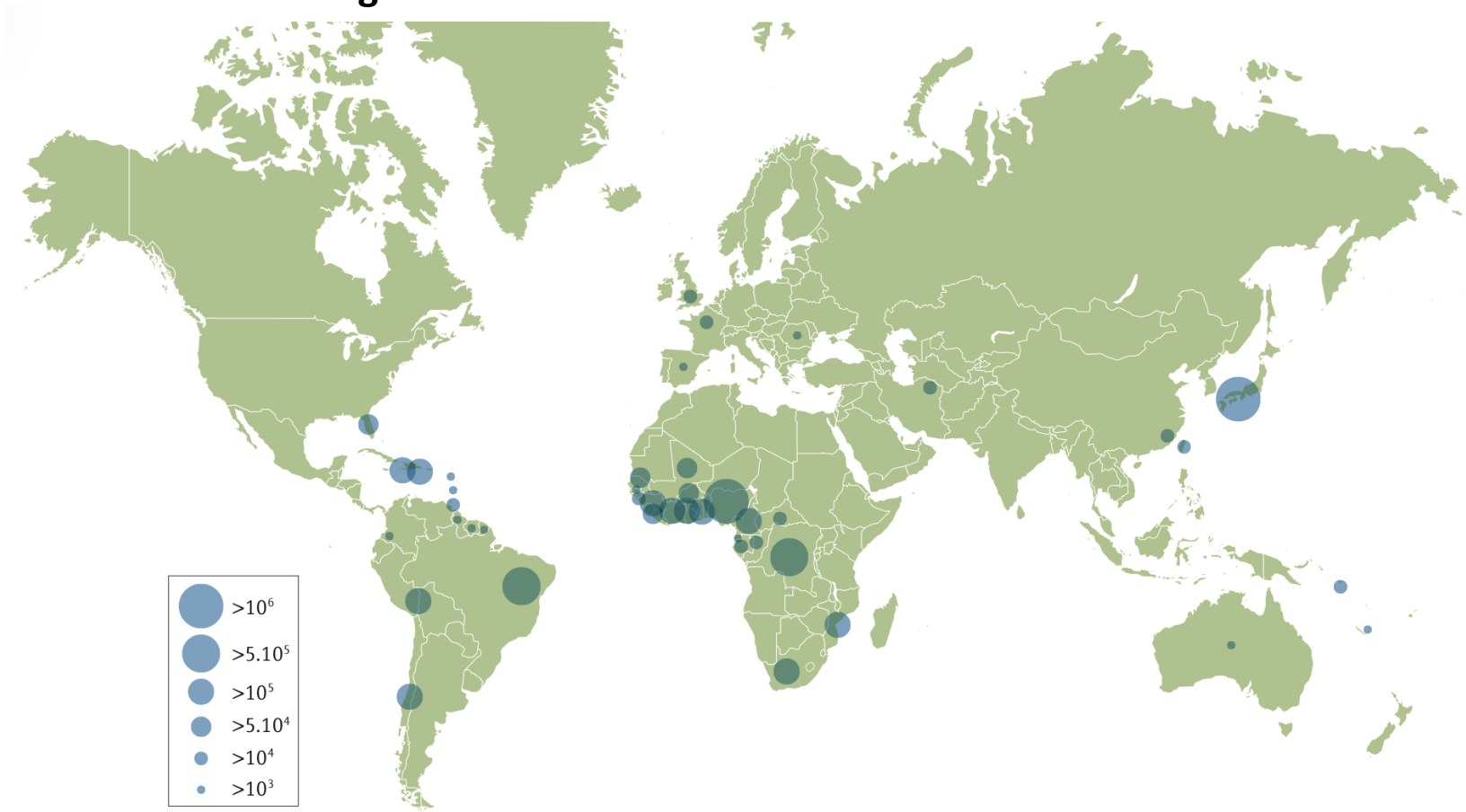


Figure 2 | **Global prevalence of HTLV-1 infection in endemic areas.** Circles show the estimated numbers of human T-lymphotropic virus 1 (HTLV-1)-infected individuals. HTLV-1 infection is most prevalent in Japan, South America and the Caribbean basin, and in west, central and southern Africa. Reproduced from REF. 18.

Sampaio GCL et al., AIDS Res Hum Retroviruses. 2023
Bangham CRM et al., Nat Rev Dis Primers. 2015

HTLV is a Neglected Disease that Remains Prevalent in Jamaica

⚠ Challenge

Year	Population (n)	Prevalence
1986	MSM (125)[1]	**5%**
1986	General Population (13,260)[2]	**1.7% 10-19 M** **9.1% ≥ 70 M** **1.9% 10-19 F** **17.4% ≥ 70 F**
1989	STD Clinic Attendees (1977)[3]	**5.7%**
1991	STD Clinic Attendees (994)[4]	**7.0% M** **7.9% F**
1998	UWI Pregnant Women (200)[5]	**2%**
2003	UWI HIV Clinic Attendees (129)[6]	**5%**
2021	UWI Pregnant Women (370)[7]	**1.6%**
2023	UWI HIV Clinic Attendees (470)[8]	**6.6%**

[1]Murphy EL et al, JAIDS, 1988
[2]Murphy EL et al, Am J Epidemiol, 1991
[3]Murphy et al, Ann Intern Med, 1989
[4]Figueroa JP et al, JAIDS, 1995
[5]Dowe G et al, WIMJ, 1998
[6]Smikle MF et al, WIMJ, 2003
[7]Leys YE et al, AJTMH, 2023
[8]Butterfield et al, unpublished

HTLV is a Neglected Disease that Remains Prevalent in Jamaica

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Year	Population (n)	Prevalence
1986	MSM (125)[1]	5%
1986	General Population (13,260)[2]	1.7% 10-19 M 9.1% ≥ 70 M 1.9% 10-19 F 17.4% ≥ 70 F
1989	STD Clinic Attendees (1977)[3]	5.7%
1991	STD Clinic Attendees (994)[4]	7.0% M 7.9% F
1998	UWI Pregnant Women (200)[5]	2%
2003	**UWI HIV Clinic Attendees (129)[6]**	**5%**
2021	UWI Pregnant Women (370)[7]	1.6%
2023	**UWI HIV Clinic Attendees (470)[8]**	**6.6%**

[1]Murphy EL et al, JAIDS, 1988
[2]Murphy EL et al, Am J Epidemiol, 1991
[3]Murphy et al, Ann Intern Med, 1989
[4]Figueroa JP et al, JAIDS, 1995
[5]Dowe G et al, WIMJ, 1998
[6]Smikle MF et al, WIMJ, 2003
[7]Leys YE et al, AJTMH, 2023
[8]Butterfield et al, unpublished

HTLV is a Neglected Disease that Remains Prevalent in Jamaica

⚠ Challenge

Year	Population (n)	Prevalence
1986	MSM (125)[1]	5%
1986	General Population (13,260)[2]	1.7% 10-19 M 9.1% ≥ 70 M 1.9% 10-19 F 17.4% ≥ 70 F
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[1]Murphy EL et al, JAIDS, 1988
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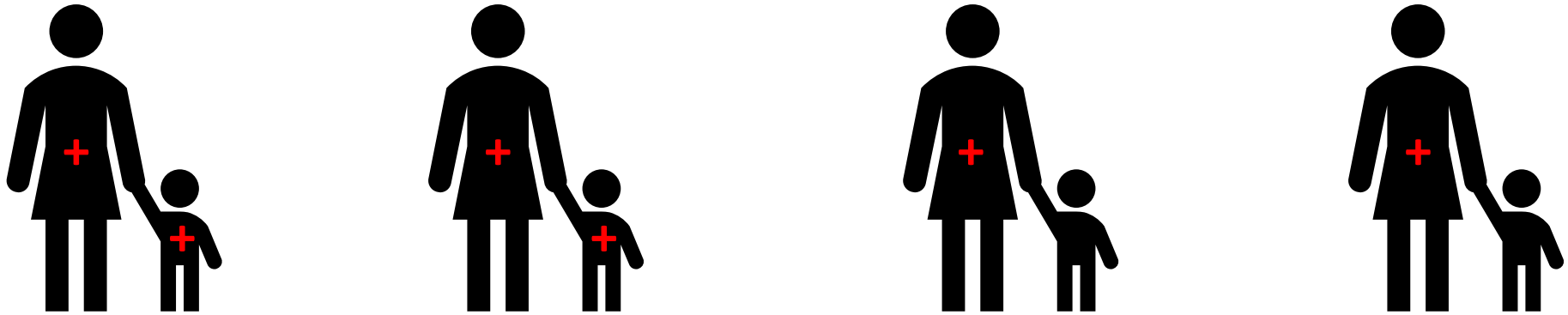
[3]Murphy et al, Ann Intern Med, 1989
[4]Figueroa JP et al, JAIDS, 1995
[5]Dowe G et al, WIMJ, 1998
[6]Smikle MF et al, WIMJ, 2003
[7]Leys YE et al, AJTMH, 2023
[8]Butterfield et al, unpublished

Silent HTLV Mother to Child Transmission Is Occurring

⚠ Challenge

Year	Population (n)	Prevalence
2021	UWI Pregnant Women (370)	1.6% (**6 mothers***)



***2 mother-child dyads unavailable**

Leys YE et al, Am J Trop Med Hyg, 2023

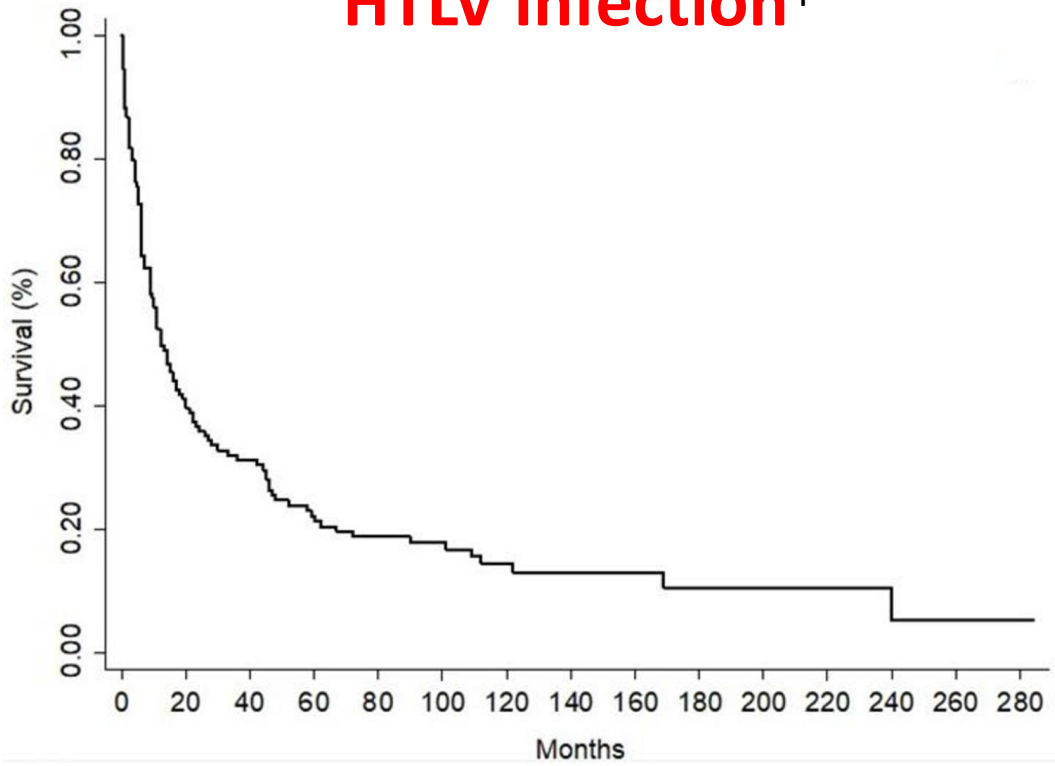
Mother to Child Transmission of HTLV Is Responsible for Most ATLL

⚠ Challenge

- Adult T-cell leukemia/lymphoma (ATLL) rare when HTLV acquired in adulthood[1]
- ***Most ATLL acquired*** from childhood HTLV infection via ***breastfeeding***[2,3]
- HTLV incidence in breastfed children[3]
  - ≥ 6 months: 20.3% children infected
  - < 6 months: 7.4% children infected

[1]Iwanaga M et al, Front Microbiol, 2012
[2]Murphy EL et al, Int J Cancer, 1989;
Hino S, Proc Jpn Acad Ser B Phy Biol Sci, 2011

Consequences of Childhood HTLV Infection[4]

