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# Mama Knows Breast: Pregnancy and the importance of infant feeding choices for women living with HIV

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4M Network of Mentor Mothers

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Pregnancy and the importance of infant feeding choices  
for women living with HIV

Cardiff: 15-17<sup>th</sup> May 2022

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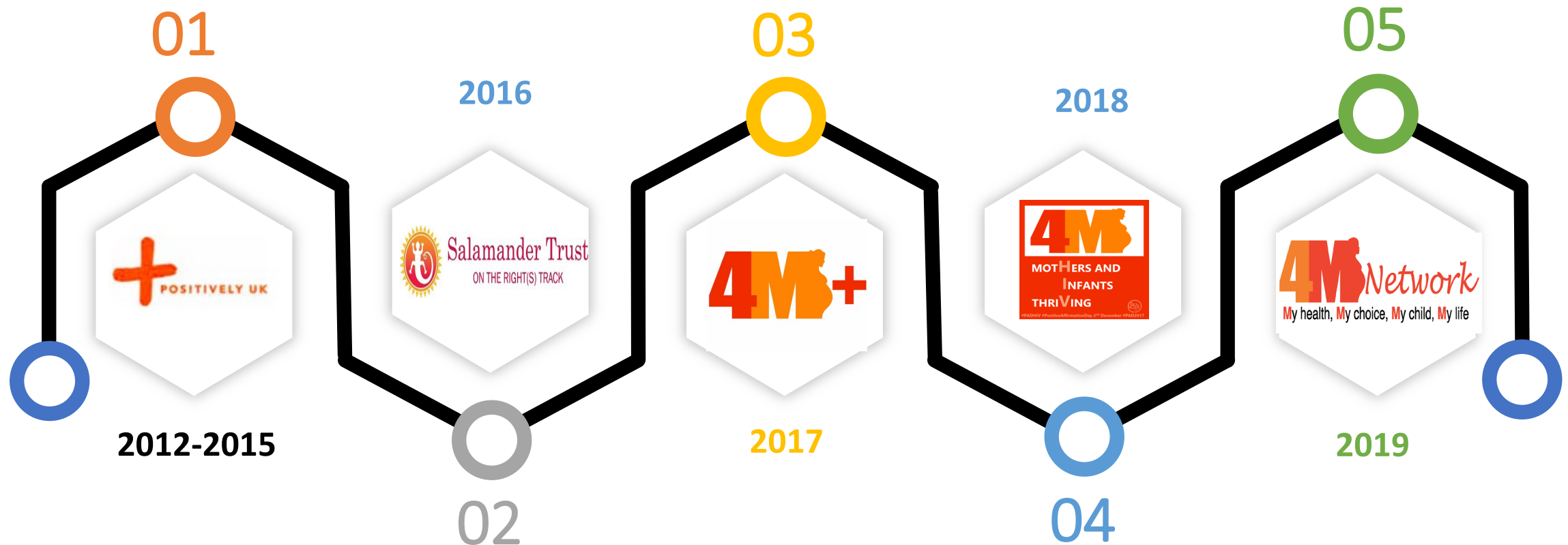
## Conflict of Interest

In relation to this presentation I declare that I have no conflict of interest

## Presentation Outline

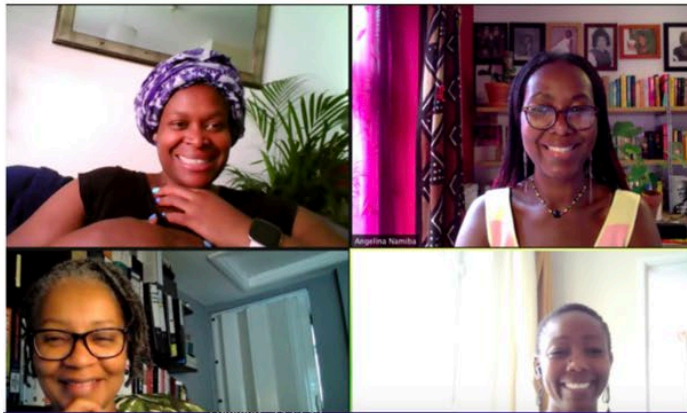
- Introduction to 4MNetwork & some of our projects
- Pregnancy, where we are now
- HIV treatment in pregnancy & infant prophylaxis
- HIV and Infant feeding
- NOURISH-UK key information
- Yummy mummy voices
- Audience participation
- Key points

# 4M Mentor Mothers Network- 'Her'story



# Mama Knows Breast: Pregnancy and the importance of infant feeding choices for women living with HIV

## Meet Our Team



### What we do

**4M is a unique peer-led programme led by Black migrant women. We train women living with HIV across the UK as Mentor Mothers to provide psycho-social support to peers in their pregnancy journey and beyond.**

It is now entirely possible that, with the right care, respect and support, women living with HIV can have babies born HIV-free through normal vaginal delivery.

