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

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

Symposium 4 - Epidemiology/Diagnosis

Chairs: Glen Barber and Bobby Brooke Herrera

Comparison of clinical features and outcomes of adult T-cell leukemia/lymphoma across geographical regions

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Conflicts of interest

I have no conflicts of interest

Background

- Adult T-cell leukemia/lymphoma (ATL) is caused by HTLV-1, and it is more prevalent in Latin America compared to the US and Europe
- Most epidemiology and clinical data derive from studies in Japan, and outcomes from patients managed in other regions are scarce
- Differences in clinical features, first-line (1L) approaches, and outcomes across world regions are unknown
- **Aims**: Describe difference in the prevalence of ATL subtypes and overall survival across regions

Methods

- Design: international multicenter retrospective cohort study

- Population: Aged ≥18 years with a pathology diagnosis of ATL

- Data source:
  - ELLA (Epidemiology of Lymphoma in Latin America, 2000-2023 period)
  - BTCP (Brazilian T-cell project, 2015-2022 period)
  - United Kingdom (2003-2023 period)
  - US (2000-2023 period)
  - Japan registry (2000-2009 period)

Methods

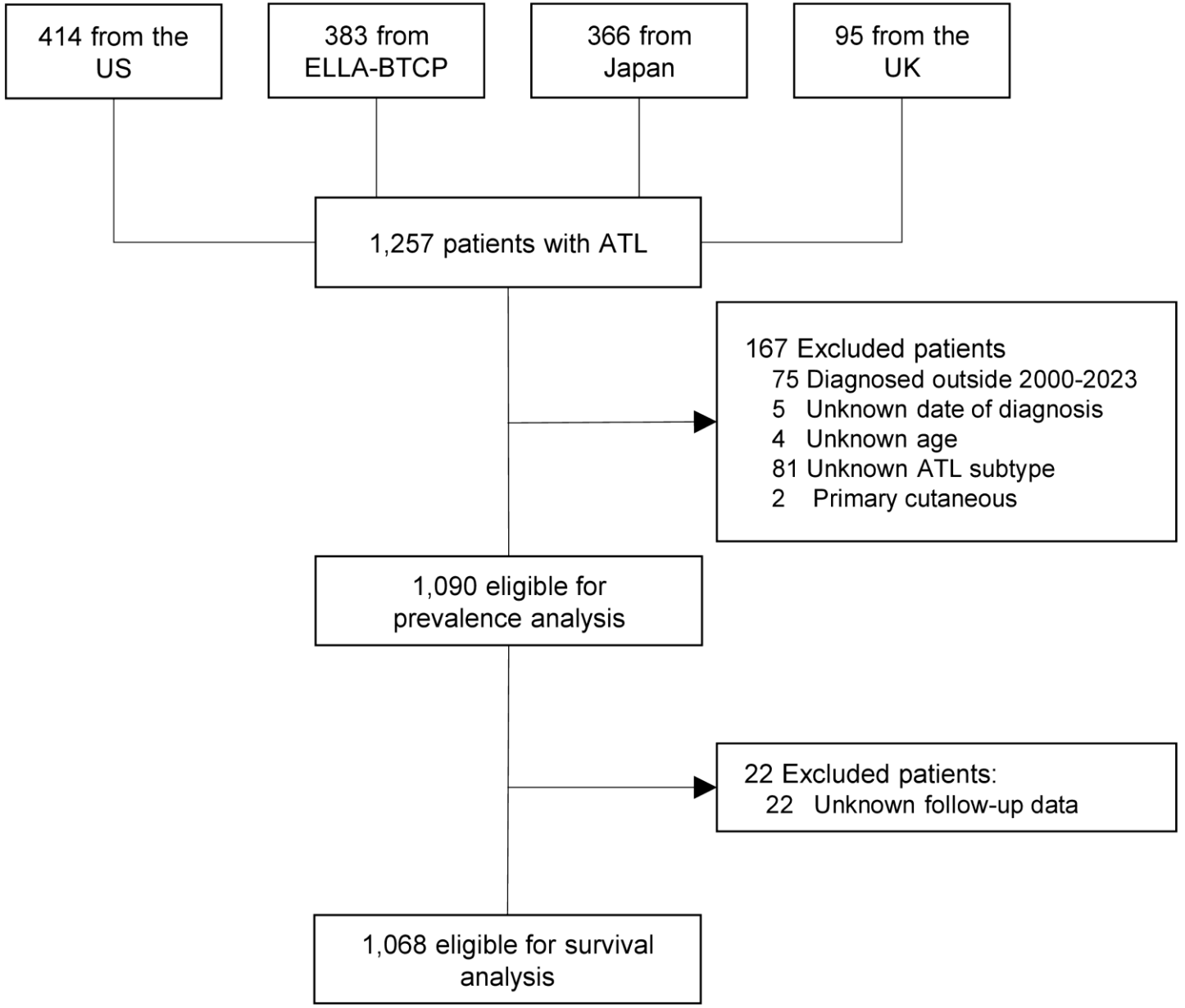
- Exposure was based on the place where patients received 1L treatment (Latin America, the US, the UK, and Japan)

- Study outcomes:
  - Prevalence of ATL subtypes: acute, lymphomatous, chronic, and smoldering ATL
  - Overall survival (OS): diagnosis to mortality or last follow-up

- Stats: Descriptive statistics, Poisson regressions, and Kaplan-Meier

Results

Study flowchart

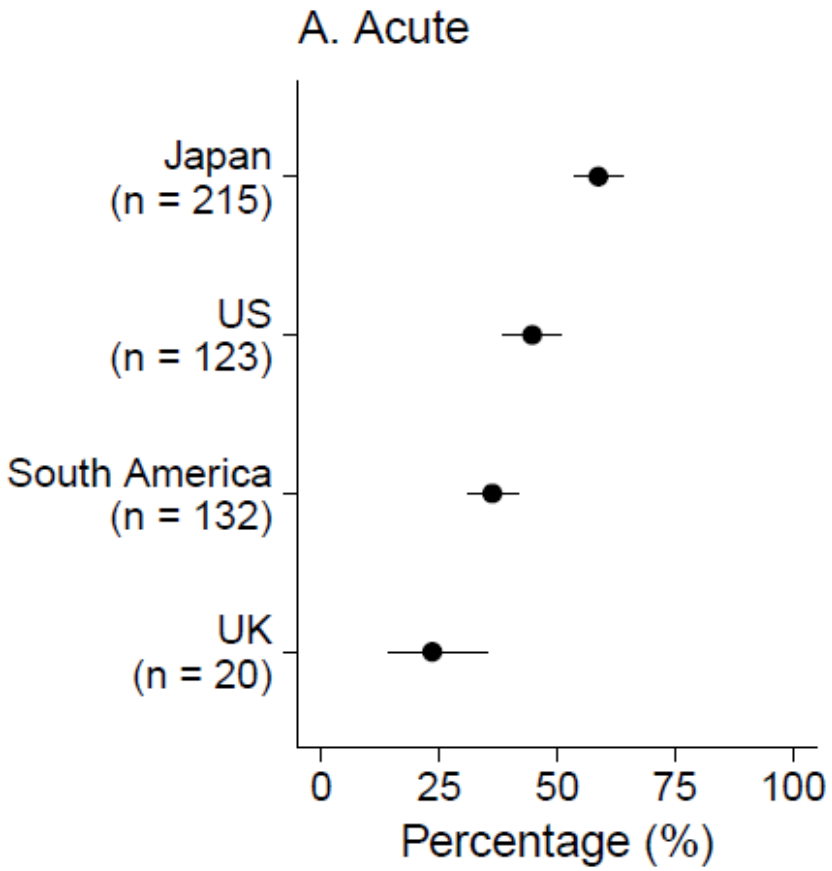


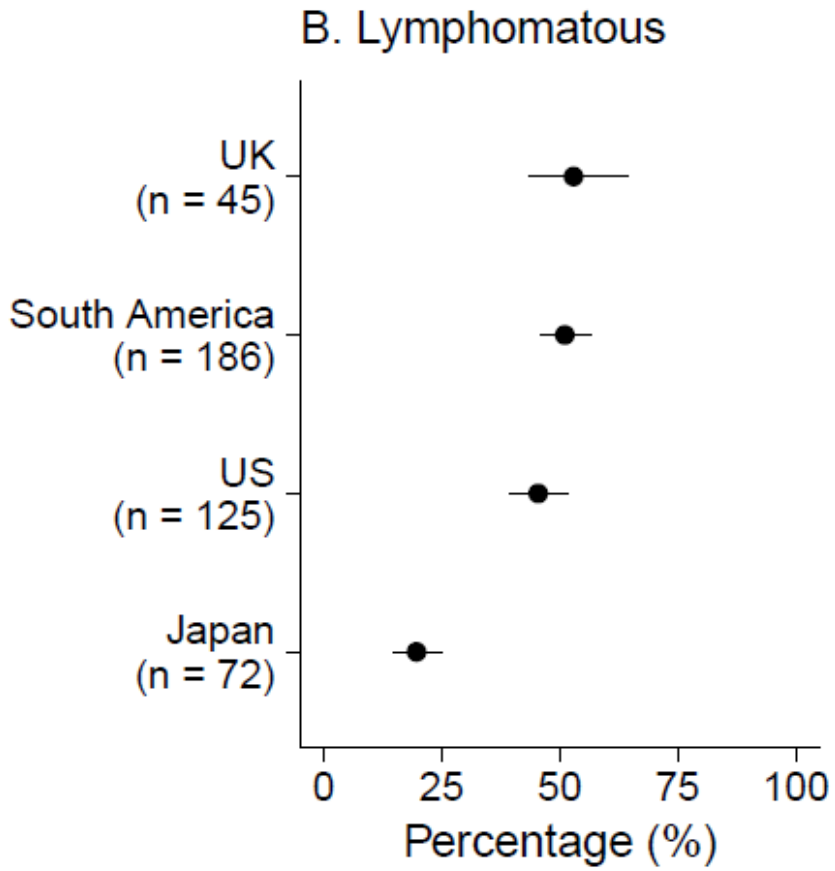
Results – Baseline features

Characteristics	Japan, N (%)	South America, N (%)	US, N (%)	UK, N (%)	P
No. of patients	366	364	275	85	
Median age (range)	66 (19-89)	54 (18-95)	57 (20-87)	52 (31-83)	< 0.001
Females	175 (48)	199 (55)	167 (61)	-	0.0048[a]
ECOG 2-4	134 (37)	134 (38)	107 (59)	22 (27)	< 0.001
Advanced-stage (III-IV)	344 (94)	312 (88)	228 (94)	57 (90)	0.007
High LDH	280 (77)	249 (82)	151 (85)	-	0.047[a]

- Younger age at diagnosis and female predominance in regions outside Japan.
- Across geographic regions, most patients had advanced-stage disease and high LDH

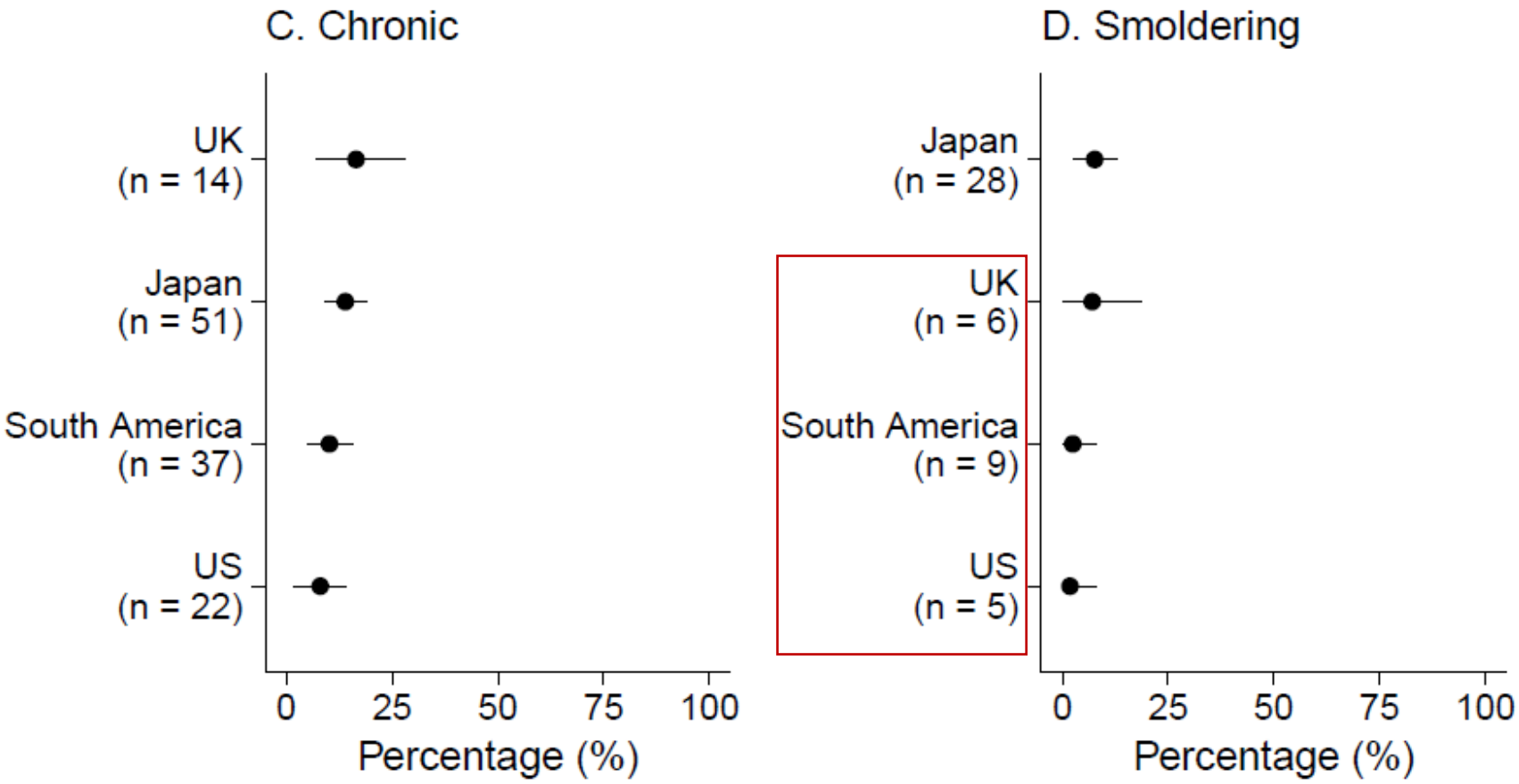
Results – Prevalence





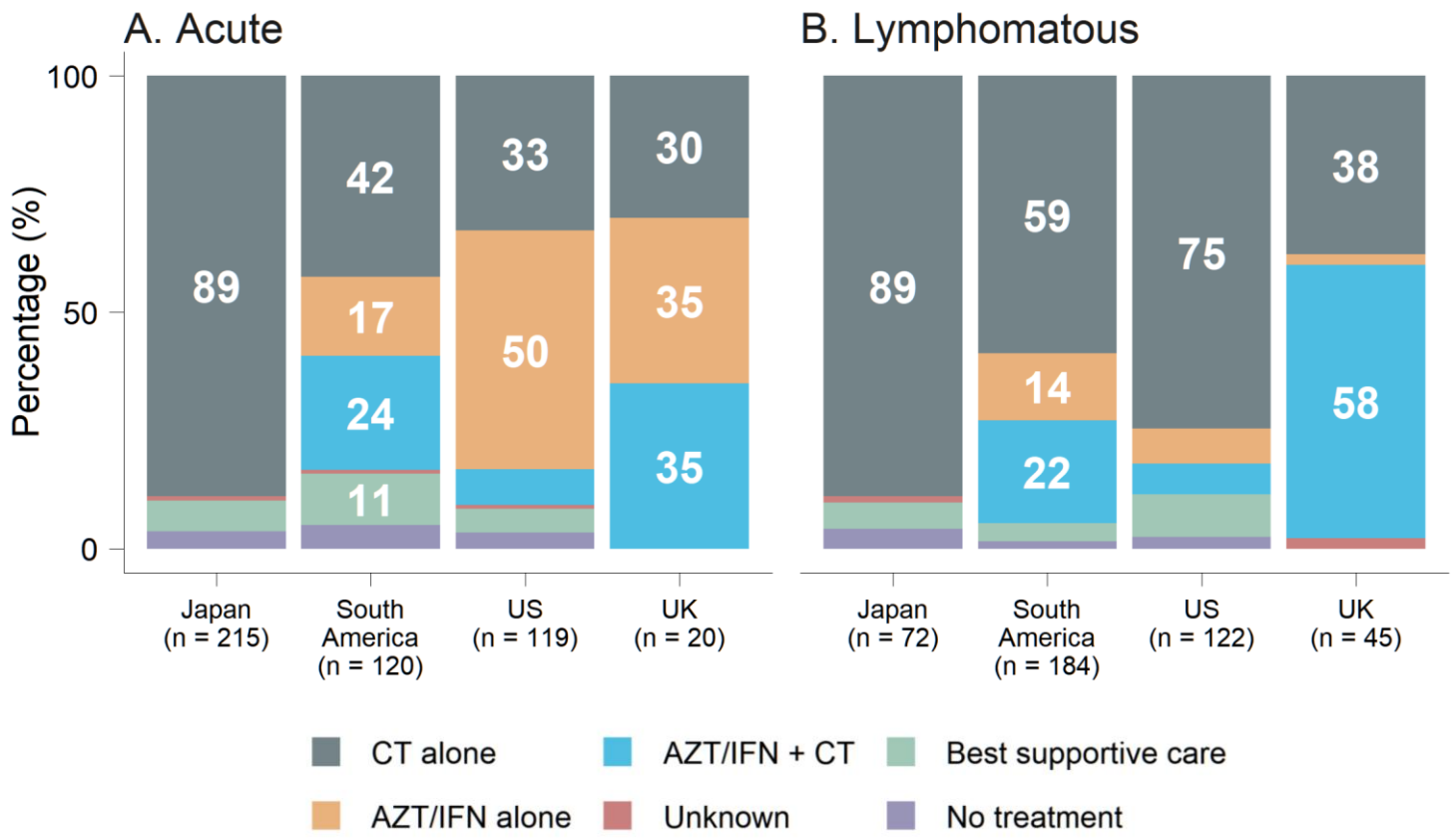
- Acute (P<0.0001)
  - Japan: 59%
  - US: 45%
  - South America: 36%
  - UK: 24%
- Lymphomatous (P<0.0001)
  - Japan: 20%
  - US: 45%
  - South America: 51%
  - UK: 53%

Results – Prevalence



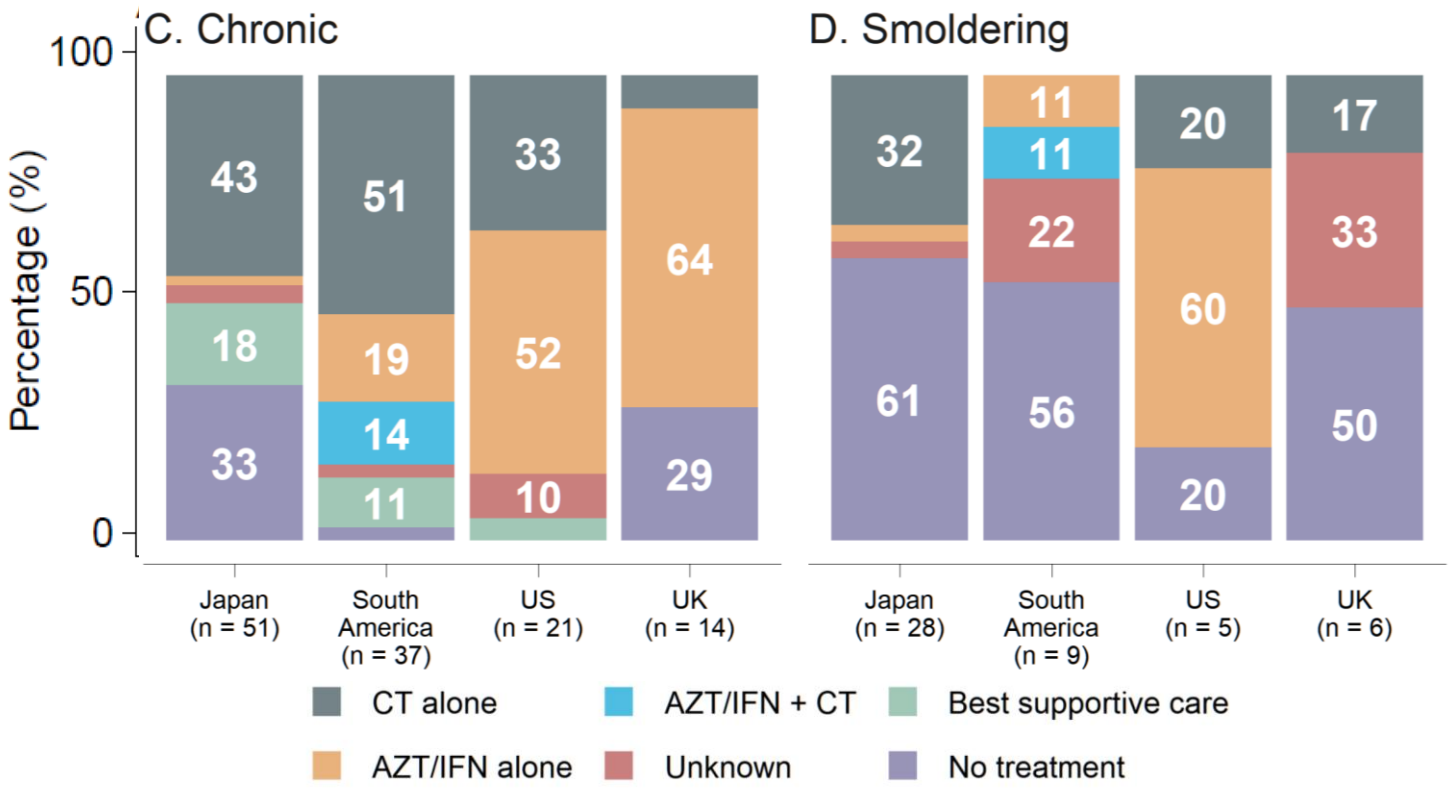
- Chronic (P=0.065)
  - Japan: 14%
  - UK: 16%
  - US: 8%
  - South America: 10%
- Smoldering (P=0.001)
  - Japan: 8%
  - UK: 7%
  - US: 2%
  - South America: 2%

Results – Treatment approaches



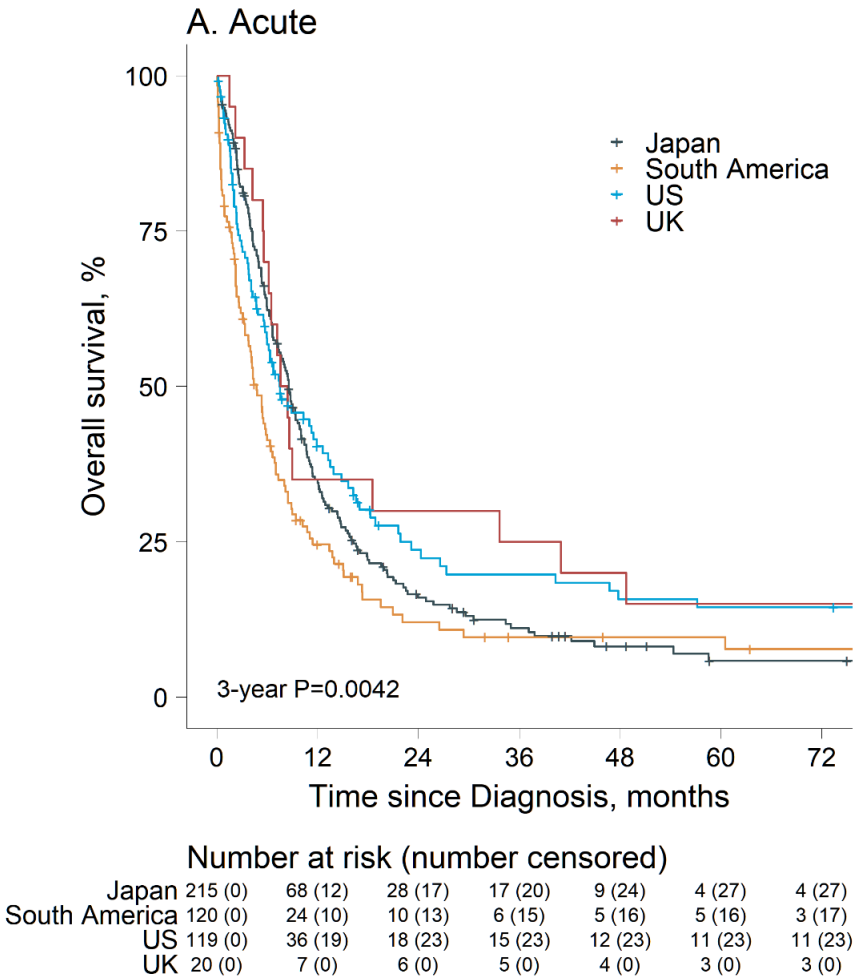
Use of AZT/IFN alone or in combination with chemotherapy is more common outside Japan