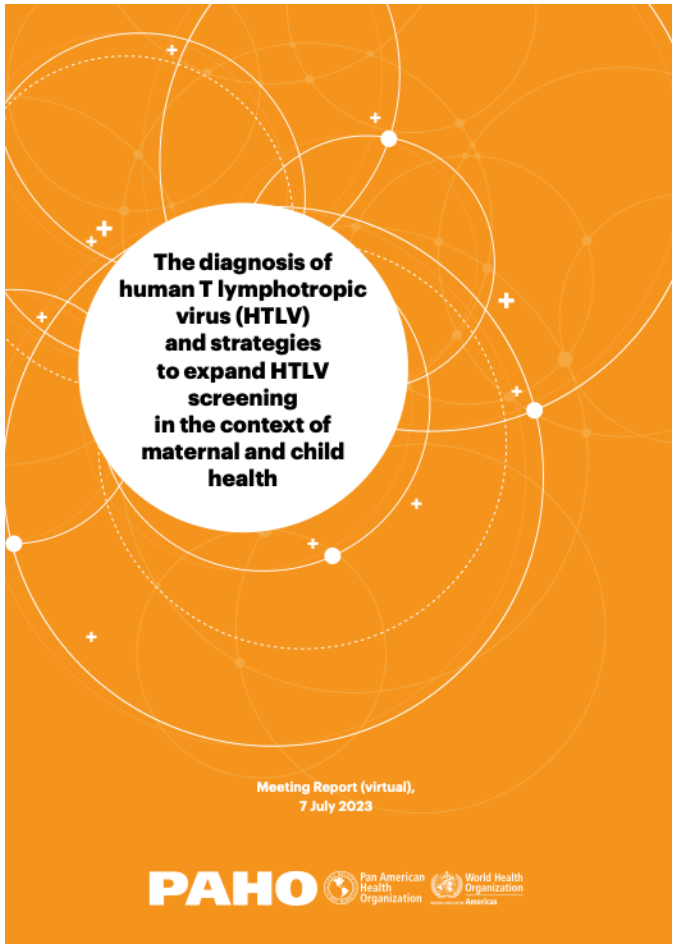


[4]Oliveira PD, PLoS NTD, 202

Opportunity

HTLV Antenatal Screening

⚠ Challenge



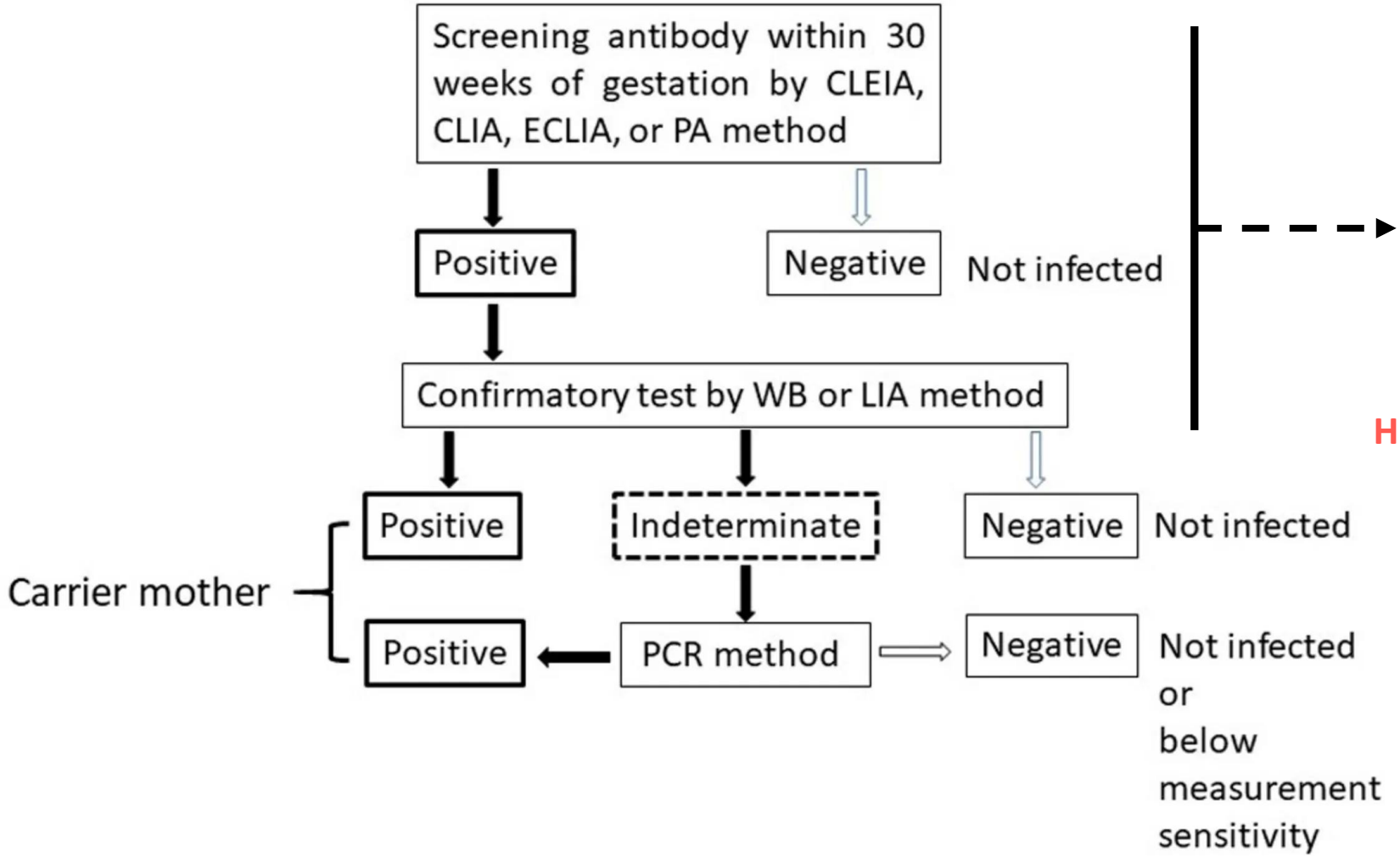
PAHO Meeting Report:

"…HTLV-1 screening of blood donors is high in the region, but ***antenatal screening is still limited***."

"…***no international guidelines for HTLV-1 diagnostics*** and national guidance may vary between countries."

HTLV Screening: Complicated, Expensive, and no Universally Accepted Algorithm

⚠ Challenge



Jamaica

US$6,300/1000 tests

(CLIA + WB)

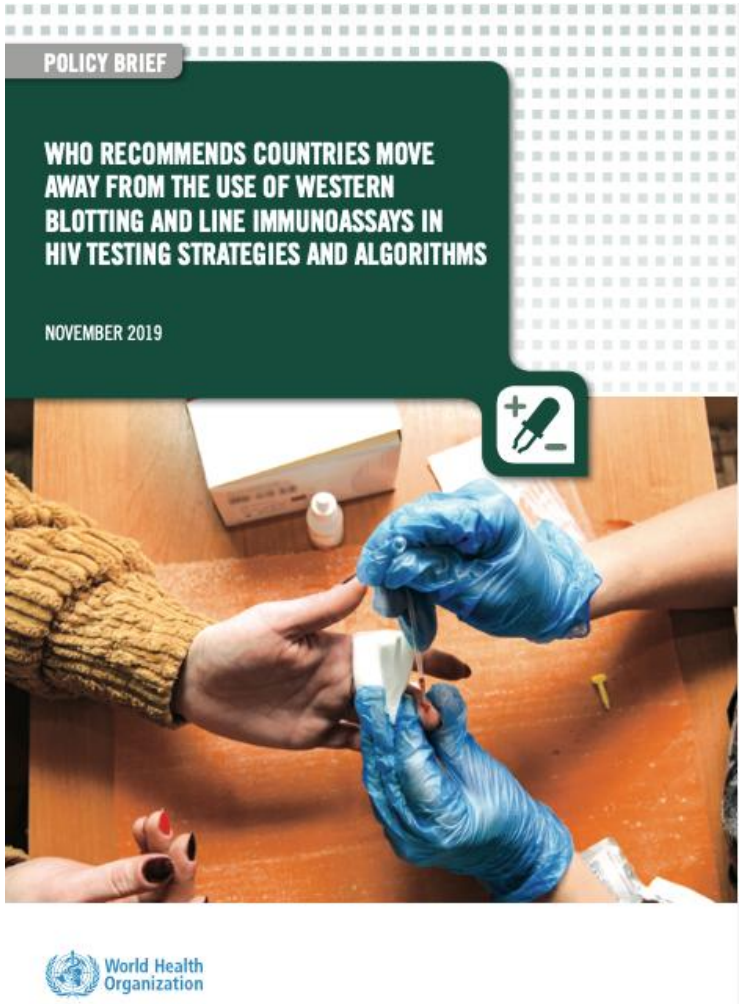
Leys YE et al., Am J Trop Med Hyg, 2023

HIV RDT ~US$1 in Jamaica

Itabashi K et al., Front Microbiol, 2020

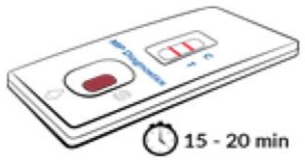
Complex Testing Is Not Recommended for HIV Diagnosis So Why for HTLV?

⚠ Challenge



"…***replacing western blotting*** and line immunoassays with… ***simpler tests include rapid diagnostic tests (RDTs)*** that… get results to the client faster, produce accurate results more often, ***cost less***, can be performed by various cadres of health providers, and can thus facilitate ***greater access*** and uptake of HIV testing services…"

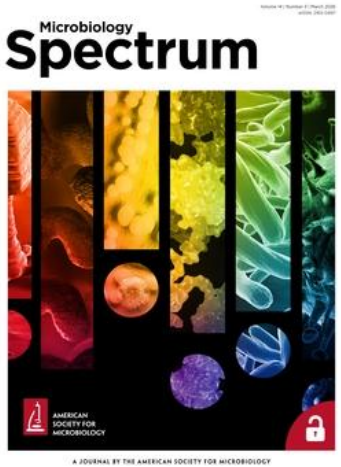
Introduction of RDT for HTLV Screening



RESEARCH Open Access

A novel high-performance rapid screening test for the detection of total HTLV-I and HTLV-II antibodies in HTLV-I/II infected patients

Lay Sin Teoh[1], Vincent Guiraud[2], Haris Ong[1], Yang Du[1], Zhihai Zhao[1*], Agnès Gautheret-Dejean[2*] and Na Xu[1*]



Performance evaluation of Espline HTLV-I/II, a newly developed rapid immunochromatographic antibody test for different diagnostic situations

Madoka Kuramitsu,[1] Haruka Momose,[1] Yuichiro Uchida,[2] Kenji Ishitsuka,[2] Ryuji Kubota,[3] Masahito Tokunaga,[4] Atae Utsunomiya,[4] Kunihiko Umekita,[5,6] Yuuki Hashikura,[6] Kisato Nosaka,[7] Ki-Ryang Koh,[8] Hitomi Nakamura,[9] Yasuko Sagara,[9] Rieko Sobata,[10] Masahiro Satake,[10] Koh Nagata,[11] Yuri Hasegawa,[11] Daisuke Sasaki,[12] Hiroo Hasegawa,[12] Tomoo Sato,[13,14] Yoshihisa Yamano,[13,14] Kou Hiraga,[1] Kenta Tezuka,[1] Emi Ikebe,[1] Sahoko Matsuoka,[1] Kazu Okuma,[15] Toshiki Watanabe,[16] Kiyonori Miura,[11] Isao Hamaguchi[1,17]

Opportunity

Antenatal Serum Samples Collected Routinely for HIV Testing Can Also Be Used for HTLV

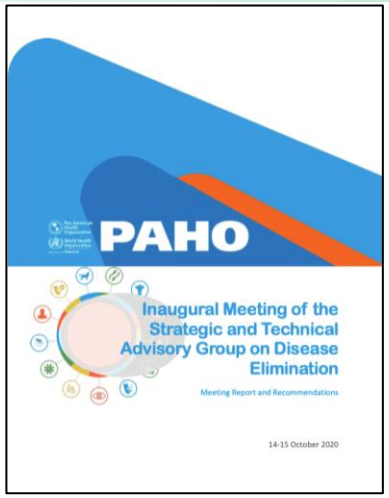
UWI Department of Microbiology

- Antenatal HIV testing is widespread
- *Serum* collected *for HIV testing* is *same sample for HTLV testing*
- Sometimes the same instrument is used for HIV testing (**left**)

Opportunity

Campaign for Elimination of HTLV

REGIONAL ELIMINATION FRAMEWORKS CREATE MOMENTUM FOR HTLV POLICY INTEGRATION



"STAG recommends PAHO to *consider expanding the range of candidates to Elimination by including other diseases/conditions such as HTLV*

Opportunity

Brazil takes a leap towards the elimination of HTLV-1 vertical transmission

Carolina Rosadas,[a,*] Draurio Barreira,[b] Pamela C. Gaspar,[b] Mayra G. Aragón,[b] Adijeane Oliveira,[c] Tatiane Assone,[d] and Angelica E. Miranda[b,**]

[a]Section of Virology, Department of Infectious Disease, Imperial College London, London, United Kingdom
[b]Brazilian Ministry of Health, Brasilia, Brazil
[c]HTLVida, Bahia, Brazil
[d]Faculty of Medicine, São Paulo University, São Paulo, Brazil

Summary

Challenge

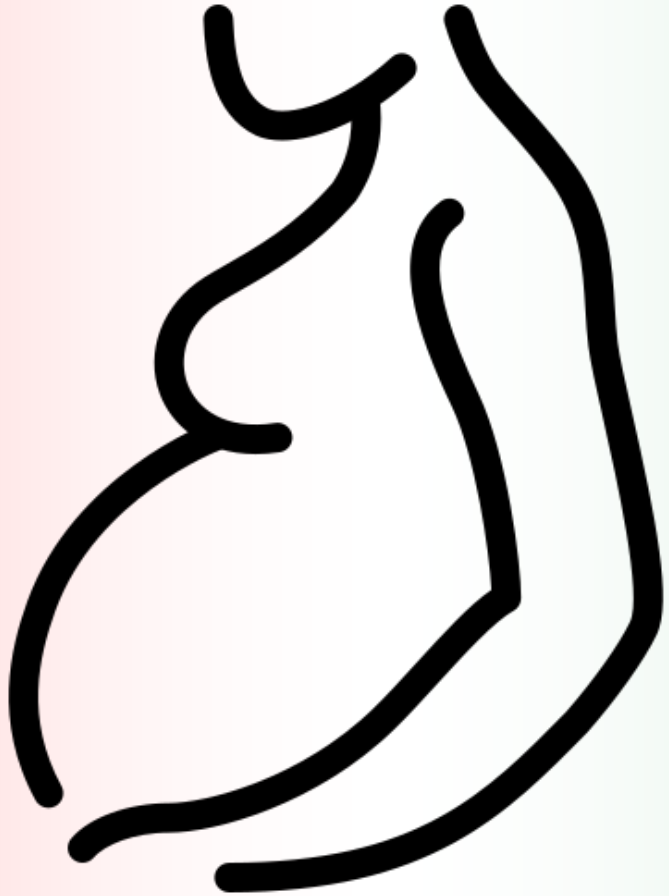
- HTLV remains neglected in LMIC
- Silent MTCT continues
- Testing remains complex and costly
- Funding remains limited for research and public health programs

Opportunity

- Reliable RDTs are emerging
- Existing HIV infrastructure can support HTLV testing
- WHO/PAHO initiatives create elimination opportunties

The Tools to Reduce HTLV Transmission Already Exist; Implementation Is Now the Major Challenge

Challenge



Opportunity

Can the Challenges be Overcome and the Opportunities Seized?

22nd International Conference on Human Retrovirology:
HTLV and Related Retroviruses
HTLV2026

June 3-6, 2026 | Philadelphia, Pennsylvania, USA

Control of endemic HTLV-1 to prevent silent global spread - lead from the ASPIRE (Adopting Sustainable Partnerships for an Innovative Research Ecosystem) Program

Damian Purcell
University of Melbourne, Australia

Control of endemic HTLV-1 to prevent silent global spread - lead from the ASPIRE Program.

→ time for IRVA to develop a TPP!