As a result of our work, Mentor Mother peer support is now promoted as good practice in the British HIV Association National Pregnancy



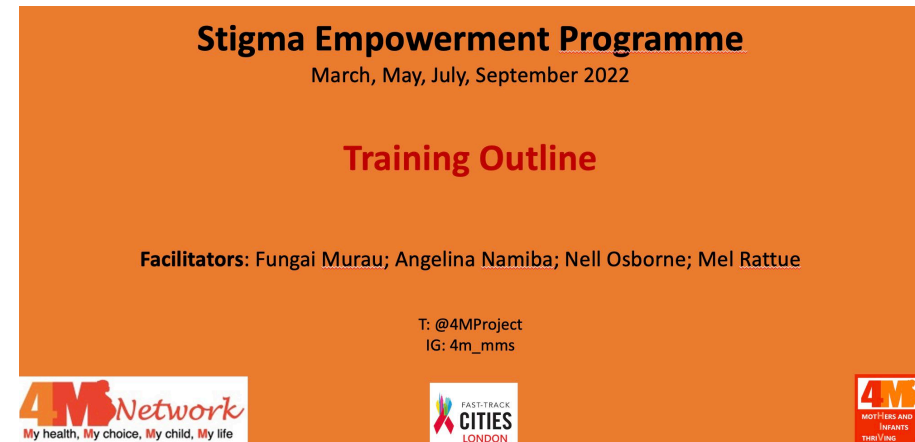
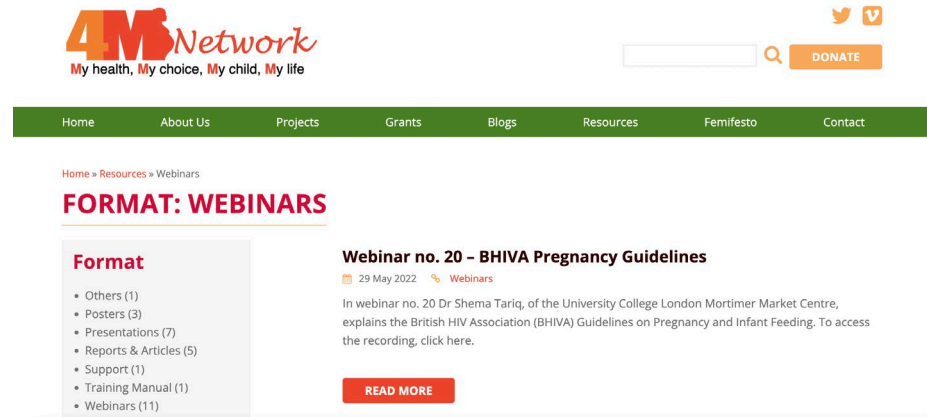
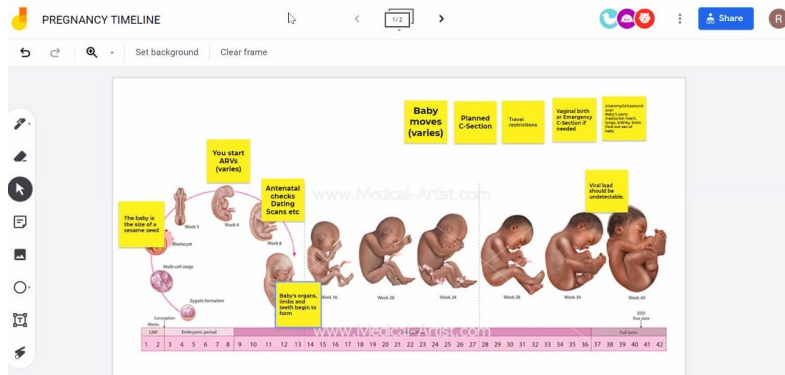
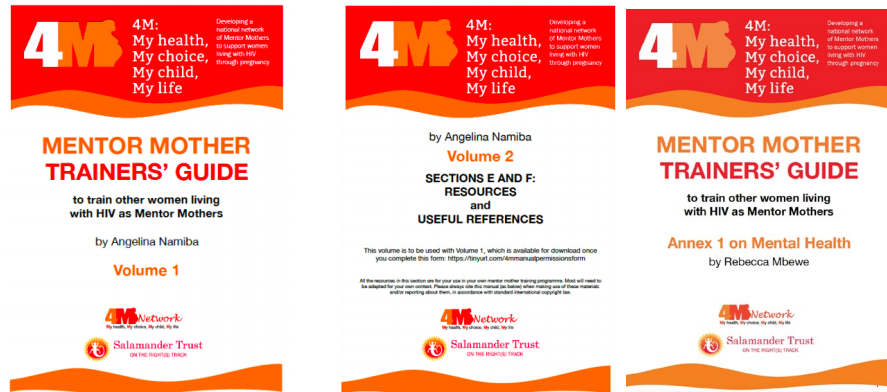
## ADVISORY STEERING GROUP

4M's Advisory Steering Group currently consists of the following members:

Professor Jane Anderson, Professor Susan Bewley, Dr Laura Byrne, Dr Rageshri Dhairyan (Chair), Gill Gordon, Fiona Hale, Dr Vicky Johnson, Longret Kwardem, Rebecca Mbewe, Angelina Namiba, Dr Shema Tariq, Dr Pat Tookey, Dr Alice Welbourn, Dr Alison Wright.

