Chest Feeding Guidelines for People Living with HIV

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International Maternal Pediatric Adolescent AIDS Clinical Trials Network

ANNUAL MEETING
2024

Notes on Inclusive Language

Some providers and patients prefer terms that are not gendered. This presentation tries to use terminology that is non-gendered.

We encourage teams to assess for and use terminology preferred by individual patients.

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Key Messages

- There has been a monumental shift in the breast/chestfeeding (B/CF) recommendations for mothers and other parents with HIV in the United States and other high-income countries.
- US guidelines have been updated to support shared decision-making regarding infant feeding choices in people with HIV who are receiving treatment with sustained viral suppression.
- IMPAACT 2046 Study will leverage the IMPAACT network's expertise and experience conducting studies among women with HIV and their infants to address current knowledge gaps on infant feeding and HIV.

Benefits of Human Milk and Chestfeeding

For Mother and Other Parents

- Supports bonding
- Lower risk of breast and ovarian cancers
- Supports heart health
- Lower risk of:
  - Breast and Ovarian Cancer
  - Diabetes
  - High Cholesterol
  - High Blood Pressure
  - Postpartum Depression
- PWH
  - Avoid unwanted disclosure
  - Address health inequities

For Infants

- Human milk is rich in nutrients and ideal nutrition
- Antibodies in human milk protect infant from viruses and bacteria
- Lower risk of:
  - Ear infections
  - Chest infections
  - Allergies
  - Diabetes
- Benefits on neurodevelopment

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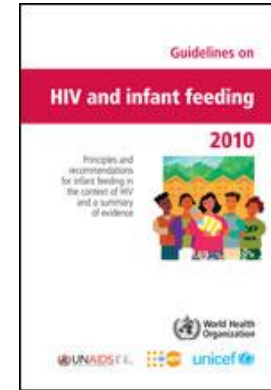
Changes in Infant Feeding Guidance Over Time

World Health
Organization



Replacement feeding

2003

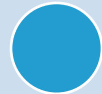
Exclusive chestfeeding and gradual weaning

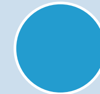
2010

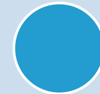
ECF for 12-24 months

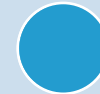
Mixed feeding better than no CF

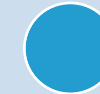
with ART











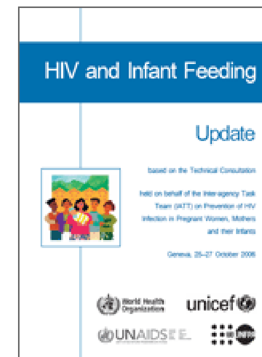
1997

Rapid weaning

2006

Exclusive CF 6-12 months with prophylaxis OR ART

2016



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Why have guidelines changed in the US?

AP

US pediatricians reverse decades-old advice against HIV-positive mothers breastfeeding

A top U.S. pediatricians' group is making a sharp policy change about breastfeeding by people with HIV. The group says they can breastfeed as long as they are taking medications that effectively suppress the virus that causes AIDS. (AP Video: Tassanee Vejpongsa/Mary Conlon)

Published 3:54 PM MDT, May 20, 2024

- Advocacy among PWH and providers
- Emerging research showing very low risk of HIV transmission in PWH on suppressive ART
- Use of better ART regimens

What are current US guidelines on infant feeding for PWH

There has been a slow evolution of the guidelines over time

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US Guideline Agreement

- PWH should receive evidence-based counseling on infant feeding
- Shared decision-making between PWH and providers
- PWH on suppressive ART who choose either formula or chestfeeding should be supported
- PWH not on ART or without sustained viral suppression should be counseled to formula feed (or use donor milk)

CDC Breastfeeding: HIV; HHS Panel on Pregnancy and HIV ; AAP

American Academy of Pediatrics

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Perspectives of Pregnant People Living With HIV

Not able to fulfill their role as a mother

Shame, guilt, and stigma

Practical difficulties of formula feeding

Disclosure of HIV status if not breast/chestfeeding

Positive Attitudes Concerning Infant feeding (PACIFY) study; Tariq, et.al. STI 2016

