INTERNATIONAL WORKSHOP ON

HIV & WOMEN 2024

FROM ADOLESCENCE TO MENOPAUSE AND BEYOND

HYBRID | WASHINGTON DC, UNITED STATES | 12-13 APRIL

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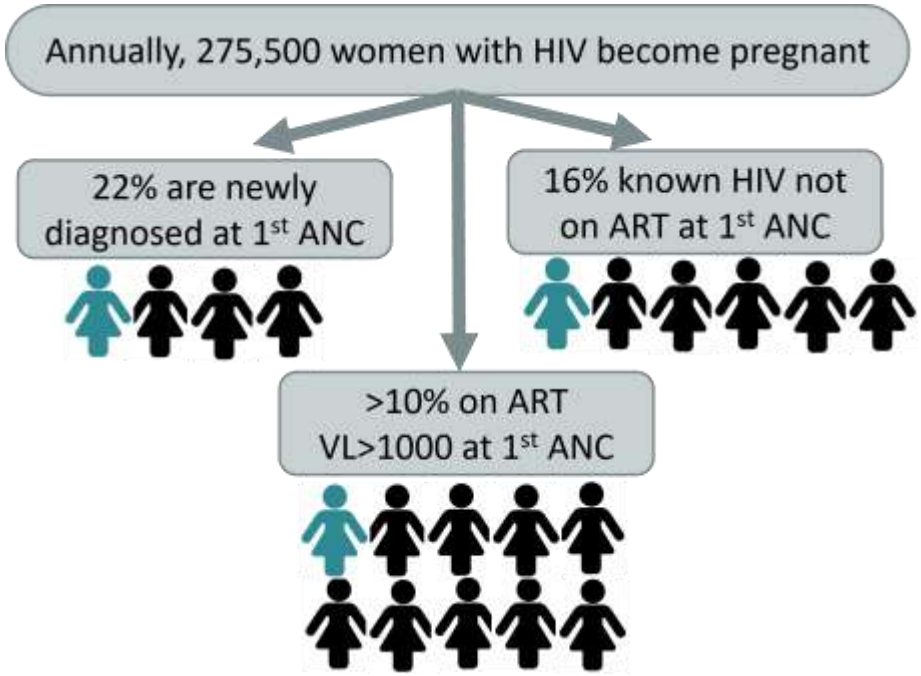
Infant Feeding Choices for Parents Living with HIV: Updates from the INFORM+ Forum Group

Background

- 2023 Woman & HIV workshop: US guidelines update highlighted global disparities and inconsistencies concerning infant feeding choices for parents living with HIV:
  - Country policies vary from criminalisation to prioritising breast/chestfeeding even in parents with viral non-suppression
  - Provider practices/attitudes and current evidence-base not always aligned
  - Perpetuates confusion, stigma and discrimination
  - Criminalisation and negative attitudes associated with human feeding being hidden and parents accessing inadequate support/care

- International forum for informed infant feeding choices for people living with HIV came together: INFORM+

Reality for a South African Provider



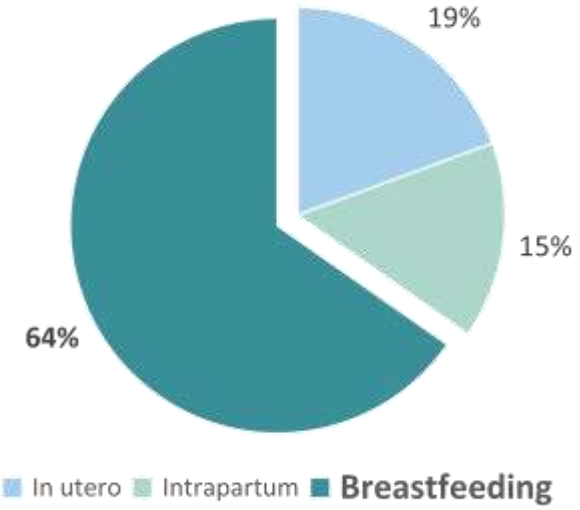
By delivery: 12-15% VL>1000

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



+/-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 factors…..