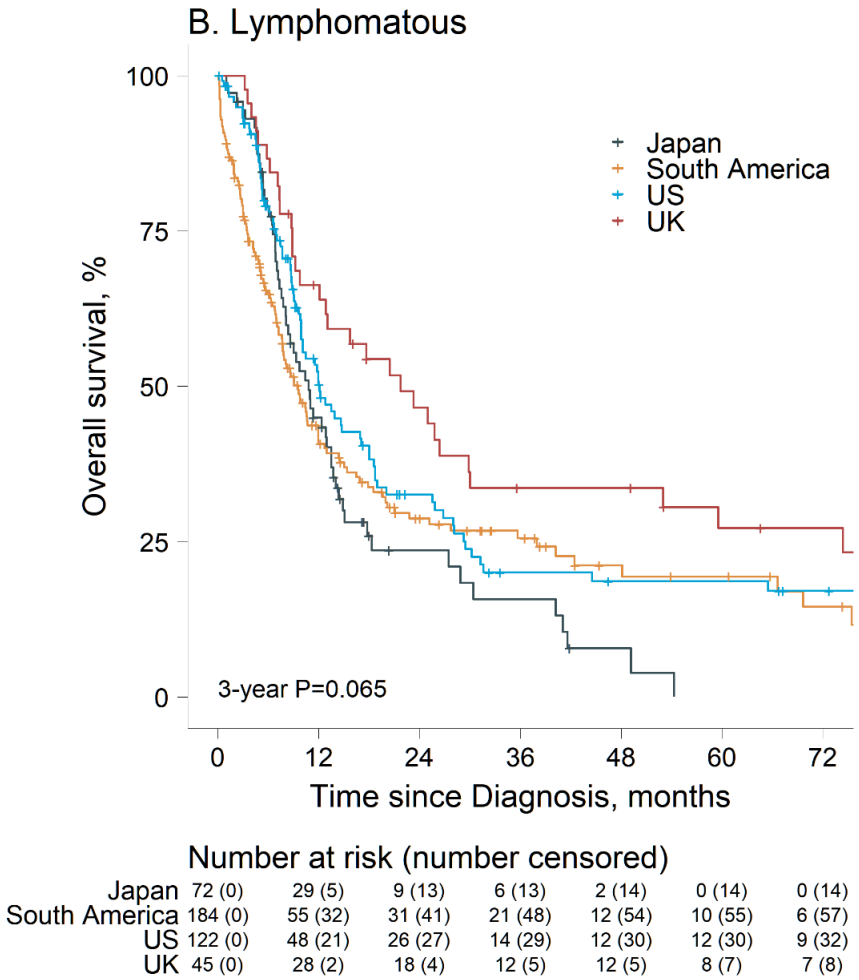
Results – Treatment approaches



Distribution vary but sample sizes are low

Results – Overall survival

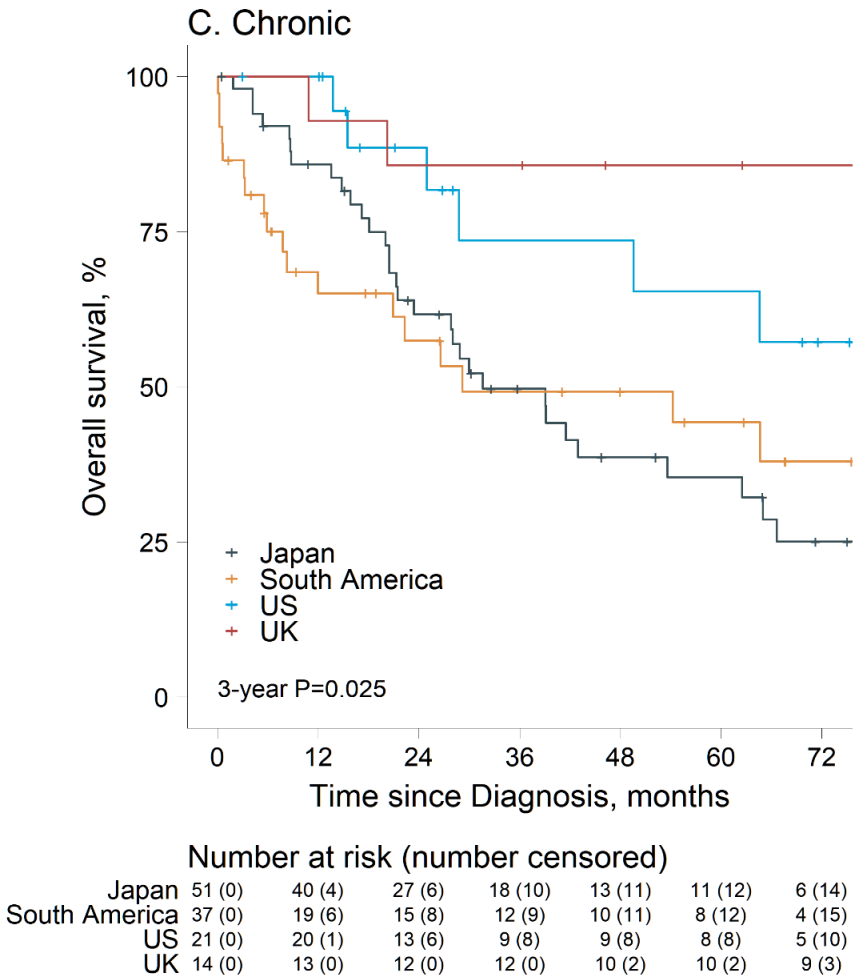


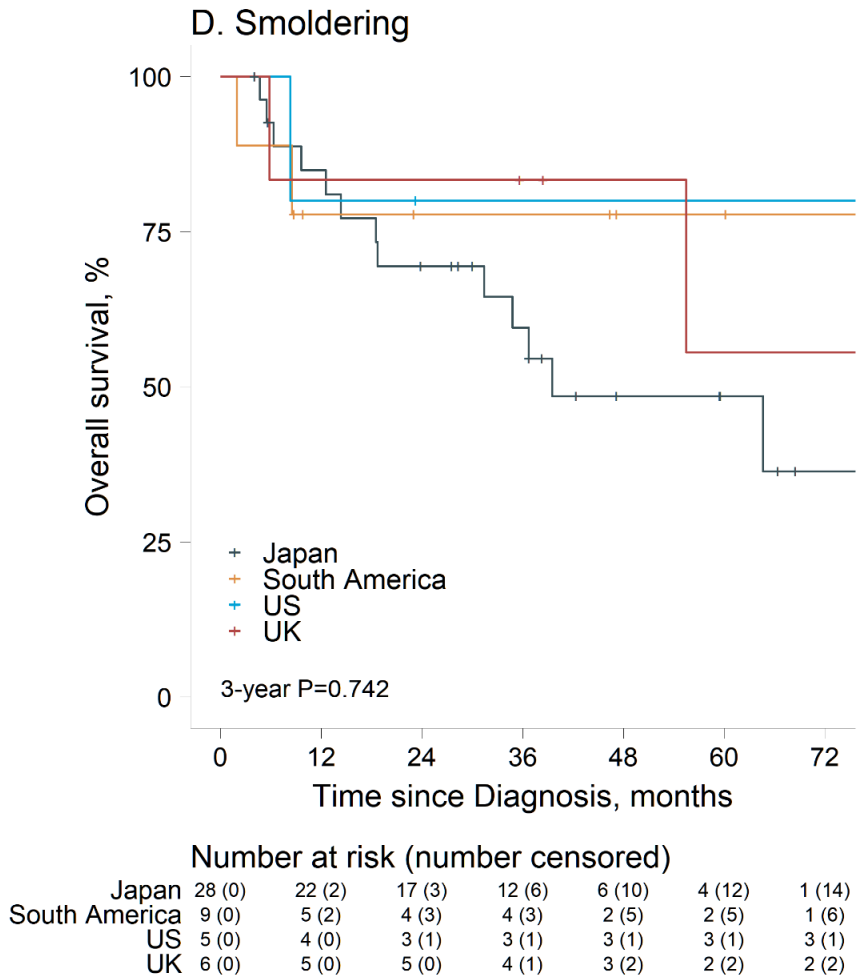


	Acute ATL 3y OS	Lymphomatous ATL 3y OS
South America	10%	26%
US	21%	20%
Japan	11%	16%
UK	25%	34%

Median follow-up was 35 months in South America

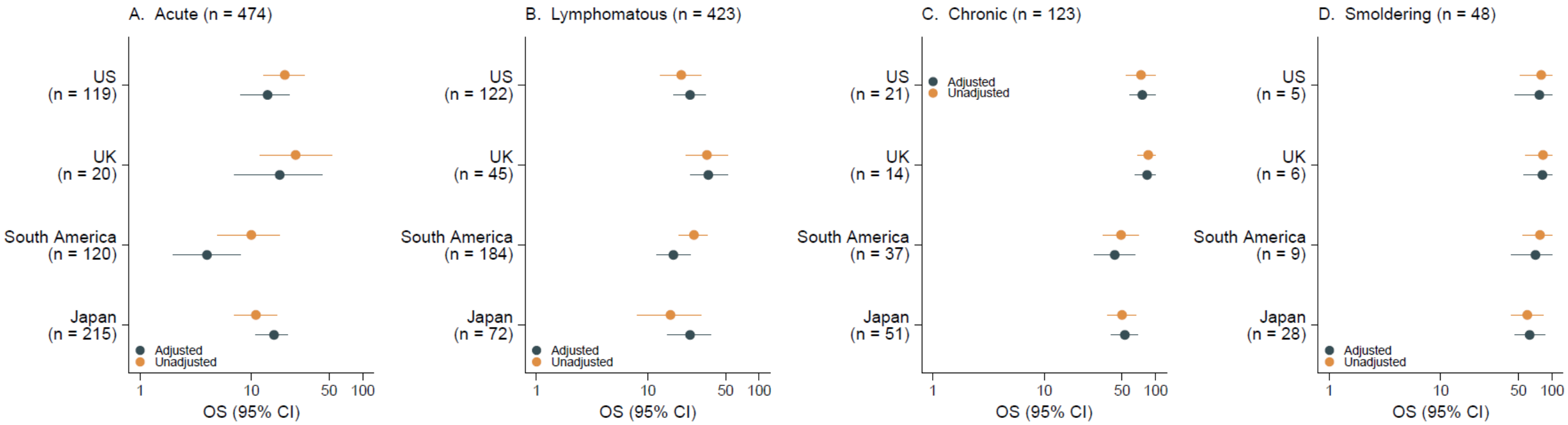
Results – Overall survival





	Chronic ATL 3y OS	Smoldering ATL 3y OS
South America	49%	78%
US	74%	80%
Japan	50%	60%
UK	86%	83%

Results – Age-adjusted OS



Conclusions

- The distribution of ATL subtypes varies globally. Lymphomatous ATL is likely more prevalent outside Japan
- Patients outside Japan are typically younger and with a slight female predominance
- 1L treatment approaches vary across geographical regions
- OS for aggressive subtypes remains poor across all regions
- Our findings could guide the design of clinical studies to develop accessible therapies through international collaboration

DOI: 10.1111/bjh.70494

PMID: 41986288

BJHaem
BRITISH JOURNAL OF HAEMATOLOGY

ORIGINAL PAPER

Haematological Malignancy – Clinical

Distribution of adult T-cell leukaemia/lymphoma subtypes and survival outcomes across geographical regions: An international retrospective cohort study

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Summary

Although adult T-cell leukaemia/lymphoma (ATL) has a higher burden in certain world regions, outcomes have not been directly compared across regions. We conducted a

Acknowledgments

- **All patients**
- GELL consortium
- Brazilian TCP consortium
- US collaborators
- Japan collaborators
- UK collaborators

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HTLV-1 infection across the life course in Colombia

Clinical burden in children, adults, and pregnant women from an endemic region

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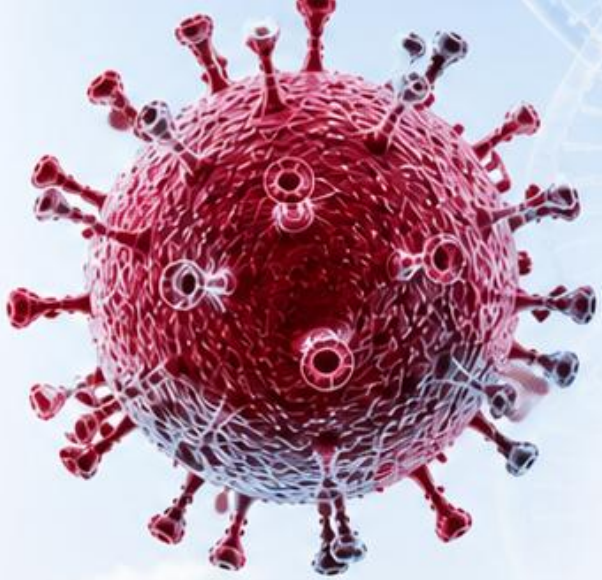
CONFLICTS OF INTEREST



I HAVE NO
CONFLICTS OF INTEREST

Colombia: an endemic but neglected setting

Available Colombian data are limited; Pacific departments such as Valle del Cauca, Chocó, Cauca, and Nariño are highly relevant for HTLV-1 transmission and disease burden.

HTLV-1 is endemic in Colombia but remains under-recognized and under-surveyed.

SEROPREVALENCE IN BLOOD DONORS

Study (Years)	Region	Positivity (%)
Cardona 2019 (2014–2018)	Antioquia	0.18
	Women	0.23
	Men	0.12
Muñoz 2018 (2014–2015)	Antioquia	0.06
Bermudez 2016 (2001–2014)	Colombia	0.03
Medina 2016 (2011–2013)	Boyacá	0.03
Macia 2016 (2012–2014)	Valle del Cauca	0.10
Martinez 2007 (1999–2004)	Bogotá	0.07
Ramirez 1988 (1985–1986)	Cauca, Valle del Cauca	
	Pacific coast	2.65†
	Interior	0

Higher prevalence reported in the Pacific coast compared to interior regions.

HIGH PREVALENCE IN POPULATION-BASED STUDIES

Study	Region / Population	Positivity (%)
Quintana 2004	Córdoba (General)	2.10
Ramirez 2000	Antioquia (Hospital)	3.60
Arango 1999	Pacific region (Indigenous)	1.00
Sanmartin 1995	Pacific region (General)	1.20
Zaninovic 1994	Nariño – Kamëntsá	8.50
Zaninovic 1986	Tumaco	3.90
Zaninovic 1986	Pacific coast	6.80

Indigenous and Afro-descendant communities in the Pacific region show the highest HTLV-1 prevalence.

CLINICAL SERIES AND CASE REPORTS

>185

CASES REPORTED

(1985–2020)

Main clinical presentations:

- Adult T-cell leukemia/lymphoma (ATLL)
- HTLV-1 associated myelopathy/tropical spastic paraparesis (HAM/TSP)
- Infectious complications
- Autoimmune manifestations
- Pediatric cases

Evidence of significant morbidity affecting all stages of life.

COLOMBIAN PACIFIC COAST

- Valle del Cauca
- Chocó
- Cauca
- Nariño

The Pacific coast concentrates the highest burden of HTLV-1 infection in Colombia.

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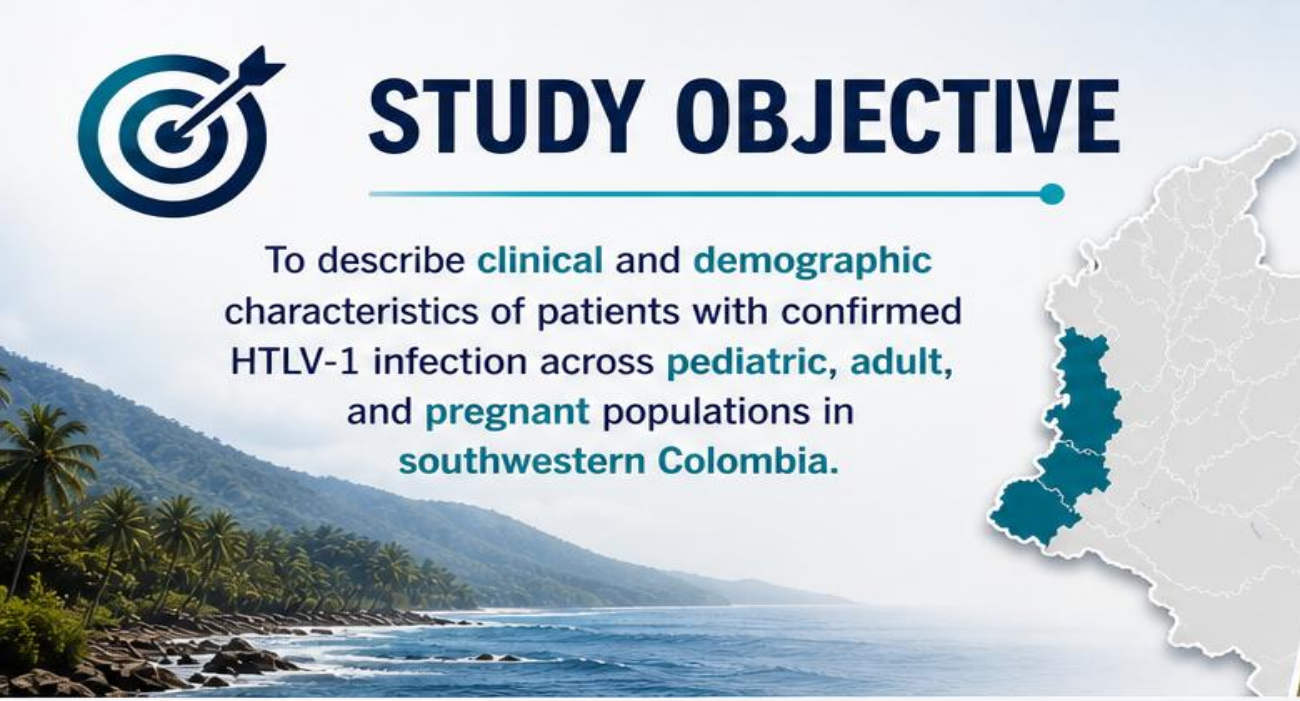
STUDY OBJECTIVE

To describe **clinical** and **demographic** characteristics of patients with confirmed HTLV-1 infection across **pediatric**, **adult**, and **pregnant** populations in **southwestern Colombia.**



STUDY DESIGN

Retrospective descriptive case series conducted at a tertiary referral hospital between **January 2021** and **December 2023**; confirmation by **Western blot.**

RETROSPECTIVE
Review of medical records

TERTIARY REFERRAL HOSPITAL
Southwestern Colombia

STUDY PERIOD
January 2021 to December 2023

CONFIRMATION BY WESTERN BLOT
Serologic confirmation of HTLV-1 infection

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Cohort composition and pediatric demographic profile

45

confirmed HTLV-1 cases

Multicenter cohort from southwestern Colombia

Cases were concentrated in the Colombian Pacific region, mainly in **Valle del Cauca, Cauca, Nariño, and Chocó.**

Clinical characteristics of pediatric patients with confirmed HTLV-1 infection

in southwestern Colombia (n=23)

Case Case	Age (years)	Sex ♀♂	Residence	Pulmonary coinfection	Autoimmune	Dermatological findings	Neurologic problems	Other findings	Outcome
1	4 months	♂	Cali, Valle del Cauca	Rhinovirus–Enterovirus Bronchiolitis	No	No	No	None	Alive
2	1 year	♂	Cali, Valle del Cauca	No	No	Tinea corporis	No	Acute diarrheal disease	Alive
3	3 years	♂	López de Micay, Cauca	No	No	Infective dermatitis	No	Intestinal parasites (Ascaris, Trichuris), soft tissue infection by *S. pyogenes*	Alive
4	7 years	♀	Buenaventura, Valle del Cauca	Pulmonary aspergillosis	No	Infective dermatitis	No	Pneumopathy, *S. aureus* bacteremia, tracheitis and *P. aeruginosa*	Deceased
5	8 years	♀	San Isidro, Valle del Cauca	Pulmonary aspergillosis, *H. influenzae* pneumonia	No	Infective dermatitis	No	Pneumopathy	Alive
6	8 years	♀	Mosquera, Nariño	No	Inflammatory bowel disease (autoinmunity)	No	No	None	Alive
7	9 years	♀	Cali, Valle del Cauca	No	No	Infective dermatitis	No	ATLL	Alive
8	10 years	♀	Buenaventura, Valle del Cauca	Mixed pneumonia *H. influenzae, S. aureus S. pneumoniae*, Rhinovirus/ Enterovirus, Parainfluenza	No	Infective dermatitis	No	Pneumopathy	Alive
9	12 years	♀	Cali, Valle del Cauca	No	No	No	Vogt–Koyanagi–Harada syndrome, panuveitis	None	Alive
10	15 years	♂	Buenaventura, Valle del Cauca	Pulmonary aspergillosis	No	No	No	Pneumopathy, severe pulmonary hypertension	Alive
11	16 years	♂	Buenaventura, Valle del Cauca	Pulmonary tuberculosis	No	Infective dermatitis	No	ATLL, Ascaris, Staphylococcus *epidermidis* bacteremia, UTI by *Pseudomonas aeruginosa*, Rhinovirus/ Enterovirus infection	Alive
12	17 years	♂	Buenaventura, Valle del Cauca	No	No	No	Myelopathy	Neurogenic bladder	Alive
13	1 year	♀	Cali, Valle del Cauca	No	No	No	No	None	Alive
14	5 years	♀	Cali, Valle del Cauca	No	No	No	No	Recurrent fever	Alive
15	6 years	♂	Tumaco, Nariño	No	No	Infective dermatitis	No	None	Alive
16	7 years	♀	Buenaventura, Valle del Cauca	No	No	Infective dermatitis	No	No	Alive
17	9 years	♂	López de Micay, Cauca	No	No	No	No	Chronic diarrhea	Alive
18	11 years	♀	Cali, Valle del Cauca	No	No	Infective dermatitis	No	None	Alive
19	13 years	♀	Jamundi, Valle del Cauca	No	No	No	No	None	Alive
20	14 years	♂	Cali, Valle del Cauca	No	ITP	Infective dermatitis	No	None	Alive
21	16 years	♀	Buenaventura, Valle del Cauca	No	No	No	Myelopathy	None	Alive
22	17 years	♂	Cali, Valle del Cauca	No	No	No	No	None	Alive
23	17 years	♂	Buenaventura, Valle del Cauca	No	No	No	No	None	Alive

ATLL: Adult T-cell leukemia/lymphoma; ITP: Immune thrombocytopenic purpura; UTI: Urinary tract infection.

Demographic and clinical characteristics of adult patients infected with HTLV-1 (n=17)

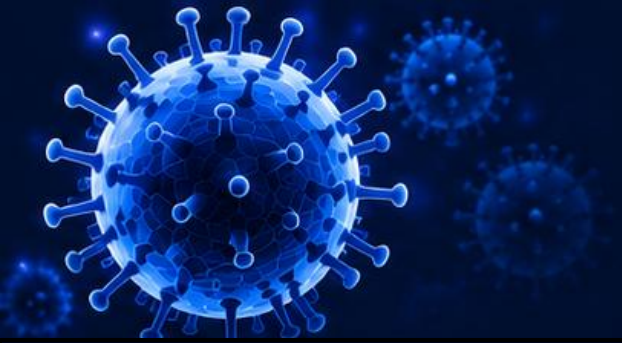
Case	Age at Diagnosis (years)	Gender	Residence	Pulmonary Coinfection	Autoimmunity	Dermatological Findings	Neurologic Findings	Other Findings	Outcome
1	30	M	Cali, Valle del Cauca	No	No	No	Tropical spastic paraparesis	Depressive syndrome; Bacteremia: *K. pneumoniae, A. baumannii, P. aeruginosa*	Deceased
2	65	M	Danubio, Valle del Cauca	Pneumonia by SARS-CoV-2	No	No	Dysphagia	ATLL	Deceased
3	48	M	Buenaventura, Valle del Cauca	Aspergillosis Pneumonia by SARS-CoV-2	No	Cutaneous T-cell lymphoma	Dysphagia	Methicillin-resistant *S. aureus* bacteremia	Deceased
4	43	M	Timbiquí, Cauca	No	No	No	Multiple cranial neuropathies: CN II palsy, CN VI palsy, facial paralysis, CN V palsy	Infection by *Strongyloides stercoralis*	Alive
5	50	♀	Nariño	No	No	No	No	Hepatitis B infection (HBsAg positive and detectable viral load)	Alive
6	52	M	Buenaventura, Valle del Cauca	No	No	No	No	ATLL; *Methicillin*-resistant *S. aureus* bacteremia	Deceased
7	52	♀	Buenaventura, Valle del Cauca	No	No	Mature T-cell cutaneous lymphoma, IIB	No	Skin lesion infected with *MDR P. aeruginosa*	Deceased
8	57	♀	Buenaventura, Valle del Cauca	No	Sjögren´s syndrome	No	Extensive longitudinal cervical/thoracic myelitis; neurogenic bladder due to CNS infiltration	ATLL; Syphilis	Deceased
9	59	♀	Cali, Valle	No	No	No	Axonal and demyelinating neuropathy in lower limbs	None	Alive
10	47	M	Chocó	No	No	No	Dysphagia	ATLL; *C. difficile* infection	Deceased
11	72	♀	Cali, Valle del Cauca	Nosocomial pneumonia	No	No	No	ATLL	Deceased
12	52	M	Buenaventura, Valle del Cauca	Bacterial pneumonia	No	No	No	ATLL; Bacteremia by *Pseudomonas aeruginosa*	Deceased
13	23	♀	Cali, Valle del Cauca	No	No	No	No	papilledema with optic nerve drusen	Alive
14	60	♀	Cali, Valle del Cauca	Multilobar pneumonia	No	No	N	ATLL; Syphilis	Deceased
15	49	♀	Buenaventura, Valle del Cauca	No	No	Generalized xerosis	Myelopathy; overactive bladder	ATLL; *Methicillin-sensitive*	Deceased
16	18	♀	Buenaventura, Valle del Cauca	No	No	Norwegian scabies	No	ATLL; Renal disease; Infection by *Strongyloides stercoralis*	Alive
17	25	♀	Sibundoy, Putumayo	No	No	No	No	Maternal history of HAM/TSP; prolonged breastfeeding (3 years)	Alive

ATLL: Adult T-cell leukemia/lymphoma; MDR: Multidrug-resistant; CNS: Central nervous system; HBV: Hepatitis B virus; CN: Cranial nerve; HAM/TSP: HTLV-1–associated myelopathy/tropical spastic paraparesis.

Demographic and clinical characteristics of pregnant women with HTLV-1 infection in southwestern Colombia (n=5)

Case	Age (years)	City of Residence	Gestational Age (weeks)	Sexual Violence	Tattoos	Transfusion	Anti-HBs Status	Unprotected Sex (Pregnancy)	Sex Partners (Life)	HTLV-1 Symptoms
1	25	Cali	31	No	No	Yes (2015)	Negative	Yes	5–7	None
2	34	Buenaventura, Valle del Cauca	31	No	No	No	Positive	Yes	5–7	None
3	38	Cali, Valle del Cauca	30	Yes	Yes	No	Positive	Yes	2–4	None
4	36	Cali, Valle del Cauca	34	No	No	No	Positive	Yes	2–4	None
5	32	Buenaventura, Valle del Cauca	32	No	No	No	Positive	Yes	2–4	None

Anti-HBs = Antibodies against hepatitis B surface antigen



CONCLUSIONS

https://infectojuanpa.com/

Infecto Juanpa

Thank You

For your attention and commitment to child health

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SCIENCE that cares

EVIDENCE that guides

EXPERIENCE that transforms

COMMITMENT that saves lives

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Prevalence of HTLV-1 infection among family members of people living with the virus: A systematic review and meta-analysis

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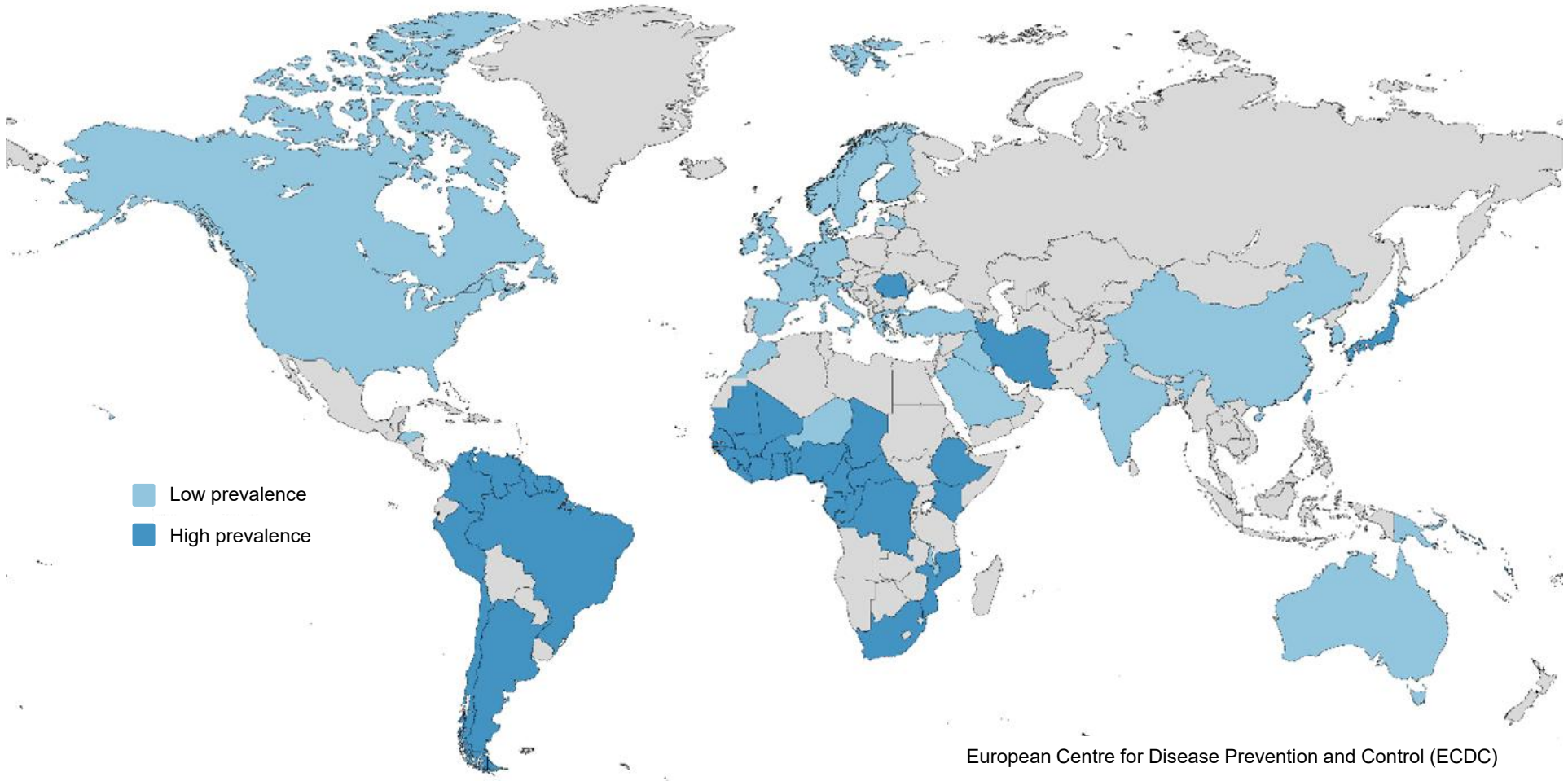
Fernanda Grassi