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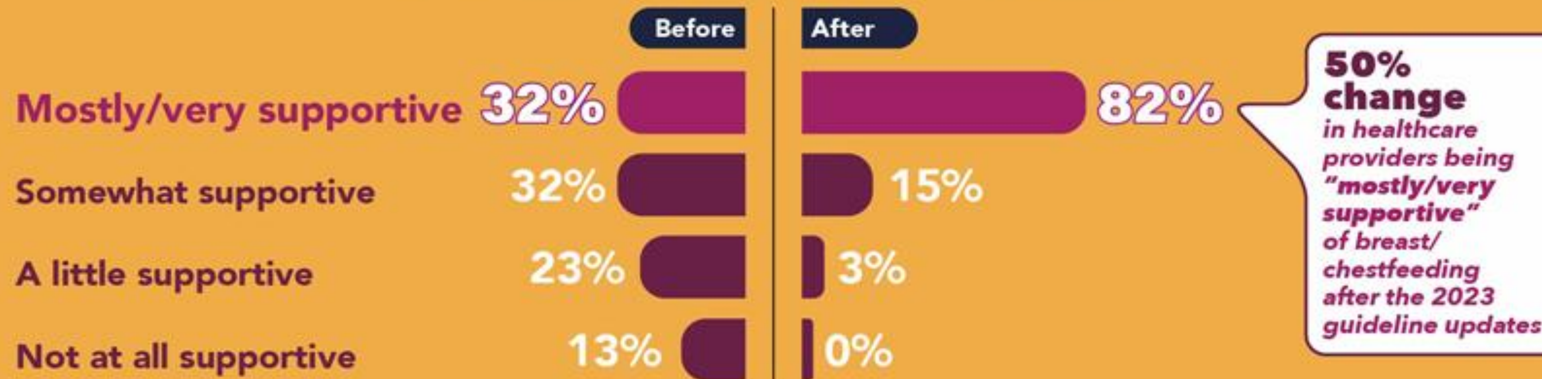
US Health Care Provider Perspectives

THE WELL PROJECT 2024 INFANT FEEDING AND HIV SURVEY REPORT

Dramatic Shift in Healthcare Provider Support of Breast/Chestfeeding after 2023 Updates to US Perinatal HIV Clinical Guidelines

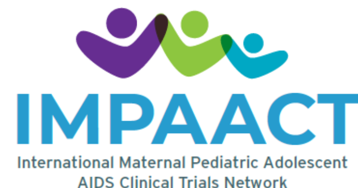


50% change *in healthcare providers being **"mostly/very supportive"** of breast/chestfeeding after the 2023 guideline updates*

View survey report: bit.ly/BEEEBAHsurvey

*Healthcare providers who indicated they were aware and familiar with the guideline updates (n=78) rated their level of support for breast/chestfeeding retrospectively.

BEEEBAH is supported by POSITIVE ACTION ViiV



What is known about the risks of HIV transmission during chestfeeding

- Studies on breastfeeding in pregnant people with HIV often do not have follow up through the entire breast/chestfeeding period
- Undetectable=Untransmittable is for sexual transmission of HIV and may not apply in breast/chestfeeding transmission
  - Consistent adherence is required
  - Time on ART matters
- Viral suppression is a prerequisite but not complete reassurance

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Recent Studies with B/CF among PWH on ART

Study	Year	Location	N	Transmission rates	Notes
PROMISE	2018	India, Malawi, South Africa, Tanzania, Uganda, Zimbabwe	2431	**0.3%** at 6mo **0.6%** at 12mo	• ART started in 2nd/3rd trimester or postpartum • LPV/r-based ART • 2 transmissions occurred in women with VL <40 just prior to detecting infant HIV
DolPHIN-2	2022	South Africa, Uganda	268	**0.5%** at 18mo	• ART started in 3rd trimester • DTG vs EFV-based ART • The 1 transmission occurred in a woman with VL <50 throughout BF
VESTED	2021	USA, India, South Africa, Zimbabwe, Uganda, Brazil, Botswana, Tanzania, Thailand	247	**0.4%**	• All started ART by 28 weeks • DTG vs EFV-based ART • 2 transmissions; one parent with detectable VL throughout, one parent highest VL 42 copies, others undetectable
PROMISE-EPI	2023	Zambia, Burkina Faso	1506	**0.5%** overall at 12 months 0.1% intervention 0.8% control	• Postnatal infant 3TC IF maternal VL ≥ 1000 copies/ml • 1 transmission in intervention arm (not adherent to 3TC); 6 in control arm

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Case Reports from high-income countries

