Infant Feeding Choices for People Living With HIV and INFORM +

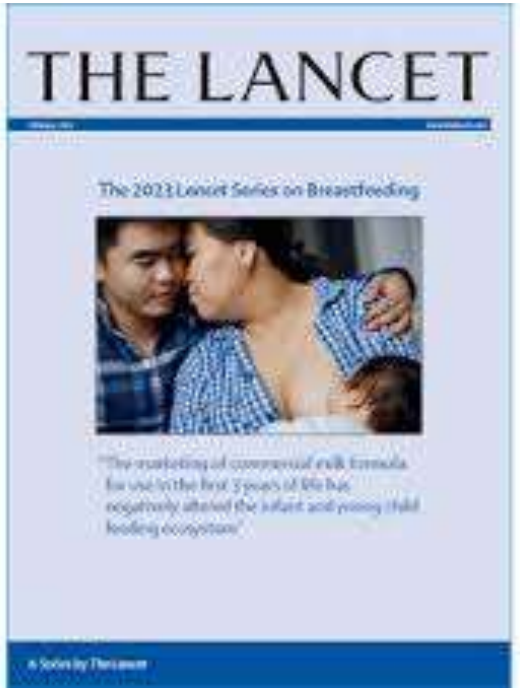
Dr Natasha Davies
South Africa

Background

INTERNATIONAL WORKSHOP ON
HIV & WOMEN 2023
FROM ADOLESCENCE TO MENOPAUSE AND BEYOND
HYBRID MEETING | 17-18 FEBRUARY 2023

2023 Update in Guidelines for Infant Feeding and HIV in the United States and Beyond

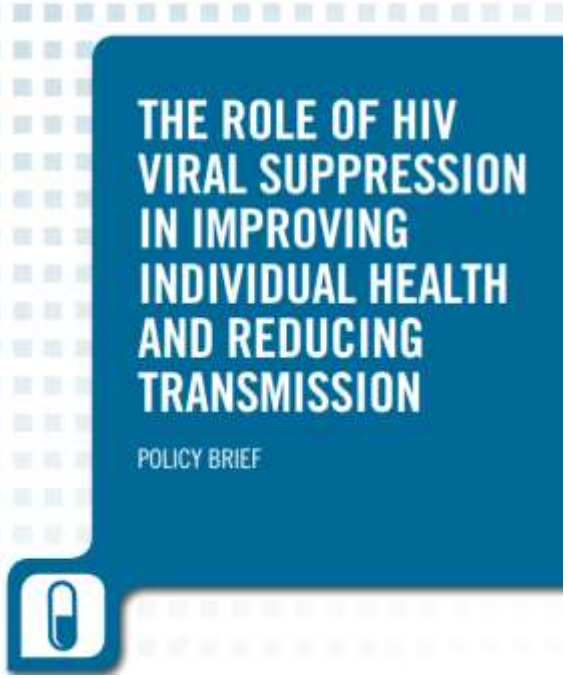
Judy Levison, MD, MPH, AAHIVS
Baylor College of Medicine, United States