Fundação Oswaldo Cruz – Fiocruz-Bahia

HTLV is a global and Neglected Global Threat



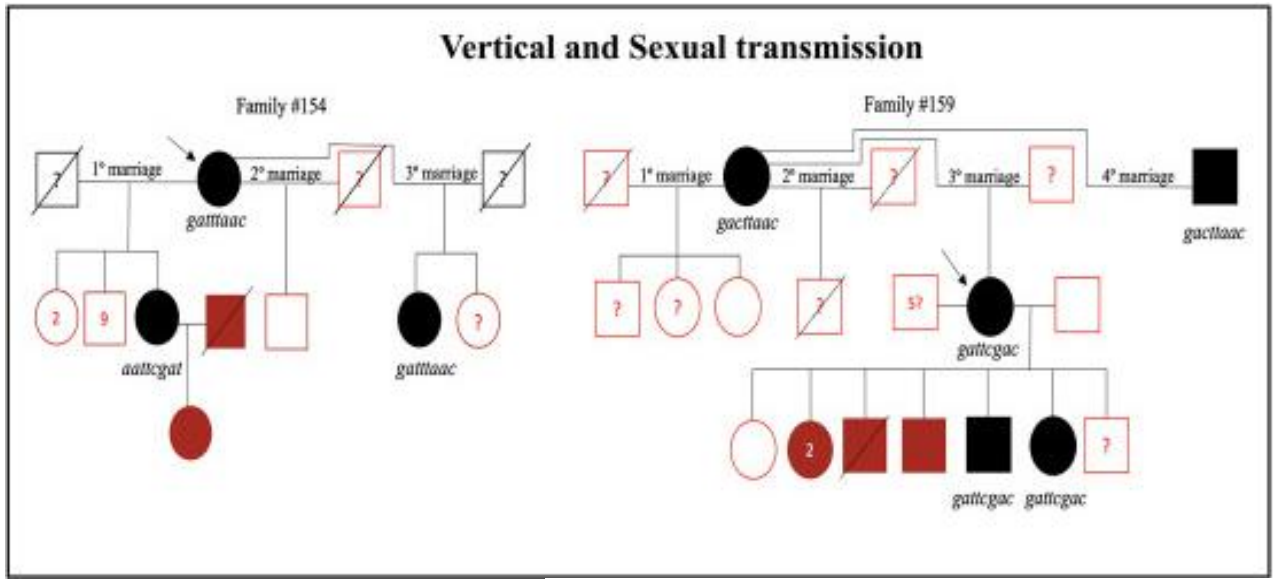
European Centre for Disease Prevention and Control (ECDC)

Global burden: 5 to 10 million infected people worldwide

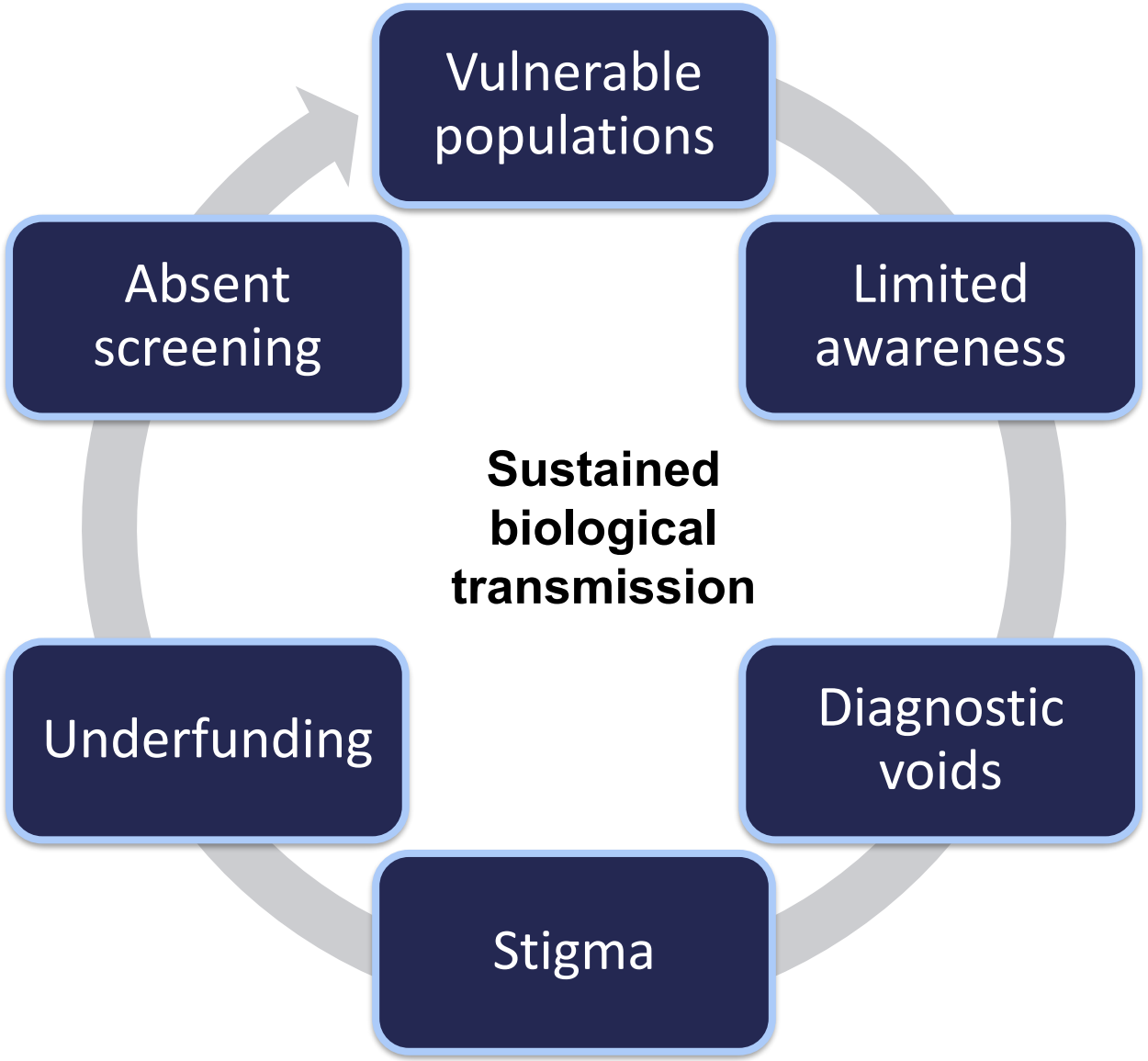
Endemic clusters: Japan, Central and West Africa, the Caribbean, Melanesia and Central/South America
Infection concentrated in countries with low Human Development Index, reflecting social and economic vulnerabilities

Factors Influencing Intrafamilial Transmission of HTLV

- Mother-to-child (MTC) and sexual transmission drive family clustering
- HTLV-1 causes a persistent, lifelong infection
- No curative or prophylactic therapy
- Co-infections such as HIV, syphilis, and other STIs amplify susceptibility.
- HAM/TSP, ATL and other associated diseases manifest in adulthood, delaying early detection



Nunes da SILVA, A et al., 2023
Doi: 10.1371/journal.pntd.0011005


Vulnerable populations
Limited awareness
Diagnostic voids
Stigma
Underfunding
Absent screening
Sustained biological transmission

Aim

- To estimate the pooled prevalence of HTLV-1 infection among family members of people living with the virus **(PLwHTLV-1)**

Methods Systematic review with meta analysis

Scan for PROSPERO protocol (CRD420251039648)

PRISMA guideline

Population: Family members of individuals already identified as living with HTLV-1 (index cases).
Exposure: Relative or sexual partner of a PLwHTLV-1
Outcome: Prevalence of HTLV-1 among family members

Search strategy: Descriptors related to HTLV-1 and familial transmission.

("HTLV-1" OR "HTLV1" OR "HTLV I" OR "HTLV-I" OR "Human T-lymphotropic virus type 1" OR "Human T-lymphotropic virus type I" OR "Human T-cell lymphotropic virus type 1" OR "Human T-cell lymphotropic virus type I" OR "Human T-cell leukemia virus type 1" OR "Human T-cell leukemia virus type I" OR "Human T-leukemia virus 1")

("Familial aggregation" OR "Family clustering" OR "Familial clustering" OR "Household transmission" OR "Intrafamilial transmission" OR "Familial transmission" OR "Mother-to-child transmission" OR "Vertical transmission" OR "Horizontal transmission" OR "Sibling transmission" OR "Parent-child transmission" OR "Intra-household transmission" OR "Family members" OR "Household members" OR "First-degree relatives" OR "Relatives" OR "Close contacts" OR "Cohabitation" OR "Kinship" OR "Family" OR "Family aggregation" OR "Family cluster" OR "Familial" OR "Families" OR "Pedigree" OR "Aggregation" OR "Intrafamily" OR "Intrafamilial" OR "Breastfeeding" OR "Breastmilk" OR "Sexual transmission" OR "Sexual contact" OR "Sexually transmitted" OR "Sexual intercourse" OR "Sexual relations" OR "Sexual partners" OR "Sexual behavior" OR "Sexual activity").

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Inclusion Criteria:
- Cross-sectional, case-control, and cohort studies
- English, Portuguese, or Spanish
- HTLV-1 infection in relatives of PLwHTLV-1

Exclusion Criteria:
- No confirmatory tests for HTLV-1 infection in index cases and/or their relatives
- HTLV-1 and HTLV-2 indistinguishable
- Family data not available

Risk assessment

JOANNA BRIGGS INSTITUTE

Results

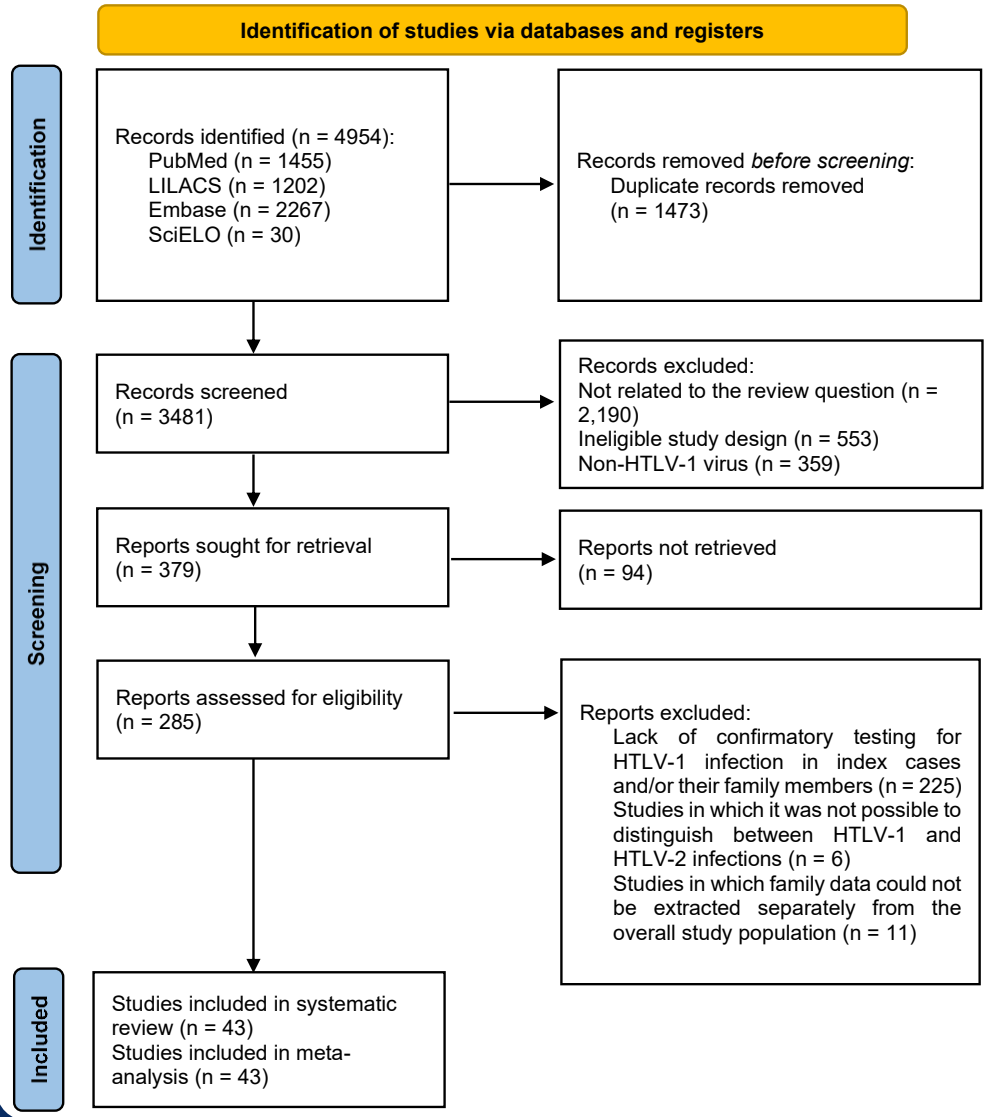
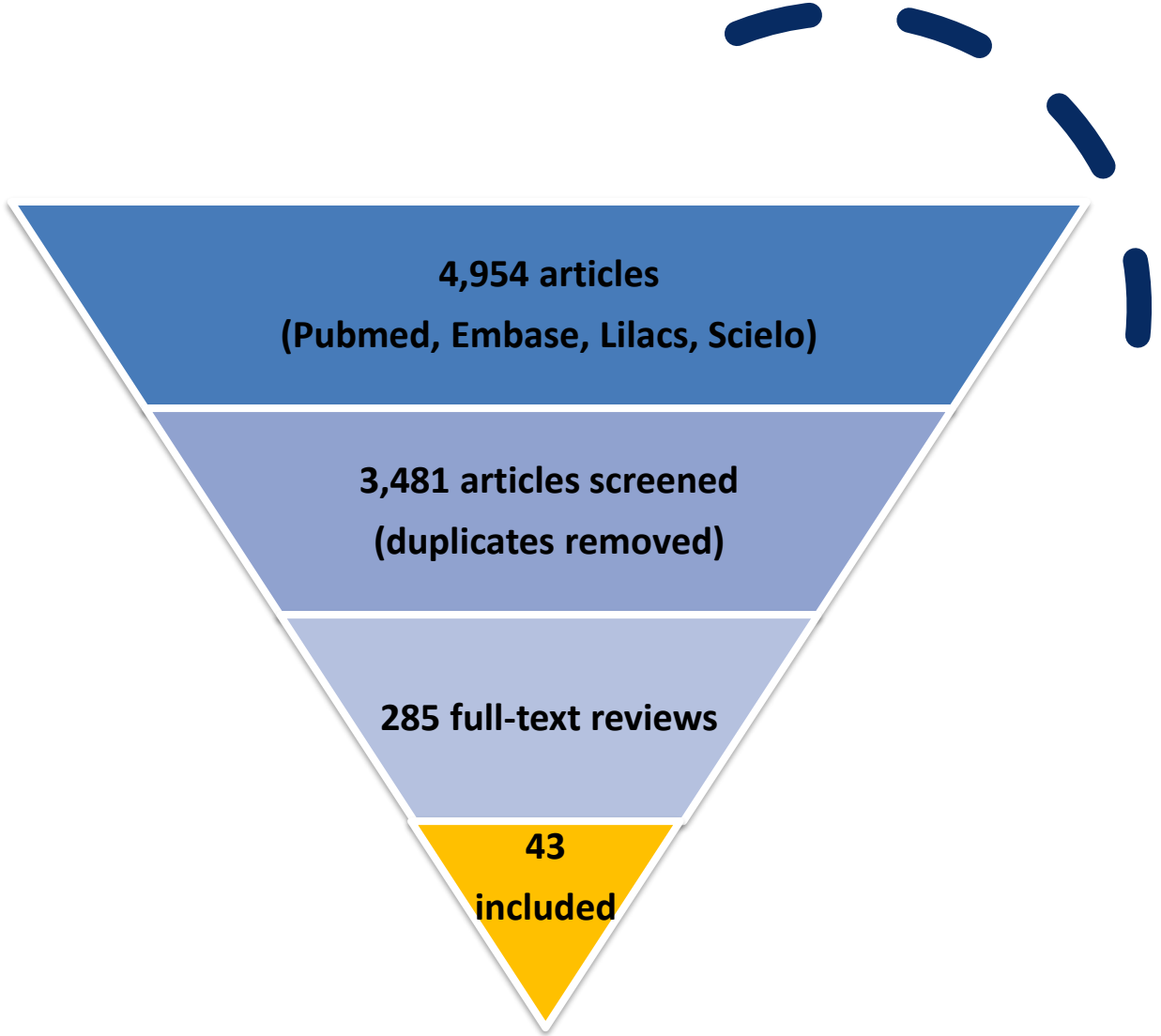
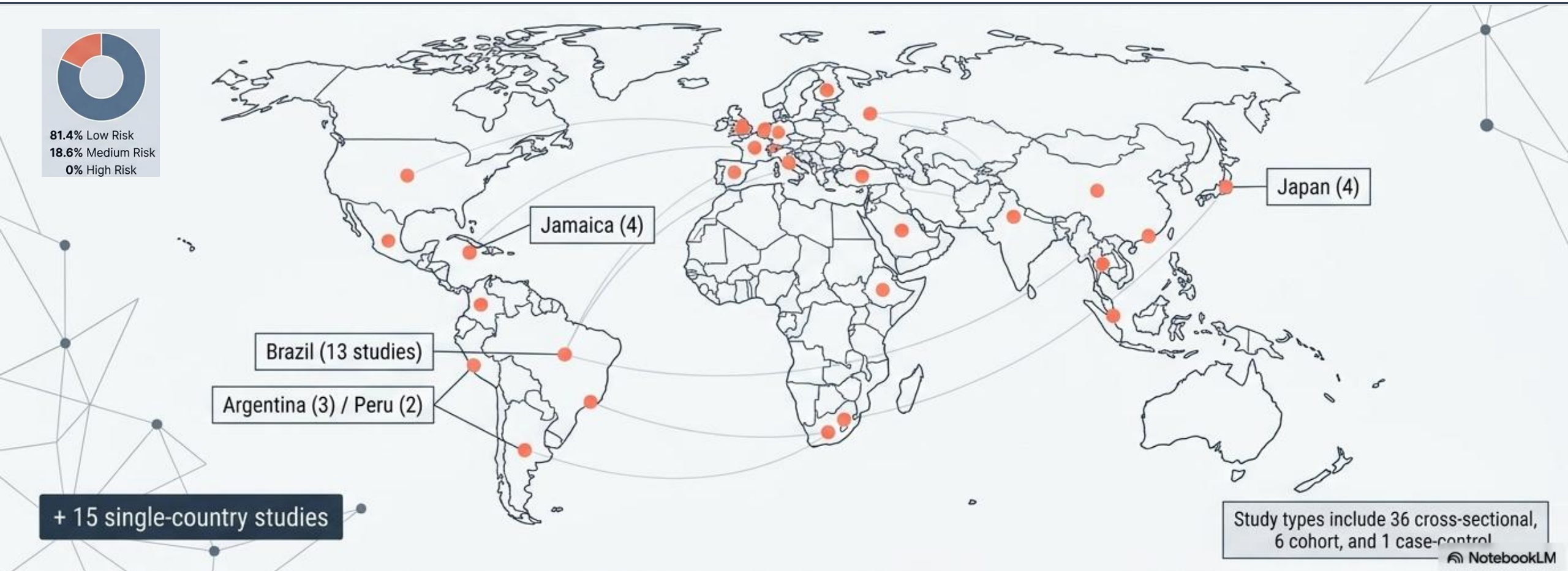


Figure 1. Flow diagram of the systematic selection of studies.



Results

43	2.524	5.925	1.468
studies (1990-2024)	Index cases	Family members	HTLV+ family members



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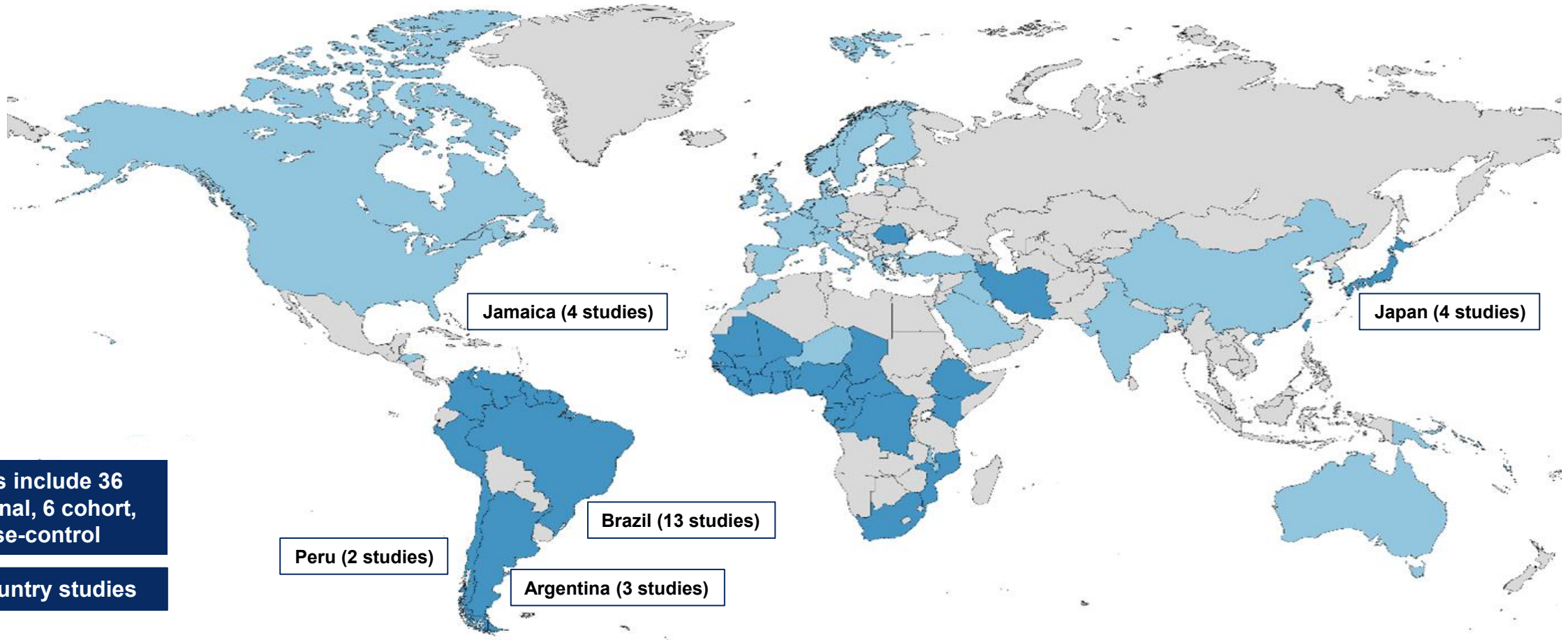
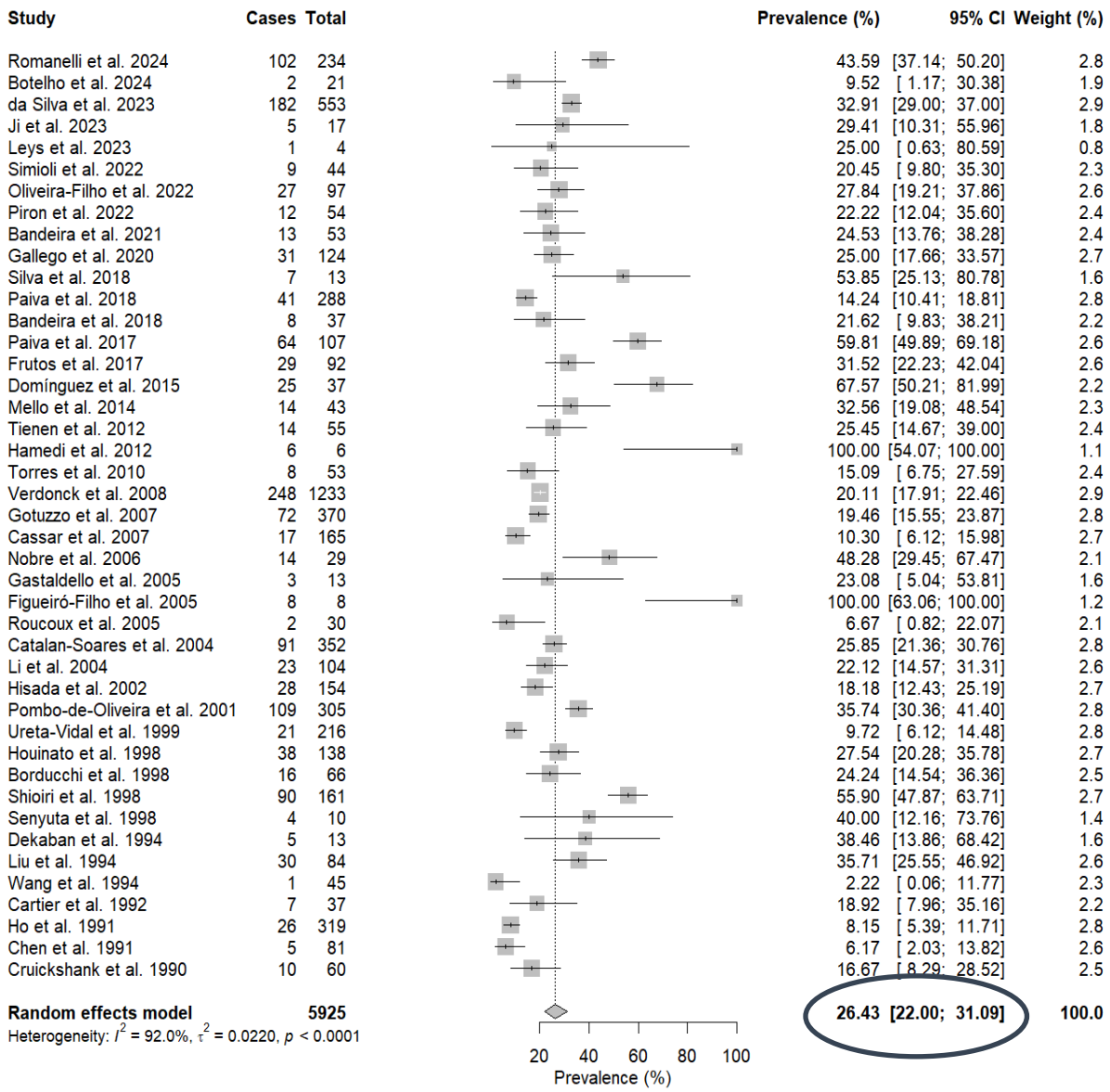


Study types include 36 cross-sectional, 6 cohort, and 1 case-control

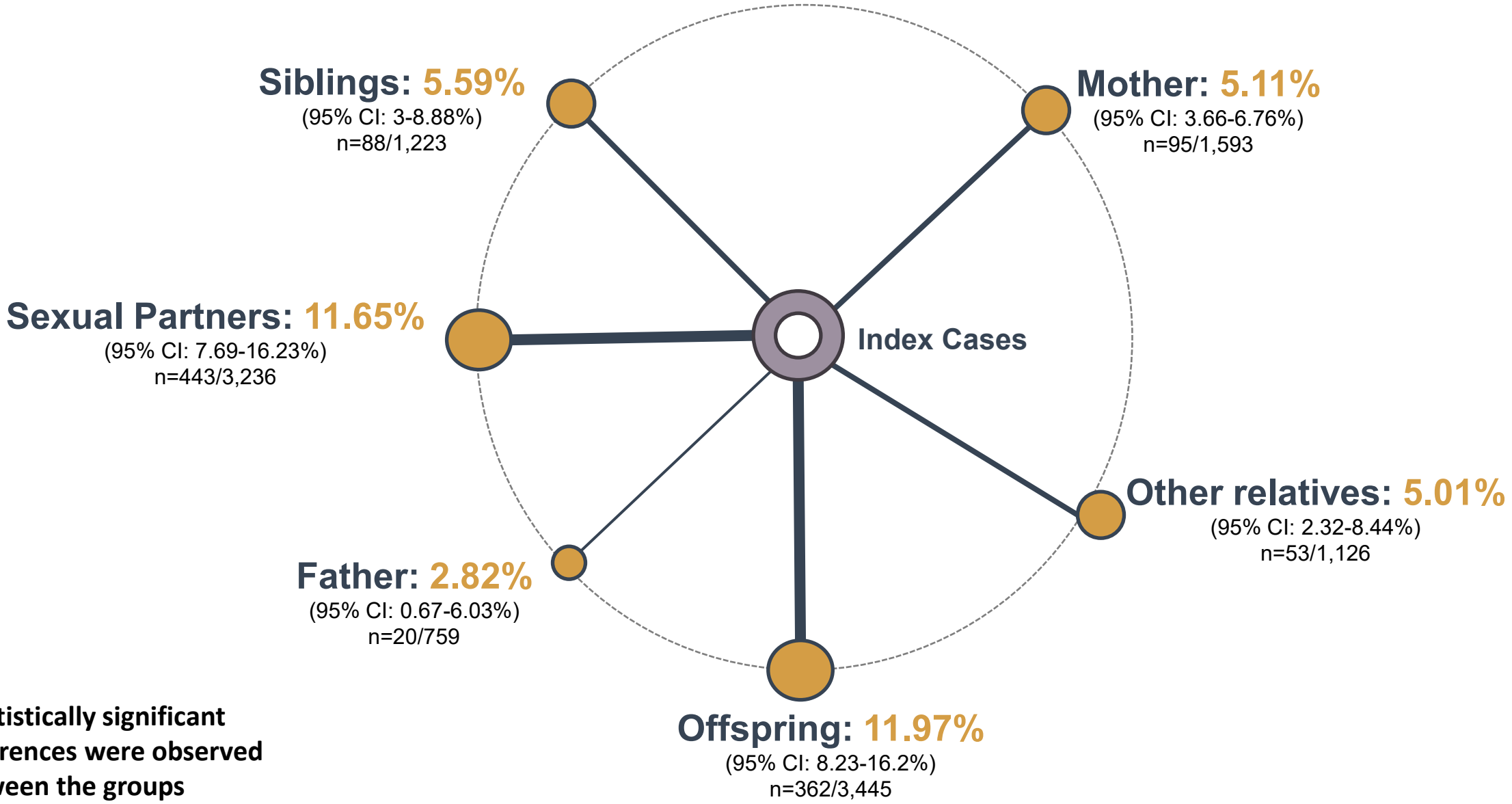
15 single-country studies

Pooled intrafamilial prevalence



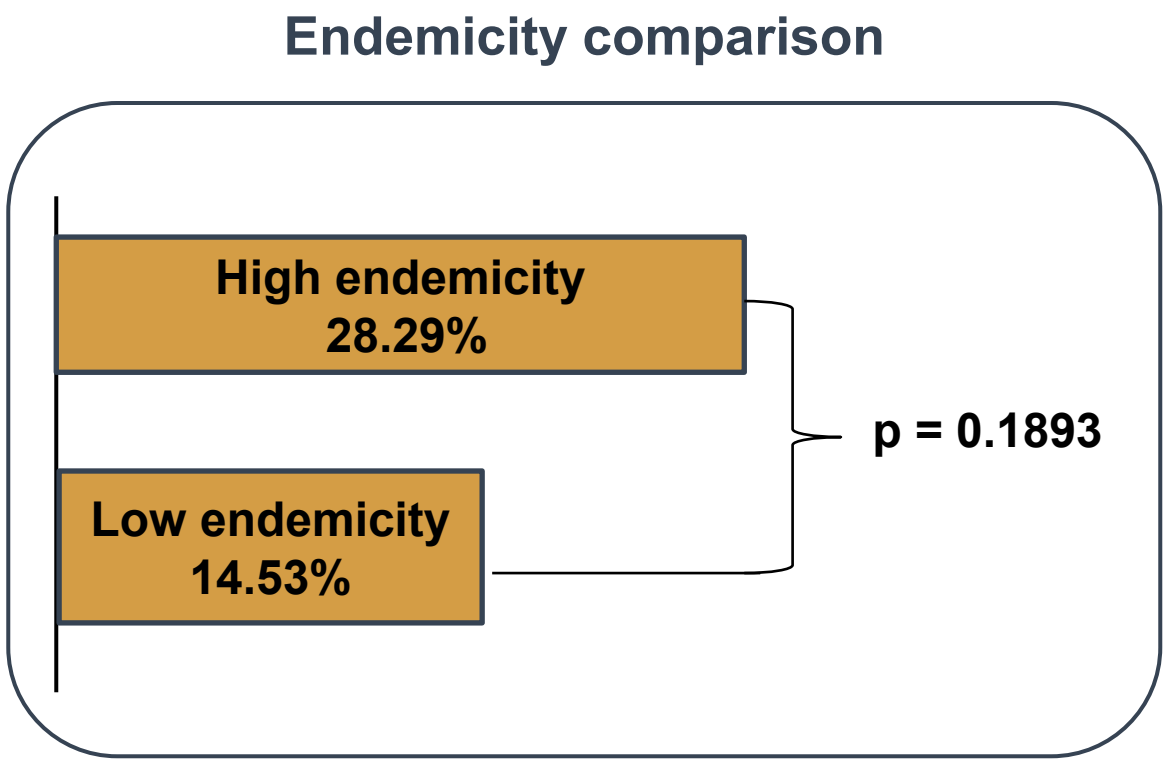
Overall Pooled Prevalence: 26.43%
(95% CI: 22.00-31.09%)
Total Infected: 1,468 Family Members