No HIV transmission to infants who received human milk in reported cases

Year	Location	Number infants	Median duration BF	Infant prophylaxis
2019	Canada	3	10 weeks	3 drugs thru end of BF
2020	Belgium	2	18 weeks	2 drugs, 4 weeks
2021	Germany	42	20 weeks	1 drug, 2 weeks
2022	Italy	13	22 weeks	1 drug, 4 weeks
2022	Germany	30	12 weeks	1 drug, 2-8 weeks
2022	US - Baltimore	10	18 weeks	3 drugs x4-6 weeks, then 1 drug thru end of BF
2022	US - DC	7	24 weeks	1-2 drugs, 4-6 weeks
2023	US - Denver	13	8 weeks	1 drug thru end of BF
2023	US/Canada – multiple	72	24 weeks	Wide variability

In summary

- Replacement feeding (with formula or donor human milk) is the only feeding method with 0% risk of HIV transmission
- But risk of transmission via breast/chestfeeding is <1% if the parent is on ART with viral suppression

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Approach to Infant Feeding Decisions

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Infant Feeding Decision Making

THE WELL PROJECT 2024 INFANT FEEDING AND HIV SURVEY REPORT

Healthcare Provider Survey Respondents Comment on 2023 Infant Feeding Guideline Updates

"I think we are long past the time where we should tell parents living with HIV how to feed their children. As providers we should ensure that they are aware of risks and benefits, just like with all other decisions, and support them to the best choice for their families."

– 2024 s

"It will be crucial for providers to put this decision-making power back in the patient's hands, which means providers must be thoroughly educated on the topic to avoid further stigma and misinformation."

– 2024 survey respondent

View survey report: bit.ly/BEEEBAHsurvey

BEEEBAH is supported by POSITIVE ACTION ViiV

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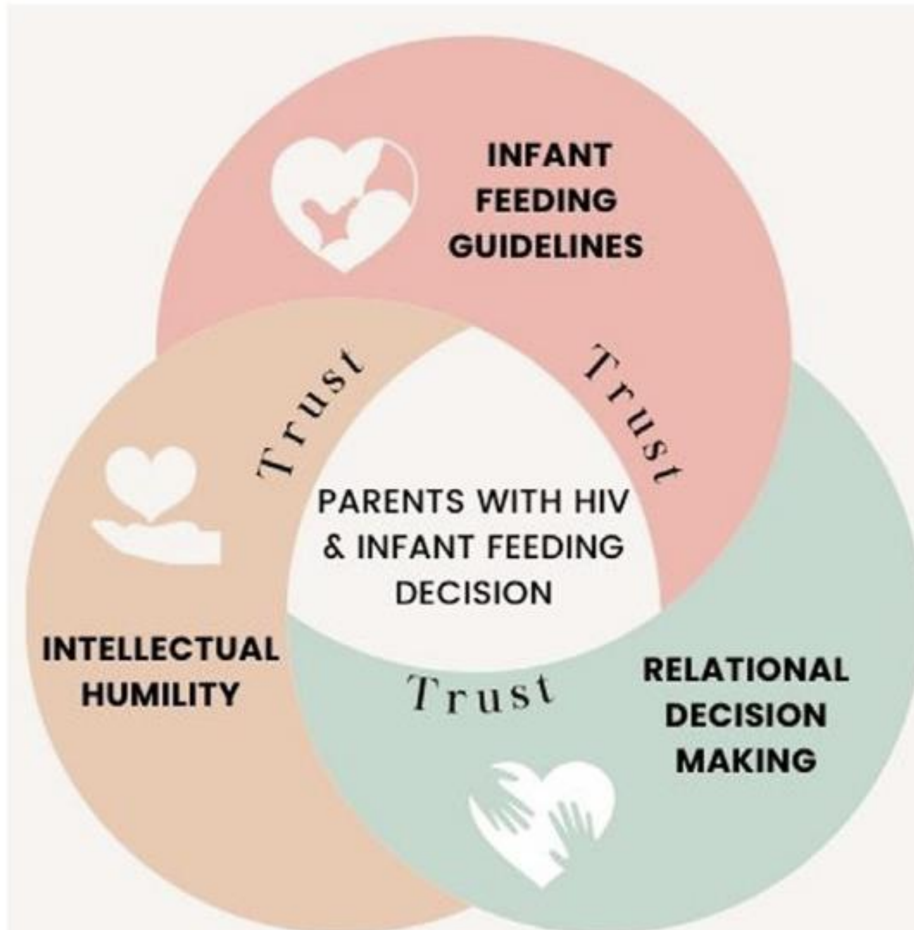

Emily Barr, PhD, CPNP, CNM, FAAN
Cizik School of Nursing UTHealth Houston, 2023

NEW EVIDENCE BASED PRACTICE RECOMMENDATION

Sharing new knowledge while respecting the expertise of the health care team and patient autonomy to foster effective collaboration, trust, and improve patient outcomes.

