



Integrated Screening Outcomes Surveillance Service

Vertical HIV Transmissions in the UK- insights into the current picture and remaining challenges

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Background

- Vertical HIV transmission has become a rare event among diagnosed women living with HIV in the UK, with a **transmission rate below 0.3% since 2012**
- Despite very high uptake of antenatal screening, a small number of vertical transmissions occur among undiagnosed women
- **Vertical transmissions are monitored by the Integrated Screening Outcomes Surveillance Service (ISOSS)**

Objective: to describe the latest picture on vertical transmissions reported to ISOSS in 2014-2019

Methods

- The **Integrated Screening Outcomes Surveillance Service (ISOSS)** conducts surveillance on behalf of the NHS Infectious Diseases in Pregnancy Screening Programme (IDPS), part of Public Health England
- Reporting to ISOSS is part of the NHS IDPS service specification. ISOSS builds on the well-established National Surveillance of HIV in Pregnancy & Childhood (NSHPC) to collect data on all screened for infections in pregnancy (HIV, syphilis and Hepatitis B) and pregnancy outcomes
- **All pregnancies to women living with HIV, their children and any children diagnosed with HIV (<16yrs age) are reported**
- Running for 30 years ISOSS holds data on over 25,000 pregnancies and children

ISOSS collects patient data under legal permissions granted to PHE under Regulation 3 of The Health Service (Control of Patient Information) Regulations 2002

Methods

- The ISOSS team investigate all new vertical transmissions of HIV occurring in children born since 2006 in the UK
- ISOSS **interview all clinicians involved in the care of the mother and baby during and after pregnancy**. Interviews are conducted across specialities including paediatrics, maternity and specialist care

Clinical Expert Review Panel

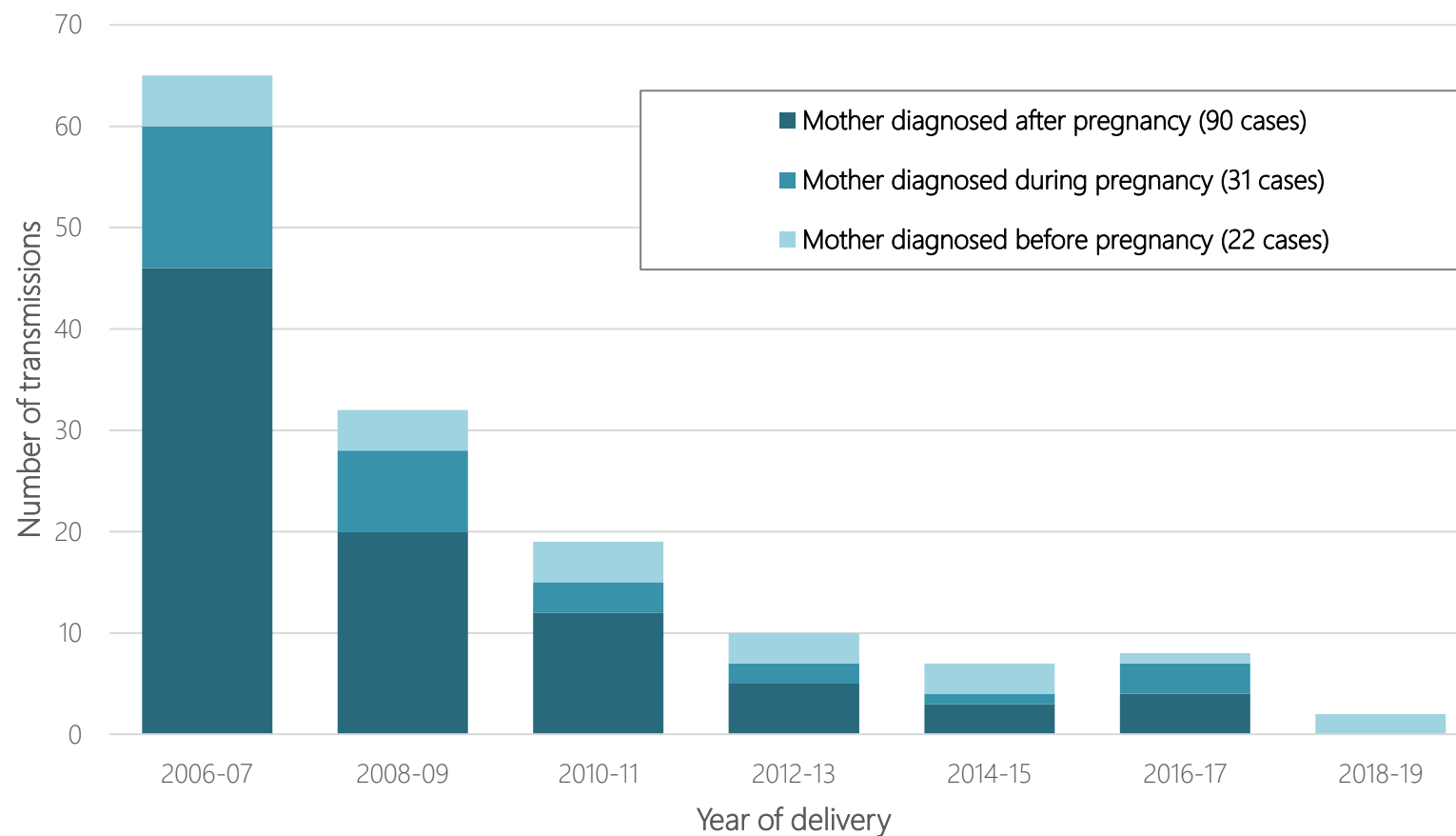
Detailed anonymised case reports are taken to the IDPS Clinical Expert Review Panel (CERP), consisting of relevant clinical specialists including maternity, laboratory, paediatrics, sexual health services

