Obstetric and paediatric HIV surveillance data from England

ISOSS
Integrated Screening Outcomes Surveillance Service

March 2023 update

ISOSS is part of NHS England Infectious Diseases in Pregnancy Screening Programme and is based at UCL Great Ormond Street Institute of Child Health

Integrated Screening Outcomes Surveillance Service – HIV surveillance

- Maternity reports of all pregnancies in women with diagnosed HIV infection through maternity units; demographics, pregnancy management, outcome via the NHS IDPS programme
- Paediatric reports of all HIV-exposed infants and diagnosed children (<16 years) through clinics; confirmation of infection status; ongoing follow-up of diagnosed children
- Enhanced surveillance of cases of reported breastfeeding
- Enhanced data collection for newly reported vertical transmissions, reviewed by Clinical Expert Review Panel (CERP)

ISOSS HIV surveillance now England only

Please note: Previous ISOSS/NSHPC slides have reported on surveillance data for all of the UK. ISOSS now only carries out surveillance in England (since 2020). These slides have been updated to include data from England only.

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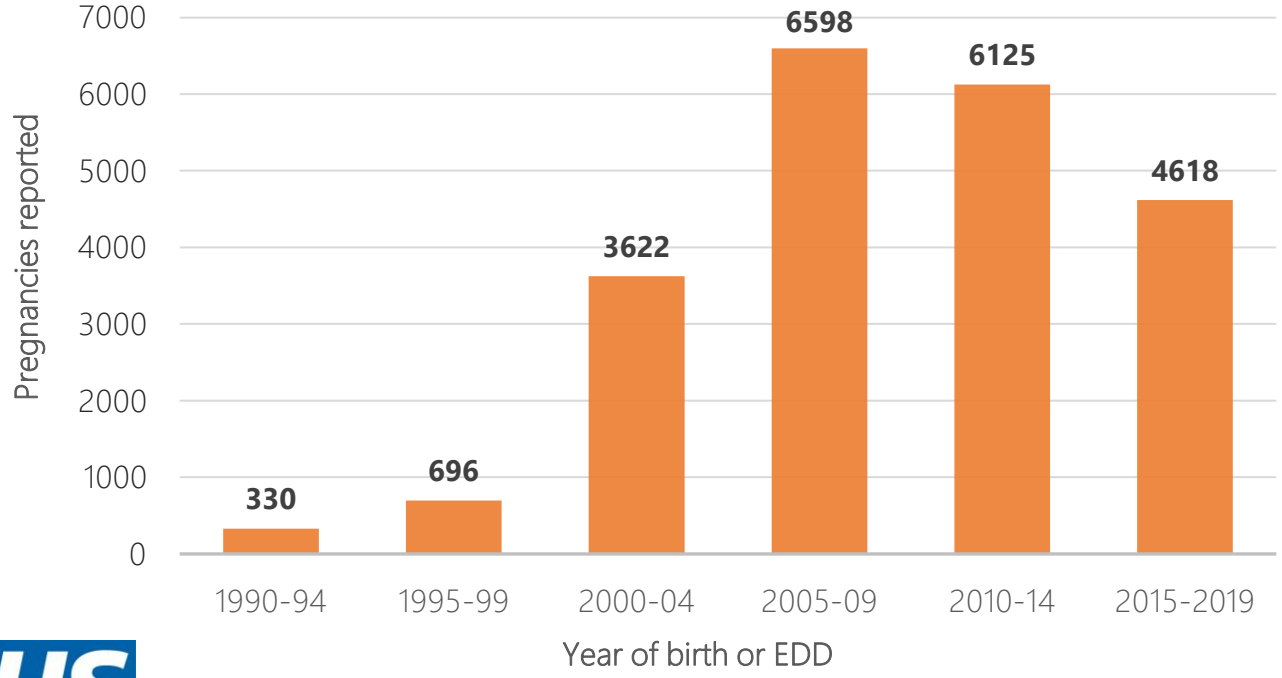
Pregnancies in women with a known HIV diagnosis, 1990 to 2019 (England)



21,989 pregnancies in diagnosed women

Source: pregnancies reported to ISOSS through maternity and paediatric surveillance by December 2022