RELATIONAL DECISION MAKING

Working in partnership using open and respectful communication while providing clear and balanced information to support trust and informed decision making. Relational decision making considers patient autonomy, the health of the newborn, the needs of the family, and socio-cultural factors

INTELLECTUAL HUMILITY

Supports relational decision making through openness to different perspectives, fostering trust, and having a willingness to revise one's beliefs and decisions in light of new evidence.

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Infant Feeding Counseling

Pre-pregnancy/ Early pregnancy	Prior to delivery	After delivery
• Open, non-judgmental • Provider offers evidence-based information for all options • Consider individual, family, community factors	• Follow up discussion • Document • Communicate with all providers and key individuals	• Provide early support for success • Monitor and address complications early • Support ART adherence Reassess risk

thewellproject

THE WELL PROJECT 2024 INFANT FEEDING AND HIV SURVEY REPORT

Top 3 Ways Healthcare Providers Say They Can Support the Infant-Feeding Decisions of Women and Other Birthing Parents Living with HIV

1. **Initiate non-judgmental discussion(s)** around infant-feeding options
2. **Provide evidence-based information** on HIV transmission for all infant-feeding options
3. Ensure the parent and infant's **entire care team** (OB/GYN, ID, pediatrician, lactation consultant, doula, midwife, etc.) **is supporting the woman's decision** on how to feed her child

View survey report: bit.ly/BEEEBAHsurvey

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THE WELL PROJECT 2024 INFANT FEEDING AND HIV SURVEY REPORT

Top 3 Obstacles Healthcare Providers Face When Considering Infant-Feeding Decisions with Women and Other Birthing Parents Living with HIV

1. **Lack of culturally responsive educational resources** for women with HIV
2. **Lack of support** from others on the care team
3. **Lack of explicit policies** in my institution/organization that support breast/chestfeeding

View survey report: bit.ly/BEEEBAHsurvey

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During infant feeding

Support and ongoing care for chestfeeding parents and their infants

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Care of breast/chestfeeding PWH

Care

- Continue ART
- Maintain undetectable viral load
- Regular viral load testing
- Screen and address postpartum depression and anxiety
- Explore need for financial, mental health or other psychosocial supports
- Provide guidance on breast care to avoid breast engorgement, sore nipples, mastitis, or breast abscess.

Support

- Postpartum adherence is a known challenge
- Lactation specialists
- Discuss and support:
  - exclusive chestfeeding
  - introduction of bottle
  - Introduction of solid foods (6 months)
  - Gradual weaning plan
  - Milk storage, return to work, travel etc.

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Care of breast/chestfeeding infants

- Regular HIV testing
  - At least every 3 months during BF
  - 4-6 weeks, 3 months and 6 months after B/CF ends
- Monitor growth
- Recognize and manage infant illness (thrush, vomiting/diarrheal illnesses)
- Infant prophylaxis?
  - Extra layer of protection
  - Discuss medication, dosing, and duration
  - Possible additional bloodwork

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IMPAACT's Opportunity to Contribute

Let's start with another set of slides

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IMPAACT 2046

UPLIFT Study (Understanding Parental Lactation and Infant Feeding decisions Tailored to people with HIV)

CDC 1 U01PS005288-01-00 and NICHD

Overall goal:

To understand the infant feeding preferences, practices, and outcomes for mothers and other parents with HIV (MoPWH) in the US

Primary Objectives

Figure 1. Key objectives that will be fulfilled through 3 Core Activities.

OBJECTIVES

OVERALL OBJECTIVE: Contribute to knowledge base on effective approaches to support health and optimize care for pregnant and postpartum PWH and their infants

CORE ACTIVITIES

1. Explore the multifaceted process of infant feeding decision-making via in-depth interviews with key stakeholders

2. Establish an observational longitudinal cohort of MoPWH to examine current infant feeding practices and outcomes

3. Develop and pilot a national voluntary registry of MoPWH who B/CF in the US

- Understand preferences for infant feeding among MoPWH in the US
- Determine best practices, costs, and benefits of supporting MoPWH to safely feed their infants
- Investigate aspects of clinical, behavioral, and social epidemiology pertaining to infant feeding decision-making among PWH, including both the pregnant person and those supporting their decision such as physicians, nurses, lactation consultants, family, and social workers
- Describe and monitor HIV transmission during B/CF and explore potential risk or protective factors, including comprehensive laboratory evaluations of the viral profile of human milk, whether transmission occurs or not
- Determine the feasibility of establishing a confidential voluntary registry of B/CF MoPWH and their infants nationwide to determine the risk and magnitude of HIV transmission via B/CF in the United States