The purpose of the panel is to:

- establish the circumstances surrounding the transmission
- identify any contributing factors and learning points
- feed recommendations into the IDPS to inform national guidelines and policy

Results

Overall: 143 vertical transmissions reported to ISOSS from 2006-19

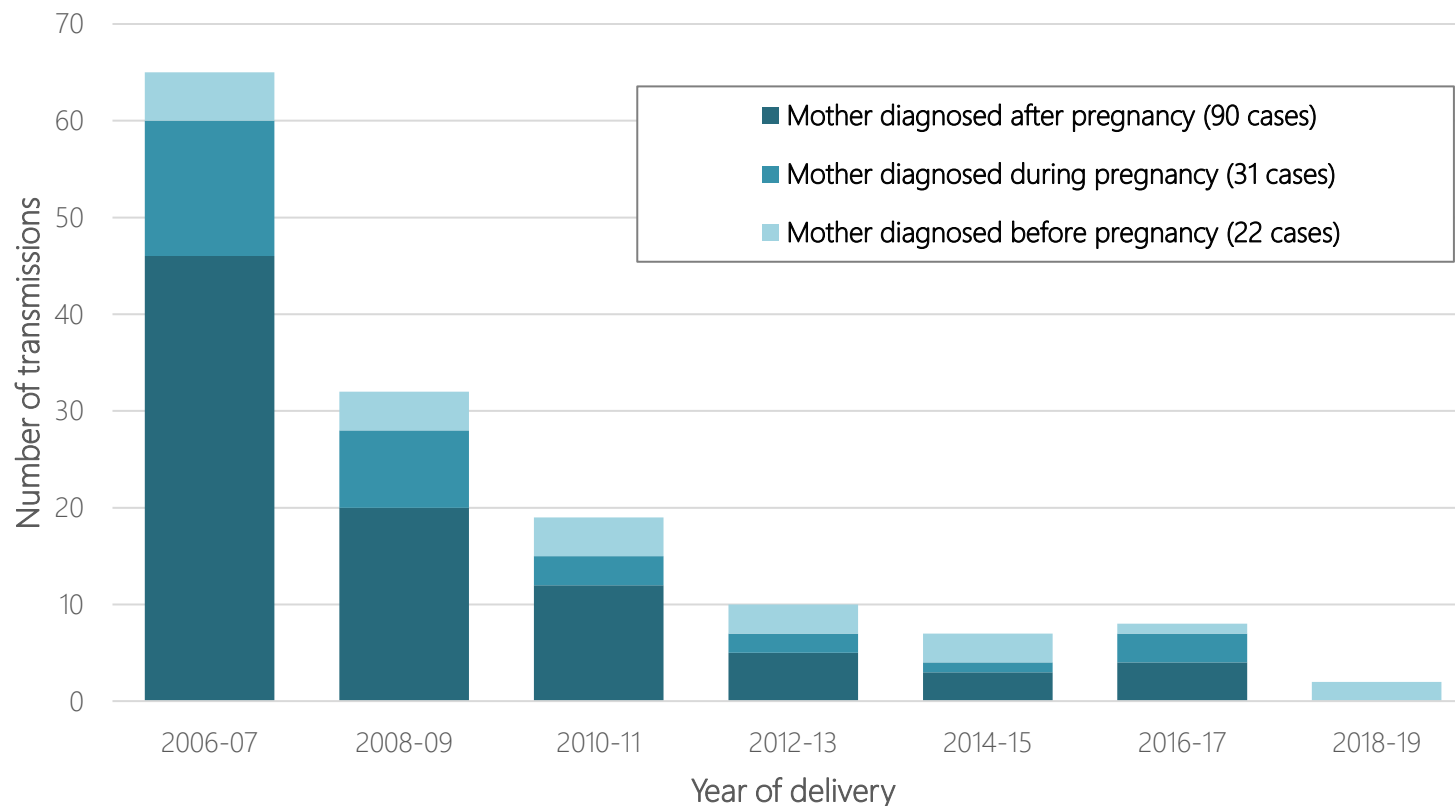


63% of transmissions were in infants born to women *undiagnosed* by time of delivery

Results

Between 2014-19: 35 vertical transmissions in children born to 33 mothers (1 set siblings, 1 twin pair)

Years of birth ranged from 2006-2019 and child age at diagnosis from birth-11years



Maternal and paediatric characteristics

Two-thirds of children born to women diagnosed after pregnancy

	Number of cases	Percentage of cases (%)
Timing of maternal diagnosis		
Before pregnancy	7	20.0%
During pregnancy	4	11.4%
After pregnancy	24	68.6%
Region of child's birth		
London	15	42.9%
Midlands and East	7	20.0%
North	6	17.1%
South	3	8.5%
England	31	88.6%
Wales, Scotland, Northern Ireland	4	11.4%
