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## Challenges facing pregnant women with HIV in the UK: drawing from research

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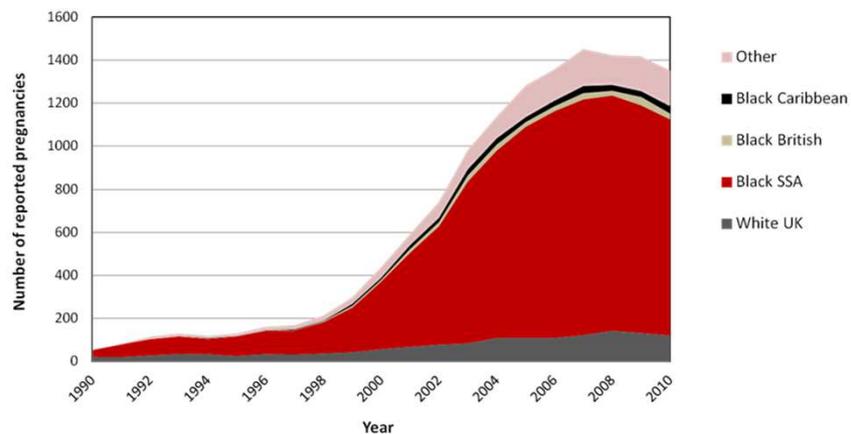


## OUTLINE



- Epidemiology
- Antenatal booking
- ART during pregnancy
- Religion
- Experiences of maternity care
- Infant feeding
- Retention in HIV care after pregnancy

## NUMBER OF PREGNANT WOMEN LIVING WITH HIV IN THE UK: 1990-2010



Source: [www.nshpc.ucl.ac.uk](http://www.nshpc.ucl.ac.uk)

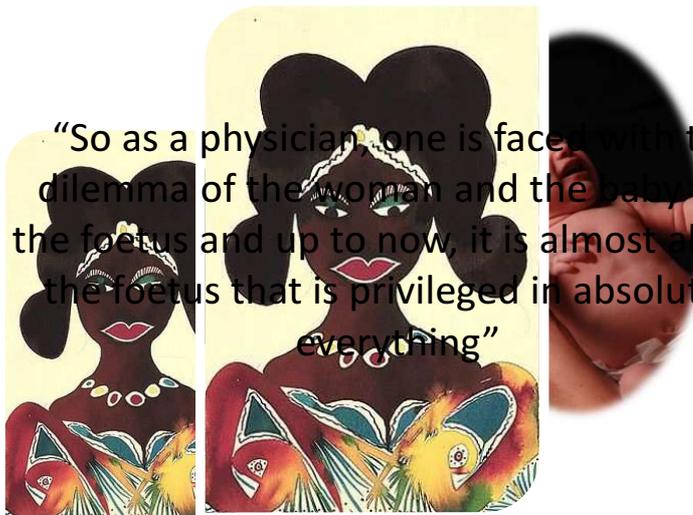
### MTCT rates in diagnosed women, UK & Ireland 2000-2011



~12,500 singleton births; significant decline in MTCT over time ( $p < 0.001$ )

Graph derived from data in Townsend *et al.* Earlier initiation of ART and further decline in mother-to-child HIV transmission rates, 2000-2011. *AIDS* 2014; 28:1049-1057

“So as a physician, one is faced with the dilemma of the woman and the baby, and the foetus and up to now, it is almost always the foetus that is privileged in absolutely everything”