Professor Damian Purcell, PhD
Head, Molecular Virology Laboratory
- Node of the Victoria mRNA Innovation Hub
Head of Industry Partnerships

Doherty Institute

ASPIRE HTLV-1 RESEARCH AUSTRALIA-JAPAN

mRNA VIC

VICTORIA State Government

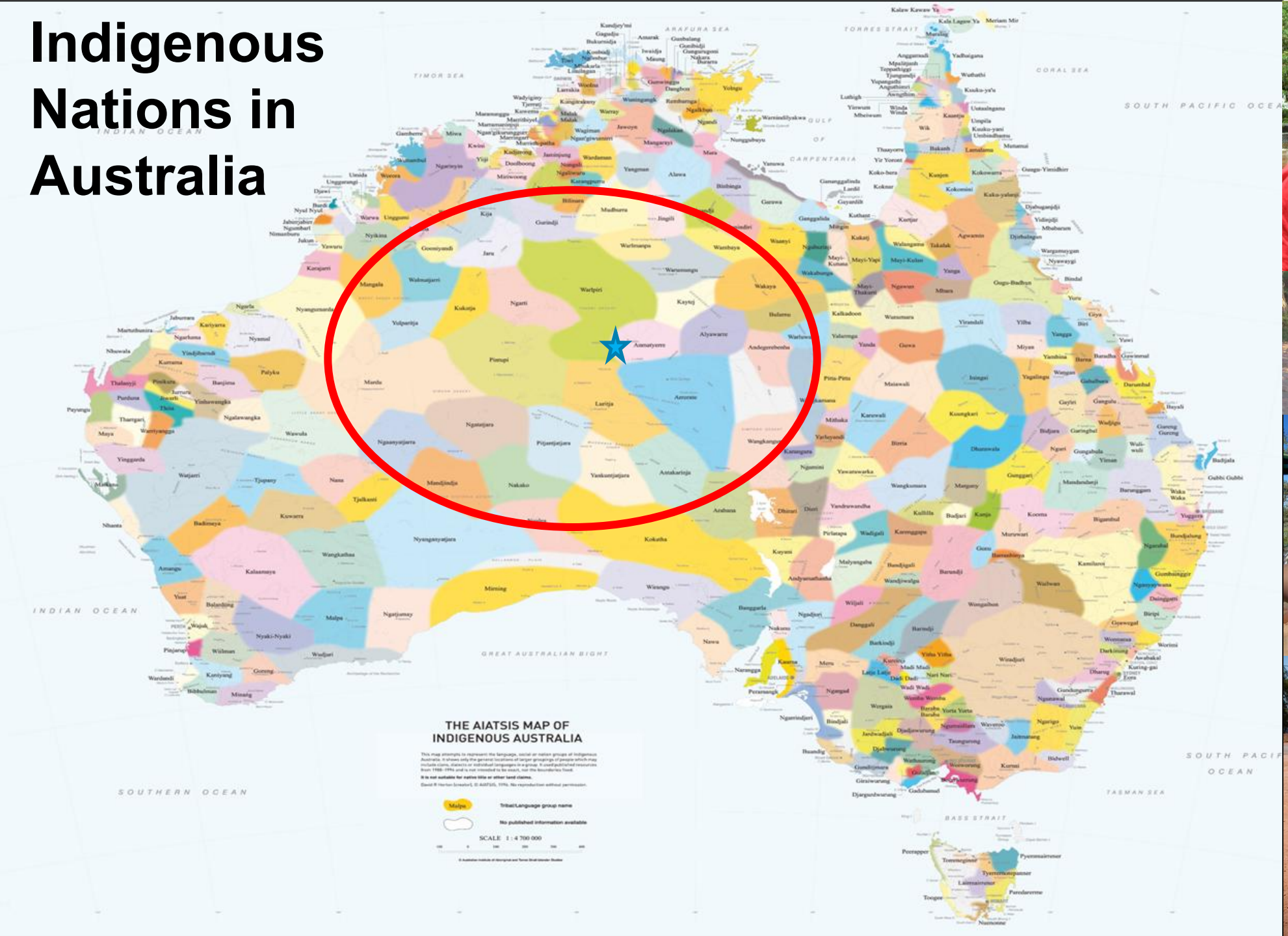
GVN GLOBAL VIRUS NETWORK Pandemic Preparedness For A Vulnerable World

THE UNIVERSITY OF MELBOURNE

The Royal Melbourne Hospital

A joint venture between The University of Melbourne and The Royal Melbourne Hospital

Indigenous Nations in Australia



HTLV-1c is focally endemic in Central Australia

Central Australia has among the highest rates of HTLV-1 infection

Indigenous peoples are ~2% of Australian population, ~25% of central and Northern Australia population

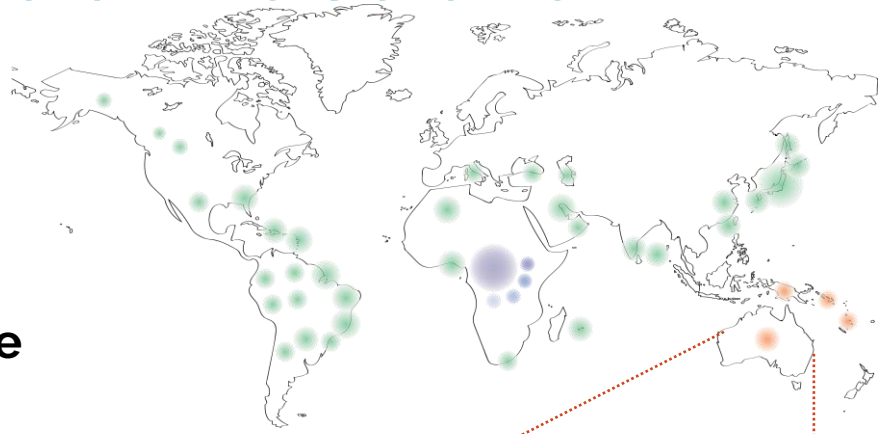
HTLV-1c infection most commonly associated with pulmonary disease

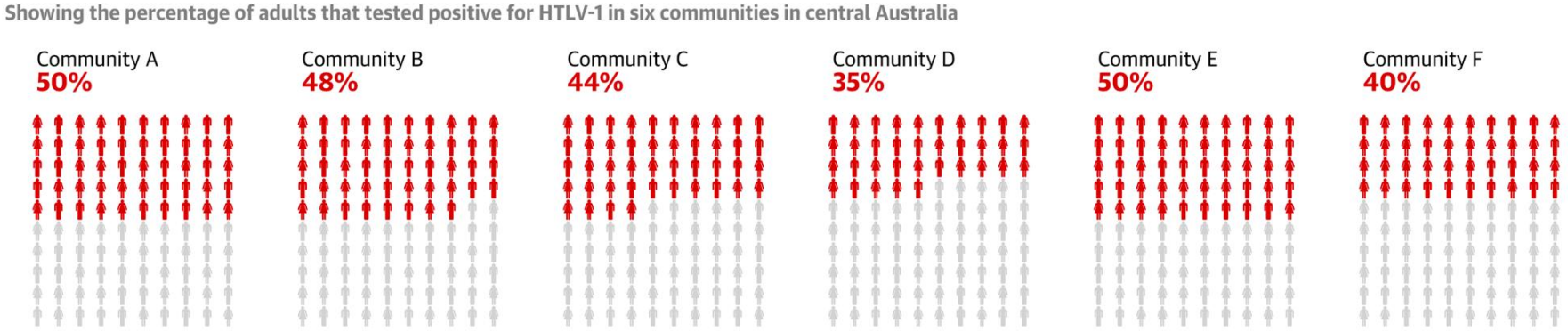
- **Bronchiectasis (Bex), COPD**
- **Also blood stream co-infections, Diabetes, Chronic Kidney Disease**
- Lower rates than HTLV-1a of ATLL (5%), and HAM myelopathy (4%)

Diseases are associated with higher proviral loads (> 1%)

Life expectancy is significantly less for those infected with HTLV-1c

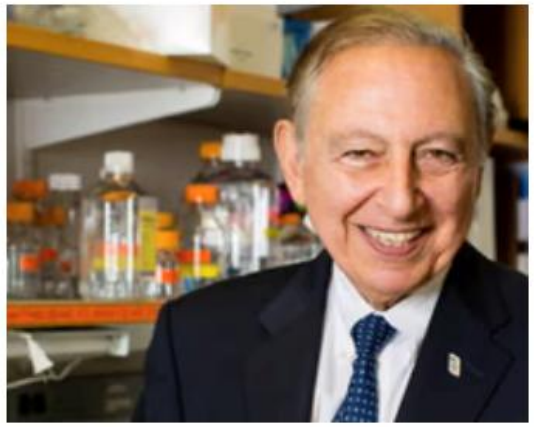
Poor awareness, few public health strategies, low research investment





Einsiedel and Woodman, MJA 2010
Einsiedel et al., PLoS NTD 2014
Einsiedel, PLOS NTD 2018
Talukder, et al, CID 2023

No therapeutics, No vaccines : Fear / Denial / Stigma



Indigenous investigations

Treat HTLV-1 virus or risk it spreading widely, doctor who discovered it warns

4 May 2018 11.14 AEST | 135

Indigenous investigations

World experts call for Australia to act on devastating HTLV-1 virus

UK clinician says central Australia's 'shocking' 45% infection rate demands action

28 Apr 2018 08.00 AEST

NACCHO

National Aboriginal Community Controlled Health Organisation

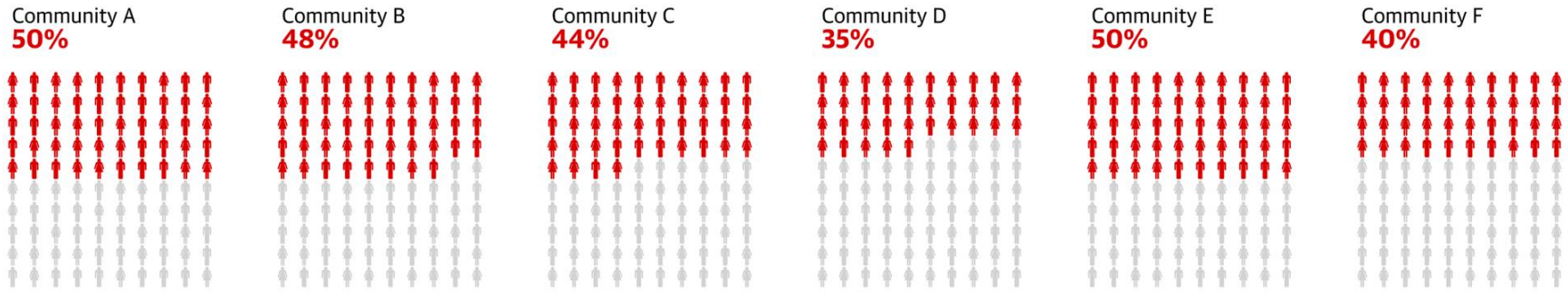
Indigenous investigations

'People are scared': the fight against a deadly virus no one has heard of

HTLV-1 is endemic across central Australia. But testing takes six months and is not freely available

24 Apr 2018 14.52 AEST

Showing the percentage of adults that tested positive for HTLV-1 in six communities in central Australia



Guardian graphic | Source: The Baker Heart and Diabetes Institute

Significant genomic differences between HTLV-1a and -1c

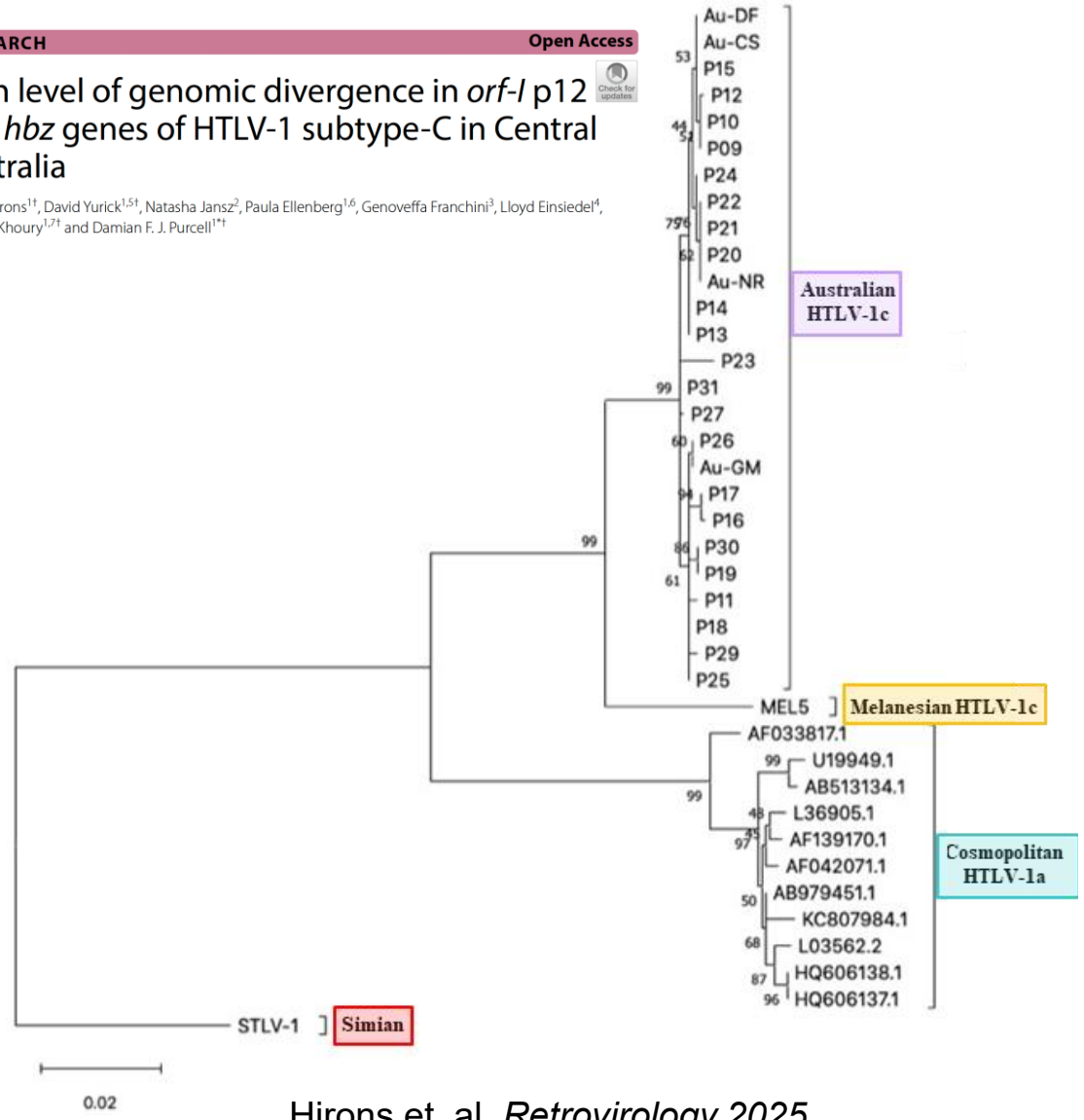
Hirons et al. Retrovirology (2024) 21:14
https://doi.org/10.1186/s12977-024-00647-w

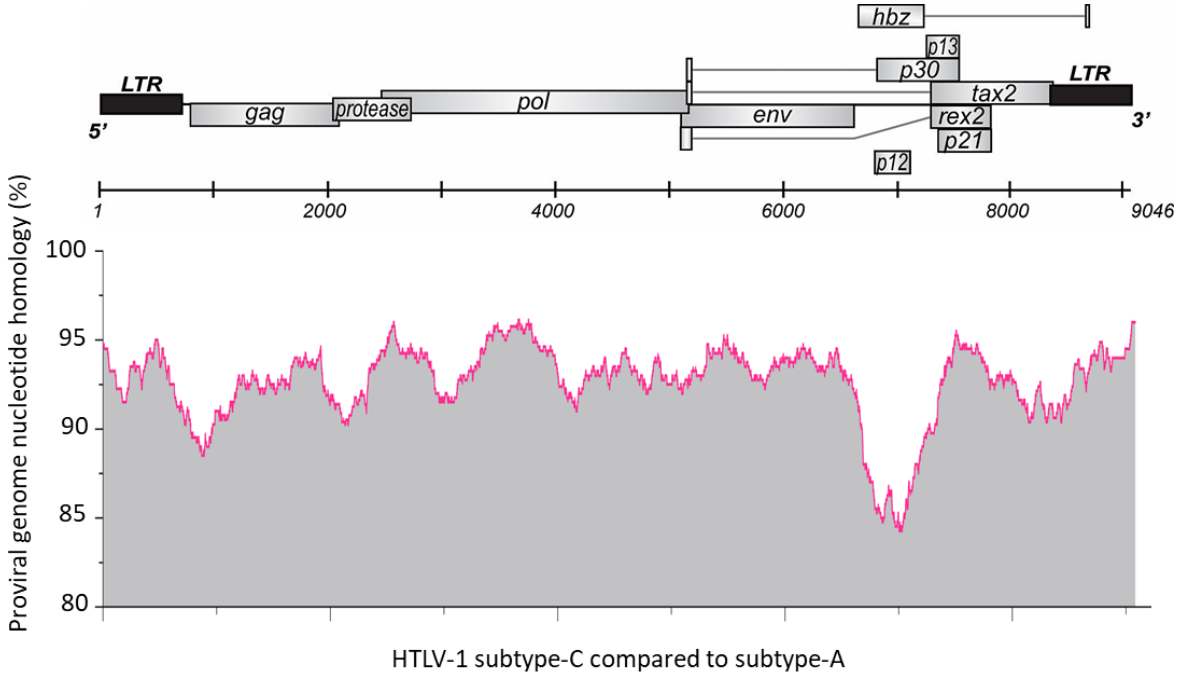
Retrovirology

RESEARCH Open Access

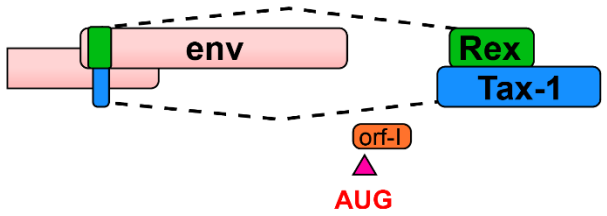
High level of genomic divergence in *orf-I* p12 and *hbz* genes of HTLV-1 subtype-C in Central Australia

