



Integrated Screening Outcomes Surveillance Service

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 <math><0.3\%</math> among diagnosed women living with HIV¹
- **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



BHIVA guidelines for the management of HIV in pregnancy and postpartum 2018

- 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 birth¹**

¹Peters et al, *Successes and emerging challenges in prevention of vertical HIV transmission in the UK & Ireland*, Glasgow 2018

Methods

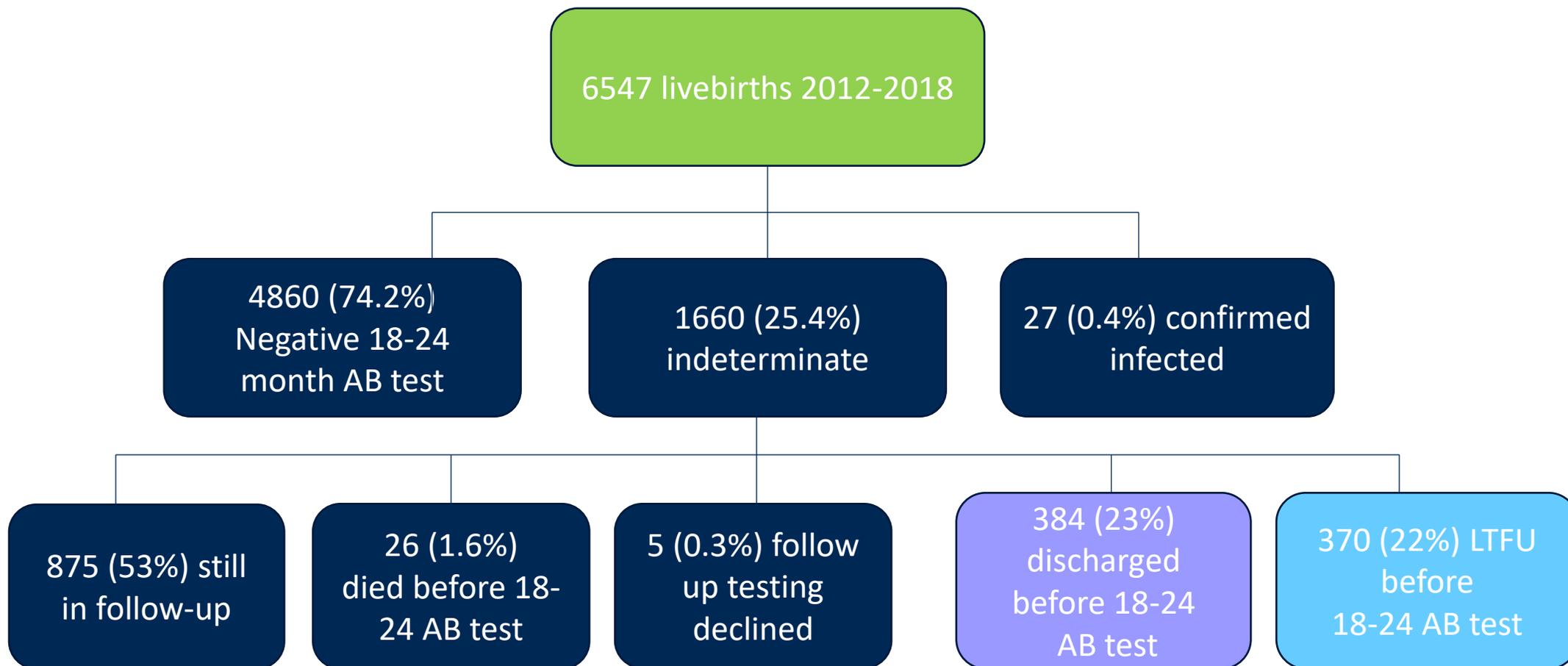
- **The Integrated Screening Outcomes Surveillance Service (ISOSS)** monitors screening outcomes for Public Health England's Infectious Diseases in Pregnancy Screening Programme (IDPS)
- ISOSS collects, analyses and reports obstetric and paediatric data on the **screened for infections in pregnancy: 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



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

| Region | No. of infants (%) |
|-------------------------------|--------------------|
| East Midlands | 13 (4%) |
| West Midlands | 43 (12%) |
| East of England | 45 (12%) |
| London | 138 (37%) |
| North East/Yorkshire & Humber | 36 (10%) |
| North West | 22 (6%) |
| South West/South Central | 27 (7%) |
| South East | 19 (5%) |
| Wales/Scotland/NI | 27 (7%) |