Woman's world region of birth		
UK	6	17.1%
Eastern Europe	3	8.6%
Sub-Saharan Africa	26	74.2%
Other	0	-

Median maternal age 33 years (IQR: 28, 36)

Three-quarters of mothers from sub-Saharan Africa and one in ten from Eastern Europe

Complicating issues

Complicating issues reported†	Number of cases	Percentage of cases (%)
Safeguarding	5	14.3
Mental health issues	9	25.7
Housing issues	7	20.0
Drug or alcohol misuse	3	8.6
Intimate partner violence	5	14.3
Uncertain immigration status	5	14.3
Financial issues	4	11.4
Language issues^	7	20.0

^ Comprehension and/or fluency in English

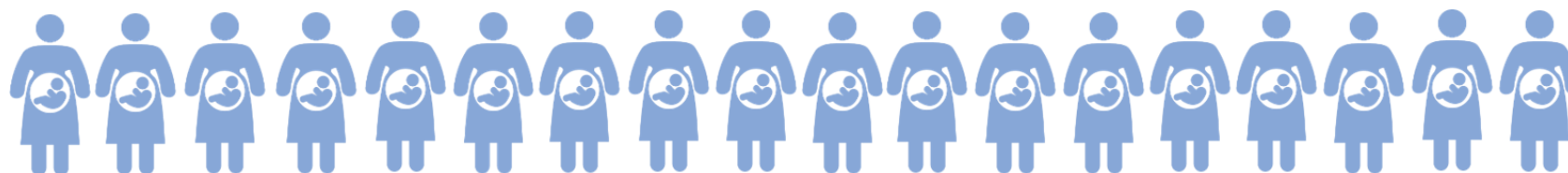
† More than one reported/overlap

- In **over half of cases** (19 out of 35), there were **complicating issues reported** at the time of the pregnancy that are thought to have contributed to the vertical transmission
- These numbers are likely to be under reported as they are based on information clinicians had available at the time of the pregnancy
- From 2020 ISOSS has collected complicating issues for all pregnancies

