

How do women with HIV decide how to feed their babies?#P040

Kasadha, B.,¹ Tariq, S.,² Nyatsanza, F.,³ Freeman-Romilly, N.,⁴ Namiba, A.,⁵ Rai, T.¹

¹University of Oxford, ²University College London (UCL), ³Cambridgeshire Community Services NHS Trust, ⁴Oxford University Hospitals NHS Foundation Trust, ⁵4M Network

BACKGROUND:

- Over 800 pregnancies occur in women with HIV annually in the UK, with very low rates of vertical transmission (0.22%).
- Transmission risk via breastfeeding is greatly reduced by antiretroviral therapy (ARTs) but is not zero.
- Current UK BHIVA guidelines recommend exclusive formula feeding, however individuals should be supported to breastfeed if they choose to, and they meet certain criteria.

AIM: We explored infant feeding decisions among pregnant women, mothers and birthing parents with HIV in the UK.

METHODS:

- Remote semi-structured interviews (April 2021—Jan 2022).
- Eligible: women and birthing parents with HIV who were pregnant or had given birth within 12 months.
- Recruited via HIV clinics and charities.

Patient and Public Involvement (PPI) panel: Five mothers with HIV were part of our patient and public involvement panel. They also sit on our advisory panel. The PPI panel has shaped the aims, design, recruitment and methods for the Nourish-UK study.

Pregnant women (n=8)

- Planning to breastfeed (n=4)
 - Motivations: **health benefits, bonding, cultural expectations**
- Planning to formula feed (n=2)
 - Motivations: **avoid HIV transmission, sharing feeding duties**
- Undecided (n=2)

Women with live births (n=28)

- Breastfed (n=8)
 - Breastfeeding period: 1 day—6+ months
 - Motivations: **health benefits, bonding, cultural expectations of motherhood, signal HIV status**
- Formula fed (n=20)
 - Motivations: **avoid HIV transmission, preferred feeding option, sharing feeding duties, lack of research on breastfeeding premature babies**

None reported vertical transmission

RESULTS:

- Women living with HIV (n=36)
- Aged 23-44 years-old
- In a relationship (n=28) - two had partners unaware of HIV status

Table 1: participants' region of birth

Region of birth	No.
Africa	21
Mainland Europe	2
UK and Ireland	11
Elsewhere	2
Total	36

Table 2: participants' ethnicity

Ethnicity	No.
Asian	3
Black African	20
Black British African	2
Black Caribbean	2
White British	6
White other	2
Missing	1
Total	36

- Diagnosed in most recent pregnancy (n=5)
- Perinatally acquired HIV (n=5)
- Detectable viral load during childbirth (n=1)
- Could afford their basic expenses 'all' or 'most' of the time (n=16)



Inconsistent infant feeding information from healthcare providers

"during the meeting with the paediatrician she had actually said to me that, "you know, if this doesn't work out you need to not be very stubborn with it." and I said, "What do you mean by stubborn?" and she said, "Well because for a lot of people, even those without HIV, breastfeeding doesn't work out and you can get sore nipples, cracked nipples, [um] you know, I even have babies who come into my clinic that are malnourished because they have mums who just didn't wanna [um] give in to giving them formula." [...] and the midwife who was in the meeting as well said, "Oh come on like that's not that, that's not that common"

- NUK01, 30 years-old, pregnant with 2nd child

Limited awareness of the updated infant feeding guidelines

"I was just made to believe that [breastfeeding] was a high risk of transmission and that it was, you know, just a no go [...] I didn't know that there was an option to do it in a safer way, especially as I was undetectable way before I gave birth."

- NUK04, 31 years-old, 2nd child

"[The guidelines are] a much needed accommodation to having a more inclusive policy that well reflects the complexities of life [...] women are gonna have different desires around breastfeeding for different reasons"

- NUK08, 31 years-old, pregnant with 1st child

Half reported not feeling supported to breastfeed by HCPs

"Well, I am sort of insisting that I want to breastfeed, which doesn't seem to go down well with the team"

- NUK17, 39 years-old, pregnant with 1st child

"I've been diagnosed for how long now, 20 years or so I just thought I'm in good health and everything, I don't see any reason why, you know, I shouldn't breast feed my baby, which I did initially we had the, what they call liquid gold when he was born. And you know, because he, he, had jaundice and the lack of awareness and the nurses who obviously are not HIV trained background, they did not know how to support me [to breastfeed]. I did call [um] there was a group [um] there was a lady that gave me the number as well, they also deal with people with HIV and give support in terms of [um] surrounding breastfeeding. I remember that evening I called them, but maybe they were out of office"

- NUK10, 44 years-old, 2nd child

Healthcare professionals support and guidance was important

"if [my husband, mum or HIV physician] had shut me down [...] said like it's not a good idea, I don't think I'd be as confident as I am now"

- NUK01, 30 years-old, pregnant with 2nd child

"I was also advised to express and then freeze it just in case I became unwell and I didn't want to stop [breastfeeding] then I could use the frozen once"

- NUK13, 38 years-old, 2nd child

Free formula milk provision easing financial concerns

"Oh, yes [I've received formula] for until the baby is a year so you can imagine what it would have been like without support, you know, if there was no support, I bet maybe most of us would stick to breastfeeding"

- NUK20, 36 years-old, 2nd child

CONCLUSION:

- BHIVA's infant feeding guidelines are not reflected in participants' experiences
- There is an informational need among women with HIV around their infant feeding options
- Free formula milk eases financial burden for most women
- More breastfeeding support and advice is needed during pregnancy and post-partum
- Data suggests some healthcare professionals (HIV and non-HIV specialists) are either unaware of updated guidelines or are unwilling to implement them in practice
- Healthcare professionals, part of multidisciplinary team supporting pregnant women and mothers with HIV, require specific training and support regarding BHIVA's infant feeding guidance



NUFFIELD DEPARTMENT OF
PRIMARY CARE
HEALTH SCIENCES
Medical Sciences Division

healthtalk.org

FUNDED BY

NIHR

National Institute
for Health Research



nourishukstudy



phc.ox.ac.uk/nourishUK

Acknowledgements: we would like to thank all our study participants and everyone who supported the recruitment.