# Mama Knows Breast: Pregnancy and the importance of infant feeding choices for women living with HIV

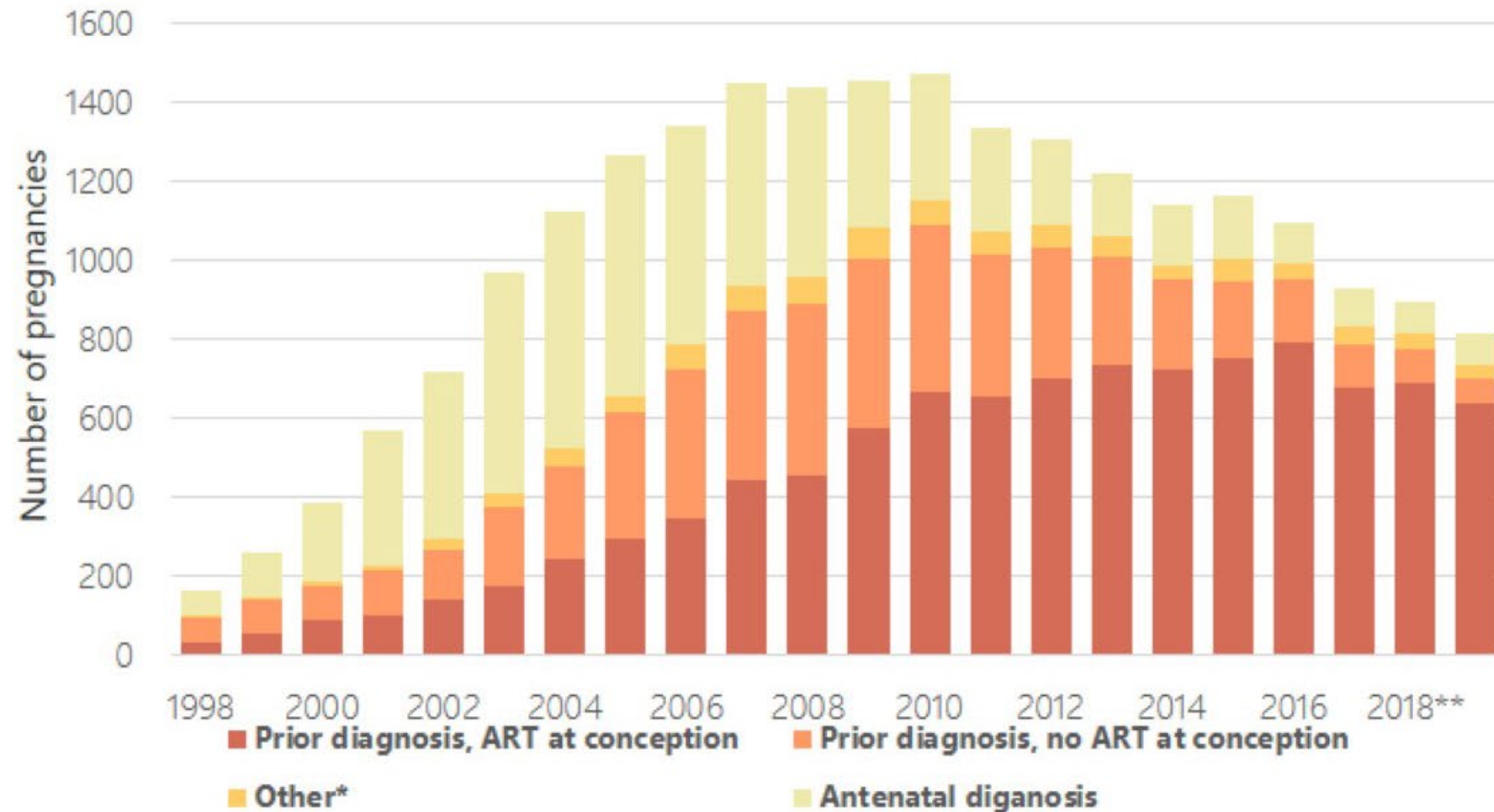
## Some of our projects



# 1 Pregnancy: where are we?



# Timing of diagnosis & ART at conception, UK 1998-2019



UK pregnancies (all outcomes) reported to ISOSS by June 2021

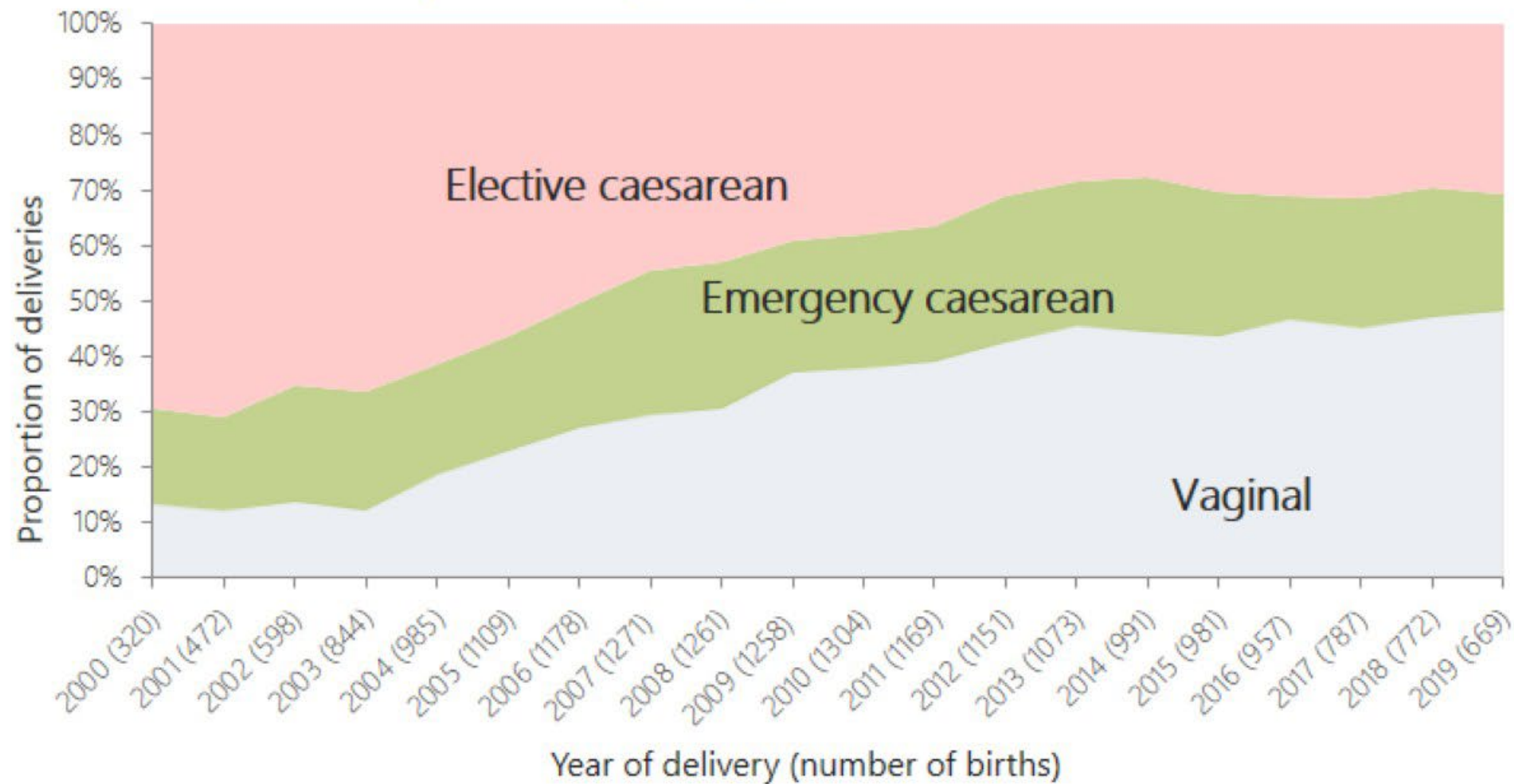
**Conception on ART**  
20.3% in 2000-2004  
75.5% in 2015-2019