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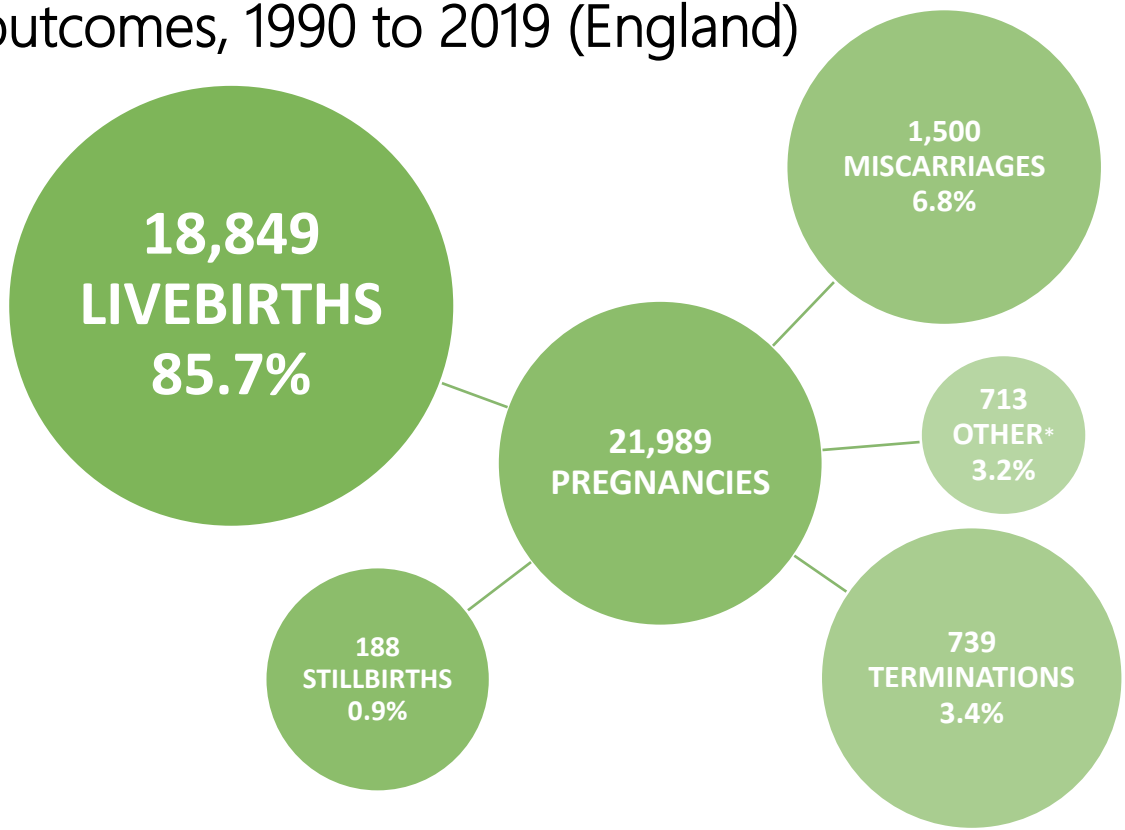
Pregnancy outcomes, 1990 to 2019 (England)



* pregnancies with outcome pending or not known and those in women who went abroad, were lost to follow-up, or died during pregnancy

Source: pregnancies reported through ISOSS maternity and paediatric surveillance by December 2022

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Maternal demographics, early 2000s and now (England)

		2000-04		2015-19
Country/region of report	London	64.9%	→	40.1%
	Rest of England	35.1%	→	59.9%
Median age (years)		30	→	34
IDU-acquired HIV		2.1%	→	0.9%
Perinatal HIV		0.03%	→	2.9%
Sub-Saharan Africa-born		78.9%	→	68.3%
Eastern Europe*-born		0.3%	→	5.9%

* includes the Baltic states (Estonia, Latvia, Lithuania)

Source: pregnancies reported through ISOSS maternity surveillance by December 2022