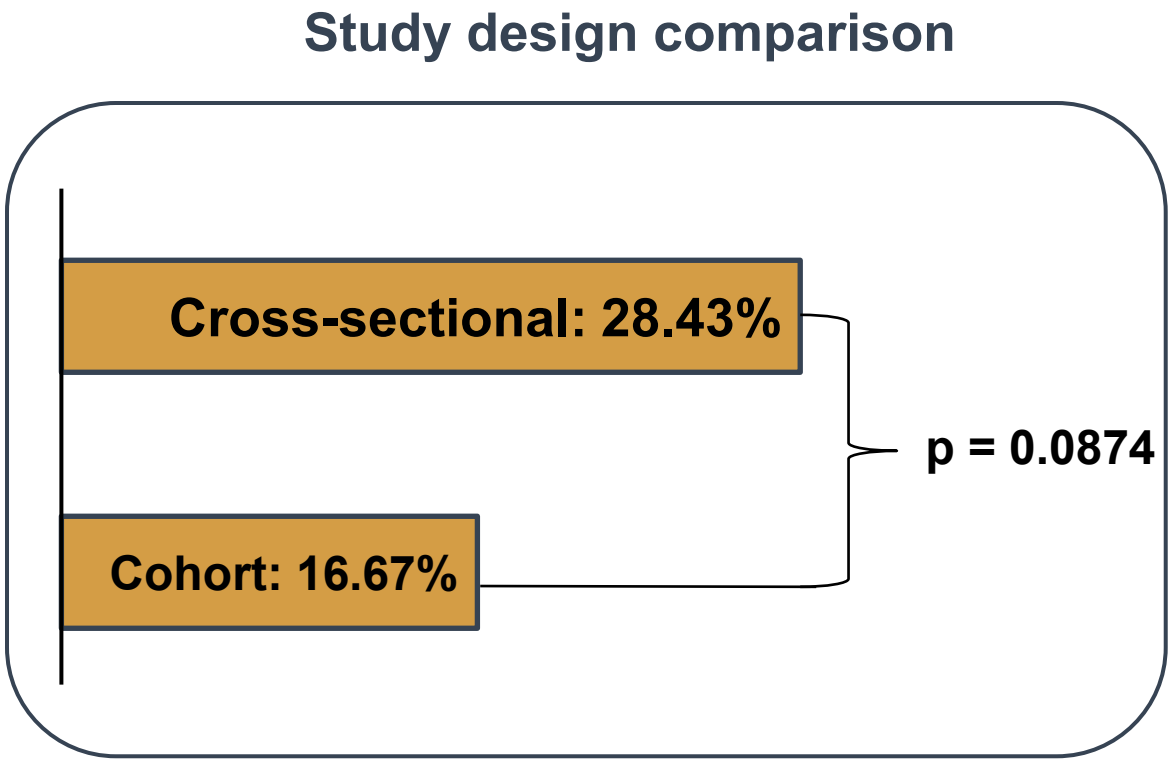
Pooled prevalence in family members



***Statistically significant differences were observed between the groups ($p < 0.0001$)**

Pooled prevalence by endemicity and study design





Conclusions

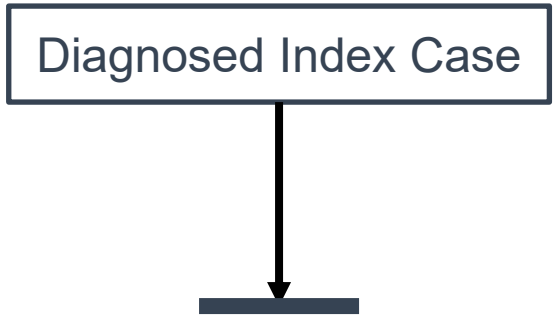
1 | Intrafamilial aggregation is substantial, with a pooled prevalence of 26.43%

2 | Sexual partners and offspring bear the highest risk and must be prioritized in clinical interventions.

3 | HTLV-1 control efforts should move beyond individual testing toward systematic family-based contact tracing to reduce intergenerational transmission and viral persistence.

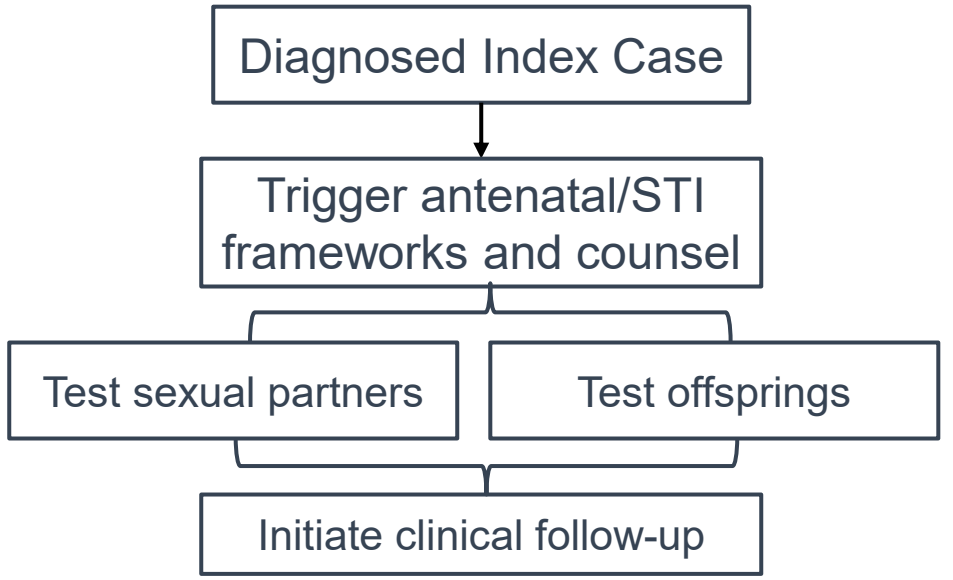
Take away lesson

Current state in most countries



Outcome: silent transmission continues undetected

Optimal state – proposed intervention



Outcome: interrupt transmission chains and enable early intervention

Countries like Japan and Brazil have proven antenatal screening is cost-effective. PAHO guidelines support integrating targeted, Family-based contact tracing into these existing maternal health and STI programs.

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Financial support

CNPq

CAPES

SUS
Sistema Único de Saúde

FIOCRUZ

FUNADESP
Fundação Nacional de Desenvolvimento do Ensino Superior Particular

Thomas Jefferson University | Drexel University | Drexel Medicine

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

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

Enhancing the accessibility of HTLV molecular testing:

Whole blood and DBS as alternative to PBMCs

Momoko Usui, Claire L Greiller, Graham P Taylor, Carolina Rosadas de Oliveira, Lucy Cook, Aileen Rowan

Imperial College London

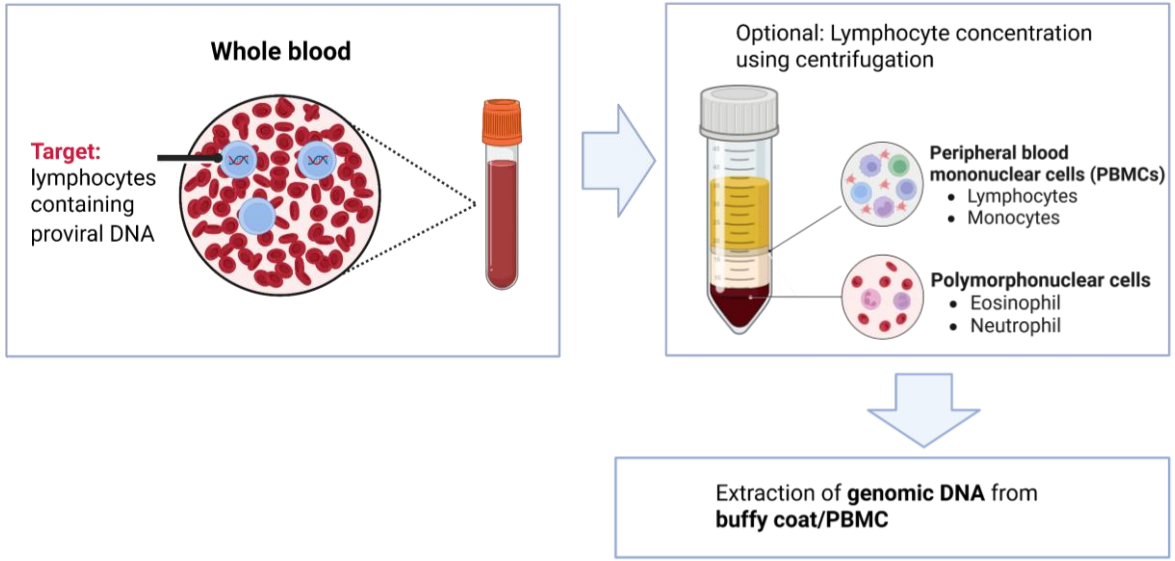
Conflicts of interest

I have no conflicts of interest

Background:

Importance of molecular testing (qPCR) in HTLV

1. Option for the serology confirmation and alternative of western blotting.
2. A marker for the risk of HTLV-associated disease development (proviral load (PVL, %)).
   In the UK, PVL>1% = risk of developing HAM/TSP, PVL>4% = risk of developing ATL
3. Monitoring a treatment response.



Problems of Molecular testing with PBMCs

Fast sample delivery to a diagnostic lab

Training needs

Expensive
- Equipment
- Reagents
- Staff time

Time-consuming

Background:

Importance of molecular testing (qPCR) in HTLV

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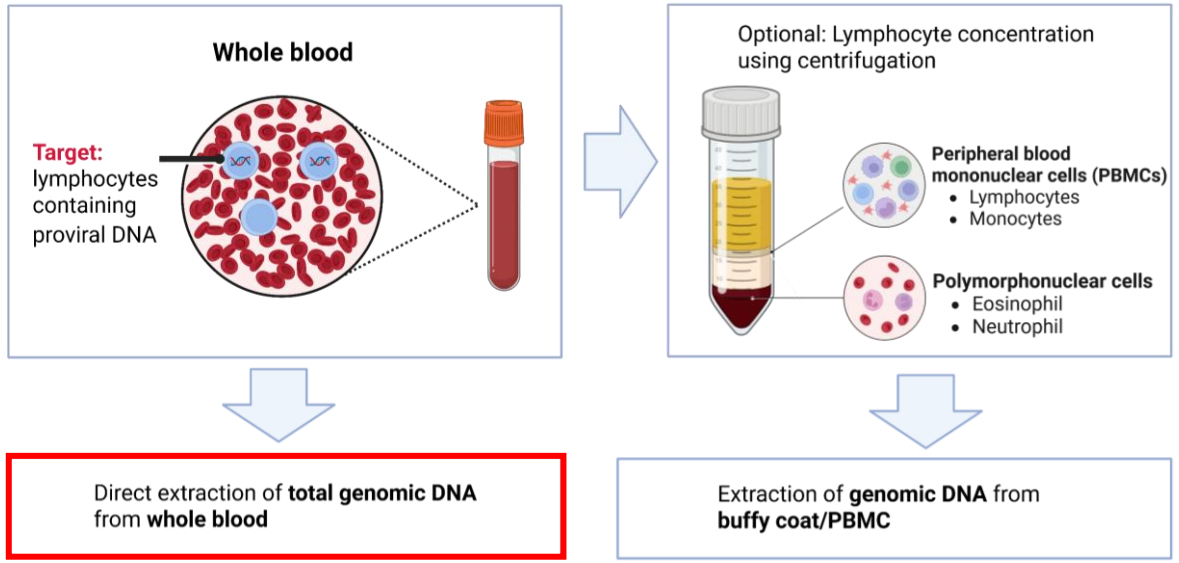


Problems of Molecular testing with PBMCs

Fast sample delivery to a diagnostic lab

Training needs

Expensive
- Equipment
- Reagents
- Staff time

Time-consuming

Aim of the project:

Evaluate whole blood (WB) and Dried Blood Spot (DBS) samples as an alternative to PBMCs to provide **faster**, **cheaper**, and **more accessible HTLV molecular testing** (qPCR).

1. Evaluating gDNA recovery from WB/DBS stored at a range of times/temperatures.
2. Comparing the **detection** of HTLV across sample types / storage duration.
3. Comparing the **quantification** of HTLV across sample types / storage duration.
4. Identifying a suitable cut-off for the risk stratification for WB/DBS samples.

Material and Methods:

Sample collection

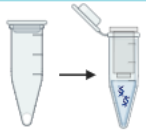
EDTA WB

Transferred at RT

DNA extraction (QIAGEN column)

PBMCs
(isolated at Day 0)

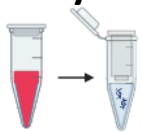
Stored at -80°C



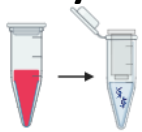
WB

Stored at various temp: -20°C -> 50 °C.

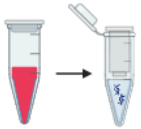
Day 0



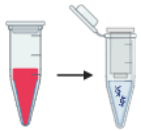
Day 2



Day 7

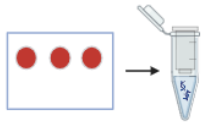


Day 14



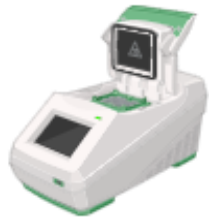
DBS
(collection at Day 0)

Stored at RT & no direct sunlight



Stored at -80°C

qPCR analysis



- UCKAS accredited
- Tax & Beta globin primers
- SYBR green
- Calculate copies relative to standard

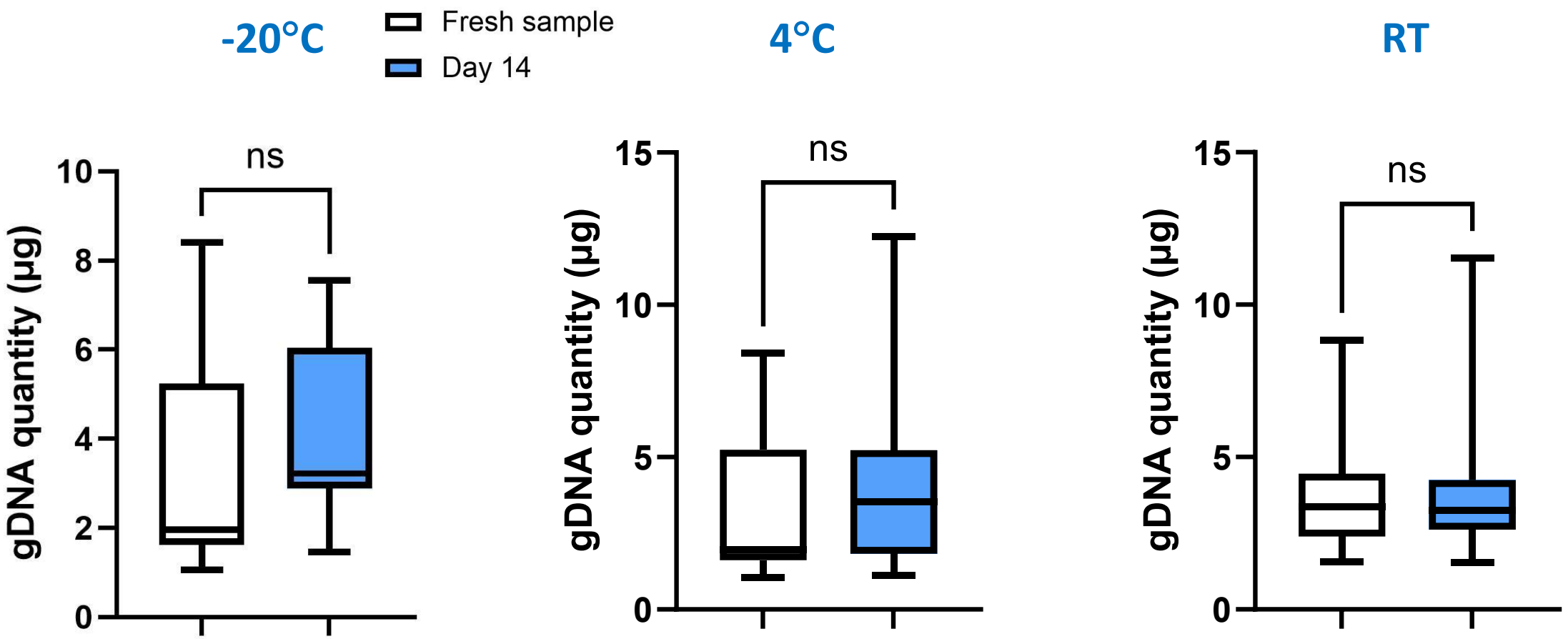
Detection:
Detection of Tax in at least 1/2 replicates

Quantification:
Calculate Proviral load (%PVL):

Tax copies/
100 human cells

1. Evaluating gDNA recovery from DBS/WB stored at a range of times/temperatures.
2. Comparing the **detection** of HTLV across sample types / storage duration.
3. Comparing the **quantification** of HTLV across sample types / storage duration.
4. Identifying a suitable cut-off for the risk stratification for WB/DBS samples.

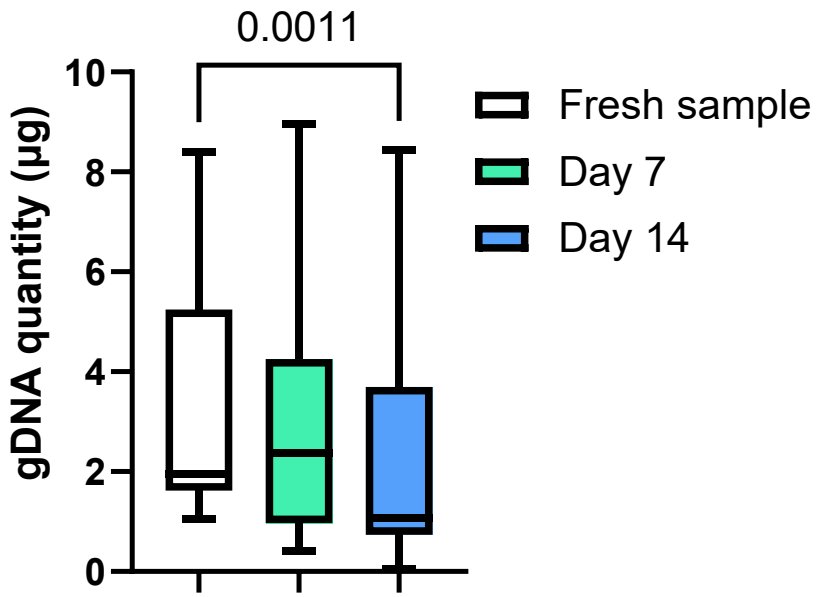
Quantity of gDNA recovered from **200µL WB** samples stored at -20°C, 4°C, and RT (~22°C)



gDNA could be recovered from EDTA WB stored at -20°C, 4°C, and RT up to 14 days.

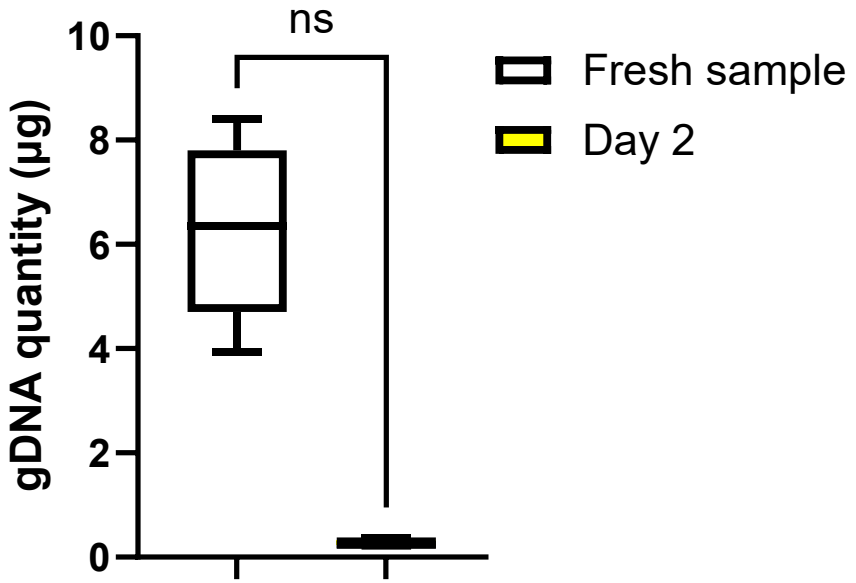
Quantity of gDNA recovered from **200µL WB** samples stored at 35°C, and 50°C

35°C



Quantity (µg)		35°C	
	Day 0	Day 7	Day 14
Mean	**3.33**	**3.08**	**2.18**
Min.	1.05	0.41	0.05
Max.	8.40	8.95	8.43

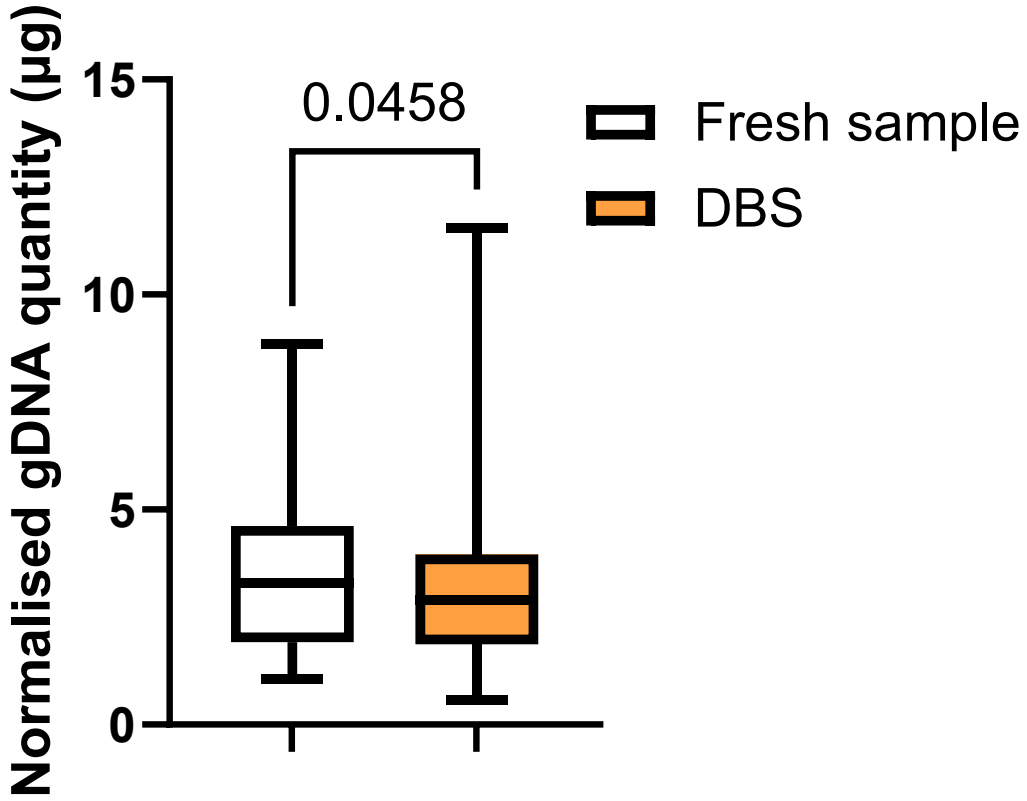
50°C



	50°C
Day 0	Day 2
3.33	**0.27**
1.05	0.22
8.40	0.36

gDNA recovery was poor in EDTA WB samples stored at 35°C for 7+ days & 50°C for 2+ days.

Quantity of gDNA recovered from **DBS** samples (equivalent to 140µL WB)



- Recovered gDNA quantity of DBS was normalised based on WB input.
- **Using an optimised protocol from NRL, gDNA quantity recovered from the DBS cards was similar to the one from fresh WB samples.**

1 Evaluating gDNA recovery from DBS/WB stored at a range of times/temperatures.

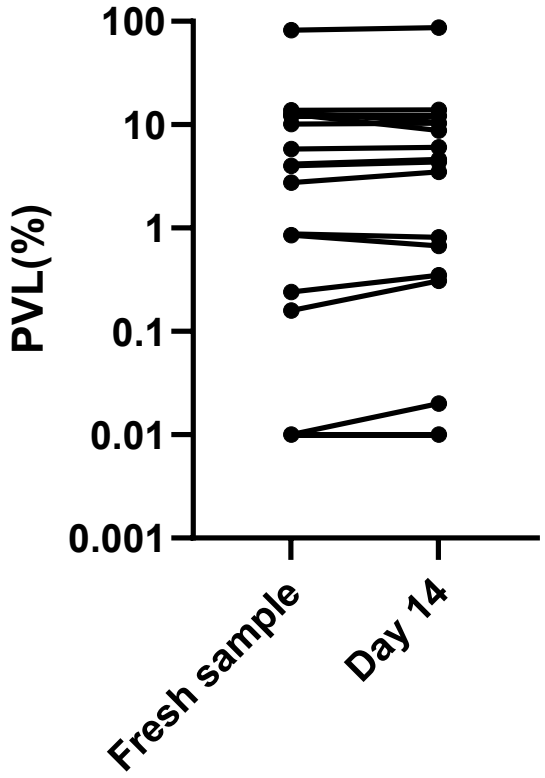
2 Comparing the **detection** of HTLV across sample types / storage duration.