Ashley Hirons[1†], David Yurick[1,5†], Natasha Jansz[2], Paula Ellenberg[1,6], Genoveffa Franchini[3], Lloyd Einsiedel[4], Georges Khoury[1,7†] and Damian F. J. Purcell[1*†]

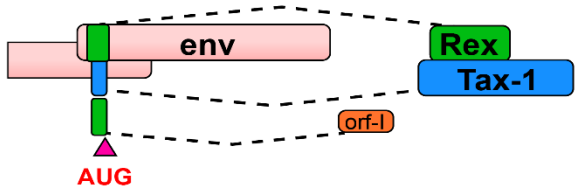




HTLV-1A



HTLV-1C

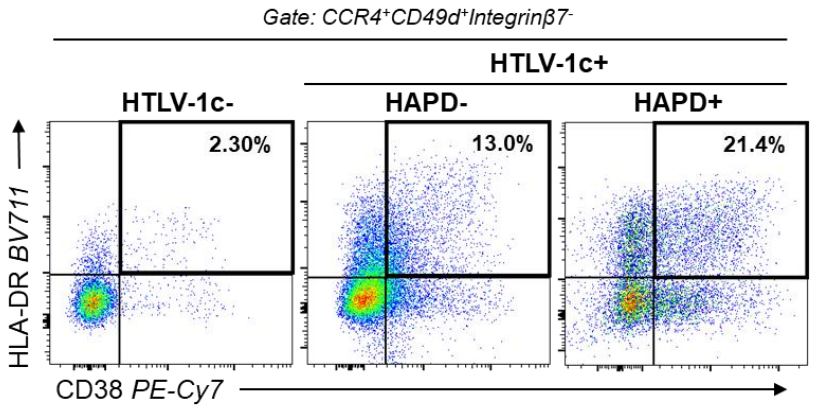


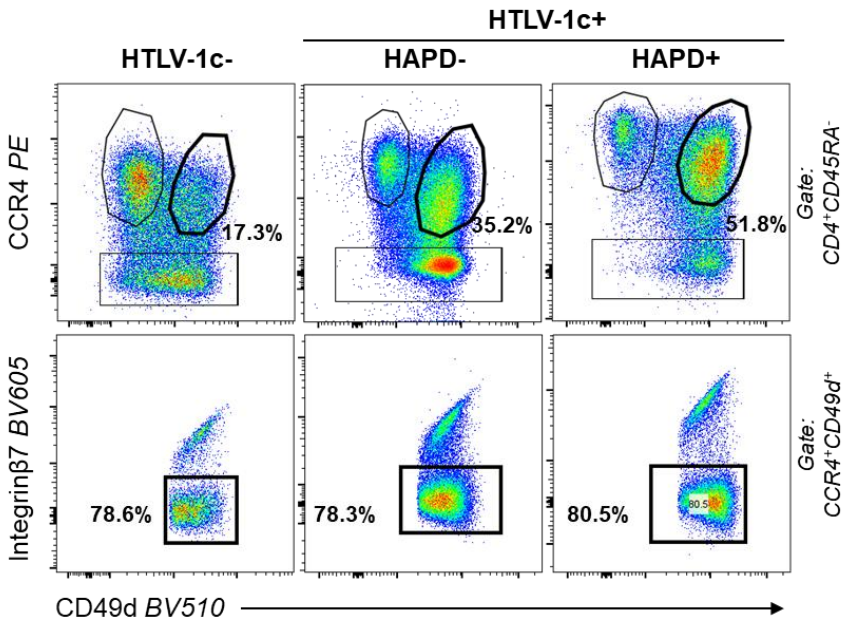
- HTLV-1c encodes a p16 variant of the p12 (*orf-I)*
- The p16 variant may contribute to higher inflammatory disease

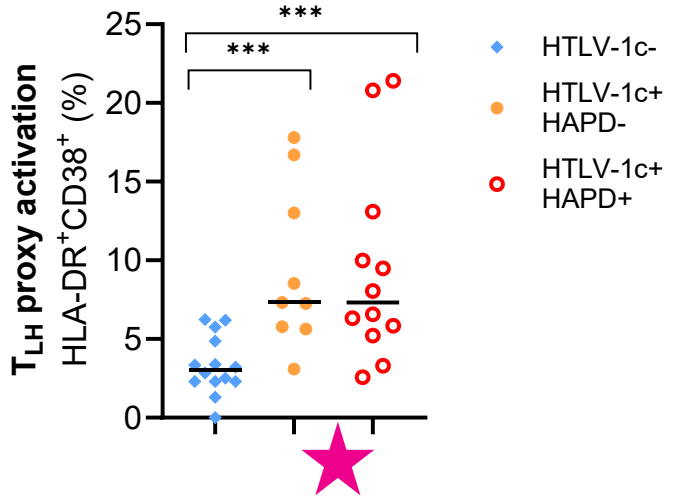
Hirons et. al. *Retrovirology 2025*

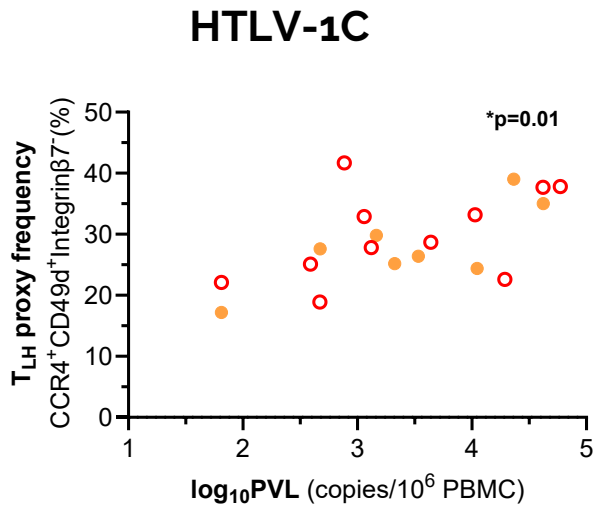
Sarkis et. al. *Nature Comms 2025*

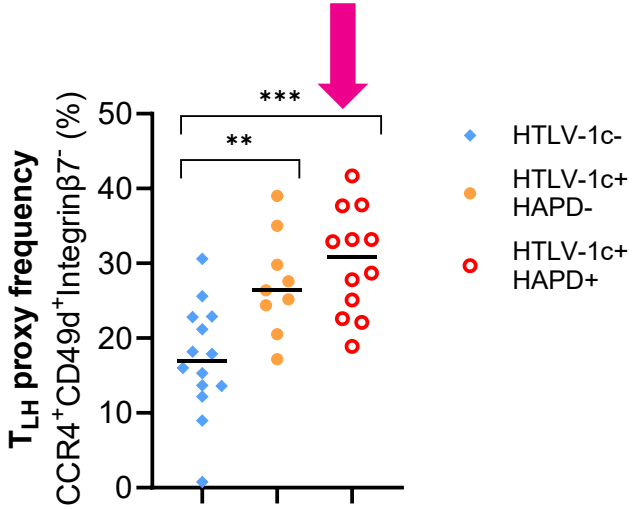
HTLV-1c associated pulmonary disease is sustained by chronically activated and infected lung-homing CD4+ T-cells

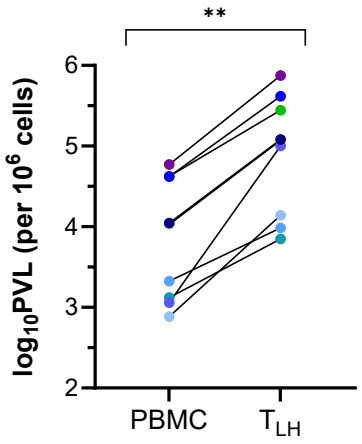












Hirons et. al. *eBioMed (in revision)*

Control of endemic HTLV-1 to prevent silent global spread

ASPIRE
Adopting Sustainable Partnerships for Innovative Research Ecosystem

Adopting Sustainable Partnerships for an Innovative Research Ecosystem (ASPIRE)

Australian Government
National Health and Medical Research Council

ASPIRE HTLV-1 RESEARCH AUSTRALIA-JAPAN

AMED
Japan Agency for Medical Research and Development

Doherty Institute
A joint venture between the University of Melbourne and Melbourne Health

THE UNIVERSITY OF MELBOURNE

WEHI
brighter together

東京大学
THE UNIVERSITY OF TOKYO

JIHS
Japan Institute for Health Security

UNSW SYDNEY

UNSW Kirby Institute

QUT

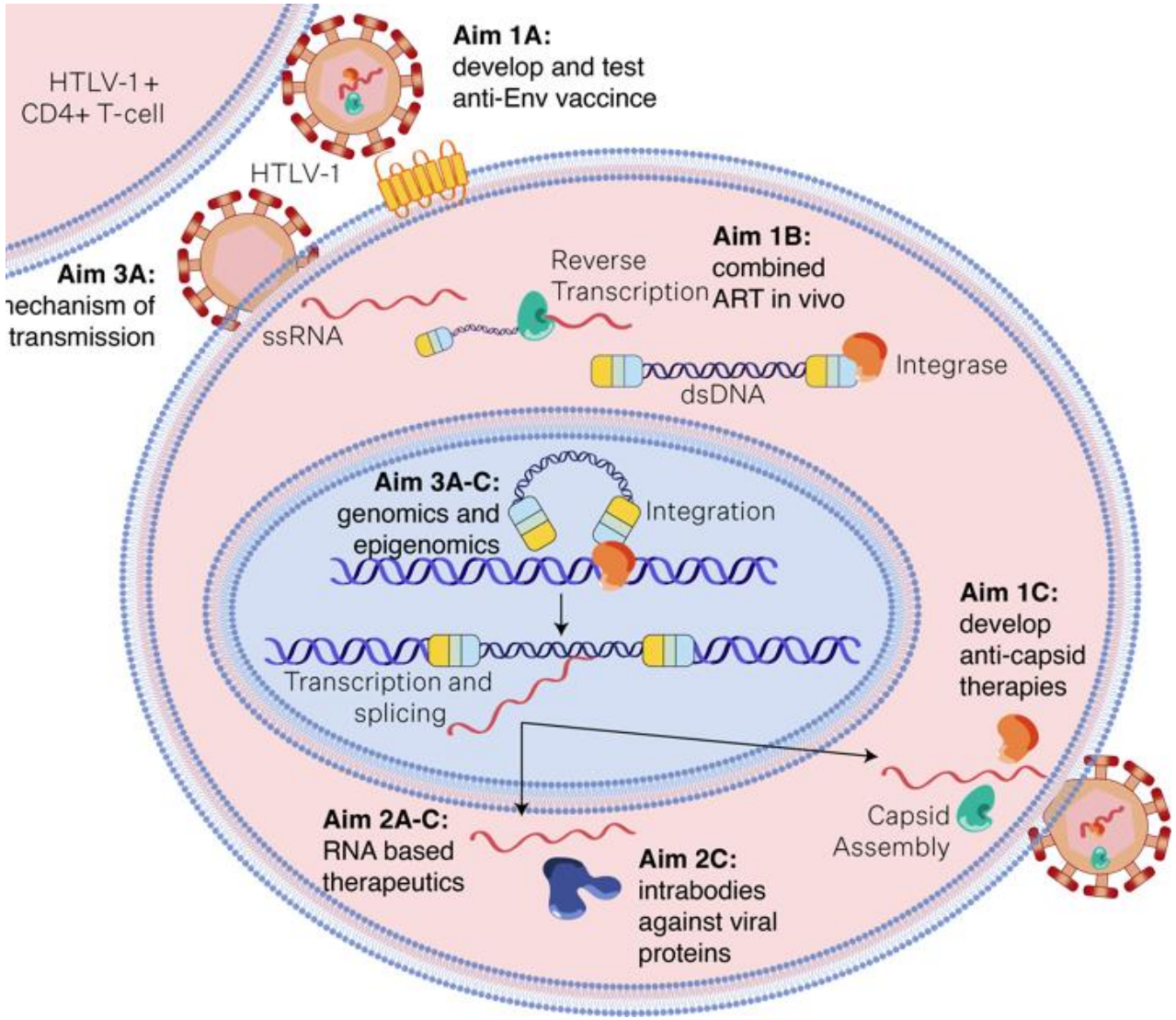
HOKKAIDO UNIVERSITY

Kumamoto University

NIID
NATIONAL INSTITUTE OF INFECTIOUS DISEASES

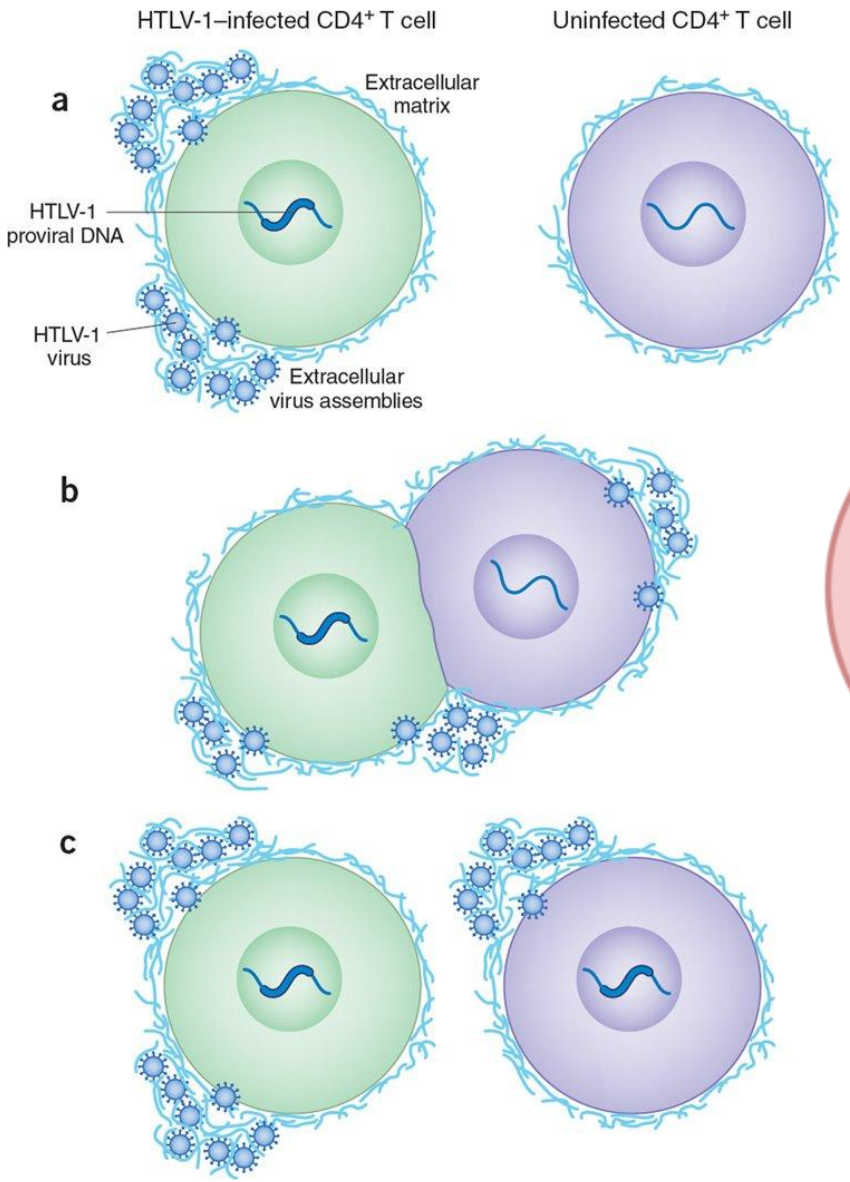
Control of endemic HTLV-1 to prevent silent global spread