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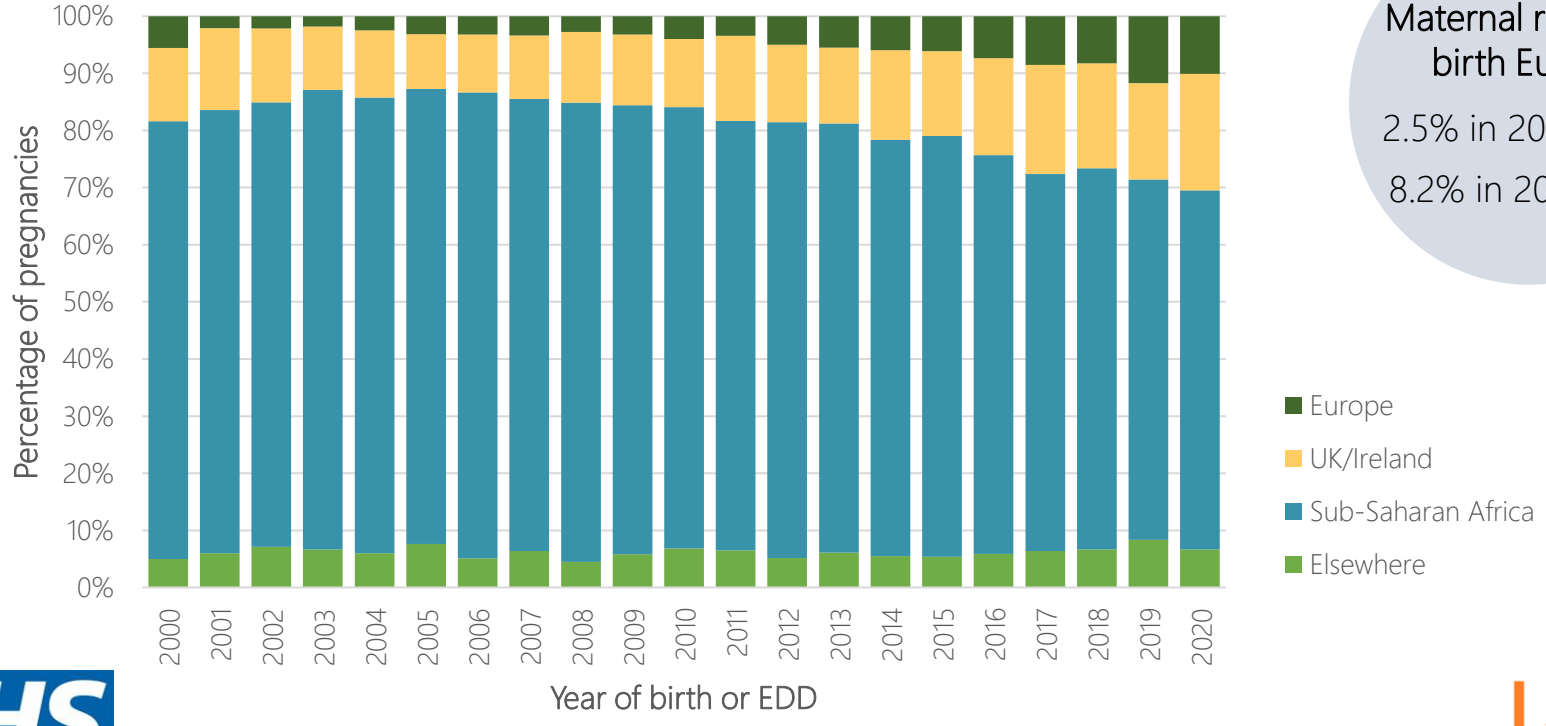
Maternal region of birth of pregnancies, 2000-2020 (England)