Formula ≠ Breastmilk

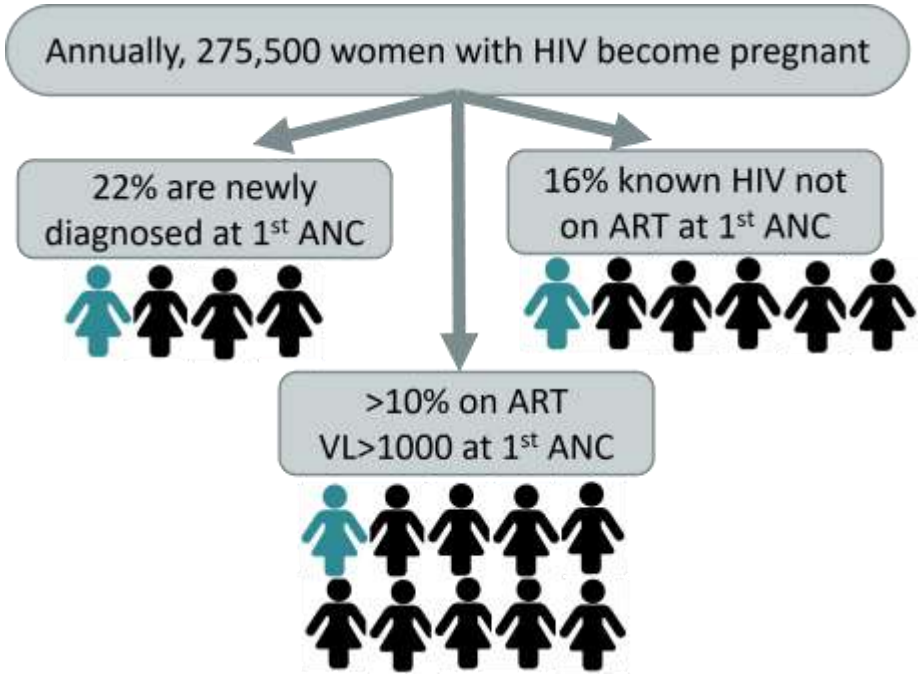
$55 billion market annually

The marketing of commercial milk formula for use in the first 3 years of life has negatively altered the infant and young child feeding ecosystem



"a pregnant mother …whose viral load is suppressed within four weeks of delivery: [WHO] **recommends breastfeeding"**

Reality for a South African Provider



By delivery: 12-15% VL>1000

26% disengage from care within 1 year of birth[1]

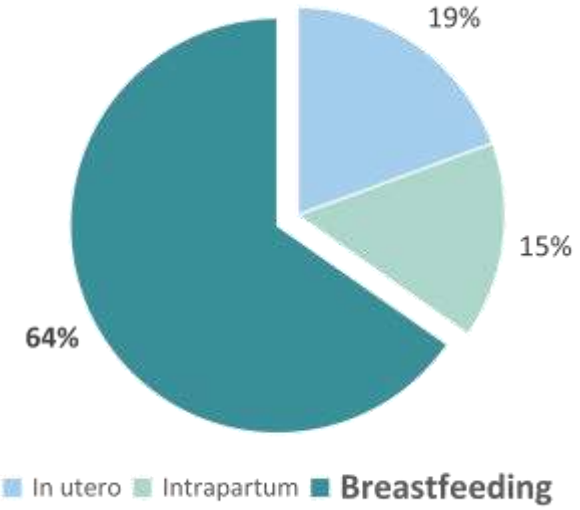
3-5% of women acquire HIV during pregnancy/breastfeeding

6.5% of eligible pregnant/breastfeeding women access PrEP

New maternal infections: 1 in 3 infant transmissions

"It is riskier for a newborn to be born to an HIV-uninfected mother than to be born to a mother living with HIV and virally suppressed on antiretroviral therapy"

(Van de Perre, 2024)



+/-7500 confirmed infant infections annually

By end of breastfeeding, transmissions believed +/-4%

BUT

More <5yrs children die of pneumonia, diarrhoeal disease and malnutrition than HIV-related illnesses

[1] Phillips et al 2024

Drivers of Breastfeeding Transmission in South Africa (and elsewhere)

Poverty: socioeconomic barriers to retention and treatment continuity

Stigma and Discrimination

High mobility, poor continuity of care

Gender-based violence

Lack of person-centred care

Poor breastfeeding/ lactation support

Failing HIV prevention services

Lack of mental health support services

Overwhelmed system

Insufficient Provider Capacity and Skills

Poor monitoring and inadequate management of non-suppression

Poor engagement with fathers and family support

Negative attitudes to people with HIV

Low HIV and ARV treatment literacy

Mixed feeding in unsuppressed context

Food insecurity

Pill burden

Poor mental health

Young age

ART journey

….so many other:

social	systems	provider	personal
sozial	Systeme	Anbieter	persönlich

factors…..