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

Historical Bias in Vertical Transmission Prevention Approaches

Mother/Parent vs Infant

Avoidance of infant infections/harm prioritised over:

- **Parental health**:
  - sdNVP, AZT, ART discontinued after pregnancy/delivery once baby no longer deemed at risk
  - 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

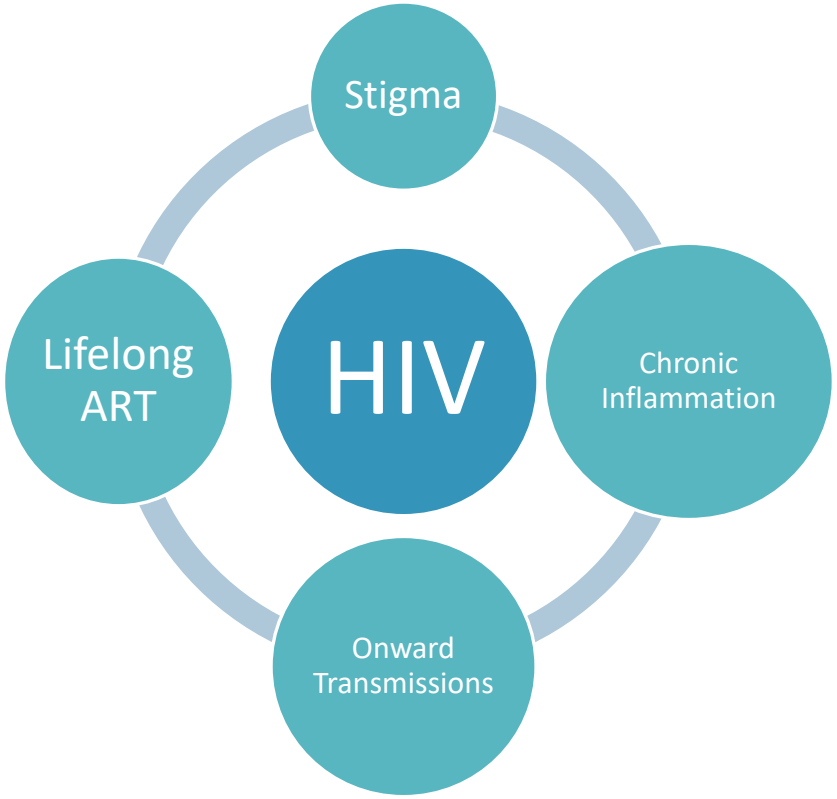
Time to redress the imbalance

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

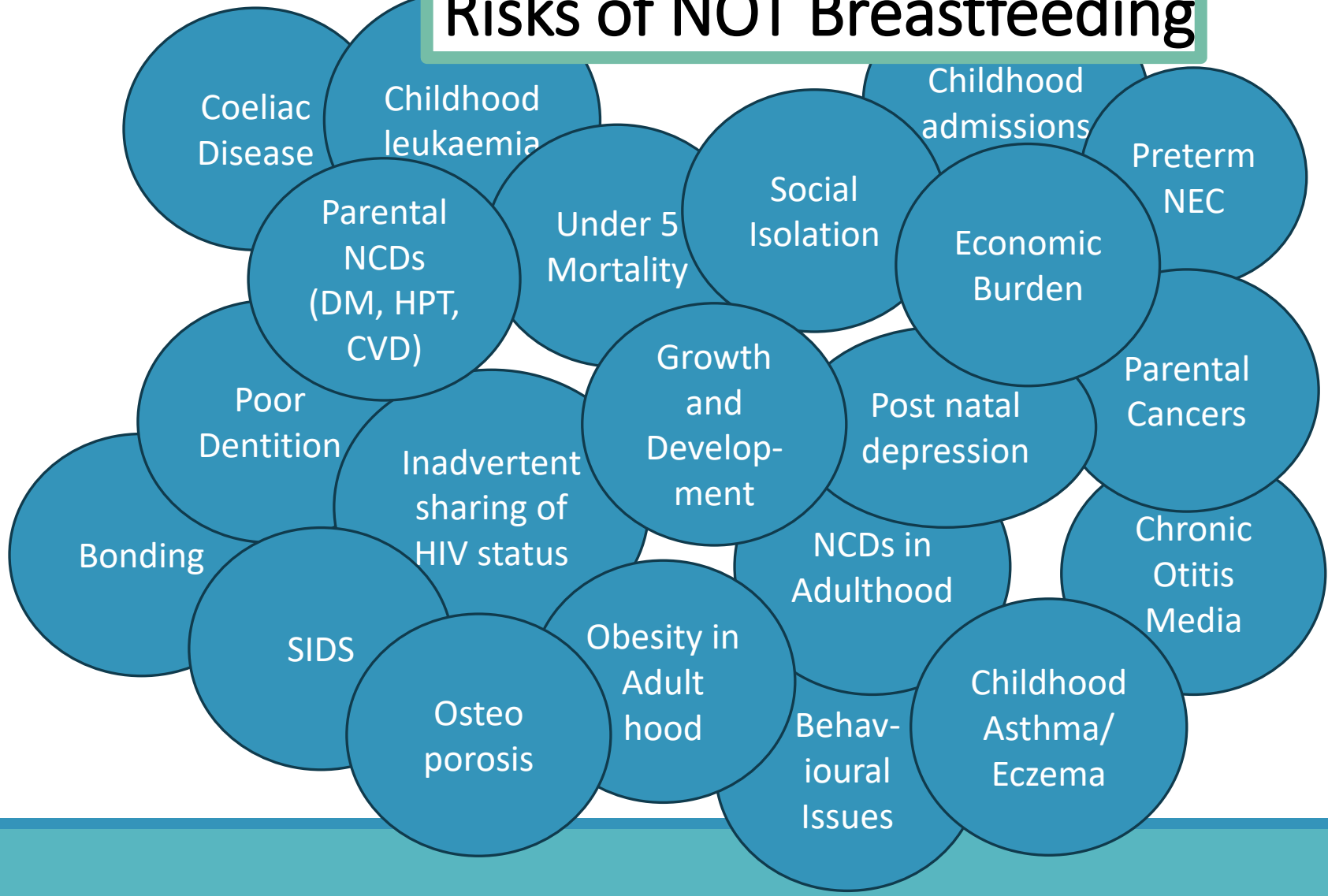
- Mothers/parents primarily perceived as vectors of disease
- Resulting in controlling policies
- Undermined autonomy
- Sexual and reproductive health and rights denied/compromised