\* contains pregnancies lacking information on precise timing of diagnosis and/or ART use

**ISOSS**  
Integrated Screening Outcomes Surveillance Service



## Mode of delivery among diagnosed women, UK 2000-2019



### Vaginal delivery

14.4% in 2000-2004

45.9% in 2015-2019

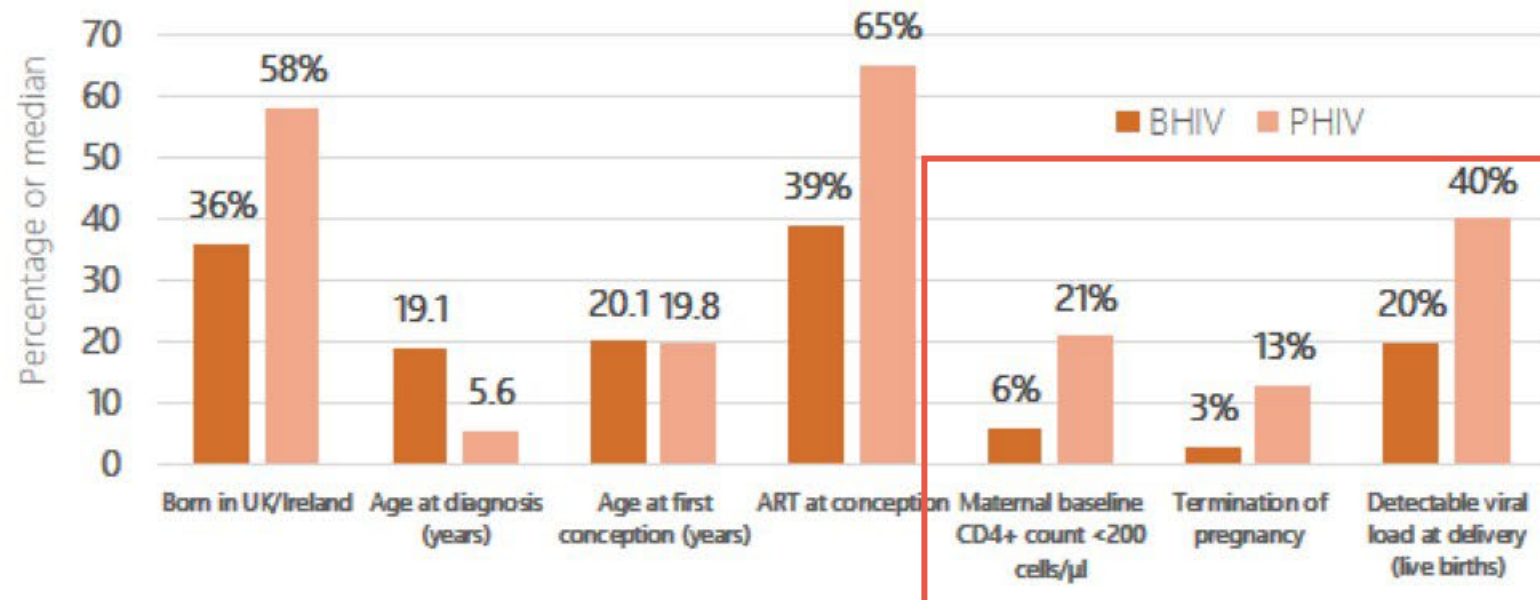
\* includes data from all ISOSS reporting sources

UK deliveries reported to ISOSS by June 2021\*

## Pregnancies in women with perinatal HIV (PHIV)

- Of 630 women reported in childhood, 45 (7%) had at least one pregnancy reported
- Pregnancy incidence rate lower in PHIV than in women of similar age in general UK population
- 70 pregnancies among 45 women with PHIV were compared with 184 pregnancies among 118 age-matched women with behaviourally-acquired HIV (BHIV)

