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

“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**

- **QUANT analysis**
  - Analysis of national surveillance data using multivariable logistic regression models
  - N=10 000

- **QUAL data collection**
  - Semi-structured interviews (44)
  - Participant observation

- **QUAL Analysis**
  - Thematic analysis of qual data
  - Integrated analysis moving between both quant and qual datasets
TRENDS IN MATERNAL AFRICAN REGION OF BIRTH
1990-2010

51% of HIV+ women book late for antenatal care
(≥ 13 weeks)
### Diagnosed During Pregnancy: Ethnicity and Late Booking

<table>
<thead>
<tr>
<th></th>
<th>Late antenatal booking</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>White (reference)</td>
<td>1.00  (Reference)</td>
<td>-</td>
</tr>
<tr>
<td>African</td>
<td>2.98  (1.45, 6.11)</td>
<td>0.003</td>
</tr>
<tr>
<td>Other black</td>
<td>3.74  (1.28, 10.94)</td>
<td>0.016</td>
</tr>
<tr>
<td>Other</td>
<td>1.02  (0.35, 2.93)</td>
<td>0.978</td>
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</tbody>
</table>

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

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<td>White (reference)</td>
<td>1.00</td>
<td>-</td>
</tr>
<tr>
<td>African</td>
<td>1.98  (1.27, 3.07)</td>
<td>0.002</td>
</tr>
<tr>
<td>Other black</td>
<td>1.21  (0.60, 2.43)</td>
<td>0.596</td>
</tr>
<tr>
<td>Other</td>
<td>0.86  (0.37, 1.96)</td>
<td>0.713</td>
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</table>

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\(^1\)
- No difference between African and white British women\(^1\)
- 80% of women on ART had undetectable HIV viral load by delivery\(^2\)
- No difference by ethnicity\(^2\)


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

AOR 1.77
p=0.005
**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.
8/15 women described negative experiences of maternity care

Source: Tariq et al. BHIVA 2014; abstract P136

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

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**DIFFICULTIES**
- culture
- lack of support
- poverty
- social pressure disclosure

**FORMULA FEEDING**
- health of baby
- financial help
- examples
- creative excuses support

**RESILIENCE**

**IMPACT**
- anxieties about child health
- bonding
- personal loss
- stigma
- isolation

Source: Tariq et al. IAS 2012, abstract 6632
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

Source: Tariq et al. BHIVA 2013, abstract O16
**LOSS TO FOLLOW-UP (1 YEAR) AND MATERNAL ETHNICITY**

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>LTFU (1 year)</th>
<th>AOR (95% CI)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>White (reference)</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>African</td>
<td>1.96 (1.44, 2.67)</td>
<td>1.96 (1.44, 2.67)</td>
</tr>
<tr>
<td>Caribbean</td>
<td>1.47 (0.88, 2.44)</td>
<td>1.47 (0.88, 2.44)</td>
</tr>
<tr>
<td>Other</td>
<td>1.00 (0.61, 1.63)</td>
<td>1.00 (0.61, 1.63)</td>
</tr>
</tbody>
</table>

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
Acknowledgements:
Supervision team (Jonathan Elford, Pat Tookey, Alexandra Pillen); Staff at NSHPC and respondents; staff at Homerton, Newham and St Thomas’; MRC; our participants