Adopting Sustainable Partnerships for an Innovative Research Ecosystem (ASPIRE)



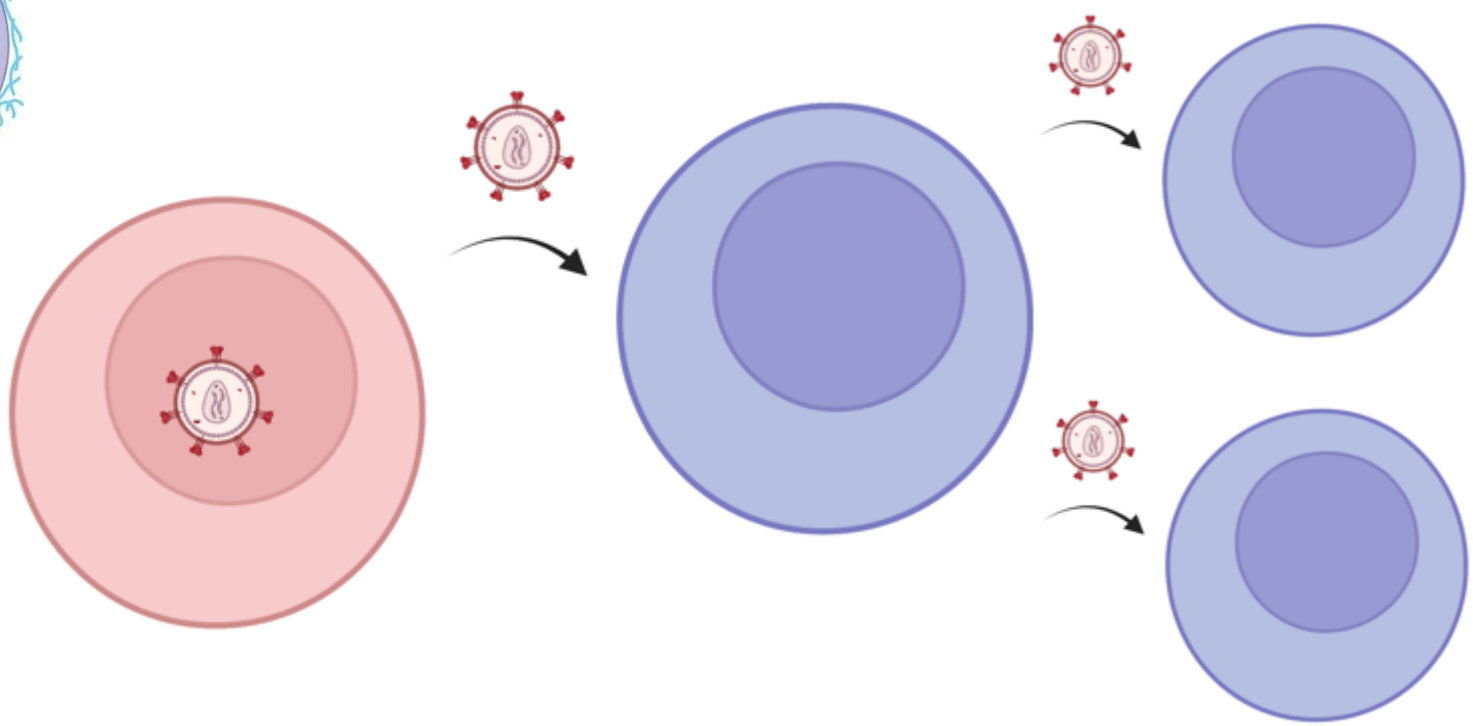
Prof. Damian Purcell	University of Melbourne
Dr. Natasha Jansz	University of Melbourne
Dr. Marcel Doerflinger	Walter and Eliza Hall Institute
Dr. Chantelle Ahlenstiel	University of New South Wales
Dr. Lloyd Einsiedel	University of Melbourne
Prof. Anthony Kelleher	University of New South Wales
Dr. Genoveffa Franchini	National Institutes of Health
Dr. David Jacques	University of New South Wales
Prof. Pall Thordarson	University of New South Wales
Prof. Tetsuro Matano	National Inst Infectious Diseases
Prof. Yorifumi Satou	Kumamoto University
Prof. Makoto Yamagishi	University of Tokyo
Dr. Samantha Grimley	University of Melbourne
Prof. Marc Pellegrini	University of Sydney
Dr. Ashley Hirons	University of Melbourne
Prof. John Skerritt	University of Melbourne
Dr. Fabiola Martin	Canberra Health Services
Dr. Paula Cevaal	University of Melbourne
Prof. Sharon Lewin	University of Melbourne

Pathways of cell-cell transmission of HTLV1c



Jones K and Green P (2012), *Nature medicine*

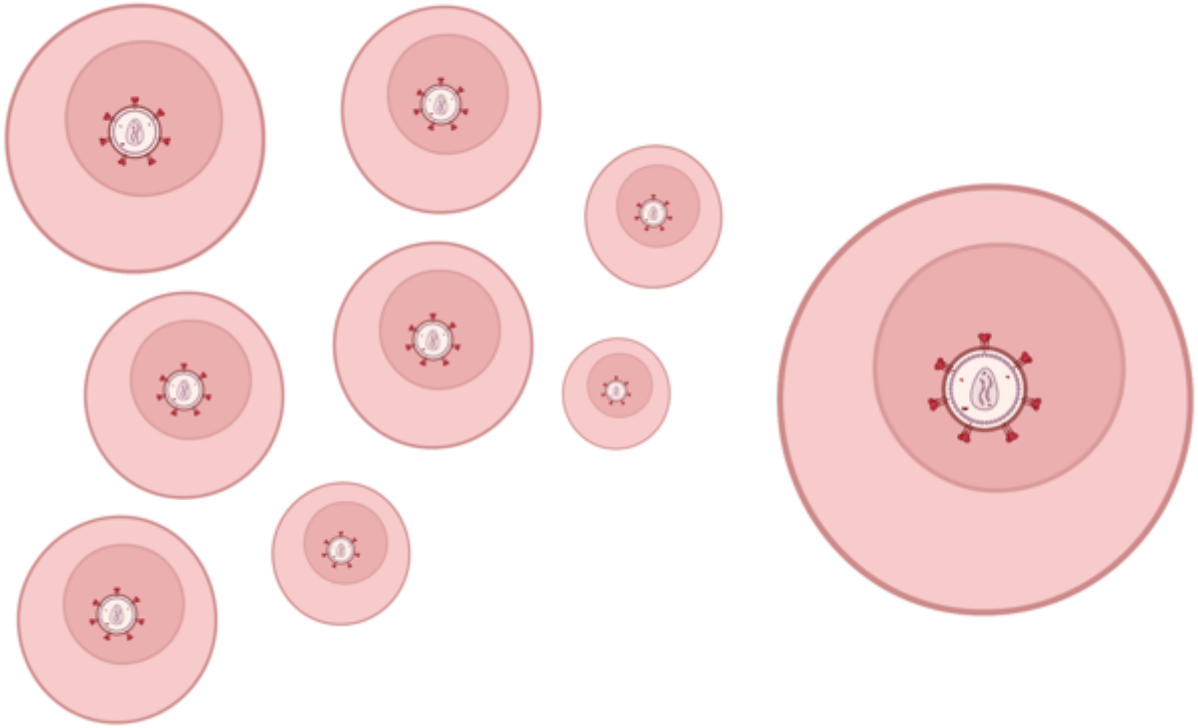
de novo viral spread / transmission



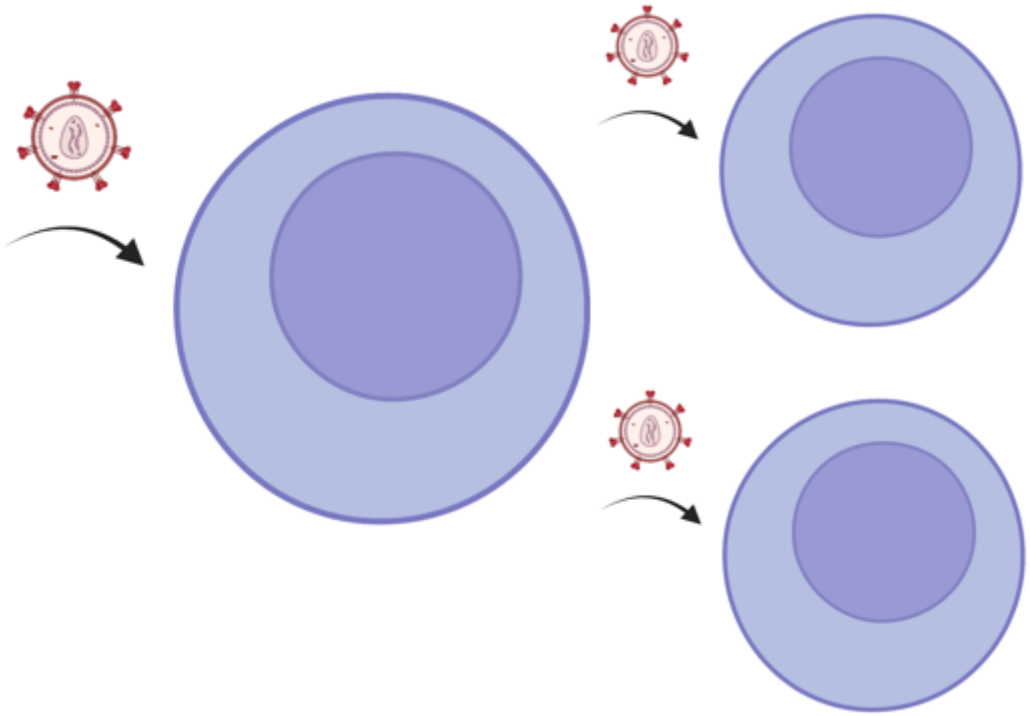
Early after an individual is exposed, HTLV spreads from cell-to-cell via an Env biofilm at the ‘immunological/viral’ synapses and replicates using viral reverse transcriptase

Pathways of cell-cell transmission of HTLV1c

proviral / clonal expansion



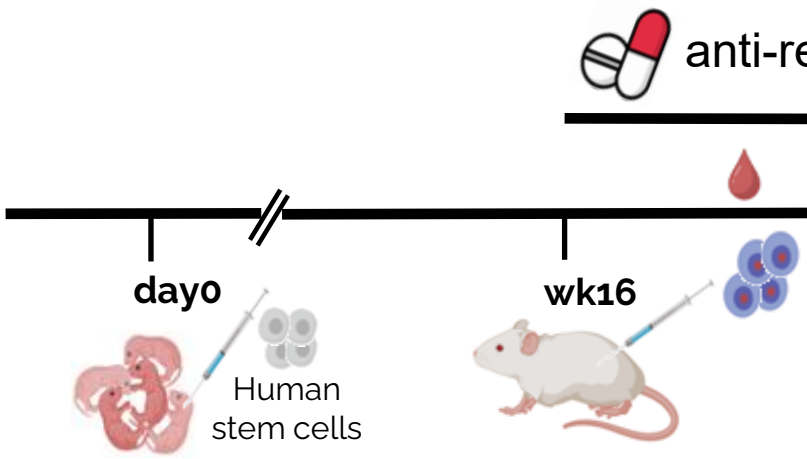
de novo viral spread / transmission



During the **chronic** stage of infection, the virus persists via clonal expansion, through replication of the provirus integrated into the host cell genome

Early after an individual is exposed, HTLV spreads from cell-to-cell via an Env biofilm at the ‘immunological/viral’ synapses and replicates using viral reverse transcriptase

HIV ART attenuates proviral expansion *in vivo - potential as PrEP*



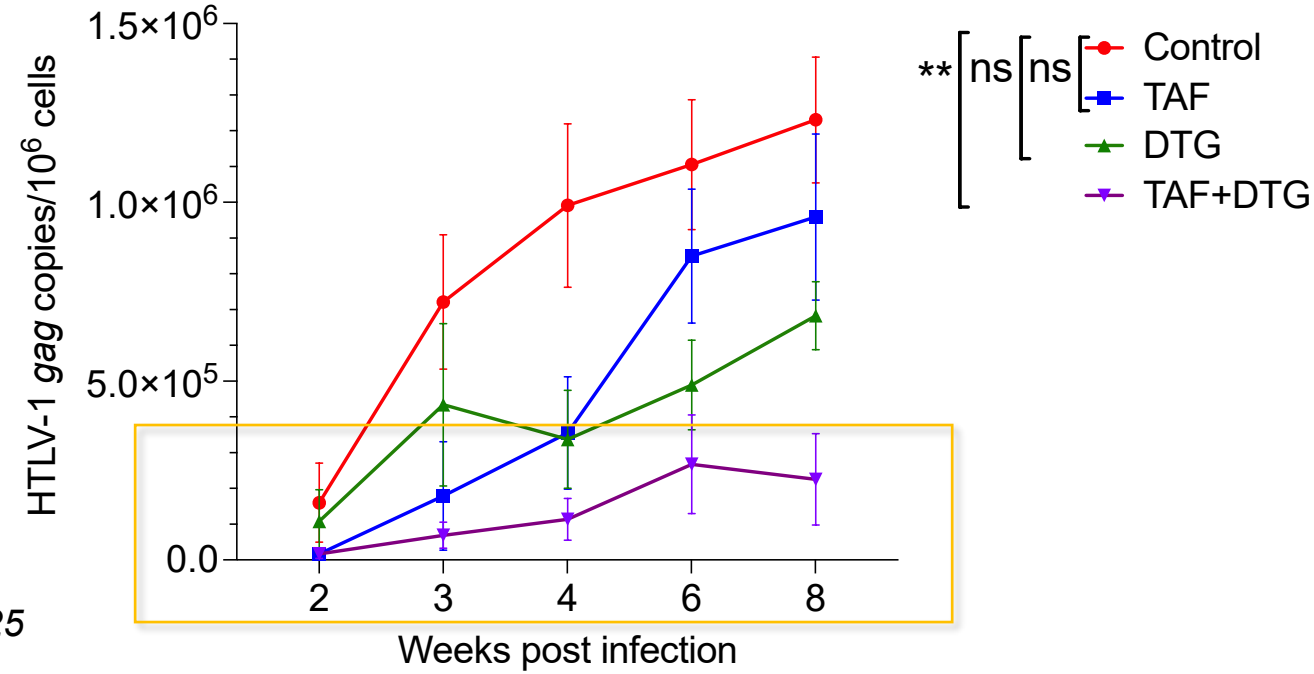
Infection with autologous HTLV-1c infected cells (not irradiated) to simulate 1% PVL and established infection. All animals on antiretroviral cover throughout the indicated time course to measure viral expansion

nucleotide reverse transcriptase inhibitor:

TAF: *tenofovir alafenamide*

integrase strand transfer inhibitor:

DTG: *dolutegravir*



40mg TAF mouse equivalent dose = 7.6mg/kg/mouse/day.
100mg DTG mouse equivalent dose =18.9mg/kg/mouse/day.