One young lady's journey

YN, 21 years old

- Born with HIV, mother died, raised by father and (later) step-mother, strained relationship
- On ART since <1 year, multiple paediatric regimens including efavirenz, nevirapine, lopinavir/rit
- In 2020 (aged 19), switched to TDF/3TC/DTG whilst unsuppressed, no HIV drug resistance testing
- VLs since 2022: 137000, 20500, 84800, 23800, 132000,
- Presented with her second pregnancy at 25 weeks' gestation: VL of 656000 copies
- Seen by me at 29 weeks, seriously ill, CD4 34, diagnosed with dissTB (urine LAM+),anaemia , Albumin 25,active syphilis, admitted. Had been off her ART for 3 weeks because of persistent vomiting.
- Repeat VL at 32 weeks: 707000 copies. 4 weeks later, 36 weeks, VL down to 229 copies
- Delivers at 36+4 gestation with VL of 39. Successfully establishes breastfeeding.
- Declines any further, additional post-natal support except occasional whatsapp check in messages

YN gave permission to share

Another young lady's journey

DM

- 16 years old
- Born with HIV, double orphan, raised by older, supportive sisters
- On ART since a few weeks old, multiple paediatric regimens
- Presented at 32 weeks' gestation with unsuppressed log 5 VL on LPV/rtv and very low adherence, not coping well with HIV status, unplanned pregnancy, depression, ART tolerability and pill burden
- Switched to TLD following resistance testing which shows full susceptibility across all classes (i.e. low adherence)
- Delivers on TLD with VL of <20. Successfully establishes breastfeeding and maintains suppression whilst breastfeeding baby to 3 months old when she stopped coming back to the specialist clinic
- 4 months' later, DM discovers she is pregnant again. Now 5 months pregnant, VL is 628 at 1st pregnancy visit
- The process starts again…

DM gave permission to share

Yet I Advocate for Supportive Policies for Breast/Chestfeeding ….Why?

High Burden, Low Income Countries

versus

Low Burden, High Income Countries

Patient Load

Health System

Historical Bias in Vertical Transmission Prevention Approaches

Mother/Parent vs Infant

Avoidance of infant infections/harm prioritised over:

- **Parental health**:
  - Old guidelines: sdNVP, AZT, ART discontinued after pregnancy/delivery once baby no longer deemed at risk
  - More recently: DTG neural tube defect scare prevented women's access to best ART for years
- **Other infant health parameters**
  - promoting formula as safest option ignores other significant health impacts and contributes to further health inequities

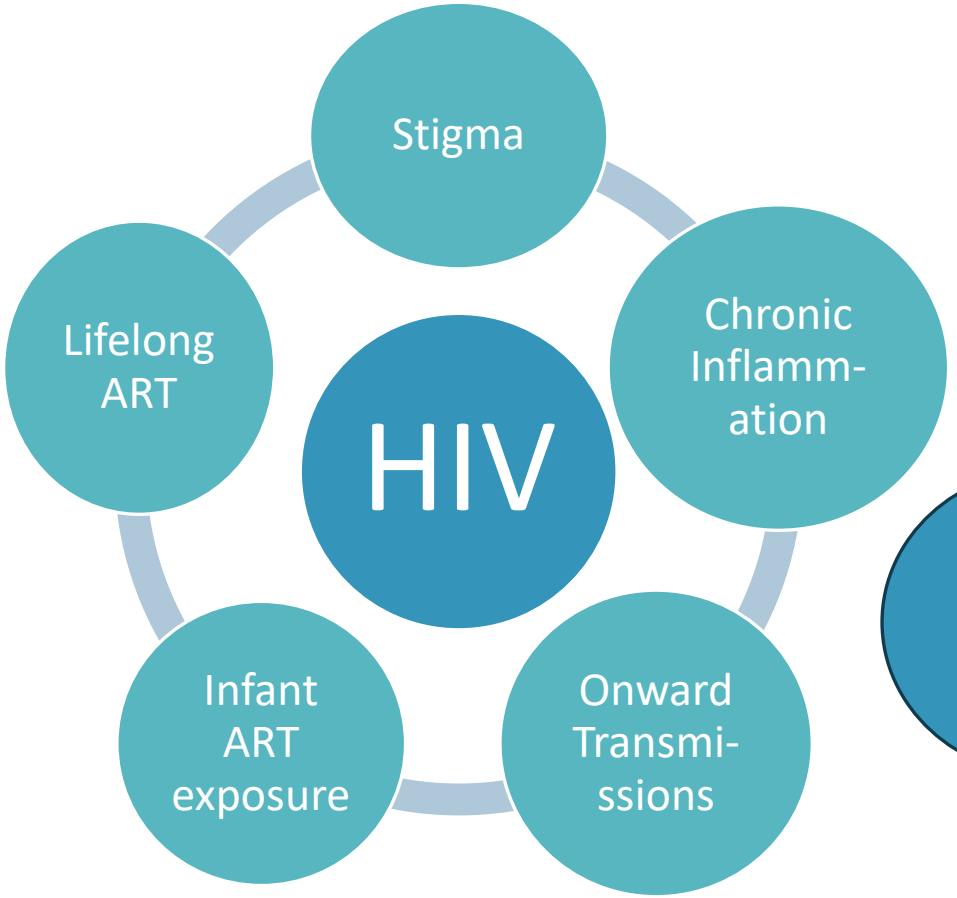
- Time to redress the imbalance
- Birthing parent and infant are equally important
- Should be equally valued
- Equal visibility in policies
- Consider health outcomes/experiences of both in equal balance