For more information

National Clinical Consultation Center

Perinatal HIV Hotline
(888) 448-8765

- Recommendations for the Use of Antiretroviral Drugs During Pregnancy and Interventions Interventions to Reduce Perinatal HIV Transmission in the United States: Infant Feeding for Individuals with HIV in the US
  - https://clinicalinfo.hiv.gov/en/guidelines/perinatal/infant-feeding-individuals-hiv-united-states?view=full
- The Well Project Expert Statement and Resources on BF and HIV in U.S. and Canada
  - http://blog.catie.ca/2019/03/11/a-step-by-step-process-on-how-we-can-support-mothers-living-with-hiv/
  - https://www.thewellproject.org/hiv-information/expert-consensus-statement-breastfeeding-and-hiv-united-states-and-canada
  - https://www.thewellproject.org/hiv-information/breastfeeding-chestfeeding-and-hiv-supporting-informed-choices
  - https://docs.google.com/spreadsheets/d/1fq1O3lHKwYdboyWaMCYhJ4QuR9RLpAgnH4fUm-H8w08/edit#gid=0
- Is U=U applicable in Breastfeeding, Lynn Mofenson, Elizabeth Glazer Pediatric AIDS Foundation
  - https://academicmedicaleducation.com/meeting/international-workshop-hiv-pediatrics-2020/video/session-4-undetectable-untransmittable

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Acknowledgements

CDC 1 U01PS005288-01-00 and NICHD
UPLIFT Study Team
Well Project
Dr. Emily Barr
Mothers and other parents with HIV

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THANK YOU!

Any questions?

You can find me at

- Lisa.abuogi@childrenscolorado.org

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Extra Slides

Let’s start with another set of slides

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Additional Provider Perspectives

2019 survey US Healthcare Providers (Tuthill et. al. JIAS)

- 93 respondents
- Over 75% reported having a PWH ask if they could breastfeed
- 29% reported caring for a patient who B/CF despite recommendations

2021 survey at over 80 institutions (Lai et. al., AID Patient Care STD)

- 100 respondents
- 86% had counseled PWH on infant feeding
- <50% had counseled or cared for a PWH during B/CF
- Providers reported discomfort with B/CF
- Some reported directive counseling against B/CF
- Perceived that non-White race, non-English language, and the presence of substance use, mental illness, and financial instability created barriers to B/CF

Tuthill, et.al. JIAS 2019; Levison et.al. CID 2019;Lai et.al. AIDS PC 2023

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US-based Guidance on Infant Feeding for people with HIV

There has been a slow evolution of the guidelines over time

What are the recommendations for counseling mothers with HIV about feeding their infants?

Mothers who have questions about breastfeeding or who want to breastfeed should receive patient-centered, evidence-based counseling on infant feeding options, allowing for shared decision-making.

If mothers choose to breastfeed, providers should emphasize the importance of adherence to ART and sustained viral suppression and address challenges to ART adherence during the postpartum period.

Last reviewed: Feb 2, 2023

CDC Breastfeeding: HIV https://www.cdc.gov/breastfeeding/breastfeeding-special-circumstances/maternal-or-infant-illnesses/hiv.html

Panel's Recommendations

- People with HIV should receive evidence-based, patient-centered counseling to support shared decision-making about infant feeding. Counseling about infant feeding should begin prior to conception or as early as possible in pregnancy; information about and plans for infant feeding should be reviewed throughout pregnancy and again after delivery **(AIII).** During counseling, people should be informed that—
  - Replacement feeding with properly prepared formula or pasteurized donor human milk from a milk bank eliminates the risk of postnatal HIV transmission to the infant **(AI).**
  - Achieving and maintaining viral suppression through antiretroviral therapy (ART) during pregnancy and postpartum decreases breastfeeding transmission risk to less than 1%, but not zero **(AI).**
- Replacement feeding with formula or banked pasteurized donor human milk is recommended to eliminate the risk of HIV transmission through breastfeeding when people with HIV are not on ART and/or do not have a suppressed viral load during pregnancy (at a minimum throughout the third trimester), as well as at delivery **(AI).**
- Individuals with HIV who are on ART with a sustained undetectable viral load and who choose to breastfeed should be supported in this decision **(AIII).**
- Individuals with HIV who choose to formula feed should be supported in this decision. Providers should ask about potential barriers to formula feeding and explore ways to address them **(AIII).**
- Engaging Child Protective Services or similar agencies is not an appropriate response to the infant feeding choices of an individual with HIV **(AIII).**

https://clinicalinfo.hiv.gov/en/guidelines/perinatal/infant-feeding-individuals-hiv-united-states