3 Comparing the **quantification** of HTLV across sample types / storage duration.

4 Identifying a suitable cut-off for the risk stratification for WB/DBS samples.

HTLV detection and PVL(%) in samples stored at -20°C (up to 14 days)

	Detected in Day 14	Not detected in Day 14
Detected in Fresh	16	0
NOT detected in Fresh	0	0

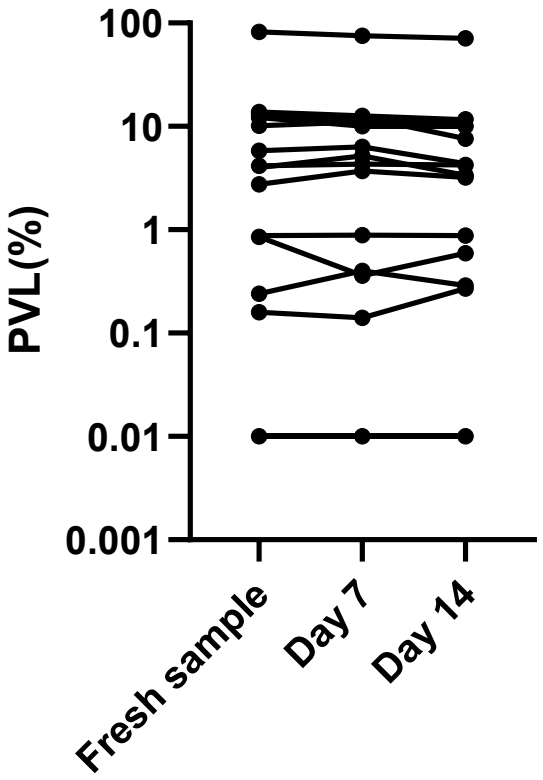


Detection: HTLV detection concordant in 16/16 samples.

HTLV detection and PVL(%) in samples stored at 4°C (up to 14 days)

	Detected in Day 7	Not detected in Day 7
Detected in Fresh	15	1
NOT detected in Fresh	0	0

	Detected in Day 14	Not detected in Day 14
Detected in Fresh	16	0
NOT detected in Fresh	0	0

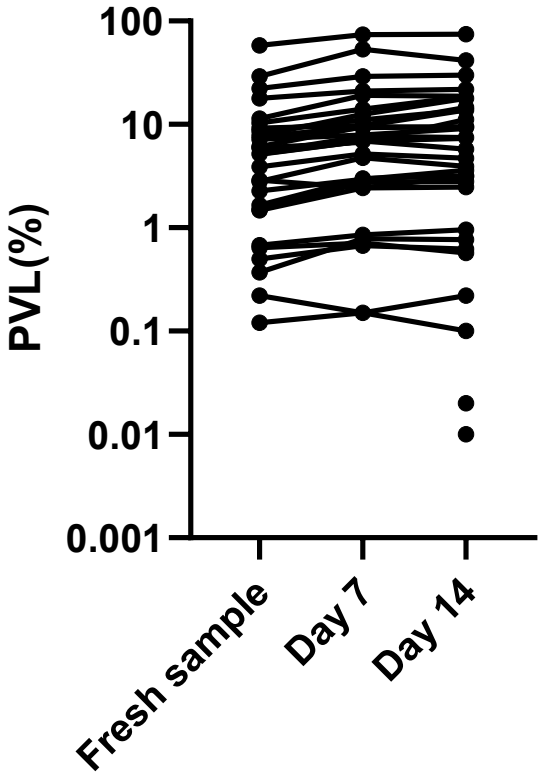


Detection: HTLV detection concordant in 15/16 samples.
Discordant sample had low PVL.

HTLV detection and PVL(%) in samples stored at RT (up to 14 days)

	Detected in Day 7	Not detected in Day 7
Detected in Fresh	30	0
NOT detected in Fresh	0	5

	Detected in Day 14	Not detected in Day 14
Detected in Fresh	30	0
NOT detected in Fresh	2	3

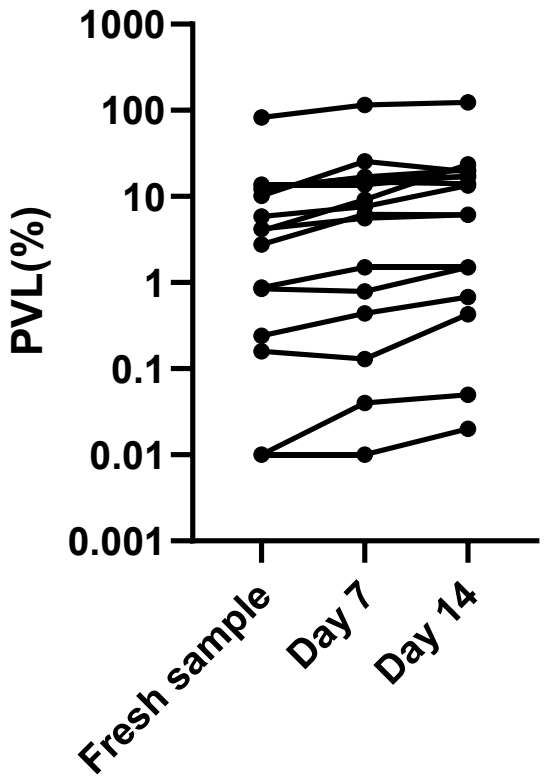


Detection: HTLV detection concordant in 33/35 samples.
Discordant samples had low PVL.

HTLV detection and PVL(%) in samples stored at 35°C (up to 14 days)

	Detected in Day 7	Not detected in Day 7
Detected in Fresh	16	0
NOT detected in Fresh	0	0

	Detected in Day 14	Not detected in Day 14
Detected in Fresh	16	0
NOT detected in Fresh	0	0



Detection: HTLV detection concordant in 16/16 samples.

1 Evaluating gDNA recovery from DBS/WB stored at a range of times/temperatures.

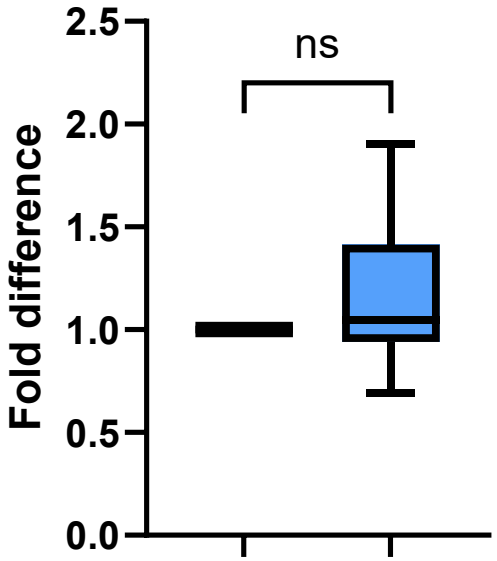
2 Comparing the **detection** of HTLV across sample types / storage duration.

3 Comparing the **quantification** of HTLV across sample types / storage duration.

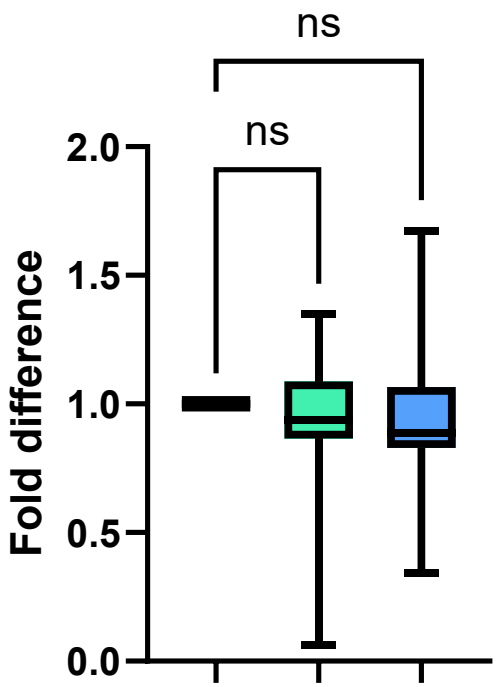
4 Identifying a suitable cut-off for the risk stratification for WB/DBS samples.

Fold difference in proviral load (%)

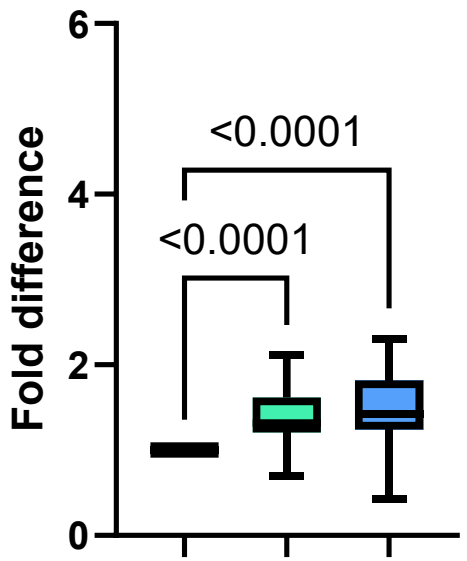
-20°C



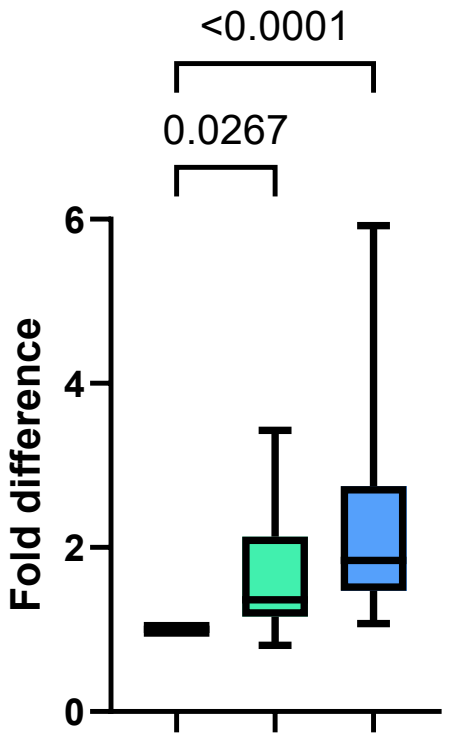
4°C



RT



35°C



Fresh sample
Day 7
Day 14

Fold difference	Day 7	Day 14
Mean	**1.38**	**1.49**

Day 7	Day 14
1.62	**2.26**

No significant difference between fresh and 14-day samples stored at -20°C and 4°C.
Increase in PVL fold difference was observed for RT and 35°C stored samples.

1. Evaluating gDNA recovery from DBS/WB stored at a range of times/temperatures.
2. Comparing the **detection** of HTLV across sample types / storage duration.
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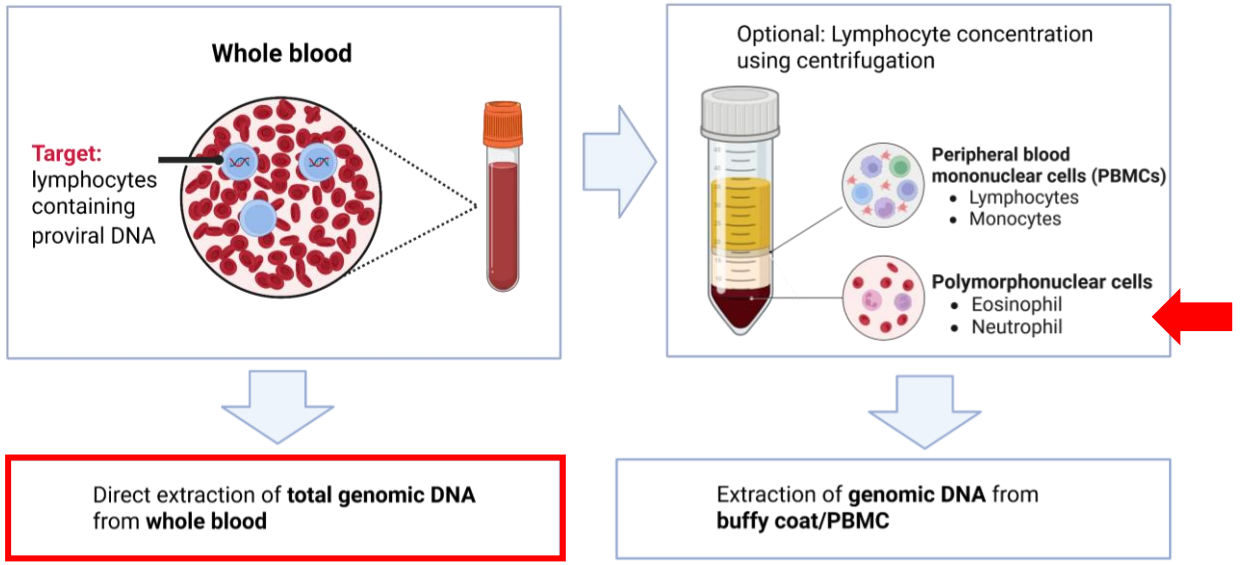
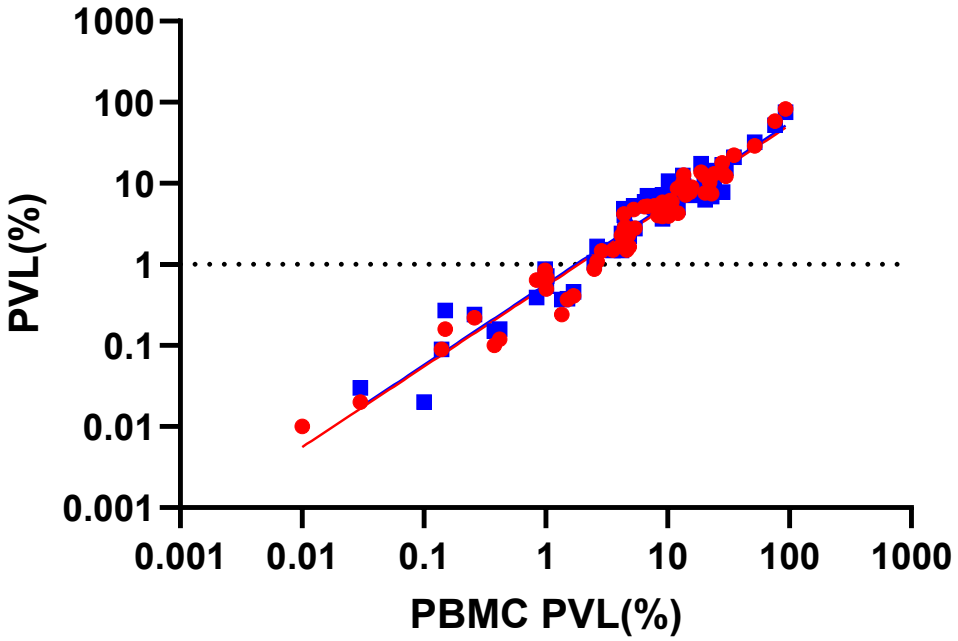


4

Identifying a suitable cut-off for the risk stratification for WB/DBS samples.

PVL difference across different sample types – PBMC, WB, and DBS

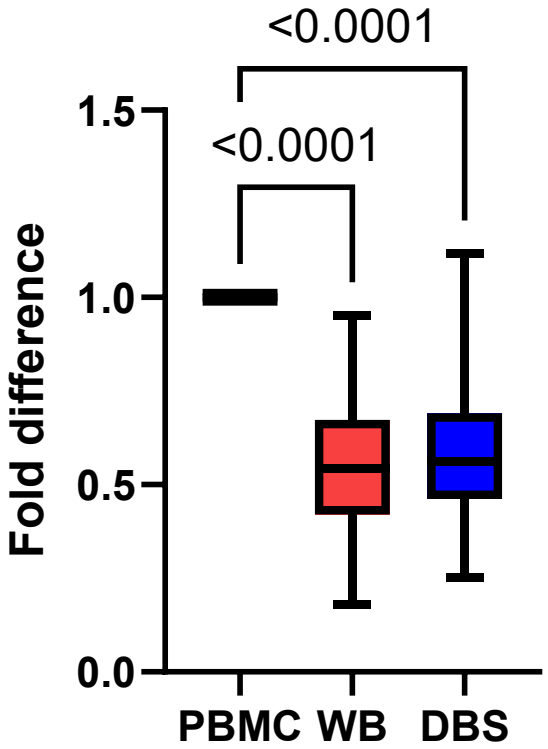


WB PVL(%)

y=0.0279x+0.0289
R2=0.9546
P<0.0001

DBS PVL(%)

y=0.0323x+0.0326
R2=0.9404
P<0.0001

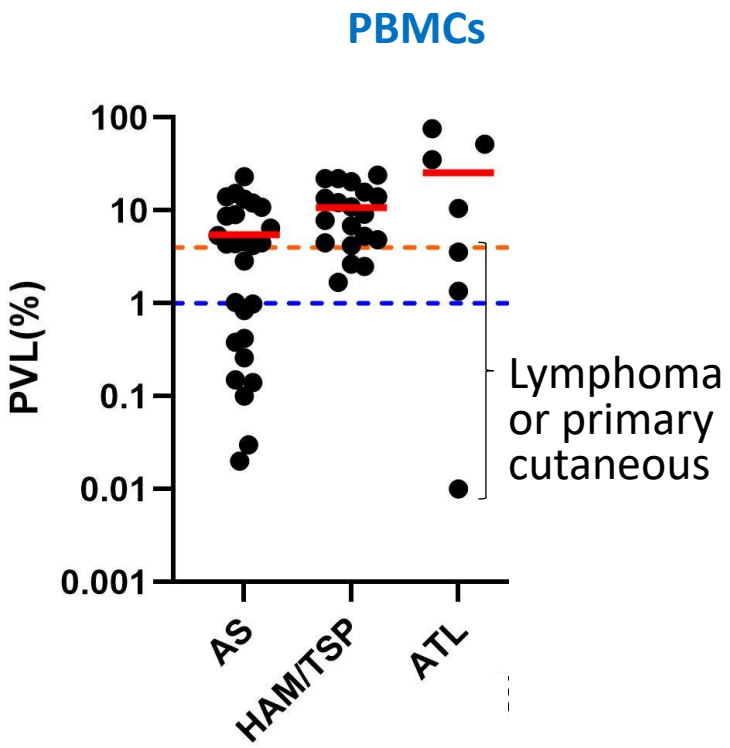


WB PVL is approximately ~0.56x of PBMC PVL.
DBS PVL is approximately ~0.60x of PBMC PVL.

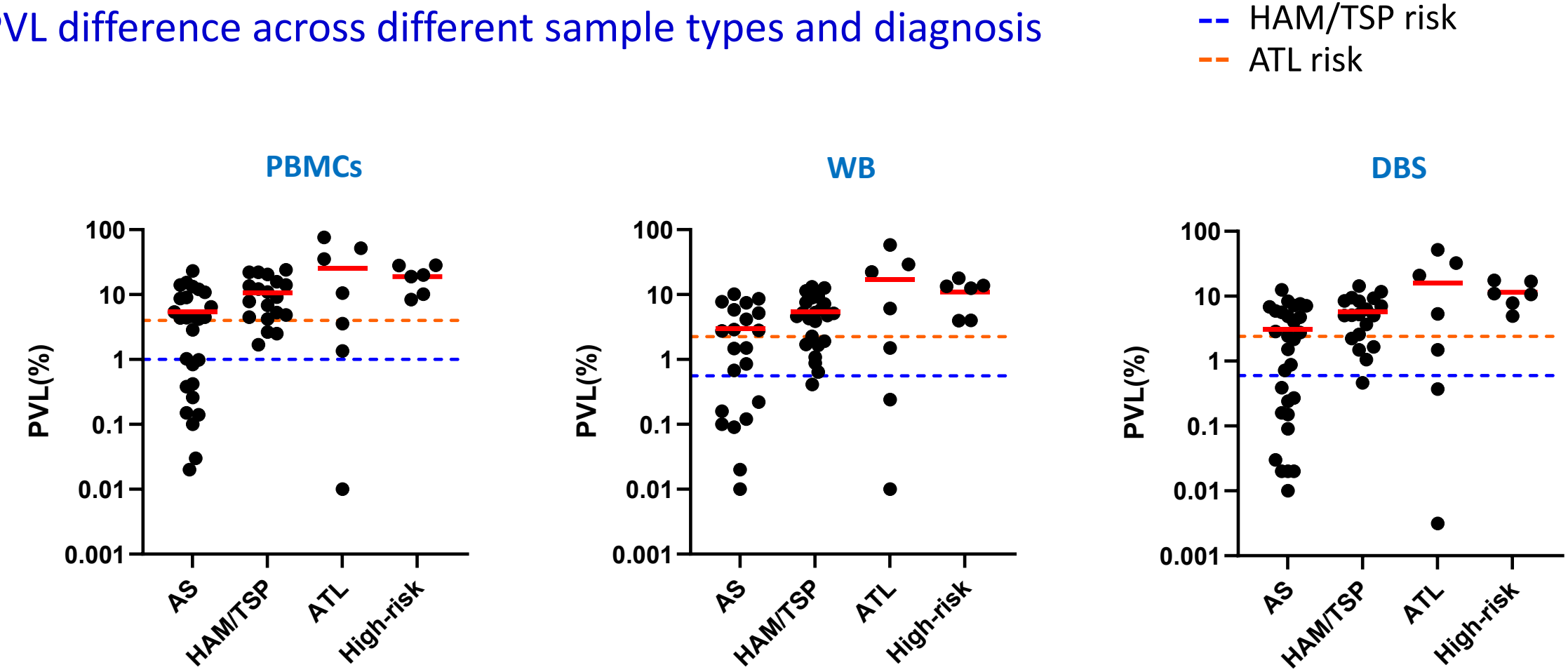
	HAM/TSP risk	ATL risk
PBMC cut-off	>1%	>4%
Estimated WB cut-off	>0.56%	>2.24%
Estimated DBS cut-off	>0.60%	>2.40%

PVL difference across different sample types and diagnosis

-- HAM/TSP risk
-- ATL risk



PVL difference across different sample types and diagnosis



	HAM/TSP	High-risk (of ATL)
PBMC cut-off	>1% (**24/24**)	>4% (**6/6**)
Estimated WB cut-off	>0.56% (**23/24**)	>2.24% (**6/6**)
Estimated DBS cut-off	>0.60% (**23/24**)	>2.40% (**6/6**)

Estimated cut-off captures majority of HAM/TSP samples and samples at high-risk of ATL development.
Still collecting more samples to identify a better cut-off.

Conclusion:

WB

Storage temperature	-20°C	4°C	RT	35°C	50°C
DNA recovery	✓	✓	✓	△ Up to 7 days	✗
HTLV detection	✓	✓	✓	△*	–
HTLV quantification	✓	✓	✗	✗	–

*poor gDNA recovery can lead to false negative.

DBS

	DBS
DNA recovery	✓
HTLV detection	✓
HTLV quantification	✓

Better option for long storage

Next step:

Collecting more matching samples (PBMS, WB, DBS) to investigate a suitable cut-off for risk stratification.

Acknowledgement:

Rowan lab

Aileen Rowan
Anat Melamed
Patricia Watber
Devon Weterings
Ruihan Liu
Maram Bouguerra

Rosadas lab

Carolina Rosadas de Oliveira
William Evans

National Reference Laboratory

Nick Vandegraaff
Fabian Busby
Melissa John

Molecular Diagnostic Unit (MDU)

Claire L Greiller
Charlotte Accattatis

National Centre for Human Retrovirology

Graham P Taylor
Lucy Cook
Divya Dhasmana
Jerico Baylon

Universidade Federal de Minas Gerais

Laura Cox

All the patient consented for the tissue bank

NIHR | Imperial Biomedical Research Centre

IMPERIAL

Thank you

Momoko Usui, Claire L Greiller, Graham P Taylor, Carolina Rosadas de Oliveira, Lucy Cook, Aileen Rowan

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

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

HTLV-I family cluster with varied outcomes and a potential exposure-related HTLV-I seroindeterminate status

Jessica Cuenca-Iglesias[1], Gabriela Garrido-Pinzás[1], Nyater Ngouth[2], Eduardo Gotuzzo[1], Steven Jacobson[2]

Jessica Cuenca-Iglesias

Instituto de Medicina Tropical "Alexander von Humboldt" (IMTAvH),
Universidad Peruana Cayetano Heredia, Lima, Perú.

Conflicts of interest

I have no conflicts of interest

Background

- HTLV-I frequently clusters within families through vertical and sexual transmission. Long-term observation of affected families provides insight into the diverse outcomes of exposure.

Method

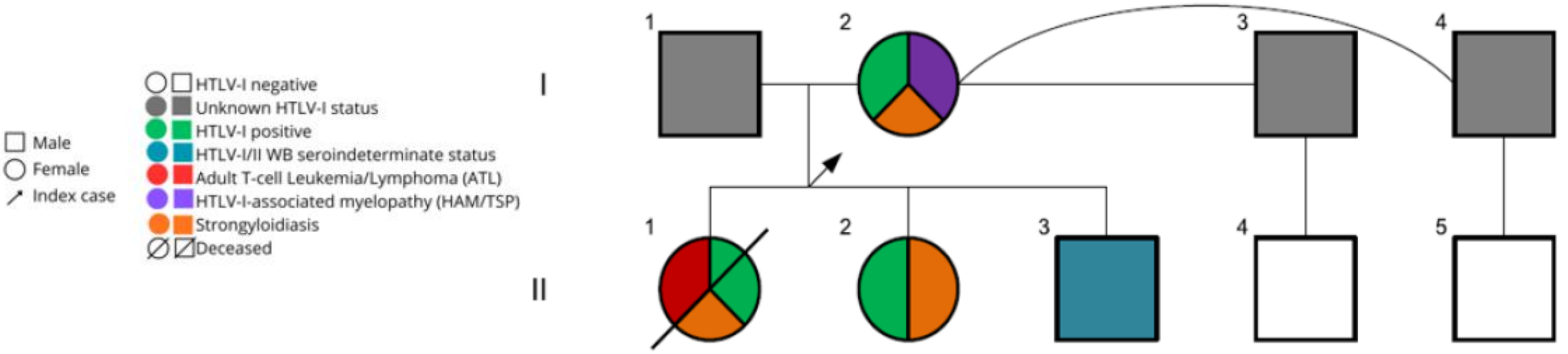
- ❑ We reviewed clinical and laboratory data from families monitored at the HTLV-I Research Unit of the IMTAvH-UPCH in Lima, Peru.
- ❑ Serologic and molecular testing were performed at IMTAvH-UPCH and NINDS/NIH using the same serum and PBMC DNA samples collected in 2024.