13 per 1000  
woman-years  
*pregnancy incidence  
rate among women  
with PHIV*



Women with PHIV  
were 3x more likely to  
have detectable viral  
load near delivery  
[OR 3.22 (CI 1.22-8.48)]

For a link to full publication, visit  
[www.ucl.ac.uk/isoss/publications-presentations](http://www.ucl.ac.uk/isoss/publications-presentations)



# ● Transmission



Pregnancy

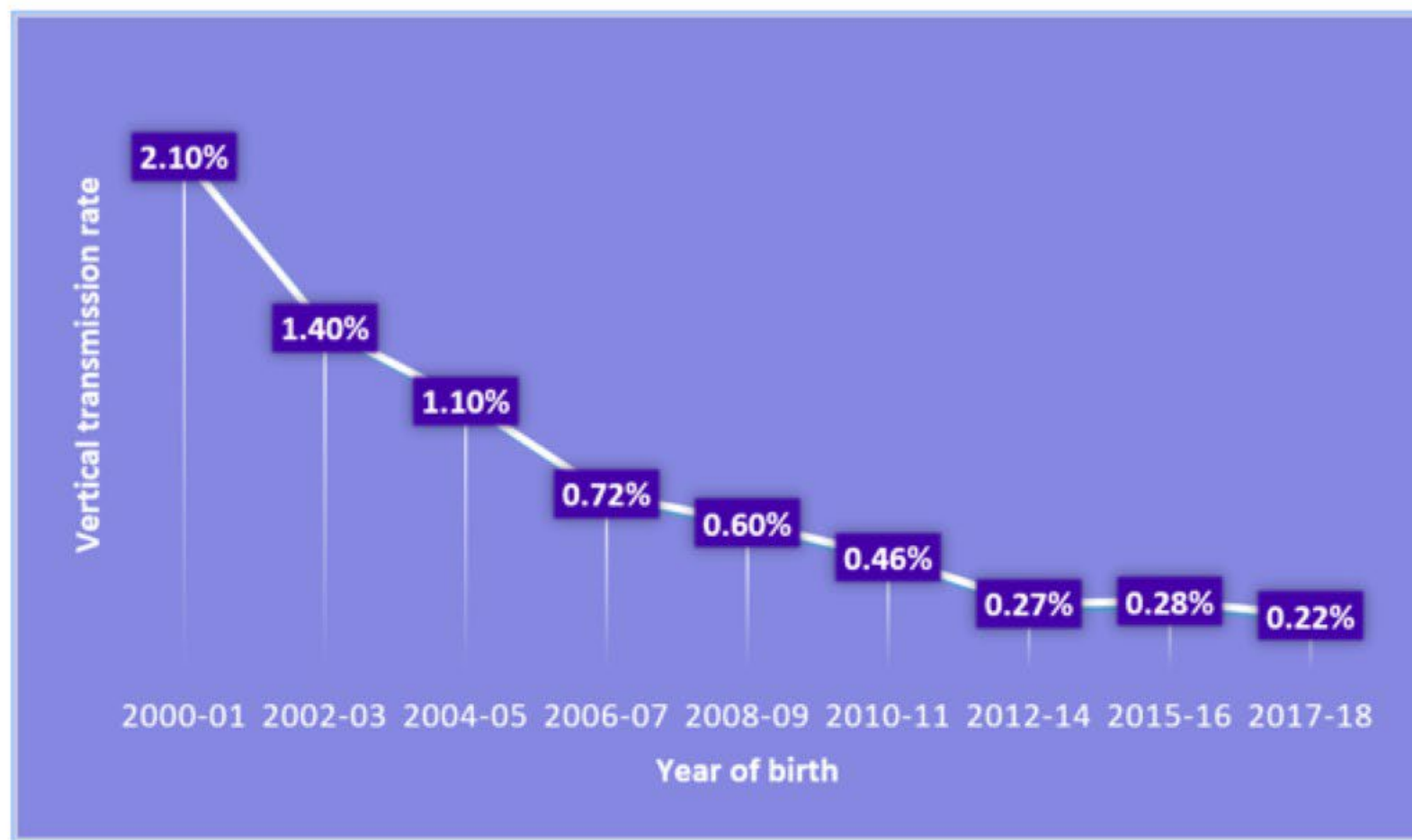


Birth

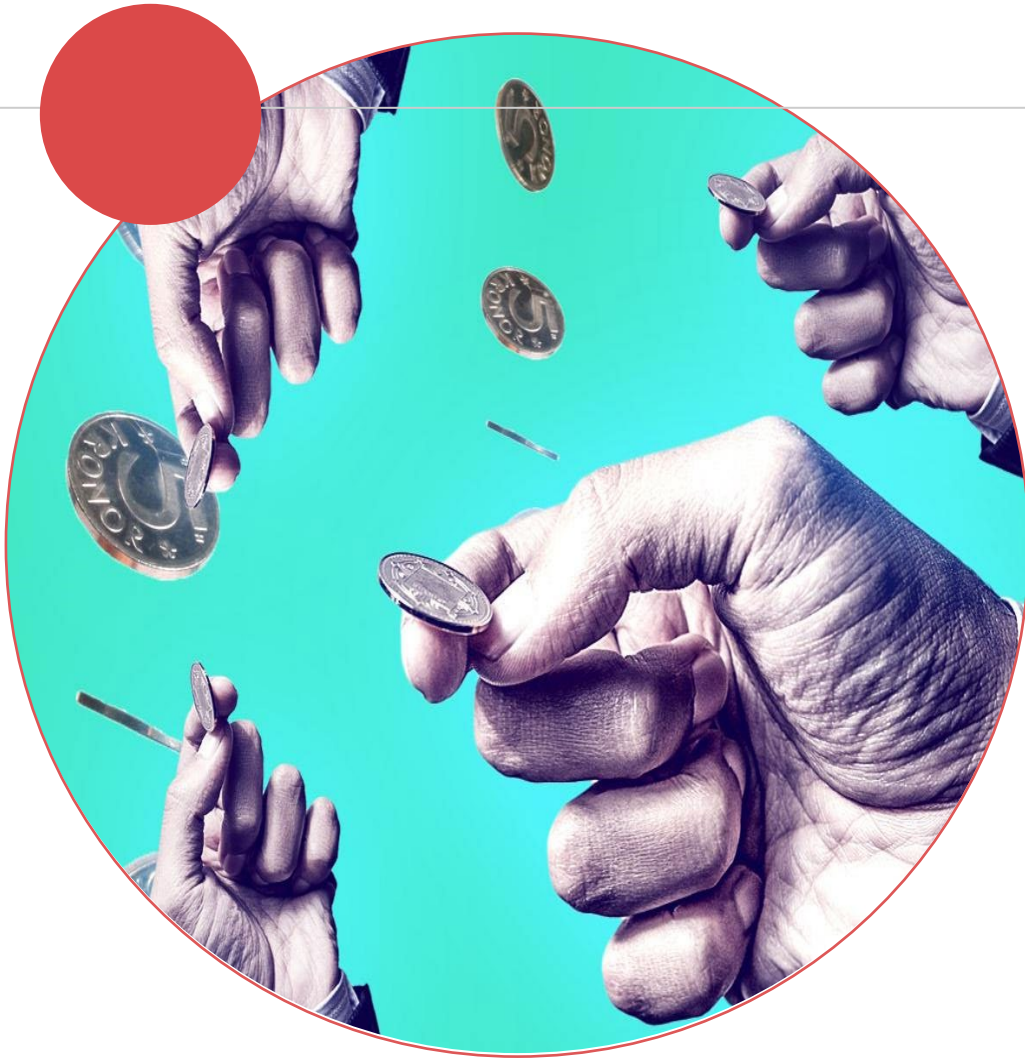


Breastfeeding

## Vertical transmission in UK, 2000-2018



Data for 2000-11 from Townsend *et al.* AIDS 2014; data for 2012-14 from Peters *et al.* CID 2016; data for 2015-16 from Peters *et al.* HIV Drug Therapy Glasgow 2018; data for 2017-18 from Peters *et al.* CROI 2021