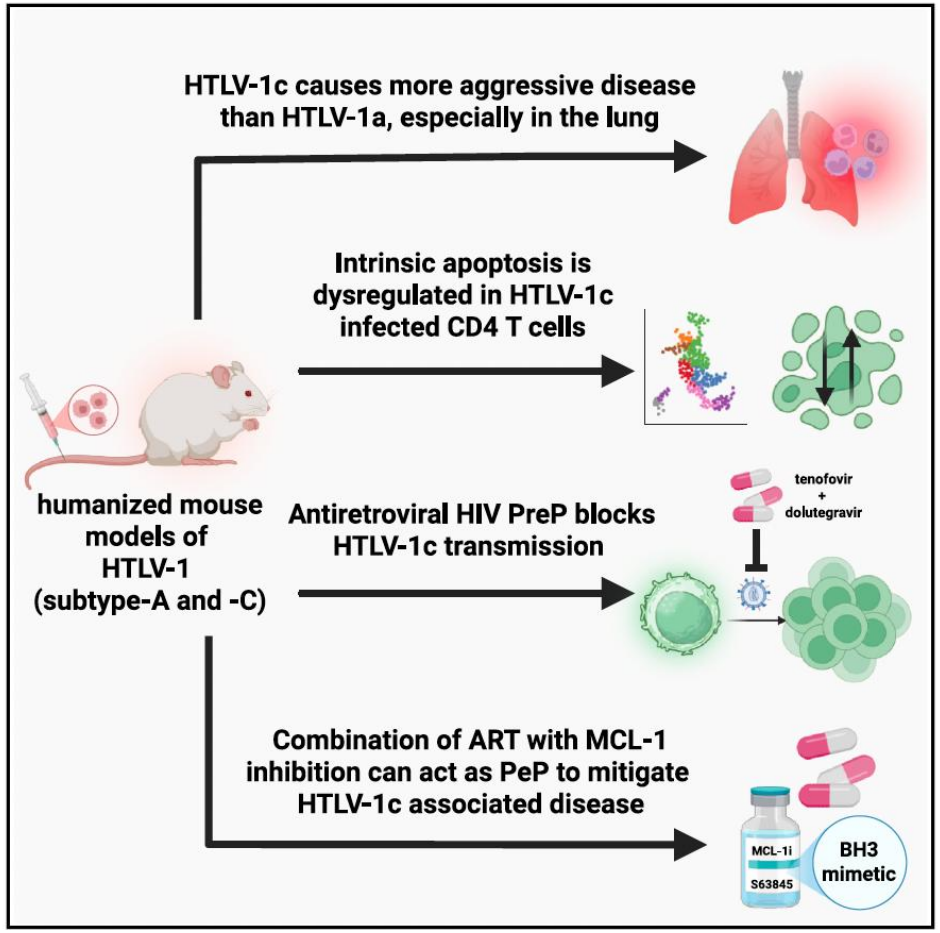
n=7-14 per group

Cooney et. al. *Cell 2025*

Cell

Combination antiretroviral therapy and MCL-1 inhibition mitigate HTLV-1 infection *in vivo*

Graphical abstract



Cooney et al., 2025, Cell *188*, 1–17
September 4, 2025
https://doi.org/10.1016/j.cell.2025.06.023

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In brief

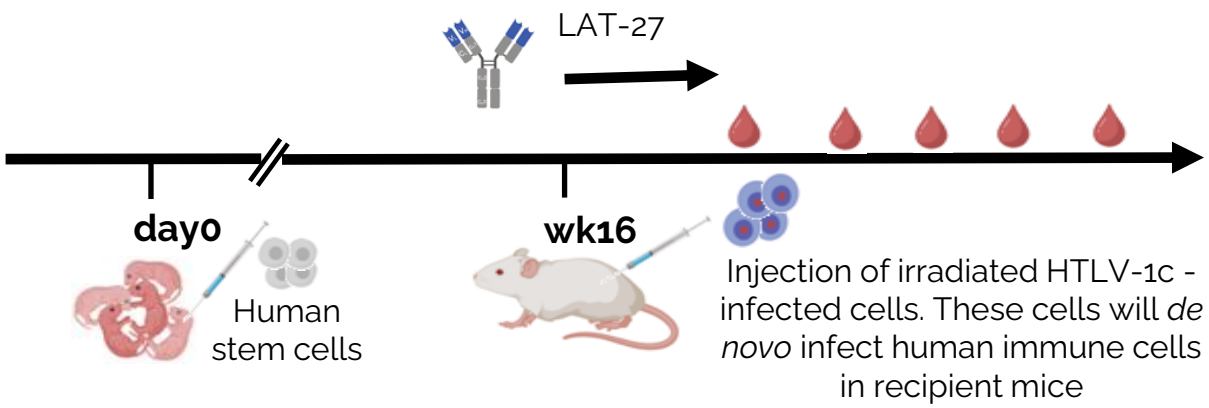
No preventative or therapeutic options are available for human T cell lymphotropic virus type-1 (HTLV-1). This study established humanized mouse models of HTLV-1 infection and found the disease in subtype-C to be slightly more aggressive than the globally more prevalent HTLV-1 subtype-A, potentially explaining higher rates of pulmonary complications associated with HTLV-1c. Clinically relevant antiretroviral therapy (tenofovir + dolutegravir) combined with MCL-1 inhibition significantly reduced HTLV-1c transmission and progression, suggesting a promising curative strategy.

Highlights

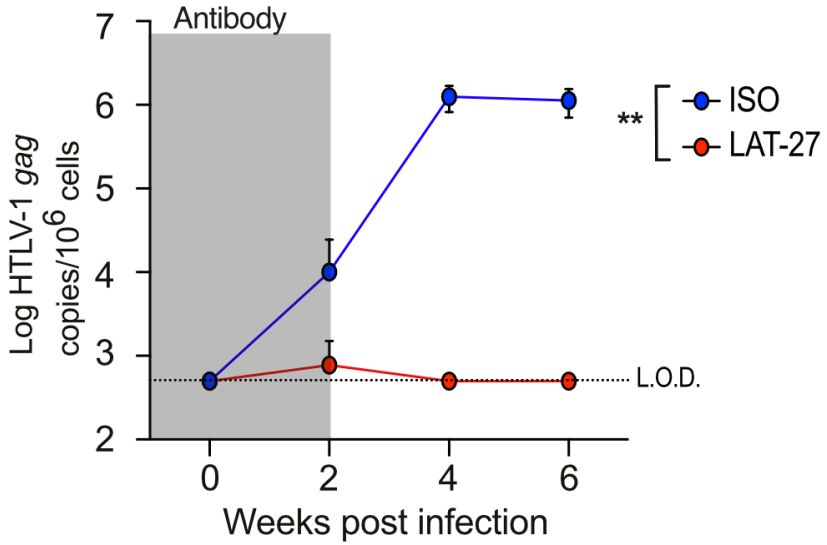
- Development of humanized mouse models of HTLV-1c and HTLV-1a
- HTLV-1c causes slightly more aggressive disease compared with HTLV-1a, notably in the lung
- Antiretrovirals used for HIV PeP and PrEP effectively block HTLV-1c transmission in our model
- MCL-1 inhibitor treatment kills infected cells and mitigates HTLV-1c disease in vivo

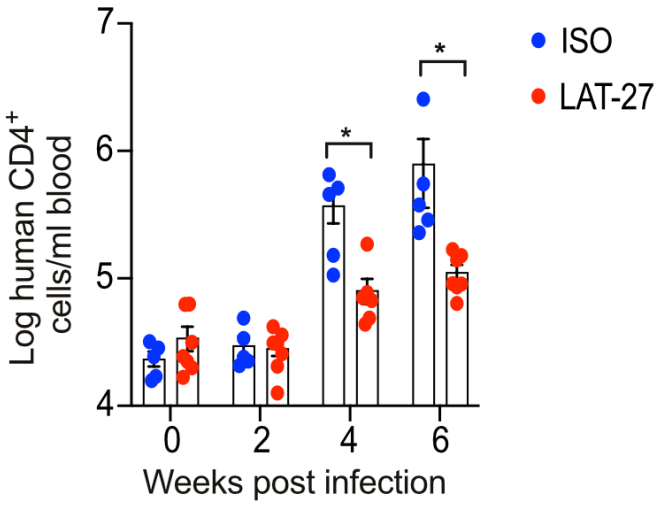
CellPress

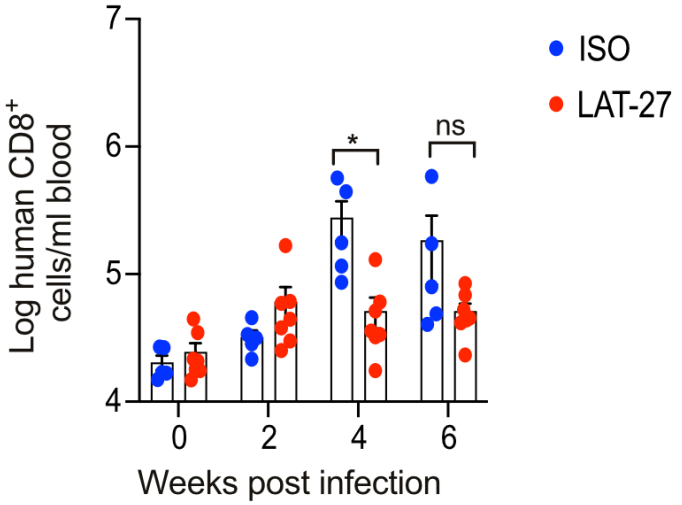
Passive mAb immunity protects from HTLV-1c infection and disease



bleed for detection of HTLV-1 provirus (ddPCR); immune phenotype (FACS)





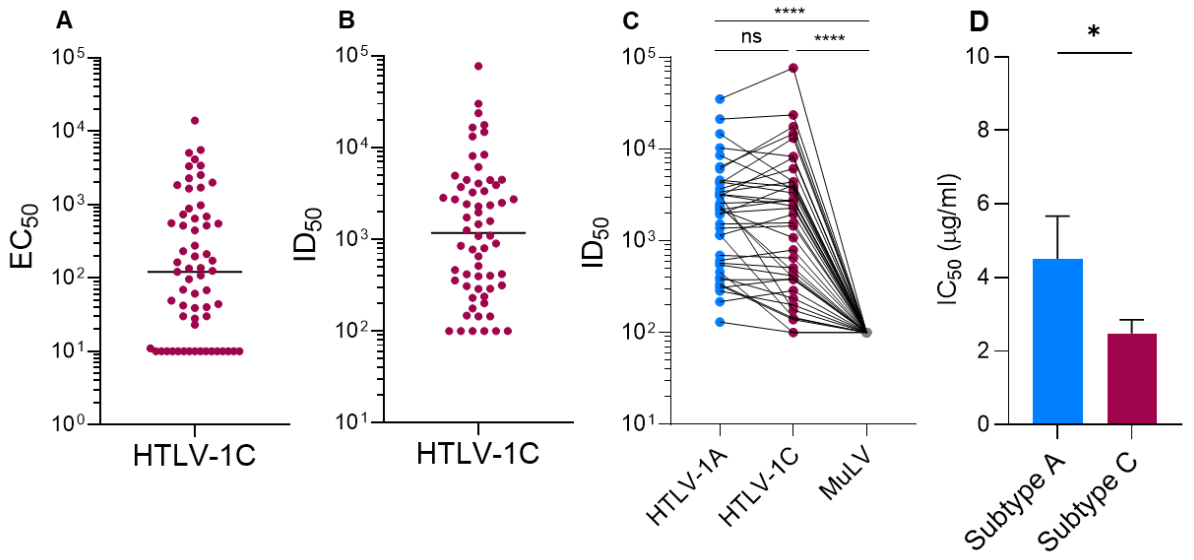


LAT-27: kind gift from Professor Yuetsu Tanaka, University of the Ryukyus, Okinawa, Japan

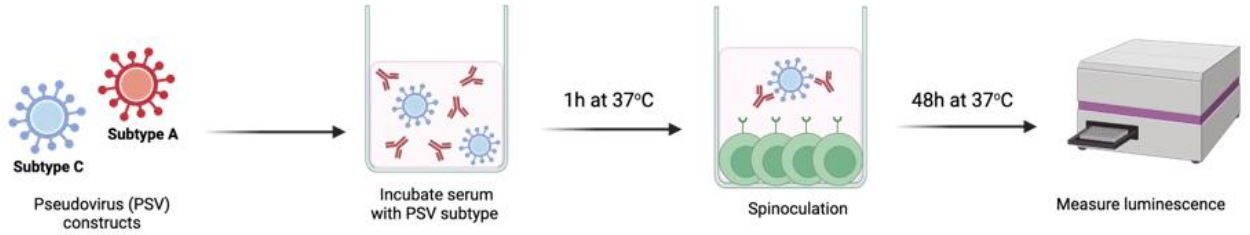
Cooney et. al. *Cell 2025 – Sup Fig. 3*

Prospects for an HTLV-1 vaccine compared with HIV

- Low structural protein diversity compared with HIV and lower level of glycan shield
- HTLV-1c+ infected people generate nAbs potent against both subtype HTLV-1c **and** HTLV-1a
- Maternal antibody assists in preventing MTCT
- Passive nAb delivery can prevent infection in a human immune system (HIS) mouse model
- Native HTLV-1a Env mRNA protective in rabbits.
  (Tu, et al. J. Virol, (2024))
- A Sendai-vectored vaccine induces Env protective NAbs in cynomolgus macaques
  Nakamura-Hoshi, Mol Therapy 2024
- Neutralizing antibody is a corelate of protection