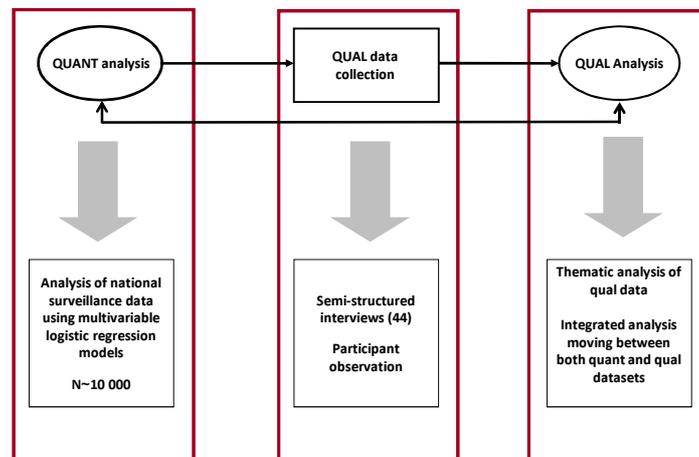


## RESEARCH QUESTION

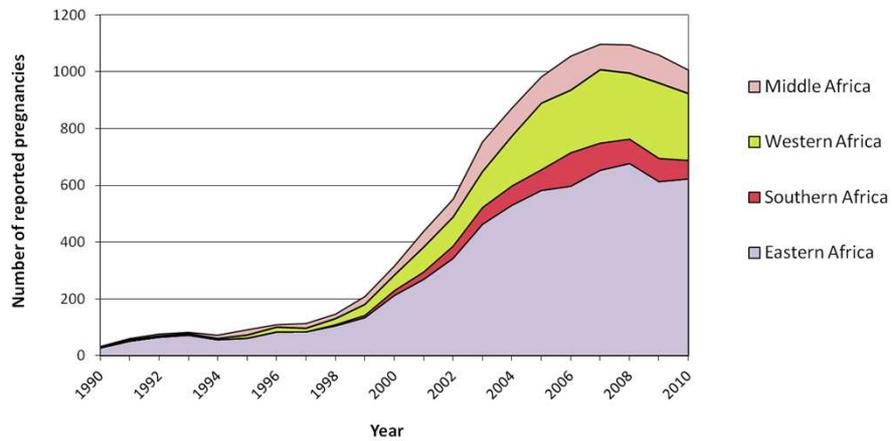


How do African women living with HIV in the UK engage with HIV services and interventions during and after pregnancy?

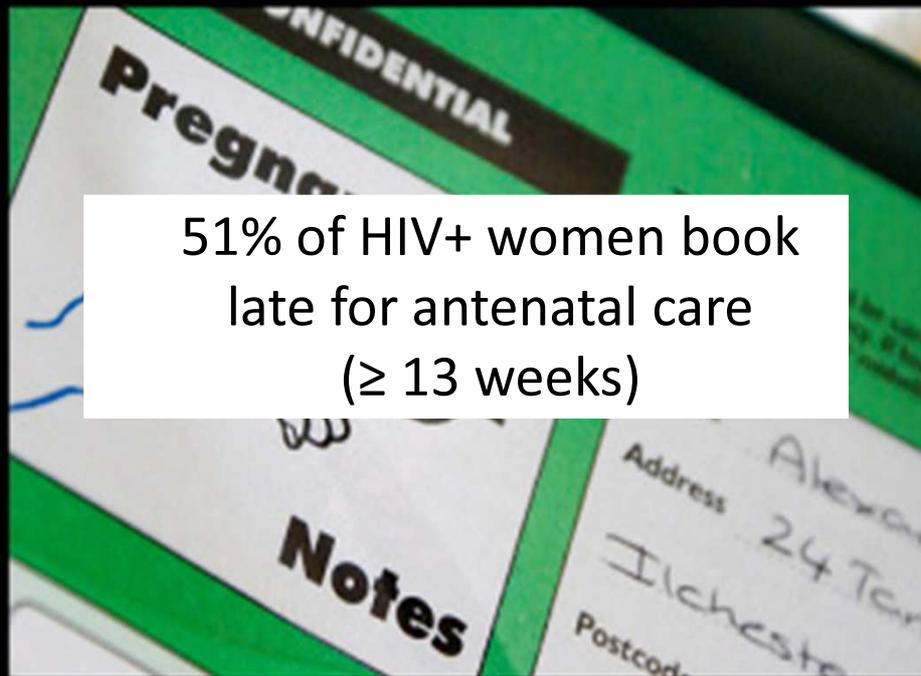
## STUDY DESIGN



TRENDS IN MATERNAL AFRICAN REGION OF BIRTH  
1990-2010



51% of HIV+ women book  
late for antenatal care  
( $\geq 13$  weeks)



## DIAGNOSED *DURING* PREGNANCY: ETHNICITY AND LATE BOOKING



	Late antenatal booking	
	AOR (95% CI)	<i>p</i>
White (reference)	1.00	-
African	2.98 (1.45, 6.11)	0.003
Other black	3.74 (1.28, 10.94)	0.016
Other	1.02(0.35, 2.93)	0.978

Adjusted for maternal age, parity and reporting region; AOR, adjusted odds ratio; CI, confidence interval

Source: Tariq et al. *AIDS Care* (2012)