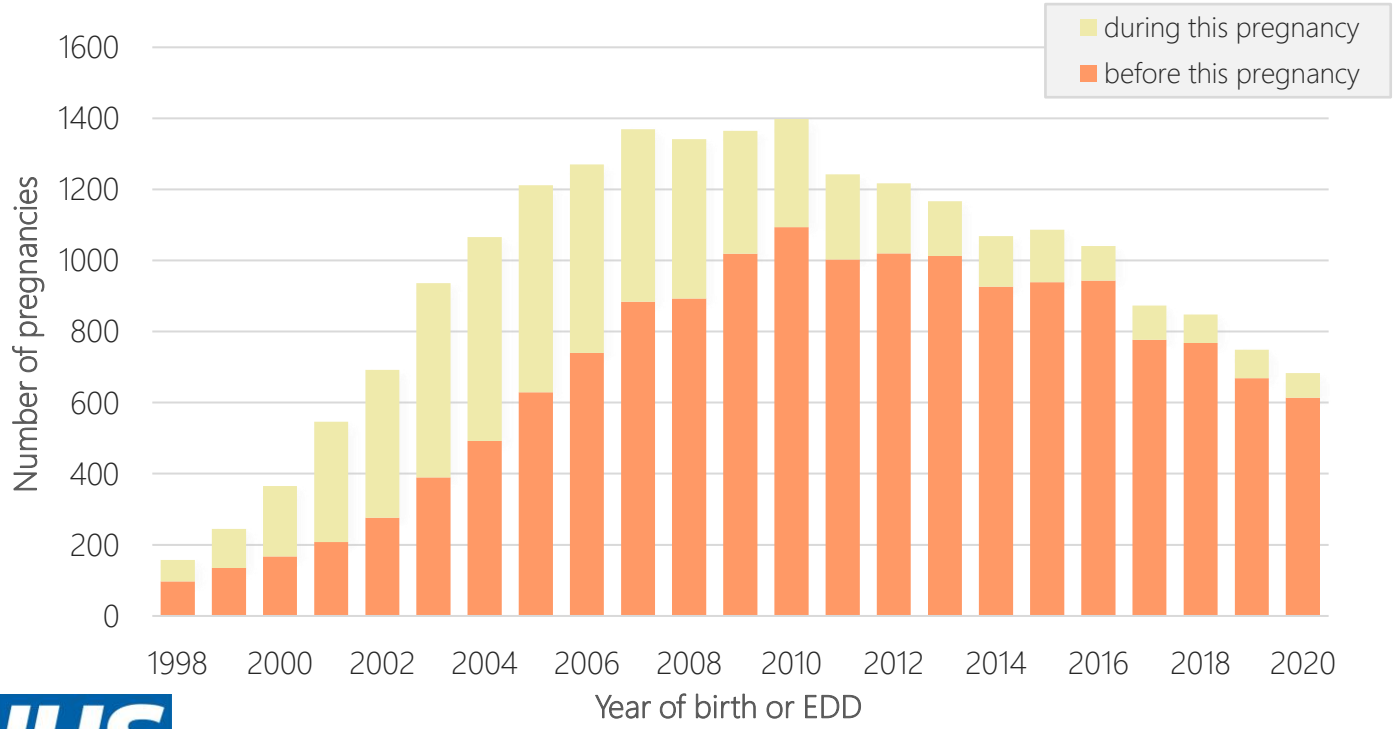
Maternal region of birth Europe

2.5% in 2000-2004

8.2% in 2015-2019

Source: pregnancies reported through ISOSS maternity surveillance by December 2022

Timing of maternal HIV diagnosis, England 1998-2020



Pre-conception diagnosis

42.5% in 2000-2004

89.1% in 2015-2019

* includes data from all ISOSS reporting sources; excludes 128 pregnancies missing timing of diagnosis