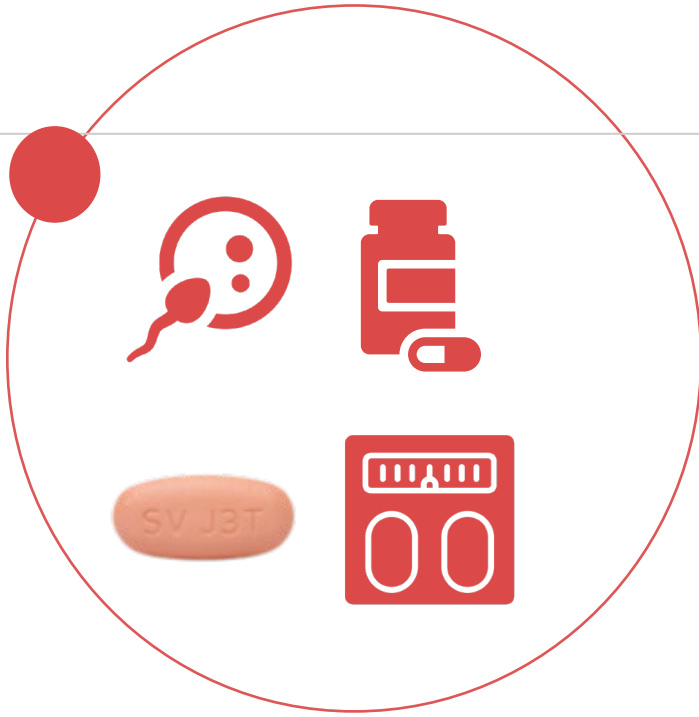


## **1 in 500 chance**

Same as getting nine heads in a row  
when you toss a coin

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## HIV treatment in pregnancy



### **Conceiving on ART**

- Stay on current medication
- PI monotherapy
- Cobicistat-based regimens
- RAL 1200mg (switch to 400mg bd)

### **Dolutegravir**

- Safe for women trying to conceive but take 5mg folic acid
- Safe to start in pregnancy >6 weeks
- Higher dose of folic acid
- No increased risk of neural tube defects
- No need for more scans