Serologic Testing	Performed at
HTLV I/II ELISA	UNIVERSIDAD PERUANA CAYETANO HEREDIA | Clínica Cayetano Heredia
HTLV I/II WB	NIH National Institute of Neurological Disorders and Stroke

Molecular Testing	Performed at	Fluorescent reporter	HTLV-I genome target	Housekeeping gene
HTLV-I PVL qPCR	UNIVERSIDAD PERUANA CAYETANO HEREDIA | Instituto de MEDICINA TROPICAL ALEXANDER VON HUMBOLDT	SYBR Green I dye	pX region (*tax*)	ERV-3
HTLV-I PVL ddPCR	NIH National Institute of Neurological Disorders and Stroke	Probes FAM (HTLV-I genome target) VIC (housekeeping gene)	*tax*	RPP30

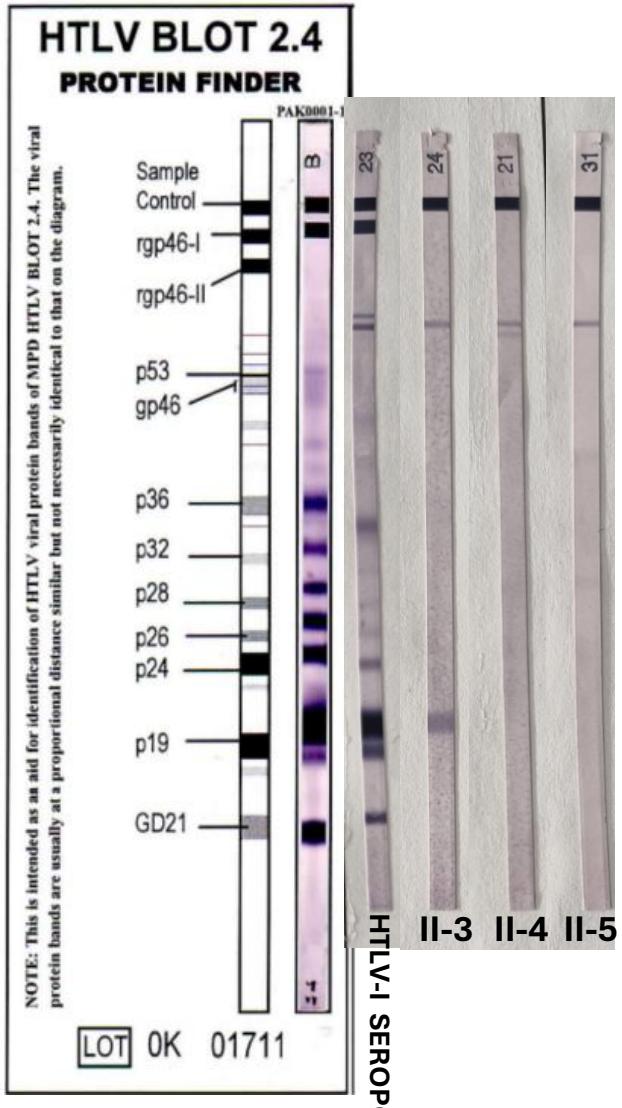
Results

Family genogram



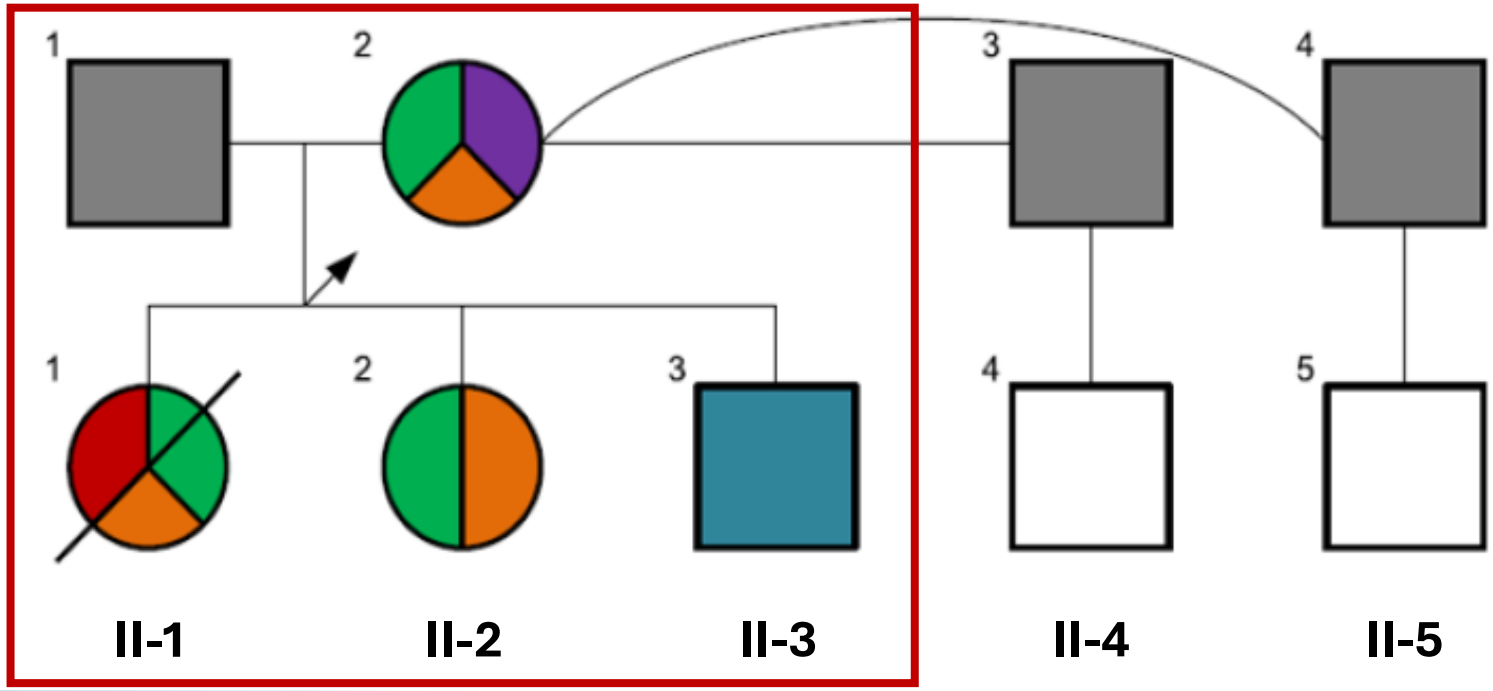
	II-1	II-2	II-3	II-4	II-5
Strongyloidiasis	1996	YES	NO	NO	NO
HTLV I/II ELISA (2024)	unavailable	unavailable	non-reactive	non-reactive	non-reactive
HTLV-I PVL qPCR (2024)	Acute ATL (2024) >10000 copies/10000 PBMC (100%)	1395 copies/10000 PBMC (13.95%)	unavailable	undetectable	unavailable

HTLV I/II Western Blot



HTLV-I SEROPOSITIVE

HTLV-I vertical transmission



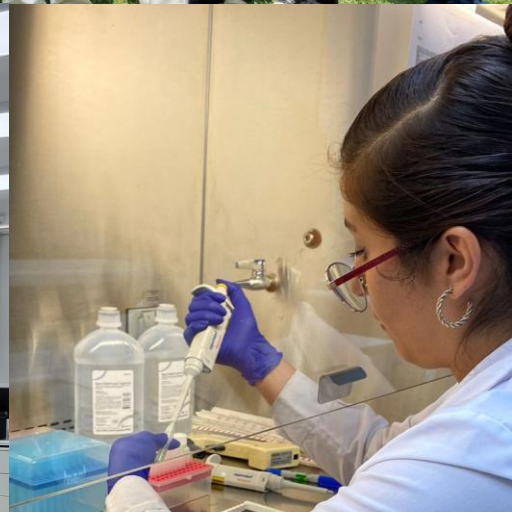
	II-1	II-2	II-3	II-4	II-5
HTLV I/II ELISA	unavailable	unavailable	non-reactive	non-reactive	non-reactive
HTLV I/II WB	unavailable	unavailable	**seroindeterminate**	seronegative	seronegative
HTLV-I PVL (PBMC DNA)	Acute ATL (2024) qPCR: 100%	qPCR: 13.95%	unavailable	undetectable (qPCR)	unavailable
Breastfeding	1-2 years	1-2 years	0-6 months	NO	0-6 months

Conclusion

- We hypothesize that limited early-life exposure to HTLV-I, such as short-duration breastfeeding, could induce partial immune responses without establishing persistent infection, potentially resulting in seroindeterminate WB results.

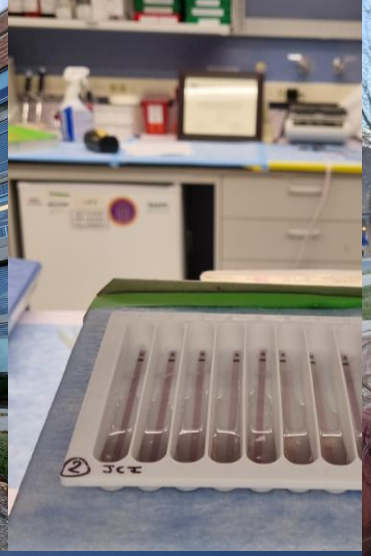
- A negative ELISA result is not sufficient; WB and PCR confirmation should be incorporated into the screening process.

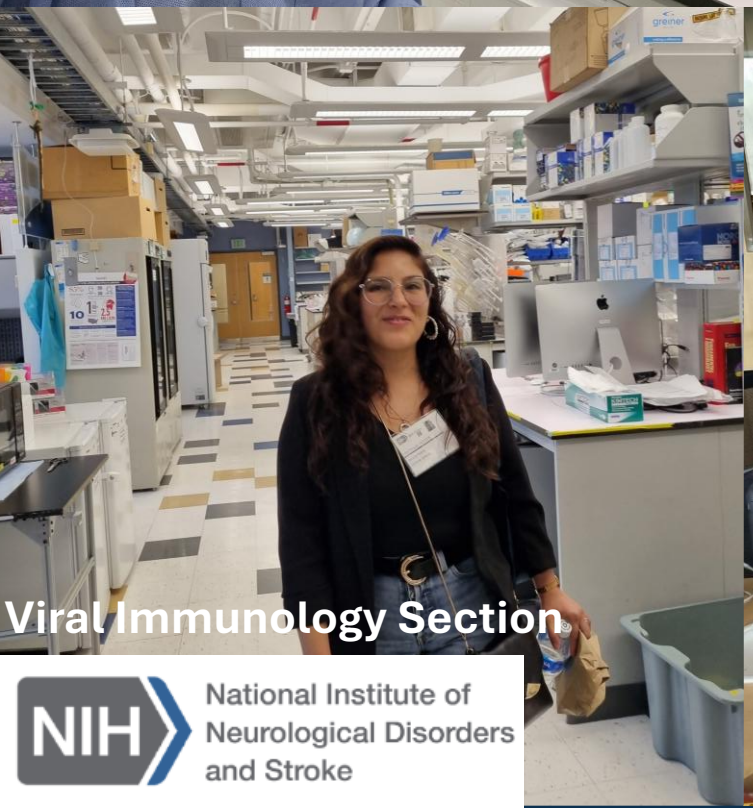
HTLV-1 Research Unit Team



UNIVERSIDAD PERUANA CAYETANO HEREDIA

Instituto de MEDICINA TROPICAL ALEXANDER VON HUMBOLDT





Viral Immunology Section

National Institute of Neurological Disorders and Stroke

National Harbor, Maryland, USA.

We can do it!!!

Let’s keep researching, doing science and generating knowledge in HTLV-I retrovirus field!!!

For more women and girls in Science!!!

Thank you

22nd International Conference on Human Retrovirology:
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Improving access to and quality of Molecular Testing for HTLV globally

Mirna Biglione
CONICET–Universidad de Buenos Aires, Argentia

Thomas Jefferson University | Drexel University | Drexel Medicine

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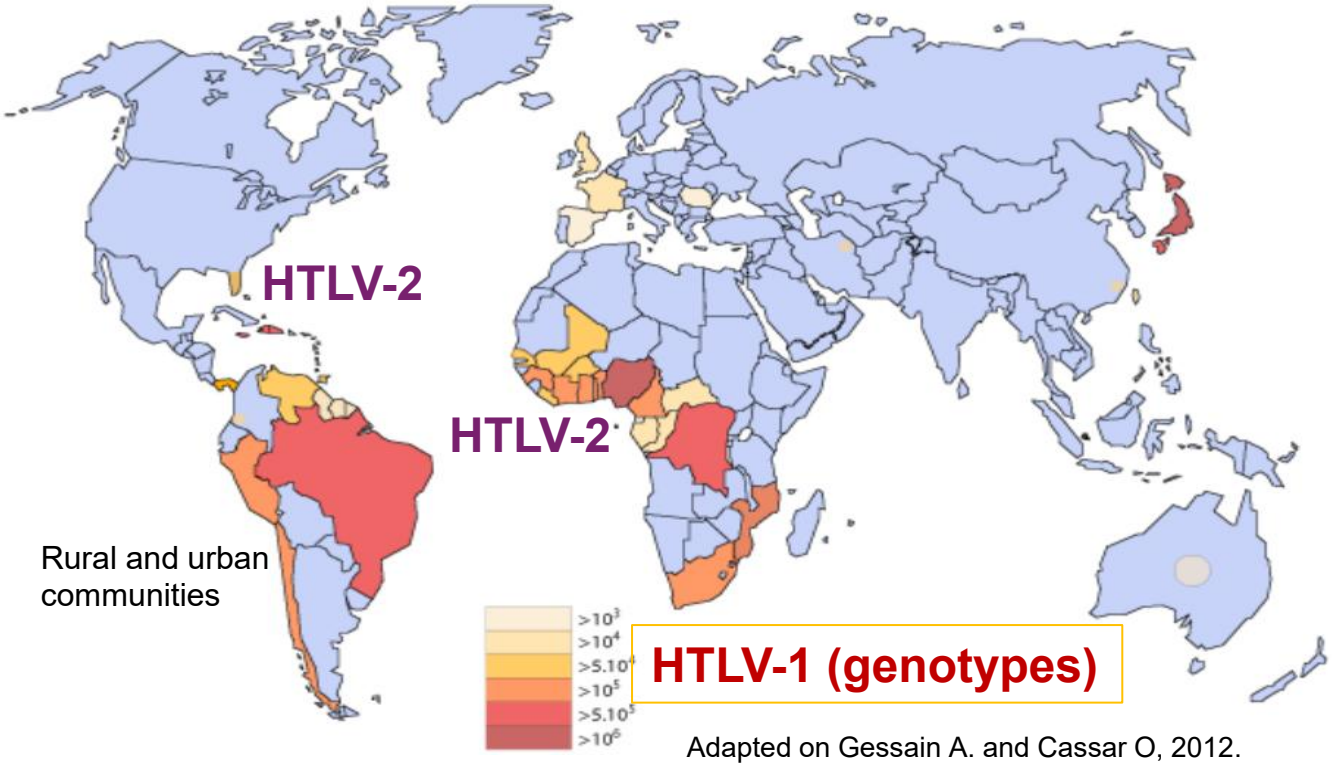
University of Buenos Aires- National Research Council (UBA-CONICET)
Argentina

INSTITUTO DE INVESTIGACIONES BIOMÉDICAS EN RETROVIRUS Y SIDA
ex Centro Nacional de Referencia para el Sida
INBIRS
CONICET

School of Medicine, University of Buenos Aires, Argentina

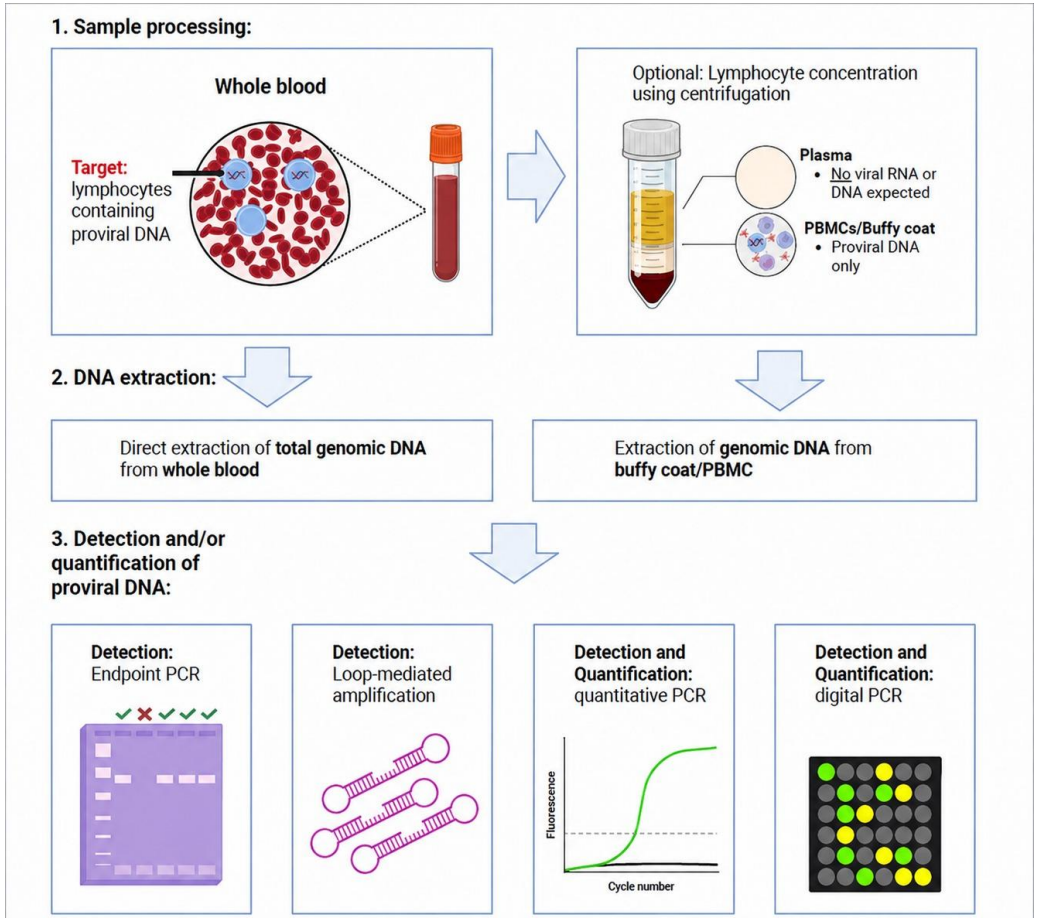
I have no conflicts of interest

Epidemiological and economic differences worldwide



Rural and urban communities

Adapted on Gessain A. and Cassar O, 2012.



Different tests and protocols are used depending on the situation and possibilities of the laboratory/city/country

The core problem

- Need for molecular confirmatory diagnosis and PVL monitoring
- No commercially available HTLV molecular tests worldwide

The Challenge

"In-house" assays developed without standardized guidance

Patients in **low-income regions** frequently face diagnostic delays, which complicates the clinical management of associated pathologies and hides the true epidemiological burden of the virus.

Background

The IRVA TESTING WORKING GROUP was established in 2023

Global Reach:

IRVA TWG is comprised of 17 experts from 10 laboratories in 7 countries.

***Coordinator: Philippa Hetzel**

Sweden
Kerstin Malm

UK
Aileen Rowan
Carolina Rosadas
Simon Carne
Lucy Cook
Daniel Bradshaw
Graham Taylor

Iran
Rahim Rezaee

Japan
Tomoo Sato
Yoshihisa Yamano
Madoka Kuramitsu
Masumichi Saito

Brazil
Tatiane Assone

Argentina
Nicolas Ducasa
Mirna Biglione

Australia
Nick Vandegraaf
Philippa Hetzel*

Mission

To support the development of accurate, reliable in-house molecular assays to detect HTLV and improve global access.

Objective:

The TWG shares knowledge and expertise to help laboratories select the methodology that best suits their capacity and resources, or to improve existing ones.

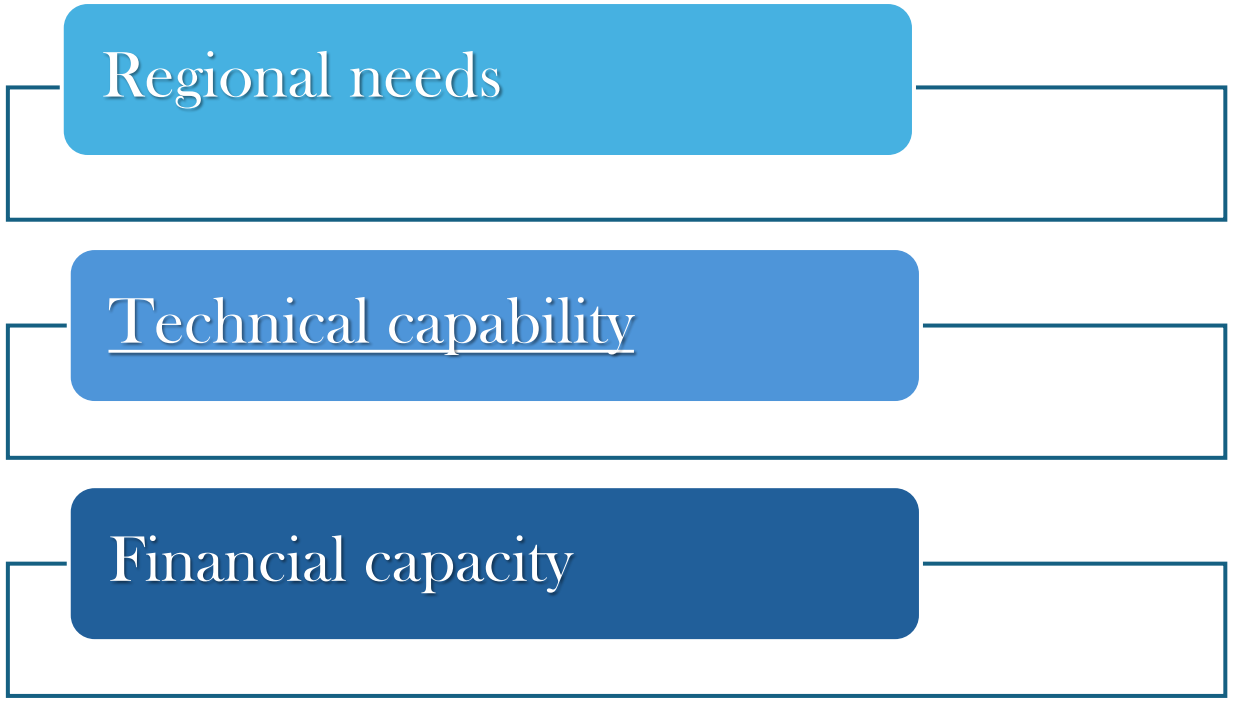
Methodology

- Colleagues from different institutions were invited to participate in the TWG.
- After accepting the proposal (TOR & EOI) **a work plan was agreed** to guide the activity (regular meeting and e-mail exchanges).
- Experts have shared their in-house molecular test protocols in a **consistent format** and carried out a **systematic review** of the methods included.

Results

A guide was developed to improve the selection and adaptation of protocols to local realities

Goal:
Allow countries to choose protocols based on:



Results

Global Overview and Regional Protocols for Molecular Diagnosis of Human T-cell Lymphotropic Virus

Philippa AS Hetzel[1*], Aileen Rowan[2], Tatiane Assone[4,5], Nick Vandegraaff[1], Graham Taylor[2], Daniel Bradshaw[6], Carolina Rosadas[2], Tomoo Sato[7,8], Yoshihisa Yamano[7,8], Madoka Kuramitsu[9], Masumichi Saito[7,10,11], S.A. Rahim Rezaee[12], Kerstin Malm[13], Simon Carne[6], Nicolas Ducasa[3], Lucy Cook[14] and Mirna Biglione[3].

A document was prepared for publication that describes and compares methods used worldwide.

- All laboratory protocols were presented in **standardized templates**.
- A detailed comparative analysis was undertaken.

Parameter	Description / options
Sample type	Whole blood, PBMCs, Buffy coat
Methodology type	Qualitative, Quantitative (qPCR, ddPCR, LAMP)
Molecular targets	HTLV-1, HTLV-2, Genes (e.g., tax, pol, LTR)
Equipment	Analytical platform, Thermal cycler model
Reagents & Materials	Primers, Probes, Standards, and Controls
Analytical performance	Limit of Detection (LoD), Limit of Quantification (LoQ)

“Global Overview and Regional Protocols for Molecular Diagnosis of HTLV”

Table 2: Internal controls, Standards and Limit of Detection

Protocol/type	Proviral gene target	Internal control target	Standard	Standard range (HTLV copies)	Limit of Detection
Japan NIID-qPCR	Pol, Tax	RNase P	TL-Om1 cell line	212,500-8	4 copies HTLV-1 per reaction
Japan StM-pPCR	Tax	RNase P	pUC-HTLV-1 plasmid	10,000-16	4 copies HTLV-1 per reaction
Iran MUMS-qPCR	Tax	Albumin	Plasmid	100,000-10	3-5 copies HTLV-1 per 10^4 cells
Australia NRL -qPCR	Tax	Albumin	In-house generated cell line	500,000-5	5.8 copies HTLV-1 per reaction
UK ICL- qPCR	Tax	Beta Globin	MT2 cell line	70,000-7	2.2 copies HTLV-1 per reaction
UK UKHSA-qPCR	Tax	mCMV spike-in	C8166 (HTLV-1), MO-T (HTLV-2) cell lines	n/a	10 copies HTLV-1 per reaction, 10 copies HTLV-2 per reaction
Brazil IAL- qPCR	Tax	Albumin	Plasmid	1,000,000-1	10 copies HTLV1/2 per reaction
Sweden OUH-ddPCR	Tax	RPP30	HTLV-1 (15493) HTLV-2 (12031), Public Health Agency of Sweden	n/a	1.4 copies HTLV-1 per reaction, 1.4 copies HTLV-2 per reaction
Argentina/ Brazil INBIRS-nPCR	Pol, Tax	Beta Actin	MT2 (HTLV-1)/ MOT (HTLV-2) cell lines	n/a	HTLV-1: 1 copy/10^3 cells HTLV-2: 15 copies/10^3 cells

Abbreviations: qPCR, quantitative PCR; mCMV, cytomegalovirus; ddPCR, digital droplet PCR; nPCR, nested PCR.

The relative advantages and disadvantages of each method were discussed to enable countries to choose the most suitable diagnostic protocol

What achievements beyond documentation?

The initiative is about people

- **Mentoring:** Testing Working Group members offer direct mentoring support and advice when required.
- **Knowledge Transfer: s**haring expertise to help develop high-quality tests.
- **Standardization of assays:** the development of standardized reference materials are in process.

A transcontinental real collaboration

Conclusion

The development of HTLV Clinical and Testing Guidelines by WHO will increase awareness about HTLV, so countries will move toward best practices in managing these retroviruses:

This document will allow to improve access to molecular diagnosis globally including **HTLV-1 and HTLV-2** detection, reduce transmission, and ensure that vulnerable populations receive appropriate care and follow-up.

Improving the efficiency of diagnosis will lead to

quality of testing services

improve access

Acknowledgements:

IRVA Testing Working Group and participating laboratories

"HTLV knows no borders, and neither does our working group.
By connecting experts from Argentina to Japan, we are ensuring that high-quality testing becomes a reality for every clinical setting."

Thomas Jefferson University | Drexel University | Drexel Medicine

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HTLV2026

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

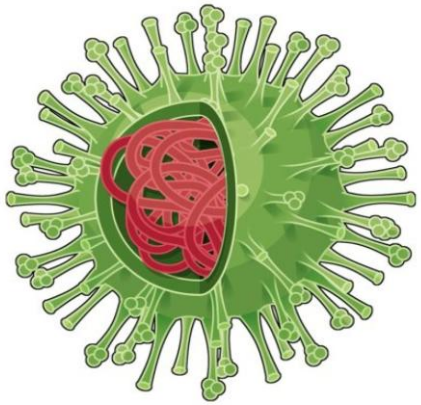
Evaluation and comparison of HTLV-1 proviral load using different methods

Gabriel O. Franco, Andreas Stocker; Eduardo M. Netto; Heliene Pereira; Carlos Brites*

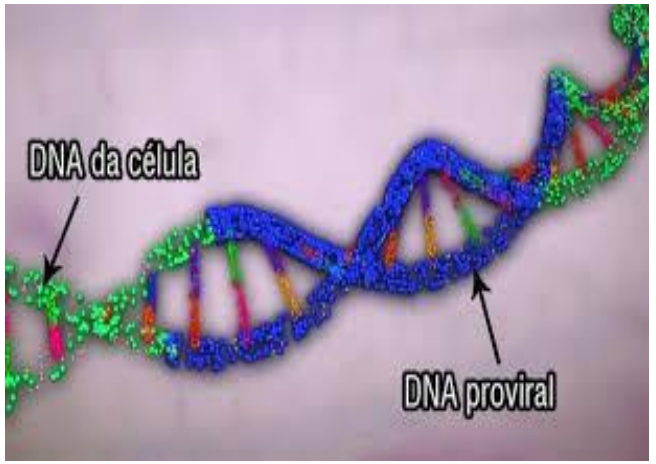
Conflicts of interest

I have no conflicts of interest

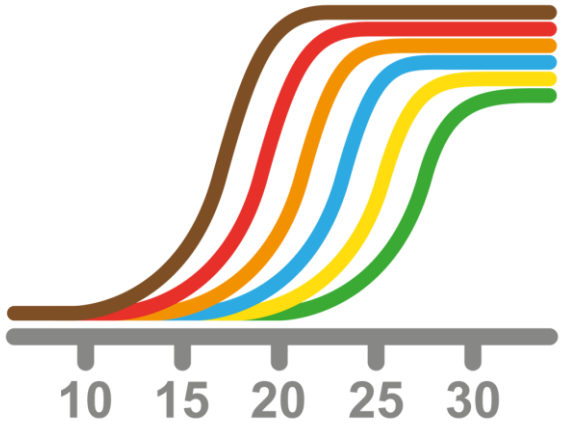
Background



HTLV-1



Proviral Load



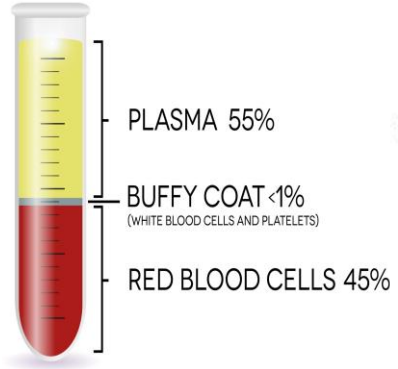
Quantification

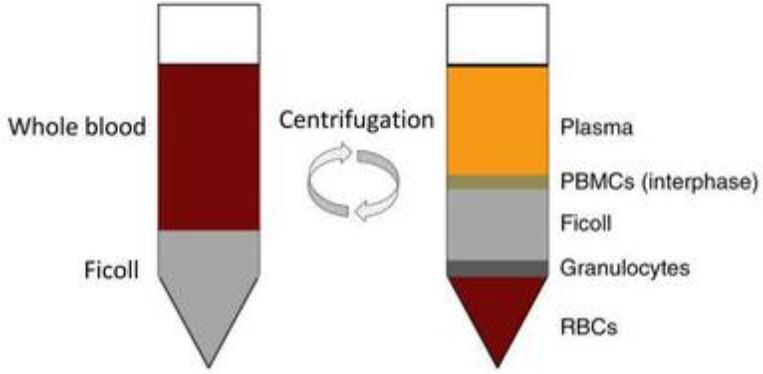
Objectives

- This study evaluated absolute quantification based on total blood volume (copies/µL of blood), based on the direct conversion of Ct values using a standard curve independent of hematological parameters or reference genes, in comparison with established volumetric and cellular protocols.