England pregnancies (all outcomes) reported to ISOSS by December 2022*

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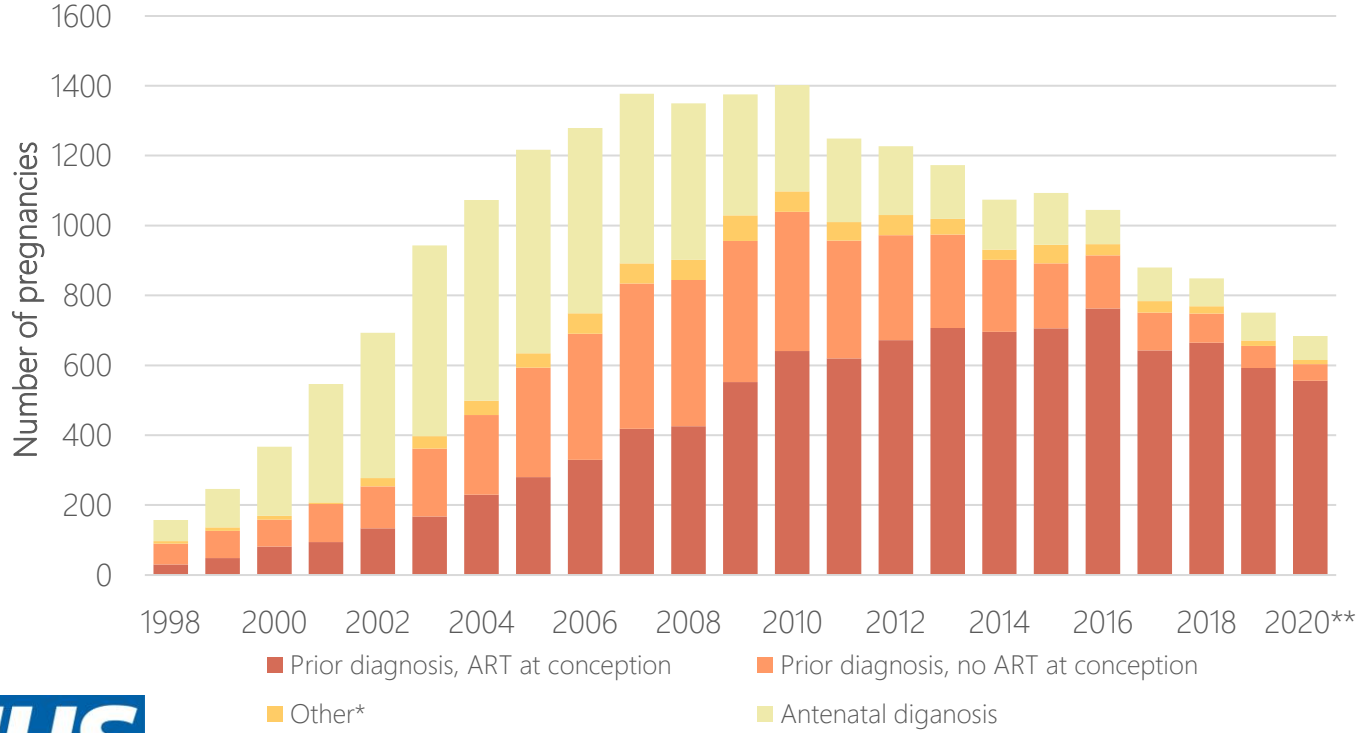
Timing of diagnosis & ART at conception, England 1998-2020



Conception on ART

20.1% in 2000-2004

75.5% in 2015-2019

* contains pregnancies lacking information on precise timing of diagnosis and/or ART use

England pregnancies (all outcomes) reported to ISOSS by December 2022

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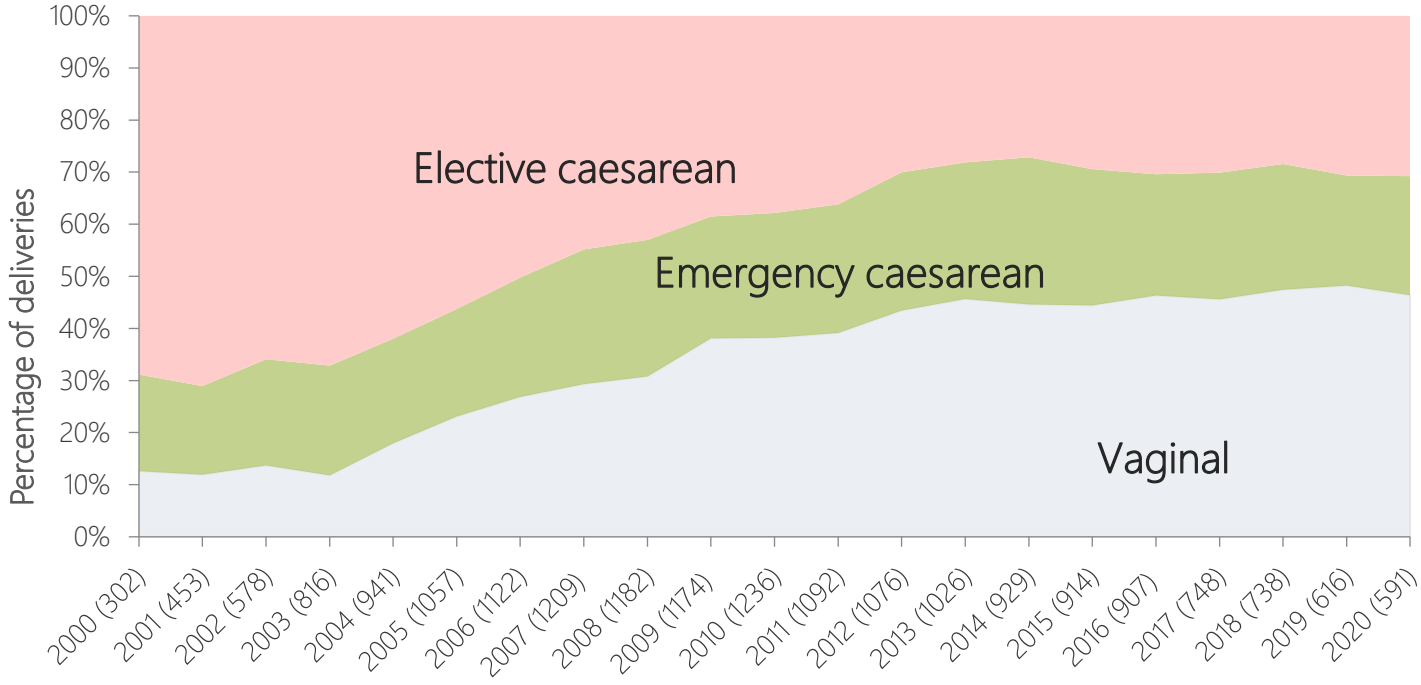
Mode of delivery among diagnosed women, England 2000-2020