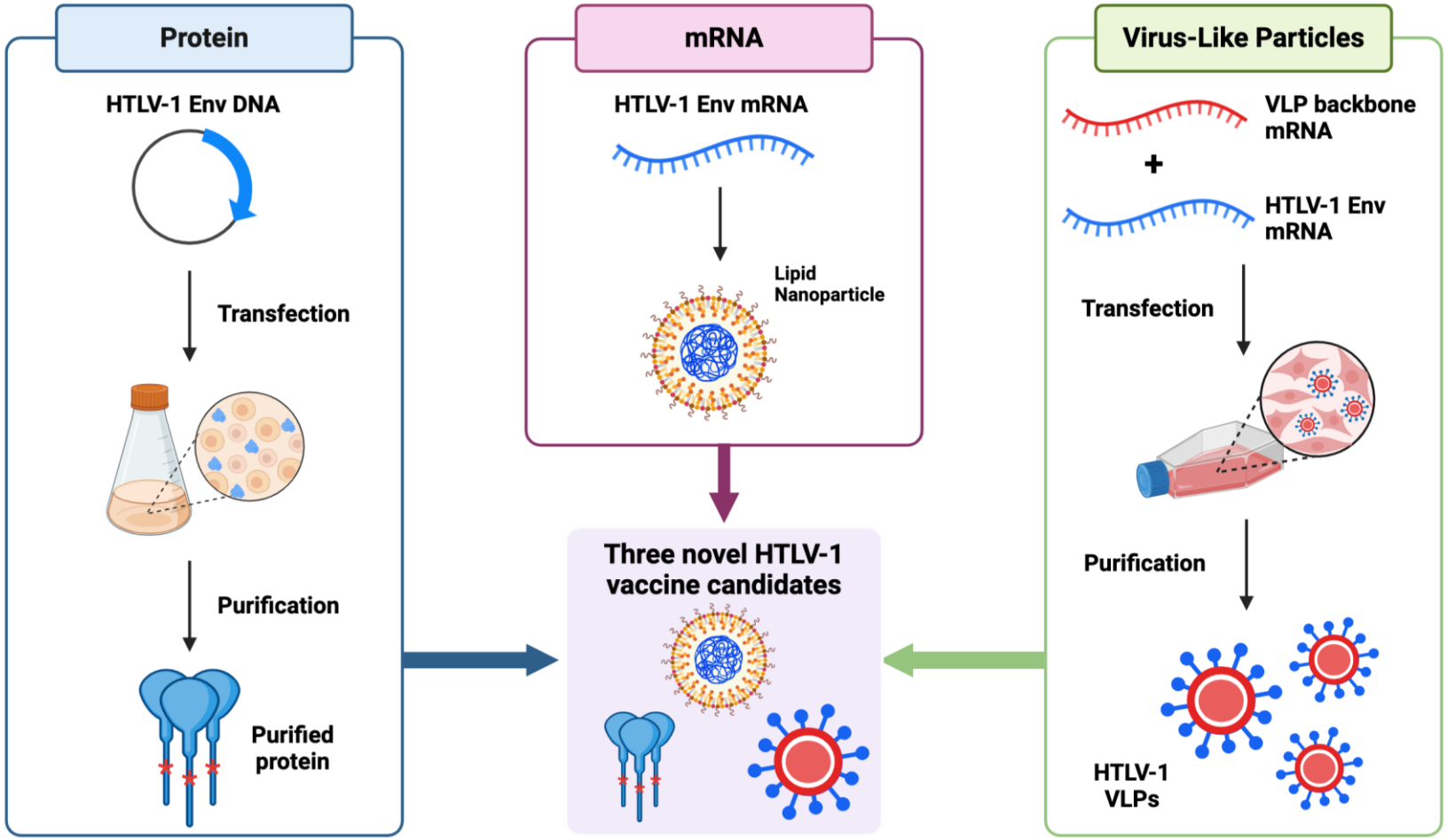


Grimley et. al. *Viruses 2026*



Pseudovirus neut. assay

HTLV-1c mRNA and protein vaccine strategies underway

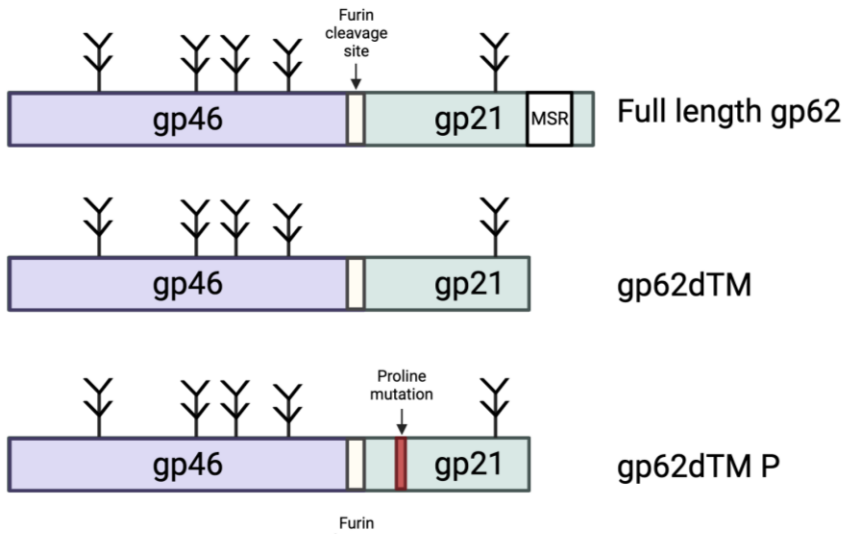


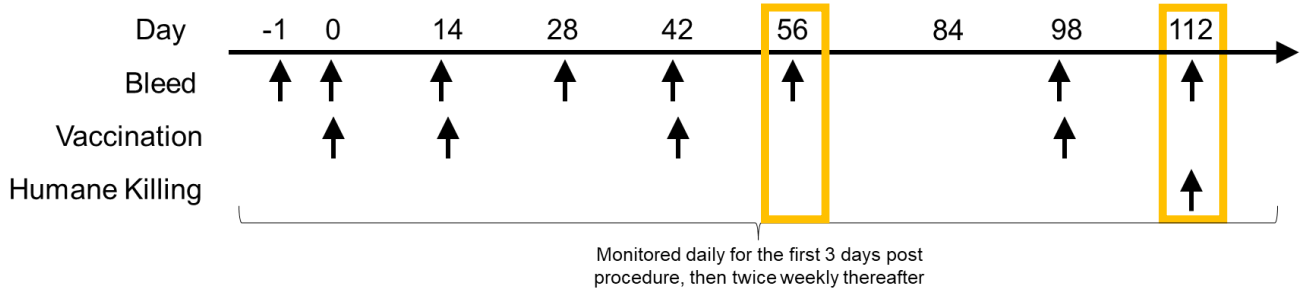
- Proline mutations to increase expression of soluble trimeric Env pre-fusion structured proteins
- Mutate amino acids that make the gp46 biofilm to decrease cell toxicity and increase protein expression
- Combine Proline and biofilm mutations to improve expression and stability of pre-fusion structured Env

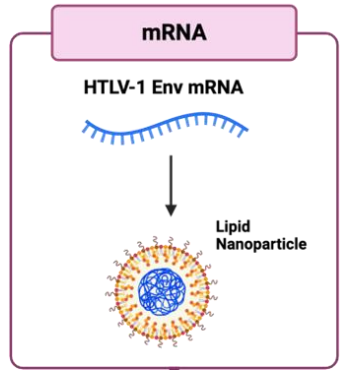
University of Queensland
Clamp2.0 Env trimers
Keith Chappell
Daniel Watterson
Paul Young

ASPIRE HTLV-1 RESEARCH AUSTRALIA-JAPAN

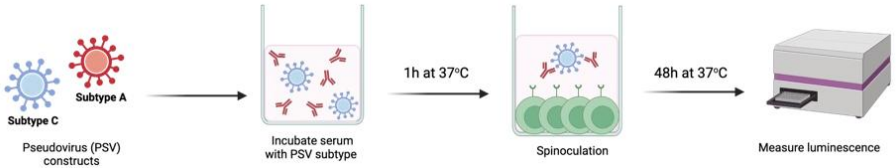
Env neutralizing Abs block both HTLV-1 subtypes



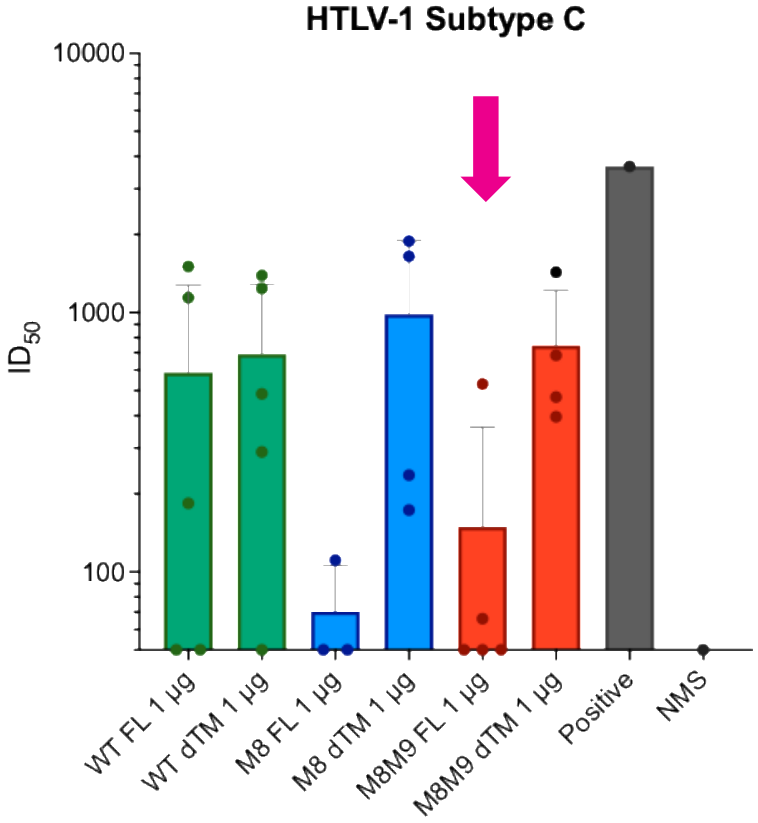


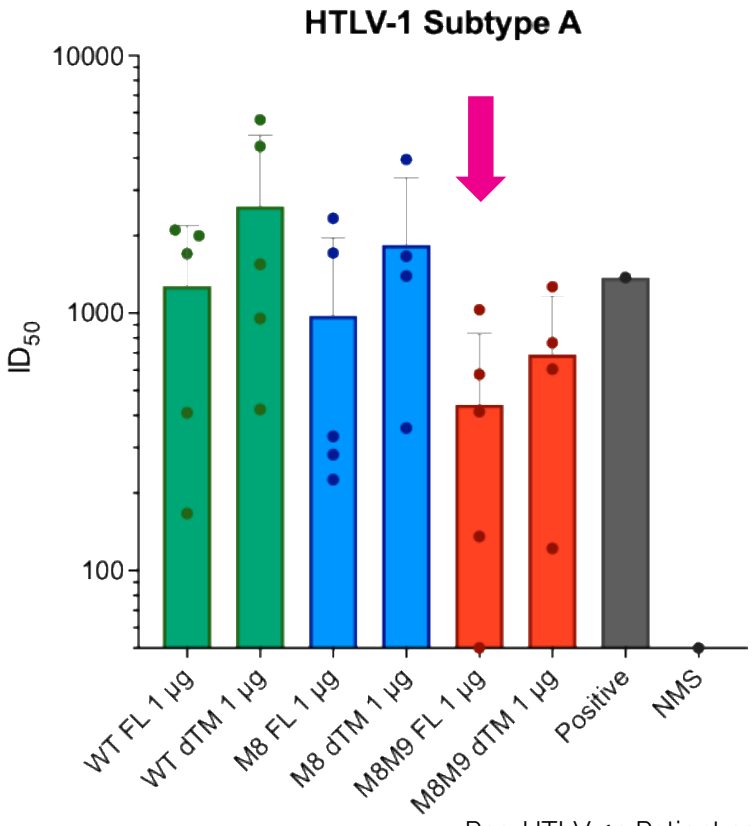


112 mutations tested for membrane anchored or soluble pre-fusion structure and reduced protein biofilm toxicity