Methods

- 53 Participants;
- 66 Whole Blood, 44 Buffy Coat, 43 PBMCs and 66 CD4+;





The qPCR design used was developed by Tamegão-Lopes, et al (2006).

Methodology

Whole Blood Volume-Based Absolute Quantification

$$PVL = 10^{(a*(Ct+CF)+b}$$

Method by Tamegão-Lopes, *et al* (2006)

$$PVL = \frac{2^{-CT\ HTLV1}}{2^{-CT\ Albumin}} * Leukocytes * 2$$

Quantification per 1,000 cells (Leukocytes or Lymphocytes)

$$PVL = \frac{(HTLV1\ Copies)}{(ALB\ Copies/2)} * 1000$$

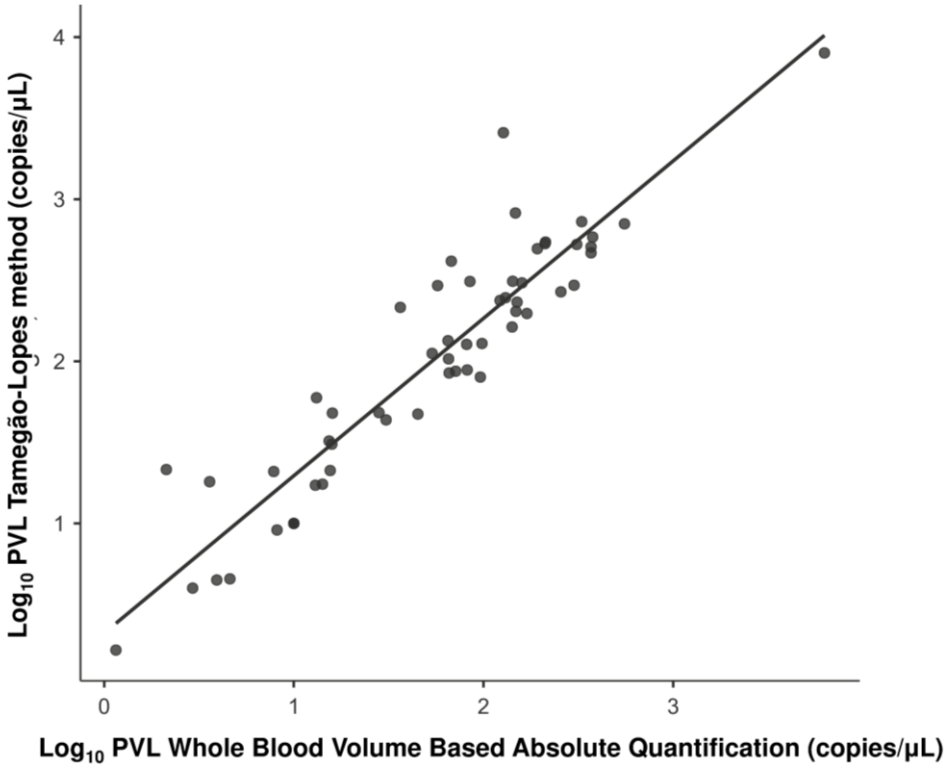
Features and Limitations

	Target	Biological Matrix	Standard Curve	Operational Limitation
Absolute quantification per uL	HTLV-1	Whole Blood	X	Standard Curve
Tamegão, *et al.* (2006)	HTLV-1 Albumin	Whole Blood		Global leukocyte counts, ALB qPCR,
Quantification per 1,000 Leukocites	HTLV-1 Albumin	Whole Blood Buffy Coat PBMC	X	ALB qPCR for cell normalization, Cell process
Quantification per 1,000 Lymphocytes	HTLV-1 Albumin	CD4+	X	ALB qPCR for cell normalization, Cell process

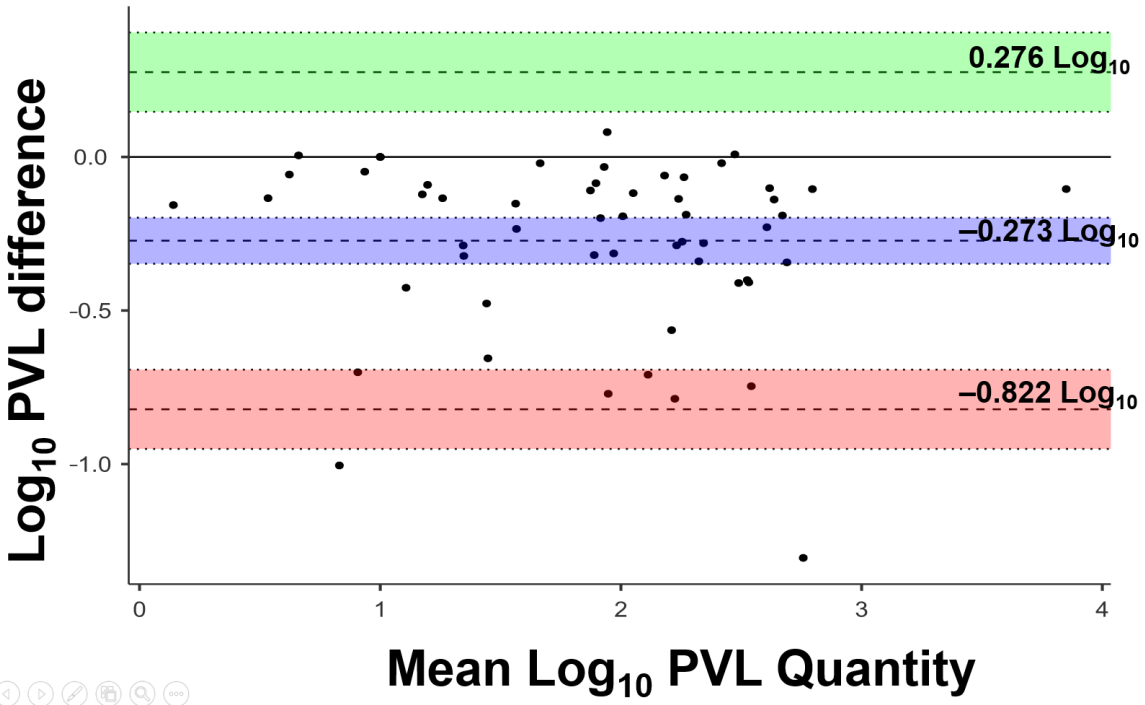
Results

Validation of Volume-Based Quantification (µL)

***r*: 0.93; *p*: <0.001**

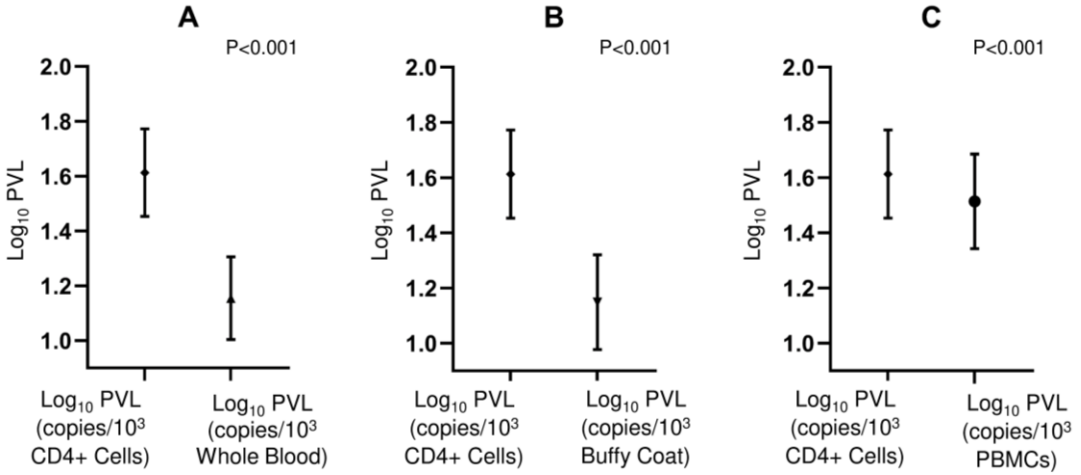


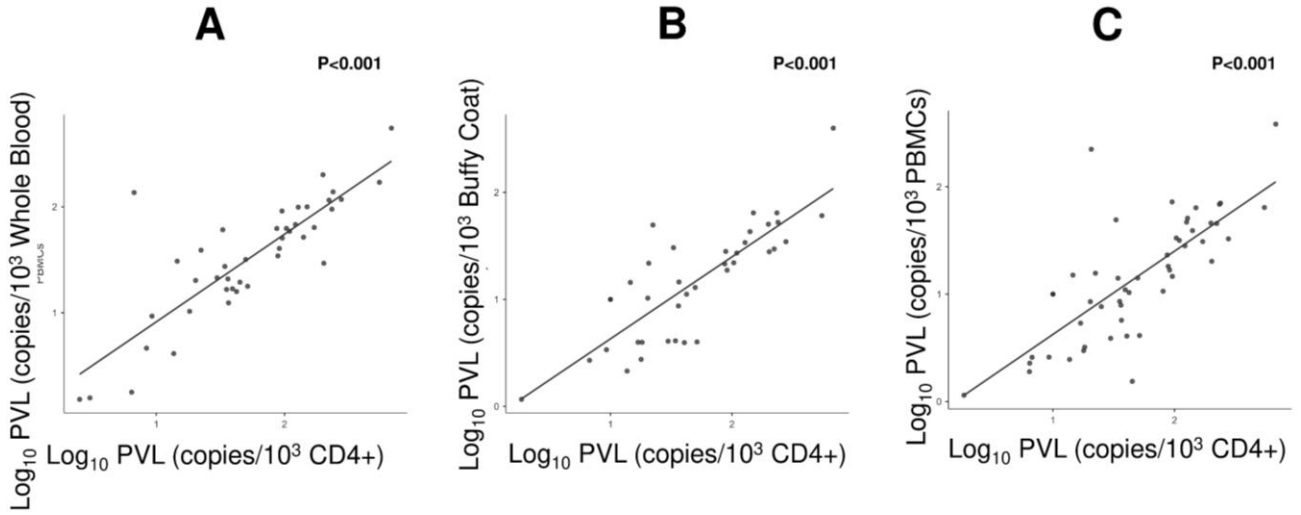
Mean Bias: -0.273; *CCC*: 0.866

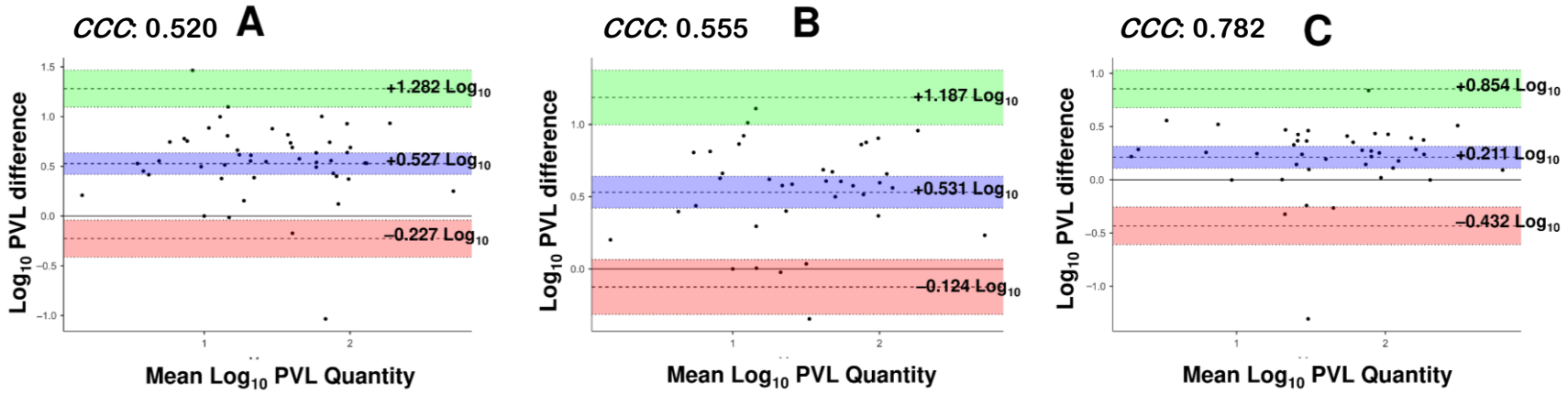


Results

Validation of Biological Matrices Based on Protocols Normalized per 1,000 Cells



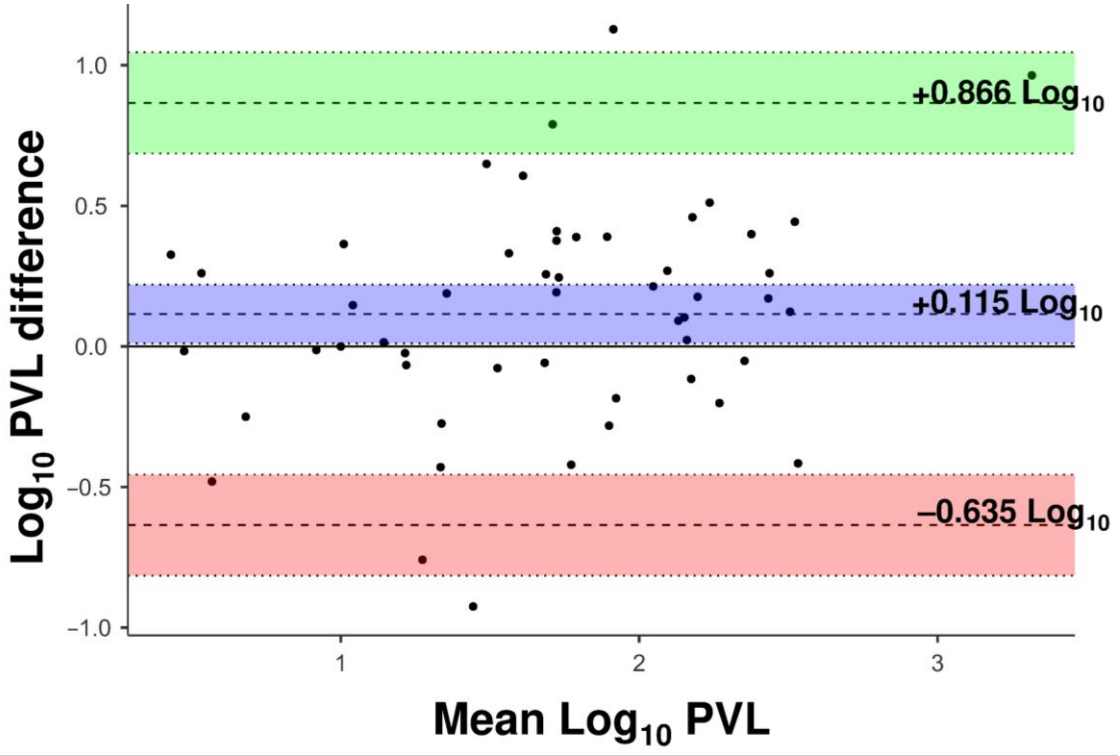




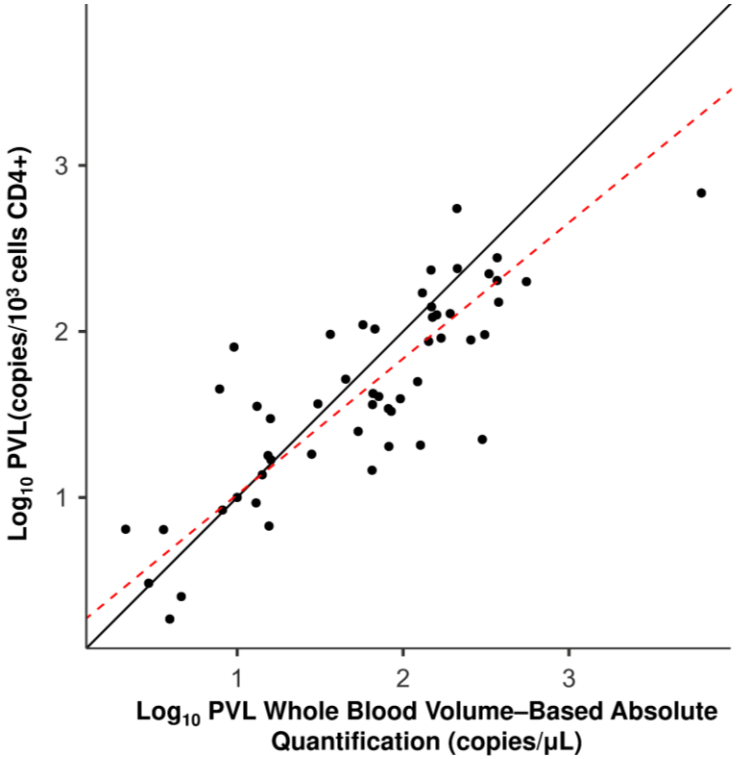
Results

Interchangeability Between Methods

Mean ± SD (log_{10})	*p*	*r*	Bias (log_{10})	CCC (95%)	LoA (95%)
1.73 ± 0.70 1.62 ± 0.62	0.031	0.84	0.115	0.811 (0.704/0.883)	−0.635/0.866



Intercept (95% CI)	Slope (95% CI)
0.197 (−0.082/0.476)	0.820 (0.664/0.975)



Conclusions

- Whole blood volume–based quantification showed high concordance with the CD4+-based protocol.
- The method reduced limitations associated with leukocyte-normalized approaches and cellular heterogeneity.
- The protocol simplifies workflow by eliminating dependence on external hematological parameters.
- WBV quantification represents a feasible and Simplified strategy for HTLV-1 molecular monitoring.

viruses

MDPI

Article

Whole Blood Volume-Based Absolute Quantification of HTLV-1 Proviral Load: A Comparative Method Evaluation Study

Gabriel O. Franco [1,2,3], Andreas Stocker [1,2,3], Eduardo M. Netto [1,2], Heliene Pereira [1,2,3] and Carlos Brites [1,2,*]

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* Correspondence: crbrites@gmail.com or crbrites@ufba.br; Tel.: +55-71-3646-3737

Tank you all

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HTLV2026

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

Population-based Patterns of Adult T-cell Leukemia/Lymphoma in the United States

Paulo S. Pinheiro, University of Miami

MIAMI MILLER SCHOOL of MEDICINE

Conflicts of interest

I have no conflicts of interest

Background

- Adult T-cell Leukemia/Lymphoma (ATLL) caused by HTLV-1, a virus commonly acquired through mother-to-child transmission via breastfeeding
- There are immigrant communities in the US from high endemic areas but the US burden of ATLL in these populations is not well characterized
- Japan reduced HTLV-1 transmission through maternal screening programs

Objective

- To quantify ATLL incidence by race/ethnicity and by detailed country/region of birth IN THE US

- To compare the incidence with endemic regions with established maternal HTLV-1 screening.

Methods

- Population-based cancer registry data from all 50 US states (CiNA) 2005-2022
  - ATLL was identified using ICD-O-3 morphology code 9827/3
  - PTCL-NOS 9702/3
  - Individuals ≥15 years old(2005 – 2022) : 3,228 cases
- Incidence rates were estimated per million population, ACS-derived population denominators stratified by age, sex, race/ethnicity, nativity, and country of birth
- Survival analysis for Florida and New York
- Sensitivity Analysis for misclassification of PTCL-NOS

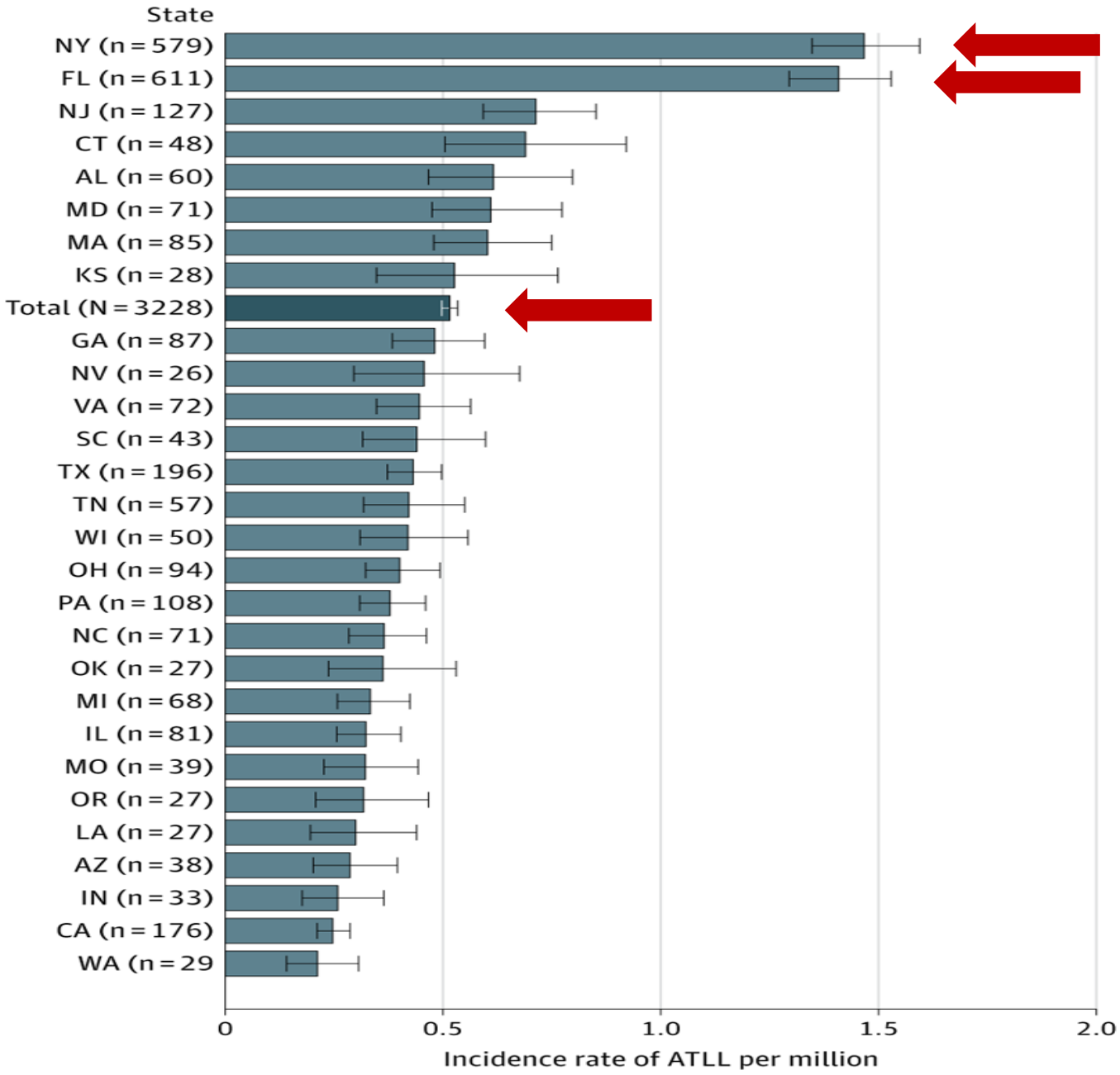
Results by Race-Ethnicity

Table 1. Characteristics and Age-Adjusted Incidence Rate per Million Population of ATLL by Race, Ethnicity, and Sex, 50 States, 2005 to 2022

Race/Ethnicity	N	Rate per Million
NH† White	1,394	0.3
NH† Black	1,300	1.9
API‡	126	0.5
Hispanic	364	0.6
Both Sexes ALL COMBINED	3,228	0.6

Results

Figure 1. Bar Graph of Age-Adjusted Incidence Rate Per Million of ATLL by US State (N ≥ 25 Cases), Standardized to the 2000 US Standard, 2005 to 2022



By Country and Region of Birth

- Analysis by detailed country of birth were restricted to 13 states: AZ, CT, FL, GA, HI, ID, IL, MA, MT, NY, OR, UT, WA

- Countries/Regions ≥20 cases were analyzed individually; quite a few Caribbean nations surpassed that threshold; Jamaica, Haiti, Grenada , Trinidad , Guyana; smaller islands were grouped by standard geographic criteria (Leeward and Windward islands)

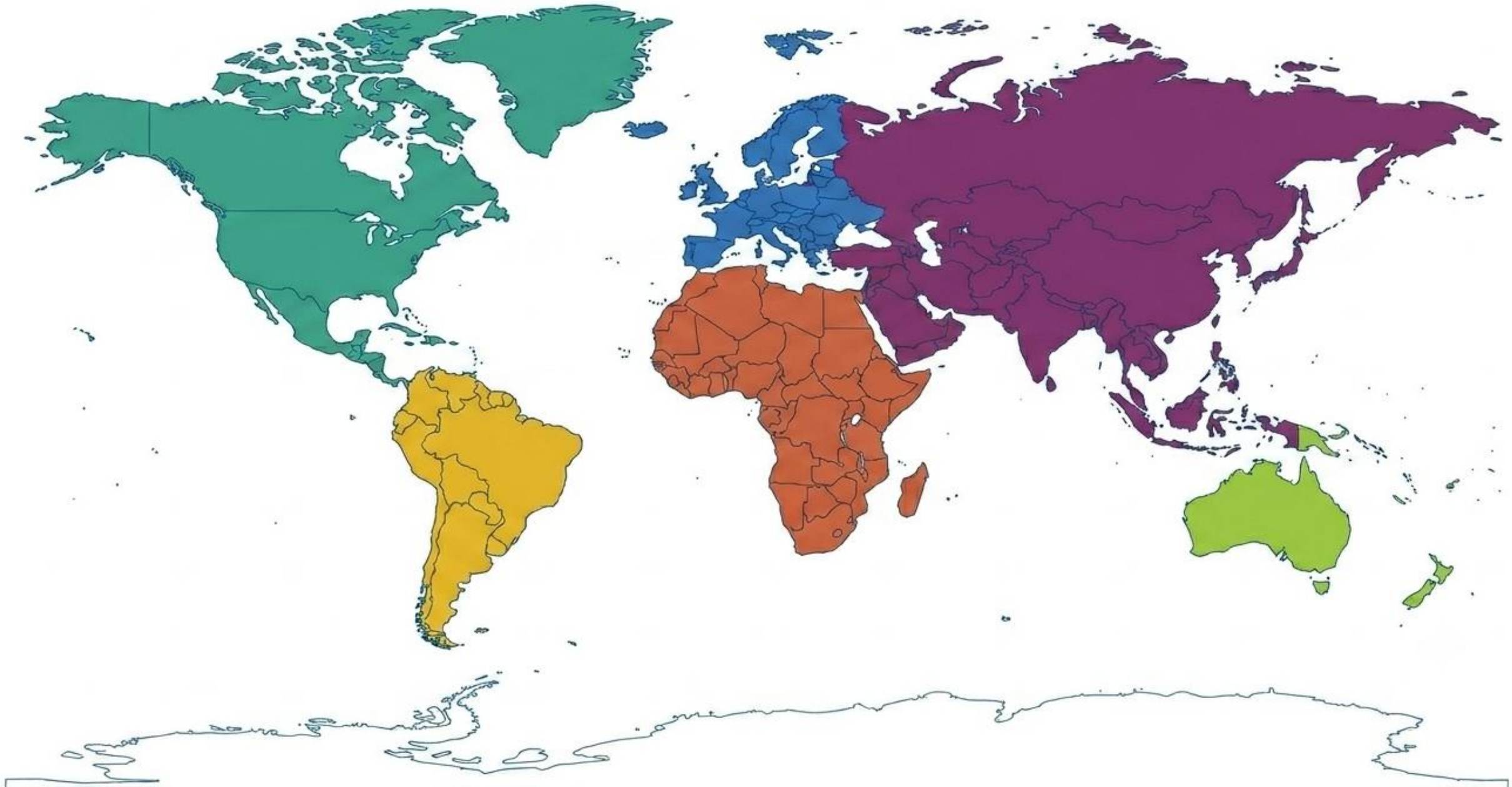
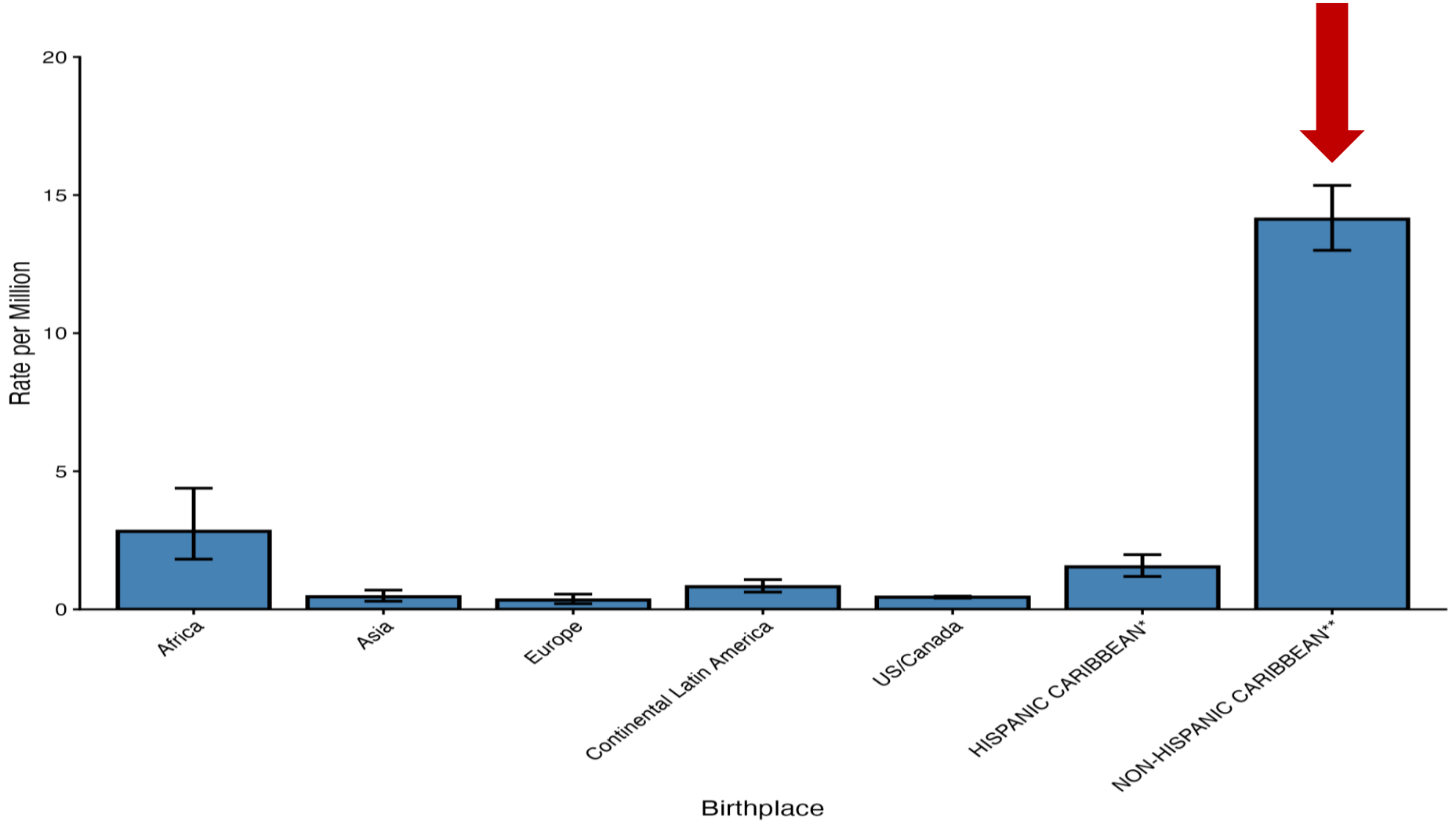