## DIAGNOSED *BEFORE* PREGNANCY: ETHNICITY AND LATE BOOKING



	Late antenatal booking	
	AOR (95% CI)	<i>p</i>
White (reference)	1.00	-
African	1.98 (1.27, 3.07)	0.002
Other black	1.21 (0.60, 2.43)	0.596
Other	0.86 (0.37, 1.96)	0.713

Adjusted for maternal age, parity and reporting region; AOR, adjusted odds ratio; CI, confidence interval

Source: Tariq et al. *AIDS Care* (2012)

## ART DURING PREGNANCY



- 97% of women received ART in pregnancy<sup>1</sup>
- No difference between African and white British women<sup>1</sup>
- 80% of women on ART had undetectable HIV viral load by delivery<sup>2</sup>
- No difference by ethnicity<sup>2</sup>

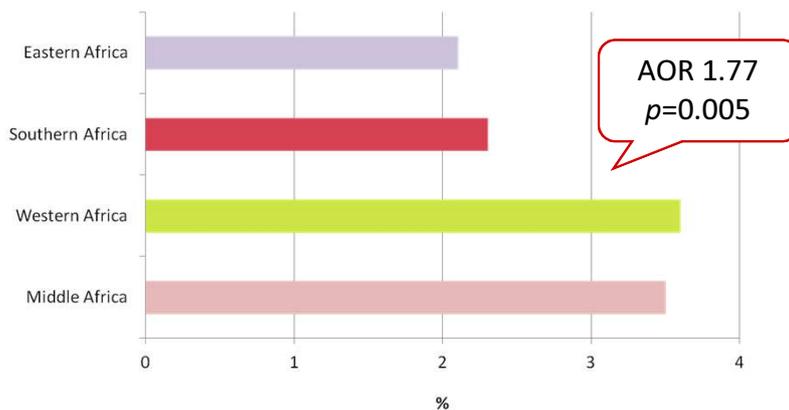
Source: 1. Tariq et al. IAS 2011: abstract TUPE283; 2. Tariq (unpublished work 2013)

## MOTIVATION TO TAKE ART



So that's basically how I thought it, you know, being on top of medication [...] and then getting the first two results of him being negative has been fantastic as well.

## ASSOCIATION BETWEEN MATERNAL AFRICAN REGION OF BIRTH AND NOT TAKING ART IN PREGNANCY



Source: Tariq et al. IAS 2011: abstract TUPE283

**BBC NEWS LONDON**

Home World UK England N.Ireland Scotland Wales Business Politics Health Education Sci/En

18 October 2011 Last updated at 01:27

### Church HIV prayer cure claims 'cause three deaths'

By Andy Dangerfield  
BBC News, London

At least three people in London with HIV have died after they stopped taking life saving drugs on the advice of their Evangelical Christian pastors.



The women died after attending churches in London where they were encouraged to stop taking the antiretroviral drugs in the belief that God would heal them, their friends and a leading HIV doctor said.

Synagogue Church Of All Nations website shows photos of people it claims have been "cured"

Responding to the BBC London investigation, Lord Fowler, the former health minister responsible for the famous Aids awareness campaign of the 1980s, condemned the practice.

"It's just wrong, bad advice that should be confronted," said the Tory peer, who chaired last month's House of Lords committee into HIV.

Jane Iwu, 48, from Newham, east London, described one case, saying: "I know of a friend who had been to a pastor. She told her to stop taking her medication - that God is a healer and has healed her."

"This lady believed it. She stopped taking her medication. She passed away," said Ms Iwu, who has HIV herself.

**Related Stories**

- HIV efforts 'woefully inadequate'
- Scientist jailed over house slave
- London HIV services cut 'outrage'



## RELIGIOUS BELIEFS



- Church fosters resilience
- Gives hope
- Social and emotional support
- What is a miracle?
  - good health
  - undetectable HIV viral load
  - HIV-negative child



## BEING PRAGMATIC



I need God and medication. It's like if you're sitting an exam. God may lead you to read something before the exam and then you can answer the question. But if you don't even carry the text book...how do you do it?

## BARRIERS TO TAKING ART



My biggest worry is the side effects. That if the medication I'm taking, how is it going to influence my child, my baby ...you know, all sorts of things come into your head like you're taking all this medication, how is it going to affect the baby?

## STIGMA



It's not like East Africa, because there 80%, are in this situation. In West Africa not a lot of people have it. Even your mum, or your brother, or your sister, or your kid... no-one will come close to you.



## NEGATIVE EXPERIENCES OF MATERNITY SERVICES



I could hear the midwife outside telling the other one to be careful as I was 'high, high risk'.

