Follow-up status of HIV exposed infants in the UK 2012-2019

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Background

• In the UK the current vertical HIV transmission rate is <0.3% among diagnosed women living with HIV\(^1\)
  - this rate excludes children whose infection status remains unknown

• BHIVA 2012 and 2018 guidelines state that all HIV-exposed infants who are not breastfed should be PCR tested at age ≤48 hours, 6 and 12 weeks and with antibody testing for seroreversion at age 18-24 months
  
  www.bhiva.org/pregnancy-guidelines

• Even if earlier PCR tests are negative, the 18-24 month confirmatory antibody test remains important as postnatal transmission may occur: some of the UK born cases of HIV vertical transmissions (VTs) reported to ISOSS have been identified through 18-24 month antibody testing with negative PCRs after birth\(^1\)

\(^1\)Peters et al, Successes and emerging challenges in prevention of vertical HIV transmission in the UK & Ireland, Glasgow 2018
Methods

• The Integrated Screening Outcomes Surveillance Service (ISOSS) monitors screening outcomes for Public Health England's Infectious Diseases in Pregnancy Screening Programme (IDPS)

• ISOSS collects, analyses and reports obstetric and paediatric data on the screened for infections in pregnancy: HIV, syphilis and hepatitis B

• Reporting to ISOSS is part of the NHS IDPS service specification: all maternity and paediatric units in England submit reports using a secure online portal

• Patient data is collected without patient consent by ISOSS with PHE Regulation 3 approval
  • For more information on ISOSS (including governance) visit www.ucl.ac.uk/isoss
Methods

• ISOSS HIV surveillance covers all women living with HIV seen for antenatal care in the UK, all HIV-exposed infants are followed-up until 18-24 months to determine infection status.

• Surveillance also covers any children diagnosed up to the age of 16 years and seen for paediatric care in the UK.

• Reports are triangulated with laboratory reports from PHE to ensure that any infants missing test results from the reporting unit have not been seen for care elsewhere (including GPs).

We report the follow-up status of 6547 HIV-exposed infants born 2012-2018, reported by December 2019.
Results: HIV-exposed infants born 2012-2018

6547 livebirths 2012-2018

4860 (74.2%) Negative 18-24 month AB test

1660 (25.4%) indeterminate

27 (0.4%) confirmed infected

875 (53%) still in follow-up

26 (1.6%) died before 18-24 AB test

5 (0.3%) follow up testing declined

384 (23%) discharged before 18-24 AB test

370 (22%) LTFU before 18-24 AB test
Infants LTFU before 18-24 month AB test

Of the 370 infants LTFU with unknown infection status:

- 67/370 had only a birth PCR test:
  - 16/67 were reported as ‘gone abroad’
- 303/370 had 6 or 12 week PCR test:
  - 43/303 were reported as ‘gone abroad’

No change over time:
50-80 infants LTFU per year

Table: Regional distribution of infants LTFU before 18-24 month antibody test

<table>
<thead>
<tr>
<th>Region</th>
<th>No. of infants (</th>
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</thead>
<tbody>
<tr>
<td>East Midlands</td>
<td>13 (4%)</td>
<td>North East/Yorkshire &amp; Humber</td>
<td>36 (10%)</td>
</tr>
<tr>
<td>West Midlands</td>
<td>43 (12%)</td>
<td>South West/South Central</td>
<td>27 (7%)</td>
</tr>
<tr>
<td>East of England</td>
<td>45 (12%)</td>
<td>South East</td>
<td>19 (5%)</td>
</tr>
<tr>
<td>London</td>
<td>138 (37%)</td>
<td>Wales/Scotland/NI</td>
<td>27 (7%)</td>
</tr>
<tr>
<td>North West</td>
<td>22 (6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>South West/South Central</td>
<td>27 (7%)</td>
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</table>
Infants discharged before 18-24 month AB test

384/6547 (6%) HIV-exposed infants were discharged under 18 months of age. 313/384 (82%) of these were discharged with a negative antibody under 18 months of age.

### Table: Infants discharged based on negative antibody test < 18 months by region

<table>
<thead>
<tr>
<th>Region</th>
<th>No. of infants (%)</th>
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</thead>
<tbody>
<tr>
<td>East Midlands</td>
<td>19 (6%)</td>
</tr>
<tr>
<td>West Midlands</td>
<td>20 (6%)</td>
</tr>
<tr>
<td>East of England</td>
<td>35 (11%)</td>
</tr>
<tr>
<td>London</td>
<td>89 (28%)</td>
</tr>
<tr>
<td>North East/Yorkshire &amp; Humber</td>
<td>28 (9%)</td>
</tr>
<tr>
<td>North West</td>
<td>22 (7%)</td>
</tr>
<tr>
<td>South West/South Central</td>
<td>29 (9%)</td>
</tr>
<tr>
<td>South East</td>
<td>33 (11%)</td>
</tr>
<tr>
<td>Wales/Scotland/NI</td>
<td>20 (6%)</td>
</tr>
</tbody>
</table>

71/384 (18%) infants were discharged based on negative PCRs only:
- 11/71 discharged at under 12 months of age
- 40/71 discharged between 12-18 months of age
- 20/71 discharged without antibody testing

Increasing number of infants are being discharged per year with negative AB test under 18 months of age:
- 2012-2015: 30-50 infants / year
- 2016-2017: 60-70 infants / year
Infants discharged before 18-24 month AB test (n=384)

24 infants with negative antibody at <12 months (min: 3 months)

53% were discharged at 17-18 months
Conclusions

Despite well-established guidelines and pathways for follow-up of HIV-exposed infants in the UK there remains some variation in practice and deviation from BHIVA guidelines.

Findings shown today have been highlighted through ISOSS paediatric network and also fed back to BHIVA.

ISOSS is uniquely placed to monitor outcomes and practice across units and regions, including the impact of COVID on clinic scheduling and attendance.

Further work to investigate possibility of inequalities/barriers to care in lost to follow up group.

Vigilance is required regarding potential postnatal transmission, especially in the era of supported breastfeeding in the UK.
Acknowledgements

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ISOSS is a part of the national Infectious Diseases in Pregnancy Screening (IDPS) Programme, with UCL commissioned to deliver the service

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