Women diagnosed after pregnancy (n=24)

16 women **screened negative in pregnancy (with confirmed negative test)**, seroconverting at some point during pregnancy or breastfeeding

- some women reported new partners or multiple partners in pregnancy
- number of women whose partner did not disclose their HIV status, as well partners who died with HIV-related symptoms



Five cases were to women **who declined HIV screening** in pregnancy (accepted all other infectious disease screening), **all pre 2010**

- one woman declined HIV screening in two pregnancies with both siblings diagnosed with HIV

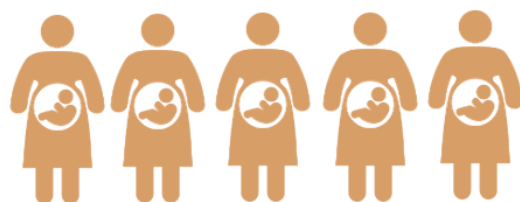


Other cases to undiagnosed women included late booking or unable to determine whether the women had seroconverted or if the women had declined screening

Women diagnosed before or during pregnancy (n=11)

In 5 cases the transmission was **postnatal** and likely due to **non-disclosed breastfeeding**

- among these there were additional complicating factors including mental health issues and social services involvement
- some women also had engagement/adherence issues with health care services in pregnancy



Other cases to diagnosed women included those who booked late/unbooked for antenatal care or no specific contributing factor identified

Child outcomes

Diagnosis

Child age at diagnosis ranged from birth to 11 years, median 2 years (IQR: 4 mth-5.6 years)

10 children had clinical indications at diagnosis, ranging from severe AIDS defining symptoms to ENT problems. 8/10 were born to women who were unaware of their HIV status by delivery.

Delays in testing

In 10 cases there were delays in the child's diagnosis ranging from a few weeks to over 2 years.

Reasons for these delays (where the woman was not diagnosed by delivery) included:

- children seen for clinical indicator reasons but not tested for HIV
- children not tested for HIV as noted woman screened negative in pregnancy
- parent(s) declined HIV testing for the child

For 3 infants born to diagnosed women, there were issues with laboratory testing relating to processing, incorrect labelling of the sample, and usual laboratory staff absence.

Conclusions

Two-thirds of recent vertical transmissions in the UK involved undiagnosed women. Issues identified here support findings from previous reviews; seroconversion was a common factor, **highlighting the importance of sexual health awareness in pregnancy**

Over half of women experienced adverse social circumstances and this is likely to be an underestimation. ISOSS collects data on inequalities for all pregnancies in women living with HIV, strengthening PHE and stakeholder initiatives

Ongoing enhanced data collection and ISOSS CERPs provide **valuable insights into the circumstances of the few transmissions still occurring in the UK**. ISOSS will also be able to provide data on evolving patterns in this group including maternal demographics to support work to address the changing needs of this group.

The ISOSS team will soon be taking on long-term HIV paediatric follow-up (previously CHIPS). CHARS will be launching by January 2022



Acknowledgements

A big thank you to all clinicians who participate in the enhanced data collection and our Clinical Expert Review Panel. Also all respondents to ISOSS and the rest of the ISOSS team

ISOSS carries out this work on behalf of the NHS Infectious Diseases in Pregnancy Screening Programme: www.gov.uk/guidance/infectious-diseases-in-pregnancy-screening-programme-overview

Please do get in touch if you have any questions: helen.peters@ucl.ac.uk

More information on ISOSS and our annual report available from:

www.ucl.ac.uk/isoss

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