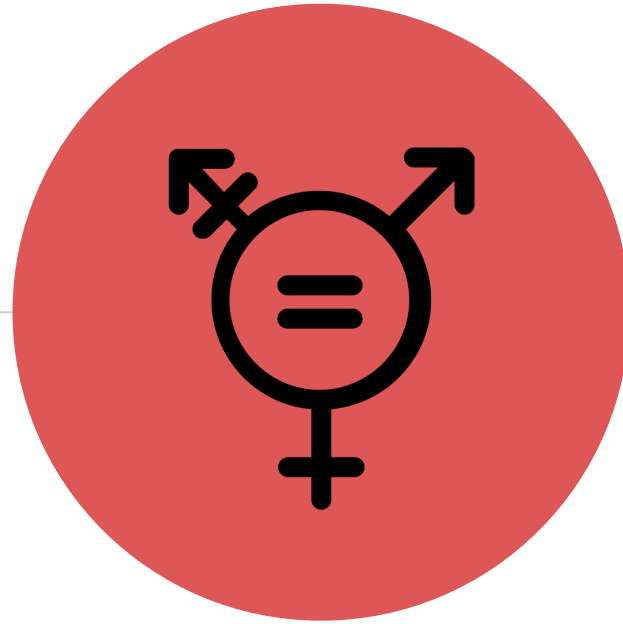
### **Dolutegravir and weight gain**

- Average 10-12.5kg weight gain
- Weight gain important for healthy pregnancy
- Dolutegravir seems to be better for pregnancy weight gain (compared to efavirenz)

### **Starting ART in pregnancy**

- Start ART by week 24
- Continue lifelong
- Higher viral load, sooner to start





# Protecting women through research<sup>1</sup>

Reduce regulatory barriers, complex NOT vulnerable population, address logistical barriers, improve research literacy, involve women with HIV

# Infant prophylaxis

## VERY LOW RISK

*Two weeks ZDV  
monotherapy*

- Mother has been on **cART** for **>10 weeks** **AND**
- **Two documented maternal HIV viral loads <50** during pregnancy at least 4 weeks apart **AND**
- Maternal **HIV viral load <50** at or after 36 weeks

## LOW RISK

*4 weeks ZDV  
monotherapy*

- If **VERY LOW RISK** criteria are not all fulfilled but
- **Maternal HIV VL is <50 HIV** at or after 36 weeks
- If **baby born <34 weeks** but most recent maternal HIV VL is **<50 HIV**

## HIGH RISK

- Use combination PEP if **maternal birth HIV VL known to be or likely to be >50**, if **uncertainty about recent maternal adherence** or if **VL not known**

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## HIV and infant feeding



# U=U does not apply to breastfeeding

Feeding parent on ART reduces risk of HIV transmission  
but risk is not zero



## U=U and breastfeeding

- U=U studies looked at sexual transmission
- Does ART reduce cell-associated virus in milk?
- Are ART levels sufficient in breastmilk?
- Limited information about ART effect on infant
- Some cases of transmission even if VL<100

# ● HIV transmission in breastfeeding trials

	HIV transmission (95% CI)	
	Bispo, et al <sup>1</sup>	PROMISE study <sup>2</sup>
At 6m	1.08% (0.32–1.85)	0.3% (0.1–0.6)
At 12m	2.93% (0.68–5.18)	0.6% (0.4–1.1)

Source: 1. Bispo S, et al. (2017). 20: 1–8; 2.Taha T. International AIDS Conference. Durban, South Africa



## **Risk of breastfeeding**

Risk is very low if mum on treatment

**3-6 per 1000**

*Abstaining from breastfeeding can have financial and psychological repercussions for women, requiring support from the HIV multidisciplinary team.*



BHIVA HIV and Pregnancy Guidelines (2018)



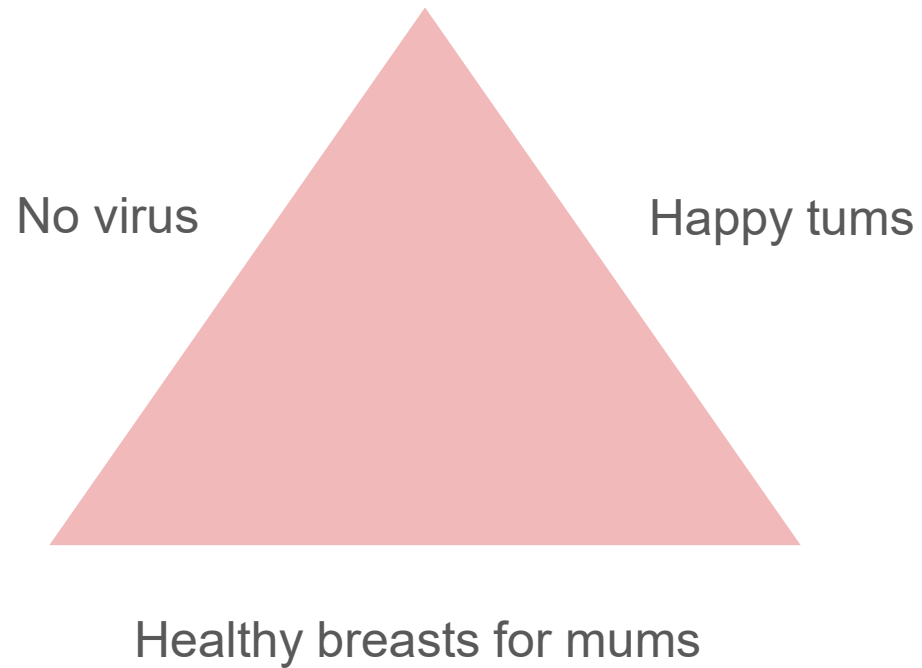
*Women who are virologically suppressed on cART with good adherence and who choose to breastfeed may be supported to do so, but should be informed about the low risk of transmission of HIV through breastfeeding in this situation and the requirement for extra maternal and infant clinical monitoring.*



BHIVA HIV and Pregnancy Guidelines (2018)