U.S. Health and Human Services

Panel on Treatment of HIV During Pregnancy and Prevention of Perinatal Transmission

Anticipated 2024 Updates Will Include:
Additional guidance on
- infant prophylaxis
-infant testing
-Viral load monitoring
-Complications

Updated: January 31, 2023
Reviewed: January 31, 2023

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Recent Studies in B/CF Pregnant People with HIV on ART

Study	Year	Location	N	Transmission rates	Notes
PROMISE	2018	India, Malawi, South Africa, Tanzania, Uganda, Zimbabwe	2431	**0.3%** at 6mo **0.6%** at 12mo	• ART started in 2nd/3rd trimester or postpartum • LPV/r-based ART • 2 transmissions occurred in women with VL <40 just prior to detecting infant HIV
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Flynn et al., JAIDS 2018;77:383-92, Malaba et al., Lancet HIV 2022, Volpe et al., JAIDS 2022; Kankasa et al., CROI 2023

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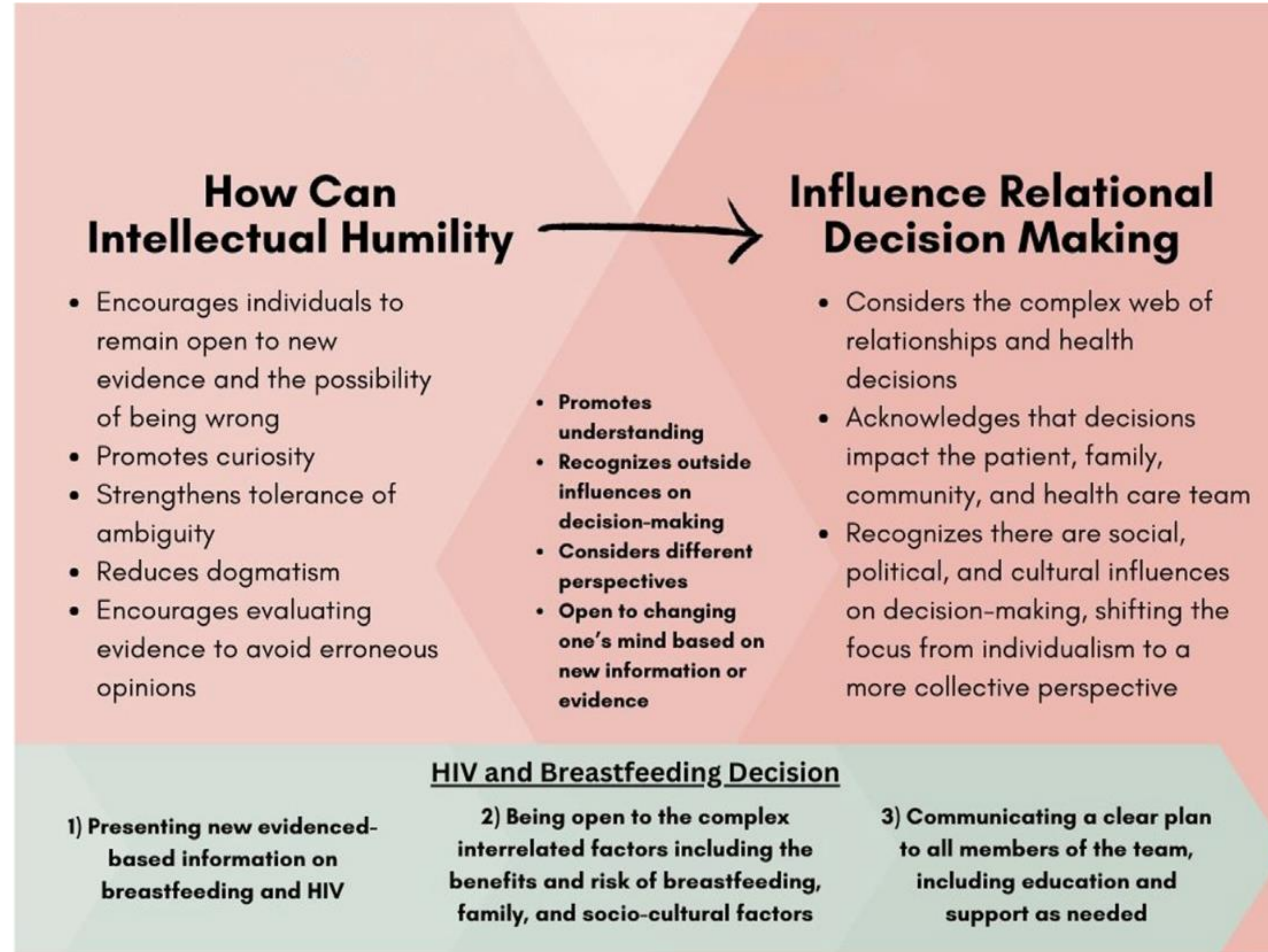
What We Know