Figure 3. Age-Adjusted Incidence Rate per Million of ATLL by Birthplace, Standardized to the 2000 US Standard, 13 States, 2005 to 2022



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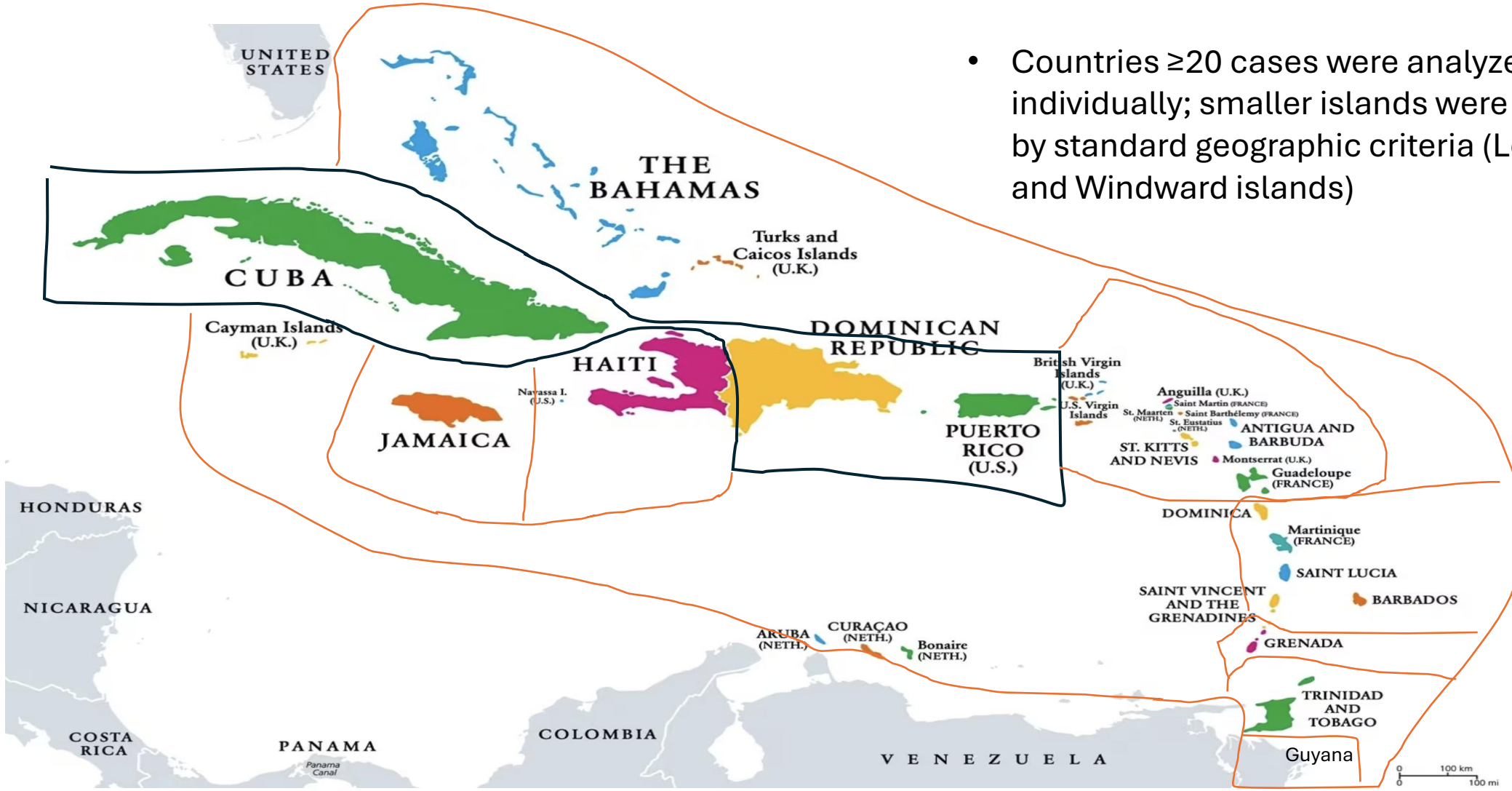
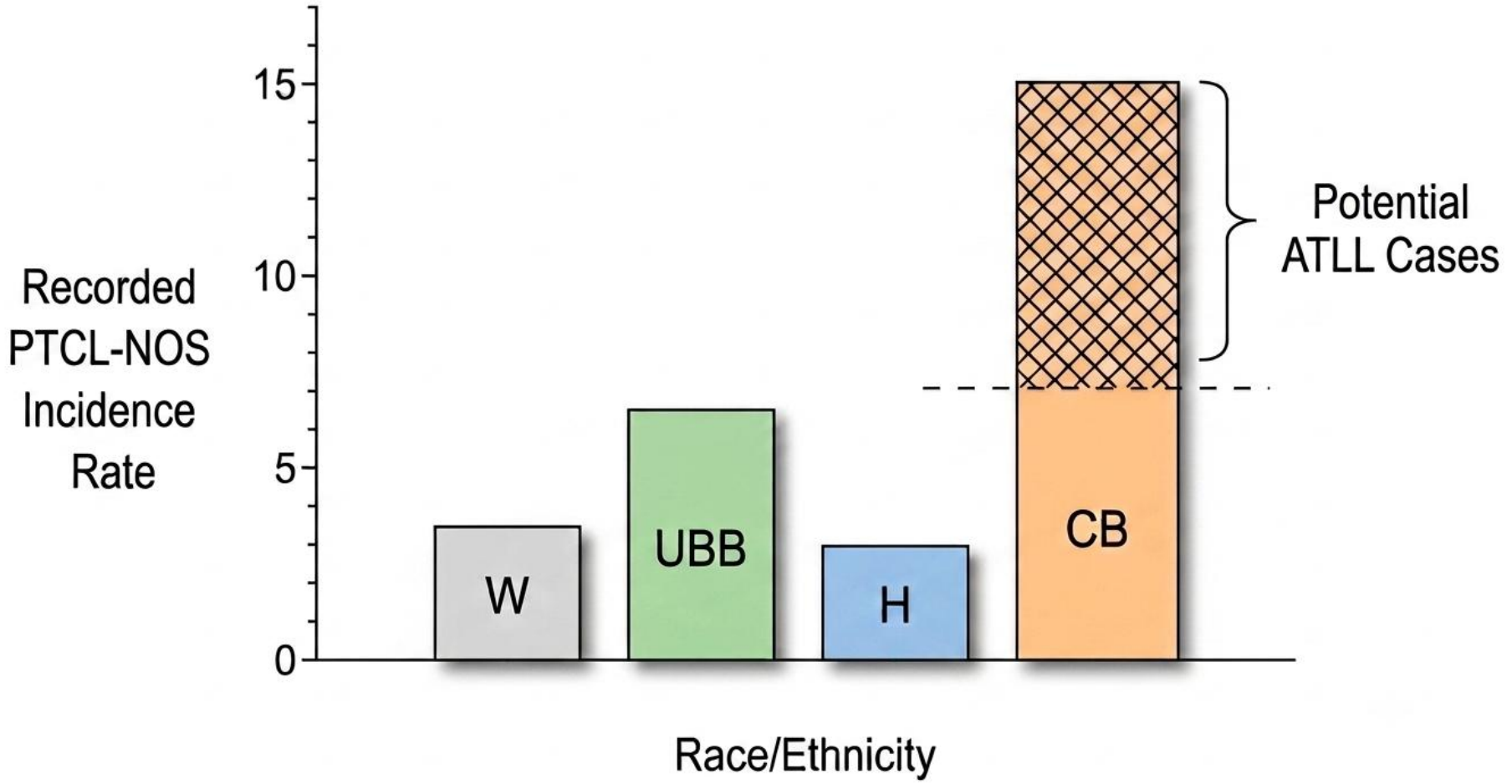
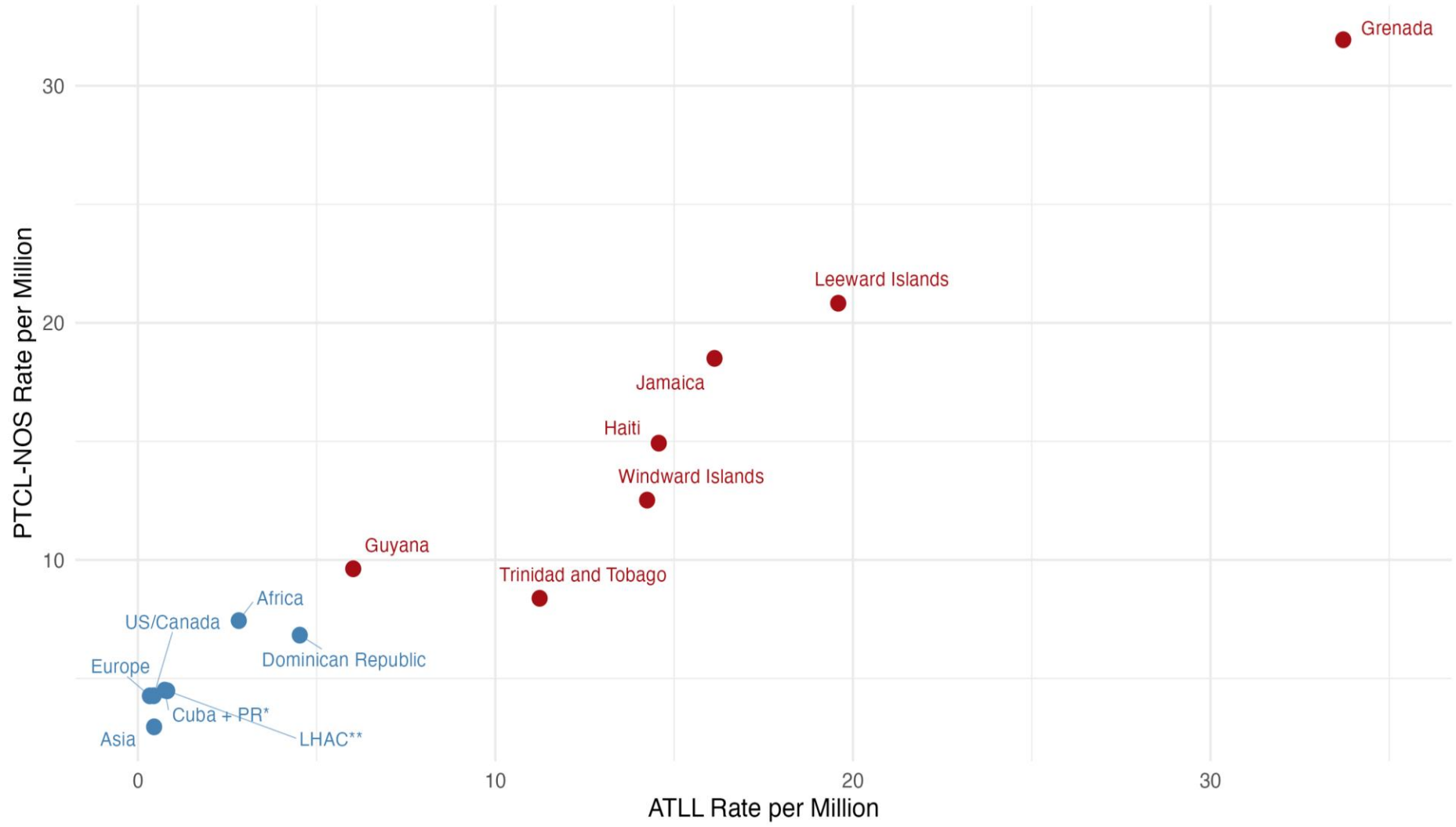


Methods: Assessment of Misclassification



MISCLASSIFICATION: Figure 2. Scatterplot of Age-Adjusted Incidence Rates ATLL and PTCL-NOS by Birthplace,13. PEARSON Correlation(+0.98,p<.01) US States, 2005–2022.



* Cuba+PR = Cuba + Puerto Rico

** LHAC = Latin America (Mexico, Central America, South America)

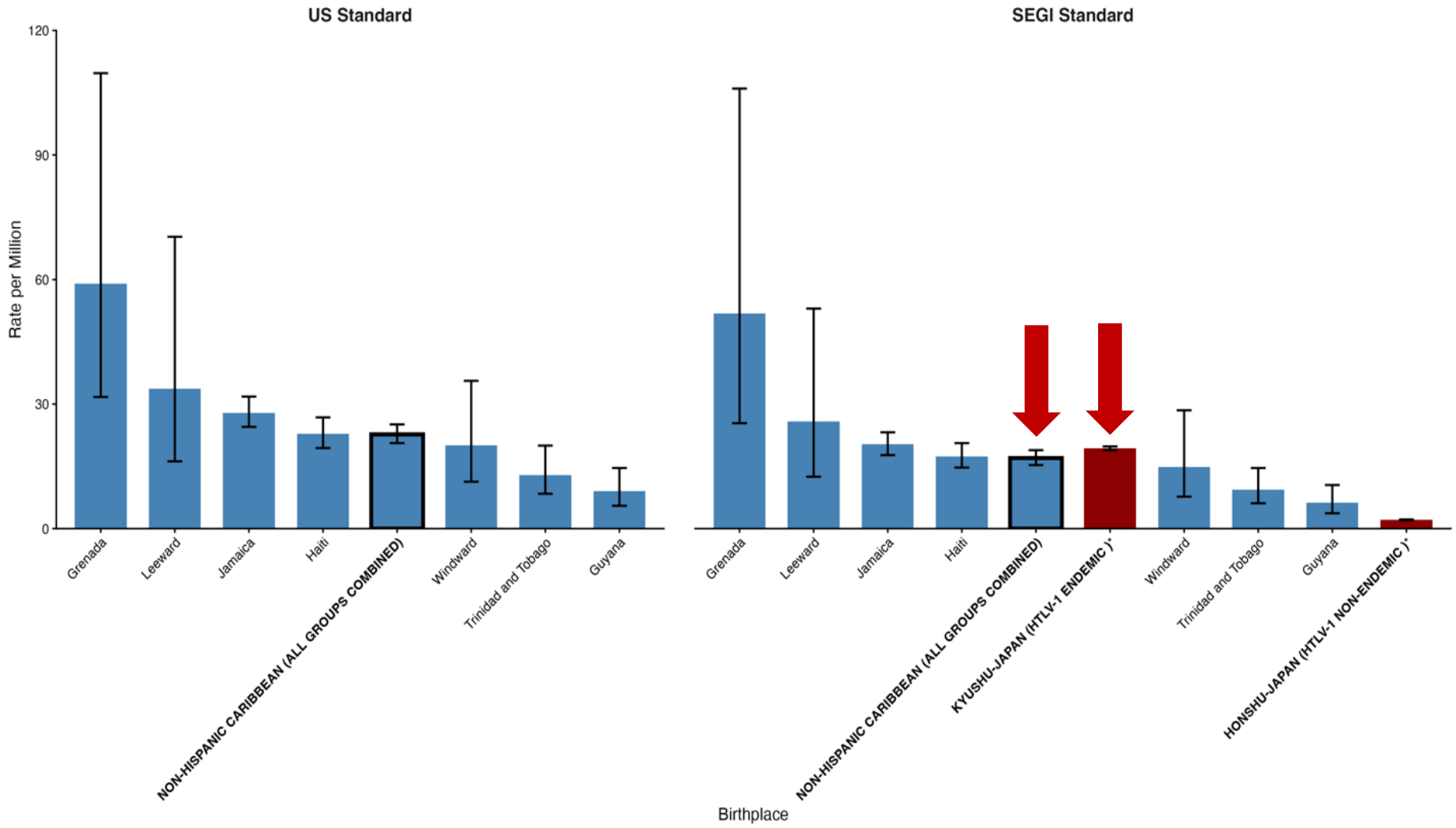
Results

Table 2. Characteristics and Age-Adjusted Incidence Rate per Million Population of ATLL by Birthplace, US 2000 Standard, 13 States, 2005 to 2022

Birthplace	Incidence Rate per Million	IRR (95%CI) †	After PTCL-NOS‡ reclassification (Rate per Million)
US/Canada (N=697)	0.4	Ref.	-
Europe (N=30)	0.3	0.8 (0.5 – 1.3)	-
Africa (N=36)	2.8	6.4 (4.1 – 10.0)	-
Asia (N=39)	0.5	1.0 (0.7 – 2.1)	-
Continental Latin America (N=73)	0.8	1.9 (1.4 – 2.5)	-
Hispanic Caribbean (N=107)	1.5	3.5 (2.7 – 4.5)	-
Dominican Republic (N=72)	4.5	10.3 (7.8 – 13.5)	-
Cuba + Puerto Rico (N=35)	0.8	1.7 (1.0 – 2.8)	-
Non-Hispanic Caribbean (N=641)	14.1	32.0 (28.6 – 35.9)	22.7
Grenada (N=28)	33.7	76.4 (40.2 – 145.3)	59.0
Guyana (N=35)	6.0	13.7 (8.0 – 23.4)	9.0
Haiti (N=189)	14.6	33.0 (27.9 – 39.2)	22.8
Jamaica (N=237)	16.1	36.6 (31.4 – 42.6)	27.9
Leeward Islands (N=27)	19.6	44.4 (25.9 – 76.1)	33.7
Trinidad and Tobago (N=51)	11.2	25.5 (18.8 – 34.5)	12.9
Windward Islands (N=36)	14.2	32.3 (19.6 – 53.2)	20.1
ALL COMBINED (N=1632)	0.8	1.9 (1.7 – 2.1)	-

Results

Figure 4. Age-adjusted incidence rate per million of ATLL after reclassification from PTCL-NOS by birthplace using US and SEGI standards for comparisons, 13 US states and HTLV-1 endemic and non-endemic areas of Japan



Key Finding

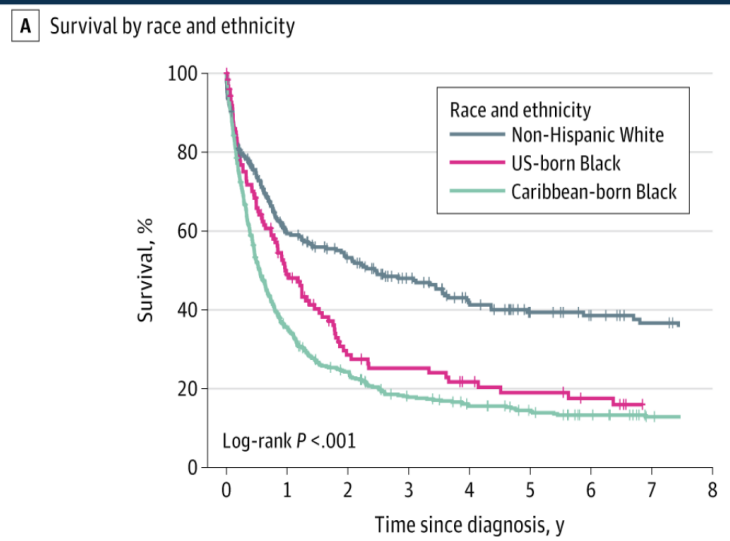
- ATLL incidence among Caribbean-born populations in the US (population of 2 million with descent 3 million) approaches or exceeds rates reported from endemic regions – Okinawa/Kyusyu in Japan.

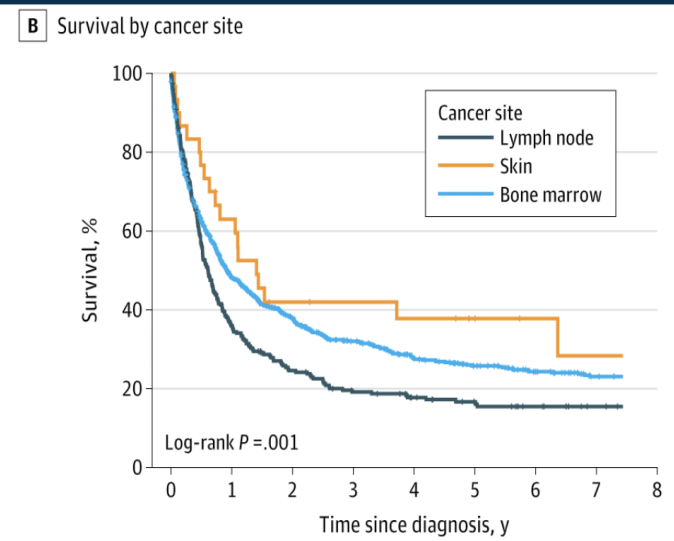
Main Results

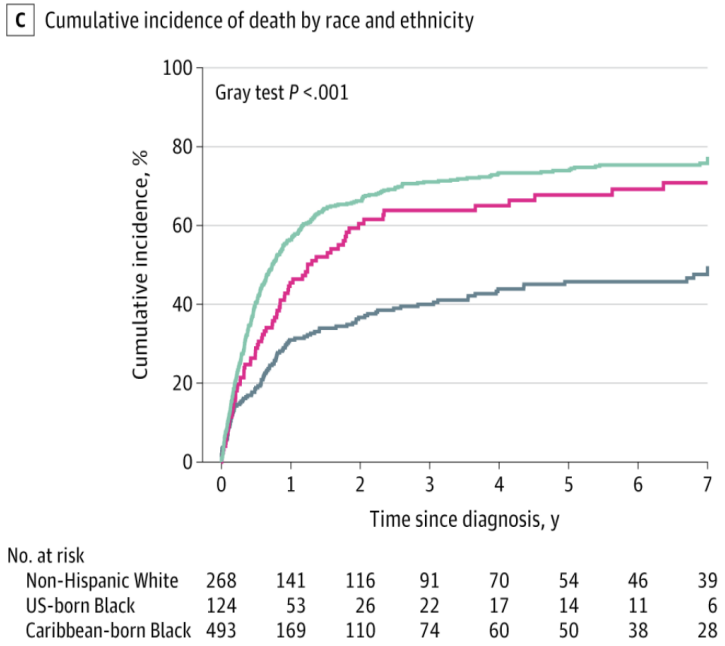
- We have at the very least 200 new ATLL cases in the US (lower end of estimation) possibly 250-300
- At least 81 cases annually are Caribbean-born (a population of 2 million in the US)
- Many are being recorded as PTCL-NOS (in the Caribbean population as many as 42%)
- In Japan there are 1,200 new ATLL cases annually, concentrated in Okinawa and Kyusyu (latest data from Okuyama et al).

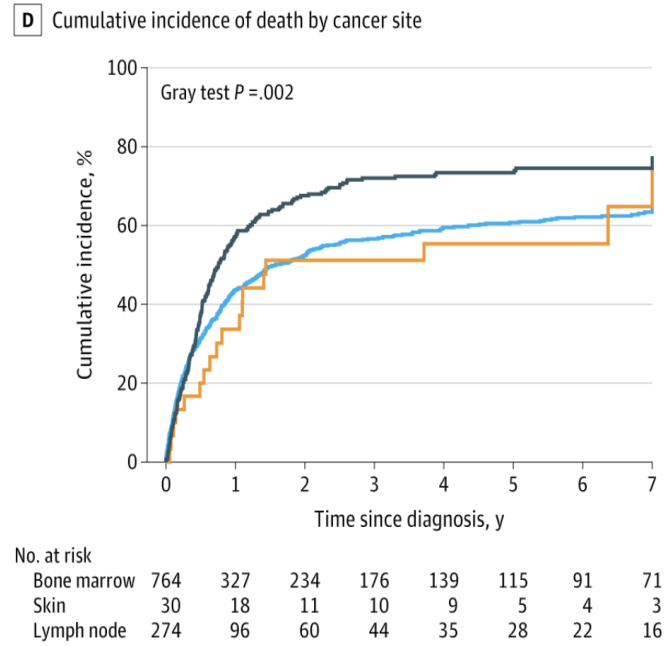
Results

- A total of 1,114 cases from NY and FL, 2005 – 2021
- 5-year overall survival was 23.8% (95%CI: 21.1 – 26.5); lowest in Caribbean-born Black individuals (14.5%; 95%CI: 11.2 – 17.8)
- Fine-Gray competing risk model
  - Caribbean-born Black patients had the highest ATLL-specific mortality (sHR 2.33; 95% CI: 1.85–2.93) vs non-Hispanic White patients
  - US-born Black patients also had increased mortality (sHR 1.84; 95% CI: 1.38–2.46)
  - Older age was independently associated with higher mortality









Missed Opportunity for Prevention

- We are screening blood donors
- But what about children born to mothers from HTLV-1 endemic Caribbean countries?
- Nearly 1 million pregnancies since 2000
- No targeted maternal screening

Conclusions

- ATLL incidence is markedly elevated among non-Hispanic Caribbean-born populations in the US
- Incidence among some Caribbean-born groups approaches levels observed in endemic regions of Japan.
- Diagnostic misclassification as PTCL-NOS likely underestimates disease burden
- Survival remains poor, particularly among Caribbean-born Black patients.

Public Health Implications

- ATLL concentrated in Caribbean-origin populations
- Earlier identification of HTLV-1 carriers
- Routine HTLV-1 testing of PTCL-NOS from endemic populations
- Increase physician awareness
- Maternal screening / prevention of mother-to-child transmission

JAMA Oncology | Original Investigation | WOMEN'S HEALTH

Adult T-Cell Leukemia/Lymphoma and Targeted Maternal Screening

Paulo S. Pinheiro, MD, PhD; Tabassum Z. Insaf, PhD; Amber N. Balda, MPH; Baozhen Qiao, PhD; Sophia H. L. George, PhD; Ayako Okuyama, PhD; Juan C. Ramos, MD

IMPORTANCE Adult T-cell leukemia/lymphoma (ATLL) is a rare but highly aggressive malignant disease caused by lifelong infection with human T-cell leukemia virus type 1 (HTLV-1), typically acquired through mother-to-child transmission. In southwestern Japan, the world's highly documented HTLV-1 endemic region, maternal HTLV-1 screening and breastfeeding counseling have reduced vertical transmission. Because of the long latency between infection and disease, reductions in ATLL burden are expected to occur over time. In the US, HTLV-1 screening is limited to blood donors, while mother-to-child transmission remains unaddressed, despite growing immigrant populations from HTLV-1–endemic regions.

Supplemental content

Pinheiro, P. S., Insaf, T. Z., Balda, A. N., Qiao, B., George, S. H. L., Okuyama, A., & Ramos, J. C. (2026). Adult T-Cell Leukemia/Lymphoma and Targeted Maternal Screening. JAMA oncology, e260859. Advance online publication. https://doi.org/10.1001/jamaoncol.2026.0859

Thank you!

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