



# UPDATED INFANT FEEDING RECOMMENDATIONS FOR US PARENTS LIVING WITH HIV:

## Empowering Patient/Provider Partnership & Communication

Authors: Ciarra Covin, Olivia G. Ford, Krista Martel, Heather O'Connor

### BACKGROUND

Shared, informed decision-making is a support strategy recommended in the US Department of Health and Human Services (HHS)'s Perinatal HIV Clinical Guidelines for navigating conversations with women and other people living with HIV. The approach requires healthy communication between patients and healthcare providers, which can build trust in this vital partnership.

This strategy is at the heart of significant updates made in January 2023 to the "Infant Feeding for Individuals with HIV in the United States" section of the guidelines, which now reflects current evidence about the less than 1% chance of HIV transmission through breast milk when the lactating parent is taking HIV medications and has an undetectable viral load. The American Academy of Pediatrics

### METHODS

In late 2021, The Well Project launched BEEBAH (Building Equity, Ethics, and Education on Breastfeeding and HIV) – a comprehensive, multi-tiered project that expands upon the organization's work around breast/chestfeeding and HIV, funded by HIV Healthcare.

Through this programming, The Well Project conducted a survey to help measure stakeholder knowledge and attitudes, as well as the impact of the HHS guidelines update. The survey, launched approximately two years into the initial three-year project, is a follow-up to a baseline knowledge survey disseminated in Fall 2022 (prior to any guideline updates). Recruitment of survey participants began February 20, 2024, and continued through March 30, 2024. The total number of complete surveys received was 226. Healthcare providers (n=117) made up 52% of the survey respondents

## LANGUAGE MATTERS

At the Well Project, we use "breastfeeding" and "breast/chestfeeding." The Well Project focuses on women across the gender spectrum and strives to be inclusive of trans men, nonbinary individuals, and all others living with and vulnerable to HIV who wish to explore these options.

### FINDINGS

#### SURVEY RESPONDENTS' ROLES

(Knowing that people in the HIV community often play multiple roles, survey respondents were asked to indicate all the roles they identify with)



#### HEALTHCARE PROVIDERS' PROFESSIONS



#### CLINICAL ROLE OF MEDICAL PROVIDERS

(respondents could check multiple roles)



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

Among the healthcare providers, 74% indicated that they had heard about the 2023 updates to the infant-feeding guidance in the US Perinatal HIV Clinical Guidelines

#### Healthcare Provider Support Before and After the 2023 Guideline Updates\*

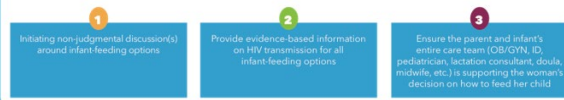


**50% increase in healthcare providers being mostly/very supportive of breast/chestfeeding after the 2023 guideline updates**

"The guidelines are a large first step. Additional work is needed to provide tools to support patient-provider communication and infant feeding decisions." –2024 survey respondent

"Before the USDHHS [sic] Guidelines changed, it was 'stickier.' Conversations were more often 'off record.' Now, there is clear support/guidance." –2024 survey respondent

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



"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 make the best choice for their families." –2024 survey respondent

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



"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

### BACKGROUND

The 2023 updates to the infant-feeding guidance in the US Perinatal HIV Clinical Guidelines dramatically increased healthcare providers' support for their patients living with HIV who may desire to breast/chestfeed.

While strides have been made in disseminating updated guidelines, gaps in awareness of these changes remain. Continued rigorous efforts are needed to increase knowledge among healthcare providers, women and other people living with HIV, and other key stakeholders and allies – including non-HIV specialists – to support parents in knowing their options and making optimal decisions for themselves and their families. Community-focused innovations in the guidelines, such as discouraging harmful

calls to CPS or similar agencies in response to infant-feeding inquiries, may also increase engagement in care and strengthen patient-provider communications.

Updated infant-feeding guidelines are already proving to be powerful tools to support shared, informed decision-making. Listening to the needs and desires of parents living with HIV and supporting them with evidence-based practice facilitates-provider relationships that honor the whole person and ultimately improve the health and well-being of parents with HIV and their children.



BEEBAH (Building Equity, Ethics, and Education on Breastfeeding and HIV) is supported by POSITIVE ACTION 

To access more resources, scan the QR code 