- Timing of breast/chestfeeding (in the absence of ART)
  - Higher risk of transmission in first 1-2 months after birth (up to 6%)
  - Steady risk of transmission throughout breast/chestfeeding (0.6-0.9% risk per month)

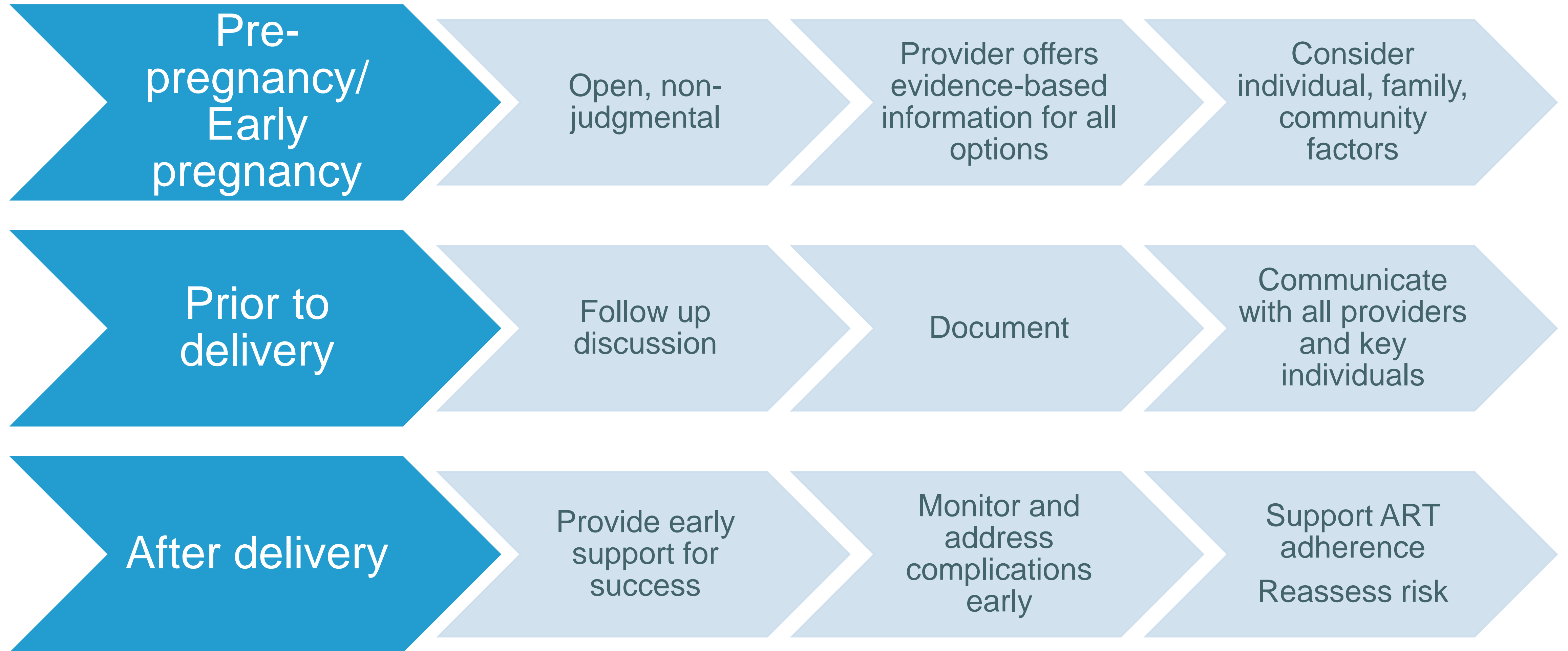
- Maternal HIV viral load (plasma RNA) is related to viral load in breast milk but not perfectly correlated
  - For every 1 log increase in plasma VL, 0.6 log increase in breast milk VL
  - People who have detectable plasma VL more likely to transmit via breast/chestfeeding
- Impact of ART on HIV virus in breast milk
  - ART reduces HIV cell-free RNA but not HIV cell-associated DNA
  - HIV cell-associated DNA is higher in early breast milk
  - A very small proportion (<1%) of people with undetectable plasma VL may have low levels of virus in their breast milk

