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Elimination of vertical transmission in the UK: what is left to do?
Results of the NSHPC audit of perinatal HIV since 2006

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Background

**Vertical transmission**

- Can occur
  - in utero
  - labour & delivery
  - postnatally through breastfeeding
- In untreated women VT rate up to 30-40%
- Rate in diagnosed women the UK all time low <0.5%
  - Universal antenatal HIV screening
  - Access to cART and specialist medical care
  - Optimised obstetric management
  - Avoidance of breastfeeding (or BF risks minimised)

Background

**Antenatal screening programme for HIV**

Antenatal HIV screening is one of the most successful universal screening programmes in the UK.

- The DoH first recommended antenatal HIV screening in areas of high prevalence in the UK in 1994, and the normalisation of HIV testing for all pregnant women was recommended in 1999
- It is now part of the UK National Screening Committee's Infectious Diseases in Pregnancy Screening programme, which currently sits in PHE
- By 2012, the estimated uptake of screening had risen to 98% of women presenting for antenatal care in England
- Current IDPS Programme Standards were revised in 2010 and fully implemented by April 2012 (now being revised)
**Background**

Previous audit of perinatal HIV in children born in England

- NSHPC jointly with CHIVA & AAU
- Collected additional data on children born in England diagnosed with perinatal HIV
- Highlighted:
  - Failures in communication (amongst clinical staff, between clinical staff & patients, between labs & clinical staff)
  - Failures by clinicians to act on suboptimal virological responses to ART
  - Adverse social circumstances of these women and children
- The findings were fed into the IDPS standards and the BHIVA & CHIVA guidelines

**Rationale**

Why did we need another audit of perinatal HIV?

- Despite the successes in preventing VT, small numbers of children who acquire HIV from their mothers are reported each year
- Over half of these children’s mothers were not diagnosed with HIV by delivery
- These children at greater risk of morbidity & mortality because they are diagnosed later
- We didn’t routinely collect information on the circumstances of the pregnancy for children born to undiagnosed women
Aims

To provide information to the IDPS programme about antenatal screening and the management of women whose infants acquire perinatal HIV in the UK, in order to contribute to

1. The monitoring and improvement of antenatal screening protocols
2. A further reduction in the risk of perinatal HIV by improving our understanding of the timing and circumstances of maternal and infant acquisition of infection

Methods

• Children born in the UK diagnosed with perinatal HIV are reported to the NSHPC routinely
• We conducted structured telephone interviews with clinicians with knowledge of the case (or access to the notes)
• For diagnosed women we interviewed both obstetric and paediatric respondents if possible
• For undiagnosed women we interviewed paediatric respondents, and obstetric respondents if they were aware that the transmission had occurred
Methods

- All contributing factors were identified in each case
- One main contributing factor was identified for each case to enable cases with similar characteristics to be grouped
- We convened an Expert Review Panel which included paediatricians, obstetricians, HIV physicians, specialist midwives, paediatric nurse specialists, representatives from the IDPS programme, and members of the voluntary sector
- The ERP reviewed a summary of each case, and is making recommendations which are currently being finalised
- The audit methodology was embedded in the routine working of the NSHPC so that enhanced surveillance is ongoing

Results

Children diagnosed with perinatal HIV born in the UK since 2006

- Woman diagnosed during pregnancy or at delivery
- Woman diagnosed before pregnancy
- Woman diagnosed after pregnancy/undiagnosed
Results

Age at diagnosis and year of birth of children with perinatal HIV born to undiagnosed women

![Chart showing age at diagnosis and year of birth](chart.png)

Results

Likely timing of child’s HIV infection

<table>
<thead>
<tr>
<th></th>
<th>Children born to diagnosed women (n=41)</th>
<th>Children born to undiagnosed women (n=67)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>In utero</td>
<td>23</td>
<td>56</td>
</tr>
<tr>
<td>In utero or intrapartum</td>
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<td>2</td>
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<td>20</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
Results

Likely intrapartum transmissions

- In 4/8 transmissions, no main contributing factor could be identified (VL<50 on cART by delivery, 1 SVD, 3 CS)
- One woman PPROM with >24h ruptured membranes before CS
- One woman delivered very preterm by em CS, only tested in labour
- One woman booked very late & only had 4 days cART before elective CS
- One woman did not suppress due to poor engagement, delivered by em CS (court order)

Complicating issues
Results

At least one complicating issue 53%

Uncertain immigration status 27%
Results

Housing problems 28%

Intimate partner violence 11%
Results

Diagnosed mental health problem 12%

Excess alcohol or drugs during pregnancy 9%
Results

Contributing factors

- One contributing factor 62%
- Two contributing factors 22%
- Three contributing factors 5%
- Four contributing factors 1%

No factor identified in 5% and insufficient information in 5%

Main contributing factor

Diagnosed women (n=41)

- Breastfeeding 17%
- Late booking 22%
- Pre-term delivery 8%
- Seroconversion 5%
- Difficulties with engagement 35%
- No contributing factor identified 13%
Results

Main contributing factor
Undiagnosed women (n=67)

- Seroconversion: 34%
- Declined antenatal HIV testing: 42%
- Breastfeeding: 2%
- Late booking: 5%
- Minimal information: 7%
- Problem with HIV test: 10%

Conclusions

- It does appear that the number of children being infected over the study period has substantially declined.
- Number now stabilised at around 5-10/year.
- The fall in the number of infected children born to undiagnosed women reflects the evolution and implementation of antenatal screening standards.
- Over half of women were reported to have experienced significant complicating factors at the time of the pregnancy (these are minimum estimates).
- The largest groups were women who declined HIV testing, women who seroconverted, and women who had difficulties with engagement with HIV care.
Conclusions

- The cases of women who declined HIV testing were concentrated in the earlier years of the audit, again reflecting improvements in screening
- We experienced real difficulties in collecting information in some cases – older cases, especially undiagnosed women
- The audit report with recommendations from the Expert Review Panel is currently being finalised and will be published shortly
- This work is ongoing, and all children born in the UK diagnosed with perinatal HIV will be subject to this enhanced surveillance
- The ERP expects to meet and review cases annually, and the findings will continue to inform screening standards, and BHIVA and CHIVA guidelines

Acknowledgments

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NSHPC Ethics
MREC/04/2/009 (audit approved as a substantial amendment)

NSHPC Current team
Principal investigator: Pat Tookey
Data manager & statistician: Helen Peters
Researchers: Kate Francis, Rebecca Sconza, Graziella Favarato, Laura Byrne
Administrative assistant: Icina Shakes
Additional support: Claire Thorne, Catherine Peckham, Mario Cortina-Borja

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Questions?
Email Laura: l.byrne@ucl.ac.uk
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