- Mothers/parents primarily perceived as vectors of disease
- Resulting in controlling policies
- Undermined autonomy
- Sexual and reproductive health and rights denied/compromised

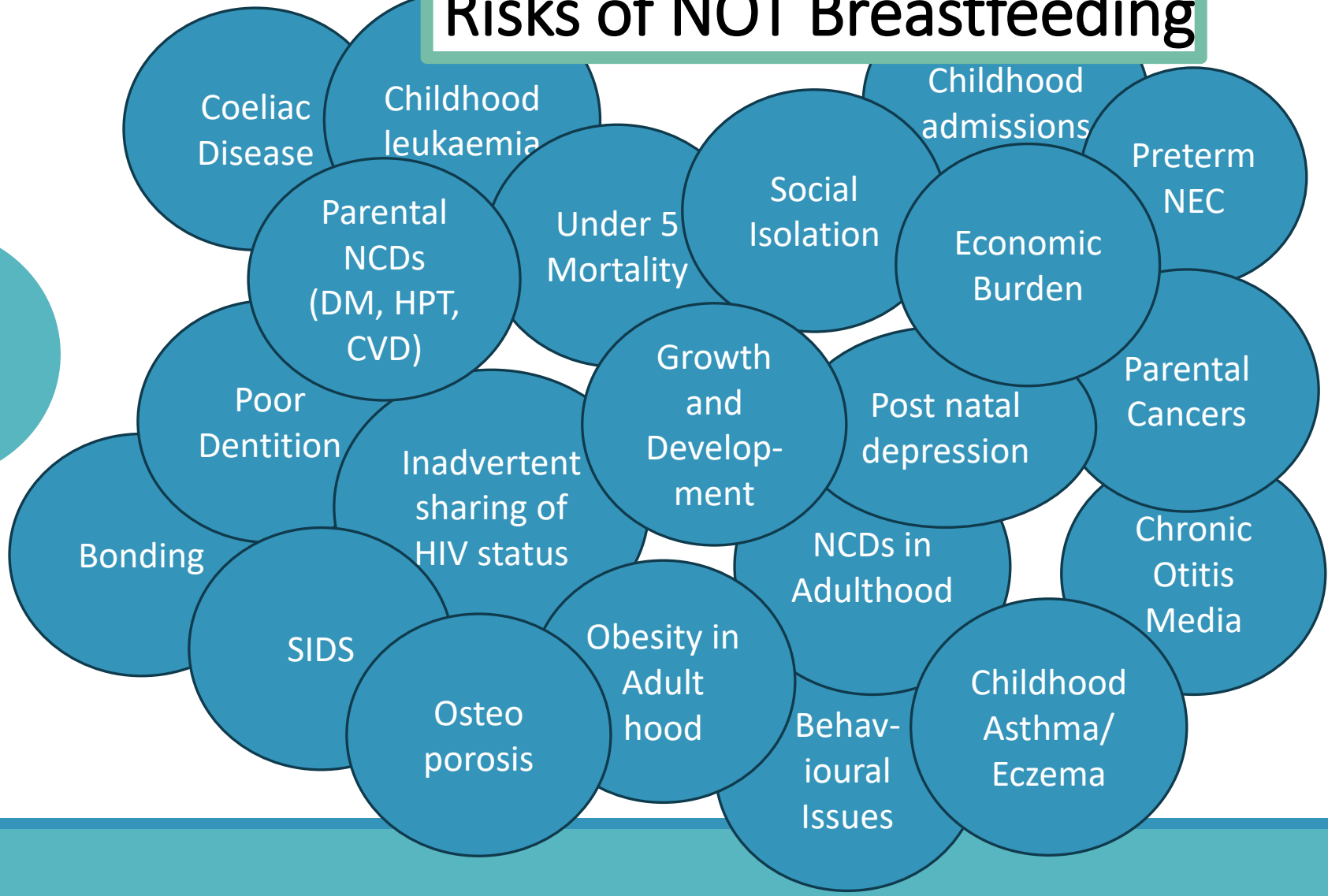
Understanding Risk

Another Bias Formula safer than Human milk for Parents with HIV

Risks of breastfeeding



Risks of NOT Breastfeeding



The influence of PROMISE

This study continues to inform the majority of high income feeding guidelines

PROMISE trial (2018)

- 14 sites: **Sub-Saharan Africa and India**
- **2431** mother-infant pairs recruited from **2011-2014**
  - 95% from PROMISE antepartum study (median ART start: 26 weeks gestation, median VL log 3.8)
  - 5% newly diagnosed in labour
  - Antenatal regimens: **AZT alone** (42%), **AZT/3TC, LPV/r** or TDF/FTC, LPV/r (53%)
  - Postnatal mART regimen: TDF/FTC/LPVr - **twice daily regimen with 5 pills daily**
- Randomised to **maternal ART or infant prophylaxis** at day 6-14 post-partum
- All infants: 6wks NVP, infant prophylaxis arm continued for 42 days post-breastfeeding cessation
- Breastfeeding continued up to 24 months in 12.5%, **mean breastfeeding duration 16 months**