Nduati et al., JAMA 2000, Moodley et al., JID. 2003, Coutsoudis et al., JID 2004, Ndirangu et al., PLosOne 2012, Davis, et al. JAIDS 2016; Roussea et al, J Inf Dis, 2003;187:741-7, Davis, et al. JAIDS 2016



How Can Intellectual Humility
Influence Relational Decision Making
• Encourages individuals to remain open to new evidence and the possibility of being wrong
• Promotes curiosity
• Strengthens tolerance of ambiguity
• Reduces dogmatism
• Encourages evaluating evidence to avoid erroneous opinions
• Promotes understanding
• Recognizes outside influences on decision-making
• Considers different perspectives
• Open to changing one's mind based on new information or evidence
• Considers the complex web of relationships and health decisions
• Acknowledges that decisions impact the patient, family, community, and health care team
• Recognizes there are social, political, and cultural influences on decision-making, shifting the focus from individualism to a more collective perspective
HIV and Breastfeeding Decision
1) Presenting new evidenced-based information on breastfeeding and HIV
2) Being open to the complex interrelated factors including the benefits and risk of breastfeeding, family, and socio-cultural factors
3) Communicating a clear plan to all members of the team, including education and support as needed

Infant Feeding Counseling



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Infant management and monitoring

There is no consensus on appropriate management of ARV prophylaxis for infants of individuals with sustained viral suppression who are breastfed. (DHHS Panel)

Table 12. Infant Antiretroviral Prophylaxis for Newborns of Mothers With Sustained Viral Suppression Who Breastfeed

Newborns at Low Risk of HIV Acquisition During Breastfeeding	
Recommended Regimen	**Recommended Duration**
ZDV	ZDV administered for 2 weeks (see Table 11 for dosing)

Optional Extended Postnatal Prophylaxis for Newborns at Low Risk of HIV Transmission During Breastfeeding	
Optional Regimen	**Optional Recommended Duration**
ZDV	ZDV administered for 4 to 6 weeks (see Table 11 for dosing)
NVP	**Simplified Age-Based Dosing for Newborns ≥32 Weeks Gestation Receiving Extended NVP Prophylaxis During Breastfeeding[a]**

Age	Volume of NVP 10 mg/mL Oral Syrup Daily
Birth to 6 weeks	1.5 mL
6 weeks to 6 months	2.0 mL
6 months to 9 months	3.0 mL
9 months to 1 to 4 weeks post-weaning	4.0 mL

Most Panel Members agree only 2 weeks of ZDV is needed as these infants should be low risk for HIV transmission.

Prolonged infant prophylaxis during B/CF is recommended by some pediatric HIV experts as an additional layer of protection.

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Conditions that may increase risk of HIV transmission
(Often inadequate data to guide management)

- Cracked/bleeding nipples
- Mastitis/engorgement/milk stasis
  - Inflammation → increased cells in milk
  - Note - rapid weaning can precipitate these conditions
- Trauma to infant mouth – e.g. frenectomy
- Infant thrush, if severe
  - Mucosal disruption = portal for entry of HIV
- Infant gastroenteritis, if severe
  - Mucosal disruption = portal for entry of HIV
- Preterm delivery (?)
- Mixed feeding (?)

Management of B/CF Complications

- Temporary complications (mastitis, thrush, bleeding nipples)
  - Give previously stored milk from date prior to complication until resolved
  - Pump and flash heat milk
  - Provide replacement feeding temporarily (donor milk or formula)
  - Discontinue B/CF
- Detectable viral load
  - Stop B/CF (use options above)
  - Immediately repeat VL
  - If repeat VL remains detectable, discontinue B/CF permanently
  - Test infant for HIV
  - *Note, 2024 HHS guidelines will provide more detailed*

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