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

| Region | No. of infants (%) |
|-------------------------------|--------------------|
| East Midlands | 19 (6%) |
| West Midlands | 20 (6%) |
| East of England | 35 (11%) |
| London | 89 (28%) |
| North East/Yorkshire & Humber | 28 (9%) |
| North West | 22 (7%) |
| South West/South Central | 29 (9%) |
| South East | 33 (11%) |
| Wales/Scotland/NI | 20 (6%) |

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

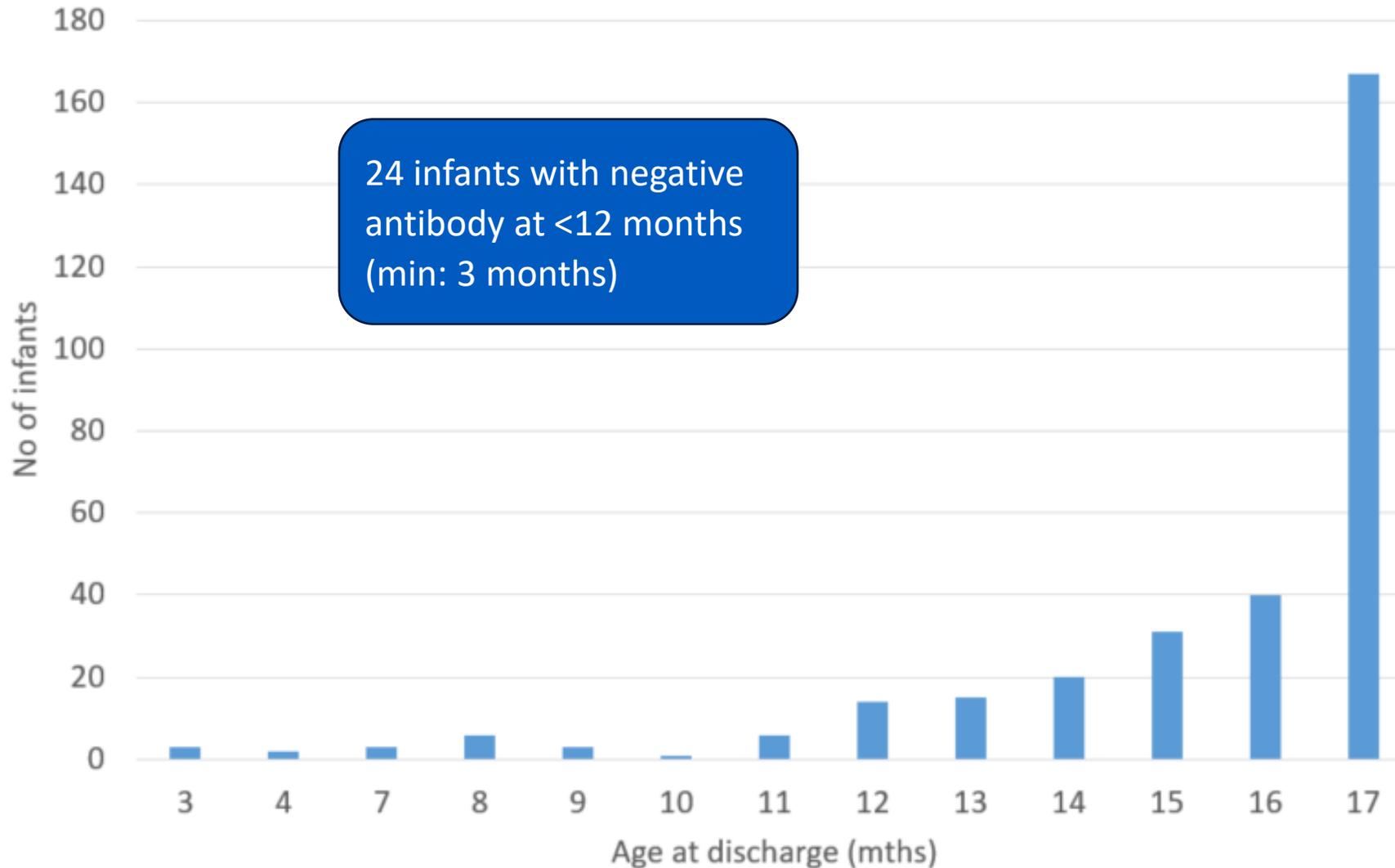
2012-2015

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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