Another Bias Formula safer than Human milk for Parents with HIV

Risk 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 parent/infant monitoring	✓	✓	✓	✓	✓	✓
Multidisciplinary team approach	✓	✓	✓	✓	✓	✓
Parent-centred, shared-decision	✓	✓	✓	✓	✓	✓

Maintaining Progress

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

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One young lady's journey

YN

21 years old

Born with HIV

Mother passed away, raised by father and (later) step mother, but not a very good relationship

On ART since younger than 1 year, multiple paediatric regimens including lopinavir/ritonavir

In 2022 (aged 19), switched to TDF/FTC/DTG from LPV/RTV whilst unsuppressed without HIV drug resistance testing

Presented at 32 weeks' gestation with

YN gave permission to share

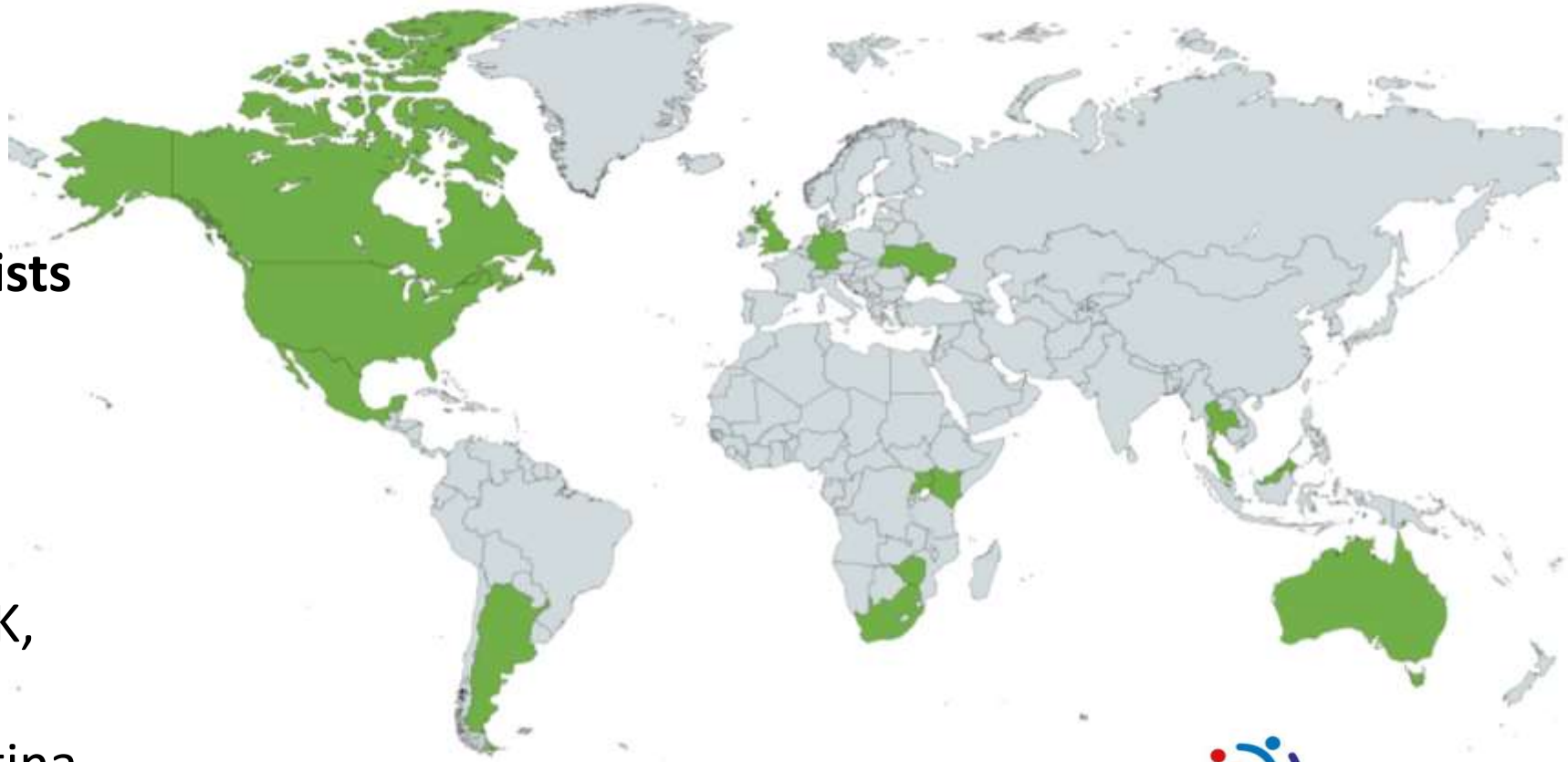
Introducing…..