- Infant HIV infections (n=14, 7 in each arm): 0.3% at 6 month, 0.6% at 12 months, 0.9% at 24 months
- **67% of infections after 6 months breastfeeding** – suggests challenges with sustained treatment continuity
- 30 infants died (1.7%), 16 in ART and 14 in prophylaxis, all infants without HIV
- **2 breastfeeding transmissions in virally suppressed mothers:** one prior low treatment continuity, one likely in-utero transmission prior to suppression

Current Paradigm: High Income Countries

	UK	Canada	Germany/ Austria	Australia	Switzerland	USA
Formula safest option	✓	✓	✗	✓	✓	✓
Limited BF duration recommended	✓	✓	✗	✓	Not stipulated	✗
Wean/Interrupt if mastitis/GIT issues	✓	✓	Individualised	✓	✓	✓
Intensified monitoring	✓	✓	✓	✓	✓	✓
Multidisciplinary team approach	✓	✓	✓	✓	✓	✓
Parent-centred, shared-decision	✓	✓	✓	✓	✓	✓
Infant prophylaxis	Varies from none if suppressed to short course to triple therapy across and within countries					

Würde sich das für Sie als Eltern freizügig oder unterstützend anfühlen?

Maintaining Progress

Build trust: breast/chestfeeding can be safe when parents living with HIV are **enabled** to do so safely