Pseudovirus neutralising Ab assay

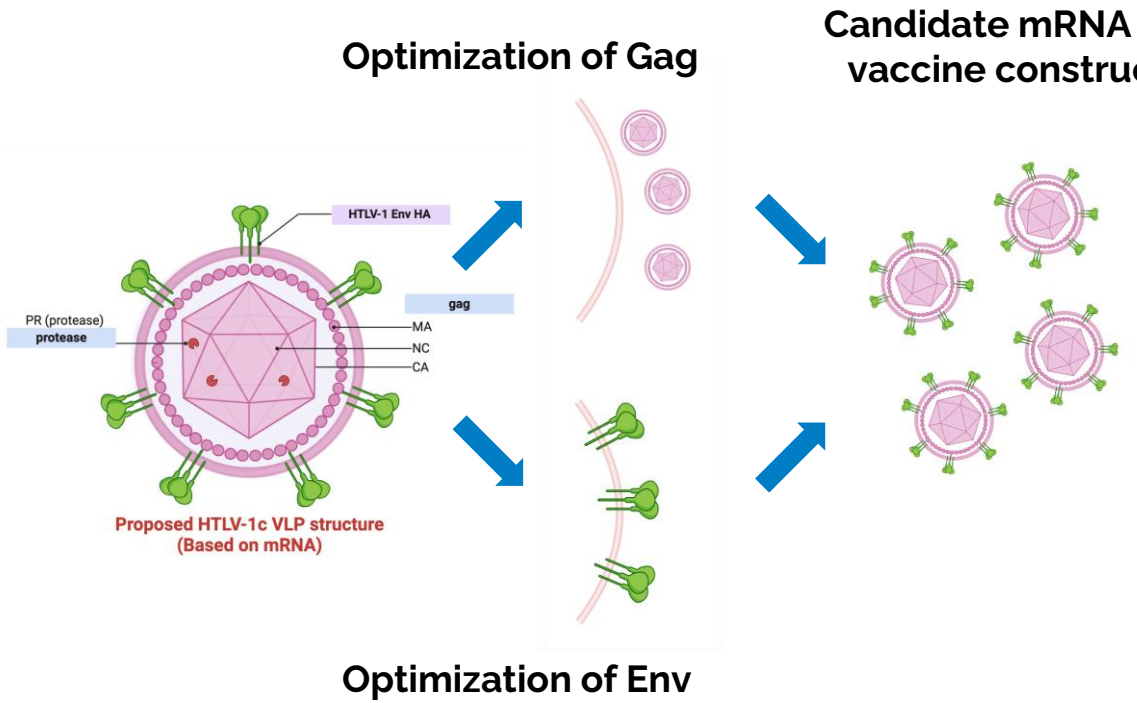


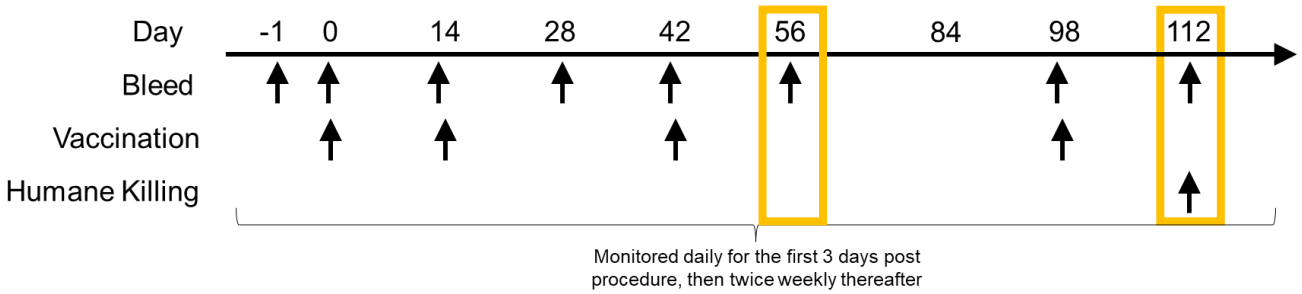


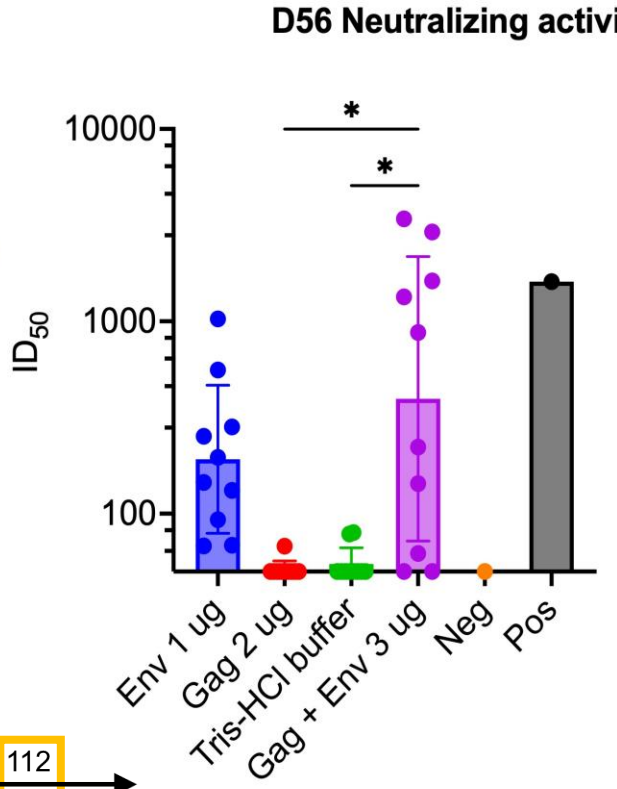
4˚ (day 112)

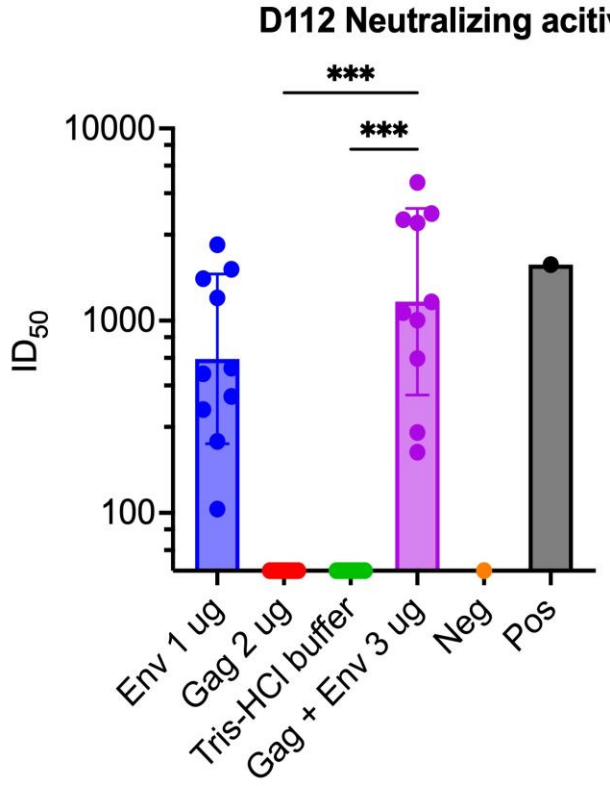
Pos: HTLV-1c Patient sera
Neg: Negative mice serum

Neutralising antibody from mRNA-LNP vaccines coding HTLV soluble-Env trimer or Gag-Env VLPs





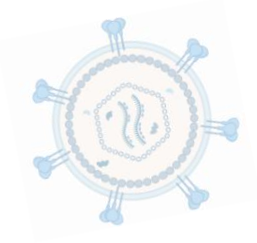




Pos: HTLV-1c Patient sera

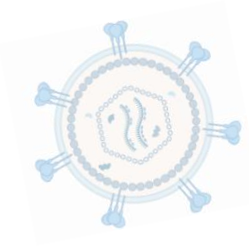
Neg: Negative mice serum

Progress with HTLV preventives and next steps



- Combinations of integrase and RT inhibitors to block transmission
- **Neutralizing antibody is the corelate of protection** ……
  → **prevents** HTLV-1 infection / or high proviral load causing disease
- HTLV-1 *env* mRNA-LNPs induce neutralizing antibody responses **in BL/6 mice**
  → **passive protection in HIS mice?**
- gp62dTM-LNPs expressing **soluble stabilized Env** induced high neutralizing titers
- HTLV Gag - stabilized Env VLPs induced high neutralizing titers at earlier time points
- *mRNA*-LNPs expressing stabilized HTLV-C *env* provide **breadth of protection for both subtypes C and A**
- **Efficacy tests in non-human primates needed** → underway in ASPIRE program labs
- **GMP clinical grade manufacture** needed for pre-clinical safety tests in humans

Progress with HTLV preventives and next steps



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cytiva

GVN
GLOBAL VIRUS NETWORK
Pandemic Preparedness For A Vulnerable World

mRNAVAC

Clinical grade mRNA manufacture in Melbourne

VICTORIA State Government Australia

moderna

BIONTECH

mRNAVIC

BioNTech is partnering with mRNA Victoria to enable and foster innovative mRNA research and development in the Australian ecosystem.

With Thanks

All the volunteers that have contributed samples for these studies

The Peter Doherty Institute

Samantha Grimley

Ashley Hirons

Natasha Jansz

Sarah Collins

Yuanhao Chen

Ashley Yap

Georgia Deliyannis

Chinn Yi Wong

Sarah Monard

Yadana Zaw

David Yurick

Paula Ellenberg

Georges Khoury

Alice Springs Hospital

Radwan Talukder

National Reference Lab

Kim Wilson

Nick Vandegraaff

Pip Hetzel

ASPIRE partners

Genoveffa Franchini

Tetsuro Matano

WEHI

James Cooney

Marcel Doerflinger

Mark Pellegrini

Uni Queensland

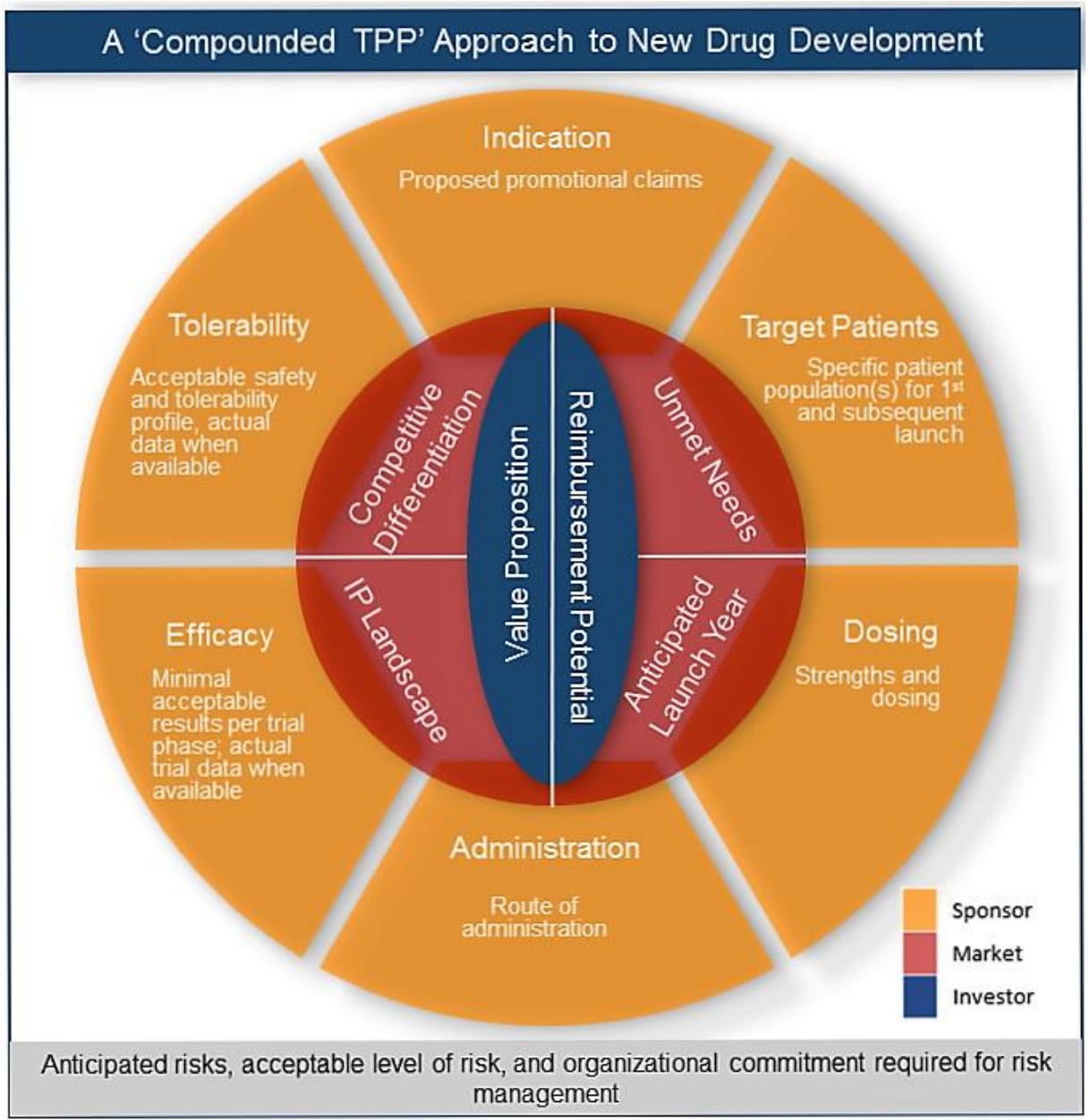
Keith Chappell

Daniel Watterson

Paul Young

Should IRVA lead development of a TPP?

- **What is a TPP (Target Product Profile)?**
- **A TPP is a strategic, evolving document that outlines the desired characteristics of a new drug, device or vaccine, serving as a roadmap for research & development from inception to regulatory approval, manufacturing, commercial introduction and on through lifecycle management (new indications, dosage forms, combinations etc).**
- **The TPP is a process used ubiquitously in industry and is gaining traction in non-commercial setting such as the WHO, and research institutes to help guide work, increasing the focus on delivering interventions for ultimate beneficiaries - patients and their clinicians.**



Target Product Profile (TPP): Starting point to tackle complexity

A Target Product Profile (TPP) is a **planning tool** to streamline the drug development process. Essentially, it emphasizes starting the drug development process with **a clear end goal.**

It includes both minimal and preferred product attributes and gives innovators a **defined framework to evaluate their drug candidate** as they move through the development process

Not a one-size-fits-all clinical template - should be **tailored to specific product, patient, and market needs** and encompass commercial considerations

It's designed to be **consulted and updated throughout a drug's developmental journey.**

FDA TPP

A voluntary, sponsor-created summary of a drug development program described in terms of labeling concepts that aligns studies with desired outcomes and facilitates focused **discussions with the FDA throughout the process**

WHO TPP

Support development of missing health products with a focus on public health priorities, access, equity, and affordability, aligned with WHO's identified needs. **Target Product Profile Directory is a free-to-use online database**.

https://seed.nih.gov/sites/default/files/2023-12/Creating-Target-Profile-for-New-Drug-Products.pdf
https://www.who.int/tools/target-product-profile-database

Primary objectives for an HTLV-1 preventive vaccine

- **Prevent development of HTLV-1 high proviral load**
- Induce protective **neutralising antibodies** and functional antibodies
- Avoid development of **chronic T-cell activation**
- Stimulate strong and durable memory B- & T-cell responses (CD4 and CD8)

Secondary objectives

- Immune targeting of tax/hbz/orf1 to prevent cell proliferation
- Ideally, one vaccine **effective against all strains** of HTLV-1
- Realistic pathway for clinical development and community acceptance

The Basic TPP Framework: Defining success to support decision making

Parameter	Essential Profile (minimal parameters for a safe, efficacious and differentiated drug)	Ideal Profile (desirable parameters that would allow higher value, access to a larger market, reduced cost of goods etc.)
Indications	*Primary Indication being Targeted*	*Broader range of indications (if applicable)*
Patient Population	*e.g. Patients aged XX years of age; Clinical diagnoses of YY condition/disorder via ZZ criteria; Inclusion criteria based on specific sub-populations for targeting*	
Therapeutic modality	*Antibody*	
Efficacy	*e.g., ≥ 40% responder rate (measured as patients with an example measure score of ≤ Y) at ZZ weeks/months following initiation of treatment*	*e.g., ≥ 70% responder rate (measured as patients with an example measure score of ≤ Y) at ZZ weeks/months following initiation of treatment*
Safety	*e.g. ≤ 20% incidence of Y adverse effect.*	*e.g. ≤ 5% incidence of Y adverse effect.*
Dosing/Administration	*e.g., Solution in pre-filled syringe, subcutaneous injection, Daily*	*e.g., Solution in pre-filled syringe, subcutaneous injection, Monthly*
Approach	*e.g. Treatment – disease modifying*	
Mechanism of Action	*e.g. Antagonist – inhibition of XX receptor resulting in reduction in YY signaling*	
Biological Activity	*e.g. Reduction in severity of XX symptoms*	

"Focusing only on proof of concept without TPP is like building a bridge to nowhere. You may prove biology, but you may not prove a product,".

A TPP "defines the value proposition and frames a clinical and commercial vision"

- March 2025, Will Maier, Senior Vice-President, ICON Drug Development Services

https://www.iconplc.com/insights/blog/2025/06/30/biotech-success-start-end-mind-and-develop-tpp-early

https://seed.nih.gov/sites/default/files/2023-12/Creating-Target-Profile-for-New-Drug-Products.pdf

Should IRVA lead a Target Product Profile (TPP)?

- TPPs **used to frame goals of the development program** to assess potential commercial prospects, guide development – focus on proposed use of the product
- **A summary of desired (optimal) and minimum properties** of the new medicine
- **Defines** target population, differentiation from currer treatment options/ unmet need, administration and dosage
- Can **build case** for investors, provisional or priority review by FDA/EMA/TGA and for later reimbursement
- Can help **shape clinical trial design** and conduct discussions with regulators and safety endpoints
- **TPPs needed for HTLV-1 preventives and therapeutics** usually more flexible that for other acute vital or bacterial infections – e.g. multiple doses/ day, higher doses, adverse events