INFORM+

GLOBAL ALLIANCE FOR
EQUITY IN INFANT FEEDING
AND HIV

Membership

- 32 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



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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

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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

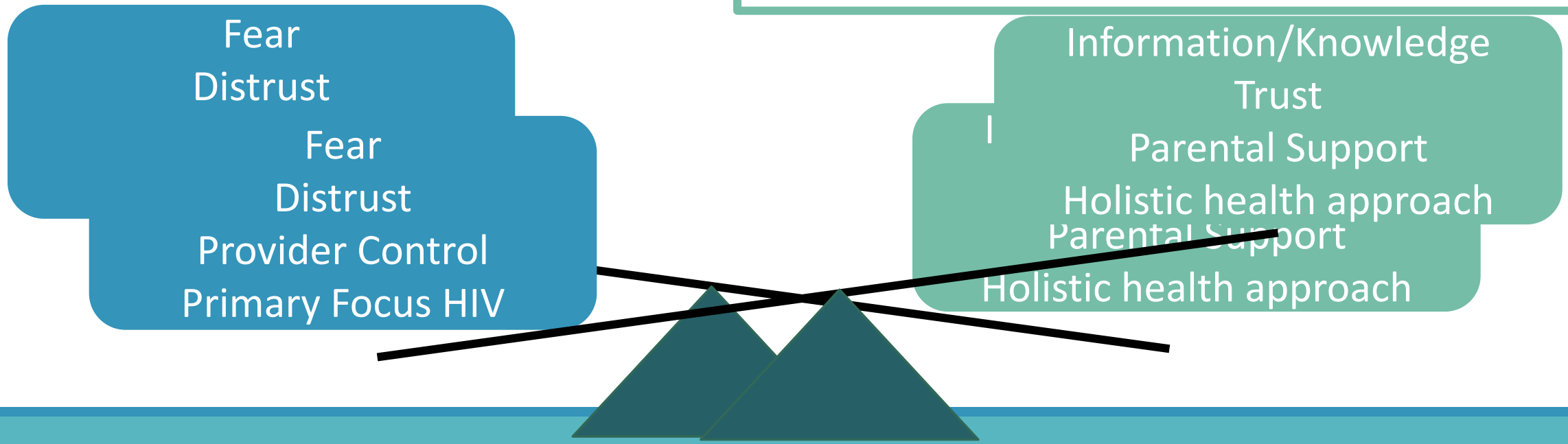
- VL test frequency
- VL rebound management: how much, interrupt, wean or infant prophylaxis
- POC* breastmilk viral load tests
- Infant prophylaxis regimens/need
- Immune cell proviral DNA – transmission risk?

**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**



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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