INFORMATION

Information

CHOICE

Auswahl

SUPPORT

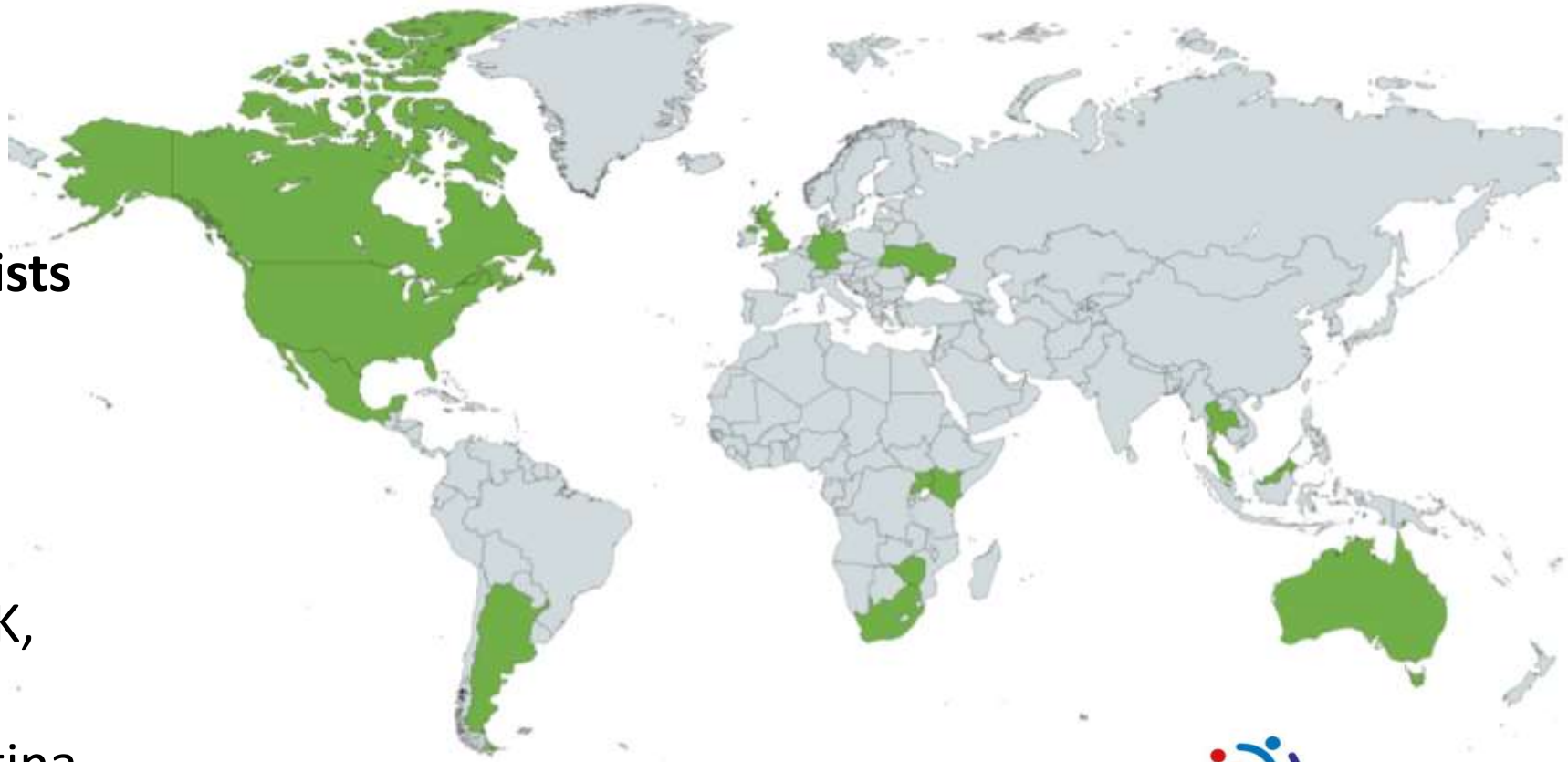
Unterstützung

Introducing…..