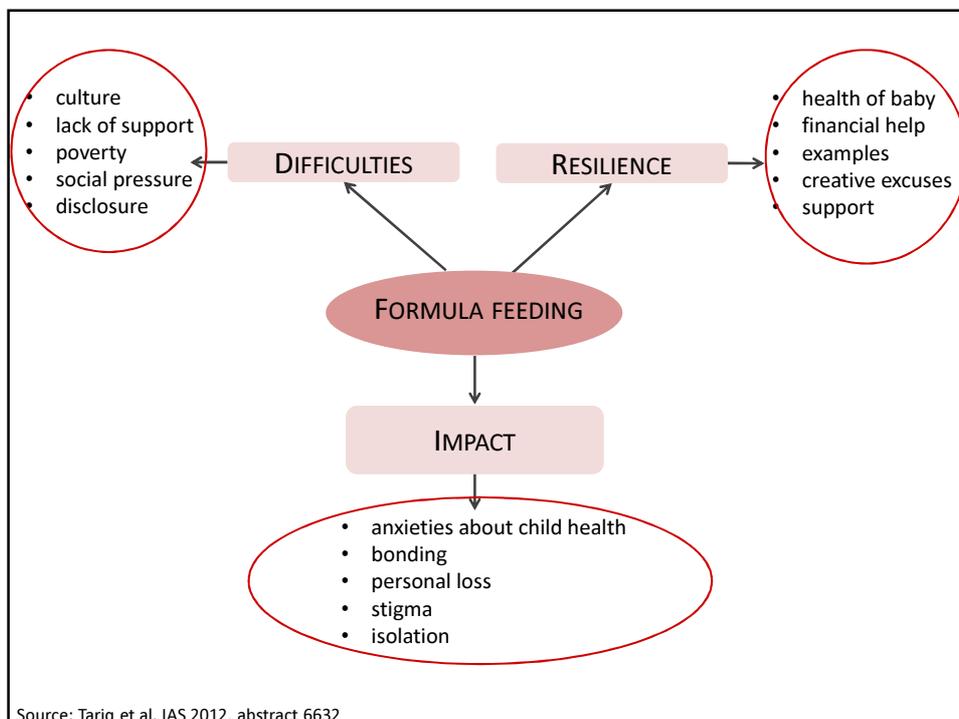
When I think about the experiences I had...I wanted four or five kids. Now I said to my husband 'no, this is the end of it'.

Source: Tariq et al. BHIVA 2014, abstract P136

## INFANT FEEDING



- ART reduces risk of transmission to <5%
- Does not eliminate risk
- Long-term risk to HIV-negative child of ART exposure?
- BHIVA guidelines: avoid breastfeeding
- Breastfeeding culturally normative



## INFANT FEEDING



That's what really makes me feel sad because in our culture in Africa you're supposed to breastfeed.

I feel unhappy. I just accept it, but, in my heart, it pains me, because, as a woman you have to breastfeed your baby.

## LOST TO FOLLOW UP IN THE YEAR AFTER PREGNANCY



- Combined data from NSHPC and SOPHID
- 88% matching in women reported as pregnant in 1998-2009: 8695 pregnancies
- Overall **12%** of women (1055/8695) did not access care in the year after pregnancy
- Of those who did not access care eight were known to have died

## LOSS TO FOLLOW-UP (1 YEAR) AND MATERNAL ETHNICITY



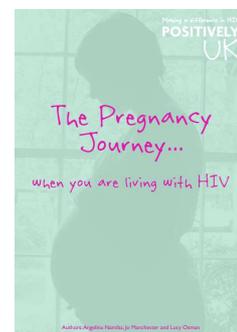
	LTFU (1 year)
	AOR (95% CI)*
White (reference)	1.00
African	1.96 (1.44, 2.67)
Caribbean	1.47 (0.88, 2.44)
Other	1.00 (0.61, 1.63)

Adjusted for maternal age, parity and reporting region; AOR, adjusted odds ratio; CI, confidence interval  
\* $p < 0.001$

## CONCLUSIONS



- Address the 'bigger picture'
- Significant challenges
- Peer and social support
- Free milk and equipment
- **Good outcomes !!!**
- Maternal love and resilience





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British HIV Association  
**BHIVA**



**FHIVA**  
federation  
of hiv  
associations

## Prevention of Infant HIV Infection: *Aiming for zero transmission*

A multidisciplinary conference for obstetricians,  
gynaecologists, HIV physicians and allied healthcare professionals

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