# ● “Safer Triangle”



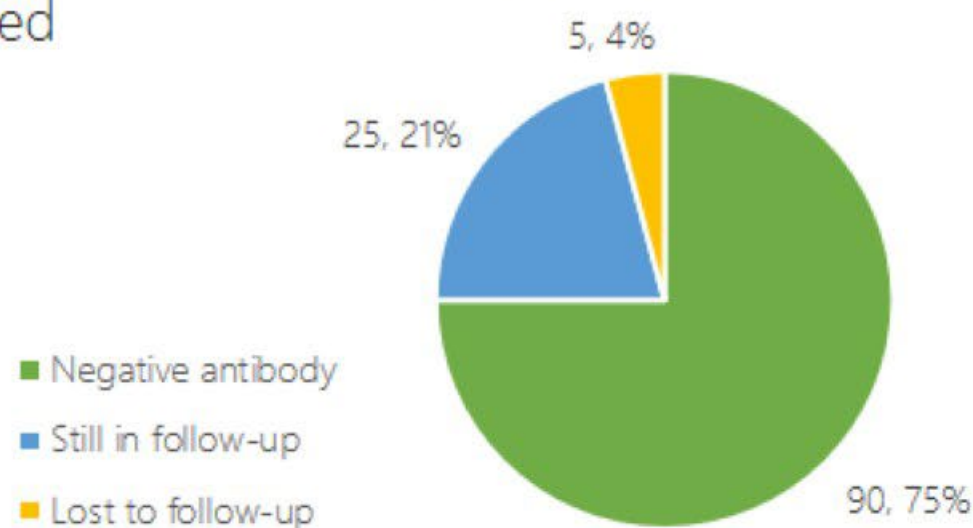
## Supported breastfeeding among women with diagnosed HIV

- Of 9133 livebirth deliveries to women with diagnosed HIV in 2012-2020, 151 (1.8%) were reported as supported to breastfeed

### Key characteristics of cases of supported breastfeeding

143/151 (95%)	Mother diagnosed before pregnancy
129/151 (85%)	Mother born abroad
35 years (31-40)	Median age at delivery (IQR)
<i>Duration of breastfeeding</i>	
1 day – 2 years	Range
7 weeks (3-16)	Median (IQR)

IQR: interquartile range



Current status of infants where breastfeeding has stopped\* (n=120) (data source: Peters *et al.* 2021 RCPCH)

For a link to full publication, visit [www.ucl.ac.uk/isoss/publications-presentations](http://www.ucl.ac.uk/isoss/publications-presentations)

\*numbers too small to provide transmission rate.



# Nourish-UK: Key Information

- Participant interviews
- Participants (n=36), aged 23 to 44 years-old
- Majority (n=20) Black African
- Partnered/married (n=28) – two partners unaware of HIV status
- Diagnosed during most recent pregnancy (n=5); perinatal HIV (n=5)
- Majority (n=28) were postpartum; majority (20 of 28 participants) formula fed



FUNDED BY

**NIHR**

National Institute  
for Health Research

# Snapshot of Nourish-UK findings

- Inconsistent infant feeding information and support from HCPs
  - If families receive conflicting infant feeding advice within their medical team, how do we resolve this?
- Participants had limited awareness of the updated BHIVA guidelines
  - How do we ensure informed infant feeding choices and understanding of 'risk'?
- Half reported not feeling supported to breastfeed by HCPs
  - What happens if it doesn't go to 'plan'? E.g. latching or lactating issues shortly after birth are common.
  - Some participants who wanted to breastfeed had to 'self-advocate' for their right to do so, despite meeting the BHIVA guidelines. How do we improve communication so that women do not have to be 'expert patients'?
- Participants stated that support from HCPs and partners is important



# Selected NOURISH-UK quotes

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## Kay, 31

- “[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”





## Marella - 30

- *“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 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”*



## Amy – 31

- *"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."*



## Gracelove - 38

- *“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”*



# More yummy mummy voices



## **Tilly – Baby no 1. Formula Baby no.2 Breastfed**

*'I am literally a walking buffet and able to feed this baby wherever, whenever, whereas before I'd have to make sure I had enough bottles, hot water, cold water, enough formula whenever I was going out and like I could be less spontaneous with my plans.'*



## Resty – Baby formula fed

*‘It was your pregnancy, it’s your baby,  
your decision matters in their growth.’*





**Angelina – Formula fed**  
*‘When I had my baby the guidelines recommended that we all had caesarean sections and did not breastfeed’.*



## Becky - Breastfed

*'I decided to breastfeed my baby because of the benefits to my child. I've had three children prior to being diagnosed and breastfed them exclusively. Hence, breastfeeding was a normal thing to me. In fact I loved it!'*





## LeaSuwanna - Breastfed

*'The first time I cried with happiness that she latched on and was happy to be getting fed.'*



# Audience Participation



## Aluiya

*Referred to 4M when pregnant. Chose to breastfeed. Was undetectable and by first test baby was negative. At 5 months old mum is starting to wean him off breastmilk. She started two days ago but he is not taking well to formula. He's taking far less than the recommended amount (300ml as opposed to 1000ml). Her breasts are also tender.*

**What would you advice her?**



## Key points

- Vertical transmission is very rare
- Most HIV medication is safe & effective
- Increasing support for breast feeding
- Mental health important
- Peer support essential
- Parents need to be trusted to make informed choices
- New guidelines underway



## Acknowledgements

Huge thanks to:

- Dr Shema Tariq – University College London (UCL)
- Helen Peters – Integrated Screening Outcomes Surveillance Service (ISOSS)
- Bakita Kasadha – NOURISH-UK
- 4M Net super Mentor Mothers LeaSuwanna & Resty
- Yummy mummies Tilly & Becky ☺