International **F**orum for **Inform**ed Infant Feeding Choices for People Living with HIV

Membership

- 33 members
- Reps for each region
- **People living with HIV and community activists** (12)
- **HIV healthcare providers/clinicians** (11)
- **Researchers/scientists** (9)
- **Policy contributors**: US, UK, Germany, Canada, South Africa, Switzerland, Argentina, Mexico, Australia, Haiti, Switzerland



INFORM+
GLOBAL ALLIANCE FOR EQUITY IN INFANT FEEDING AND HIV

INFORM+ Goals

Reframe Global Guidelines

- Challenge status quo
- Rights-based
- Parental autonomy
- Parent/ infant equal considered
- Standardised
- Balanced

Community Engagement

- Meaningful
- Collaborative
- Supportive
- Parents at the centre
- Community driven skills building for provider interactions

Research

- Advocate for funding
- Multicountry collaborations
- High resource with high burden
- Review/share new research
- Network
- Mentorship

Criminalisation

- Call to end all criminalisation
- Challenge punitive interventions or heightened surveillance approaches
- Tackle stigma, discrimination

INFORM+

Progress

- Five INFORM+ online meetings
- 3 sub-groups established

Group 1: Consensus Statement

- Global call to action
- Propose ‘optimal scenario’ standardised approach

Group 2: Evidence-based, Accessible Resources

- For policy makers, providers, parents/community
- Create repository
- Fill gaps
- Disseminate

Group 3: Drive Research Progress

- Gap analysis
- Collaborative opportunities
- ‘Eyes and ears’ network

Offering New Promise: Pushing the Research Agenda

U=U

- We need a new PROMISE
- Multicountry
- Unified database
- Feeding practices, VL levels, infant prophylaxis
- peer-to-peer support models for parental retention and treatment continuity

Human vs Formula Milk

- Infant and parent health impacts
- Mixed feeding with << VL
- Parents views
- Provider attitudes/skills
- Sociocultural/ economic considerations
- Immunological differences with/without HIV

Infant exposure to Parental ART

- Effective infant prophylaxis?
- ARV resistance risks
- Infant developmental/ health impact

Parental viral load

- VL test frequency
- VL rebound management: how much, interrupt, wean or infant prophylaxis
- POC* breastmilk viral load tests
- Infant prophylaxis regimens/need
- Immune cell proviral DNA – transmission risk?

**POC: point of care*

Conclusion: Tipping the Balance to Supporting Safe Feeding Choices

- Many policy, provider and parental approaches to infant **feeding choices** are **fear driven**
- If breastfeeding is chosen, **providers** often display an **intense need for control**
- **HIV** transmission risk remains **primary focus**, overshadowing other major health impacts of feeding choice

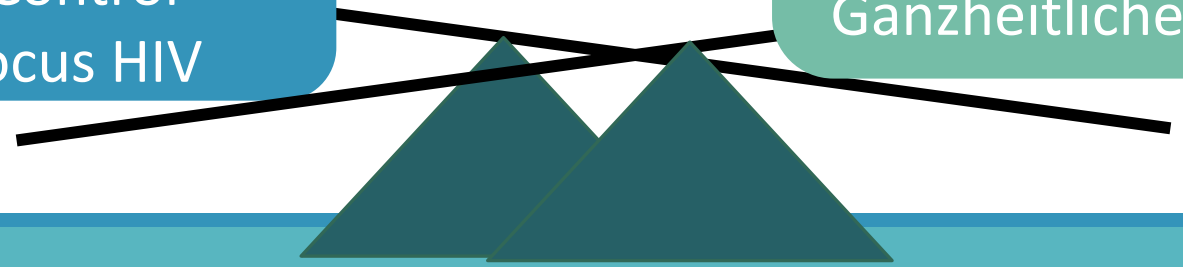
- Learn to **trust the power of an undetectable viral load**
  - Review need for cautions around mastitis, infant or parental gut disturbance when virally suppressed
- **Build trusting and open relationships with parents**
  - Consider less intensified monitoring of parent/infant
  - Encourage open conversations and planning
- **Acknowledge breastmilk and formula are not equal:**
  - Avoiding breastfeeding to attain zero HIV transmission risk prevents **parental and infant access** to myriad **other health and psychosocial benefits**

Furcht
Misstrauen
Anbieterkontrolle
Primärer HIV-Fokus

Provider Control
Primary Focus HIV

Information/Knowledge

Informationen/Wissen
Vertrauen
Unterstützung der Eltern
Ganzheitlicher Gesundheitsansatz



Take Home Message:

Build trust: breast/chestfeeding can be safe when parents living with HIV are **enabled** to do so safely

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