Vaginal delivery

14.1% in 2000-2004

46.2% in 2015-2019

* includes data from all ISOSS reporting sources

England deliveries reported to ISOSS by December 2022*

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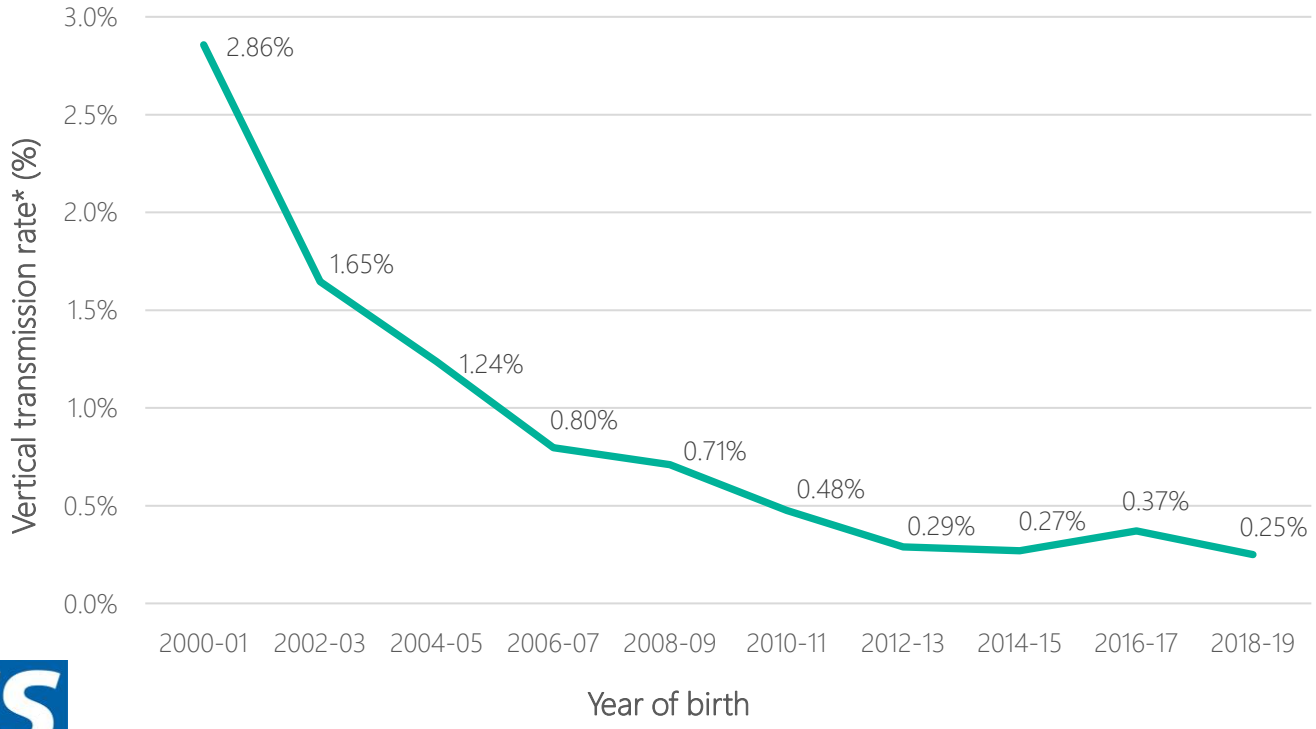
Vertical transmission in England, 2000-2019



* among infants born to women diagnosed with HIV by the point of delivery

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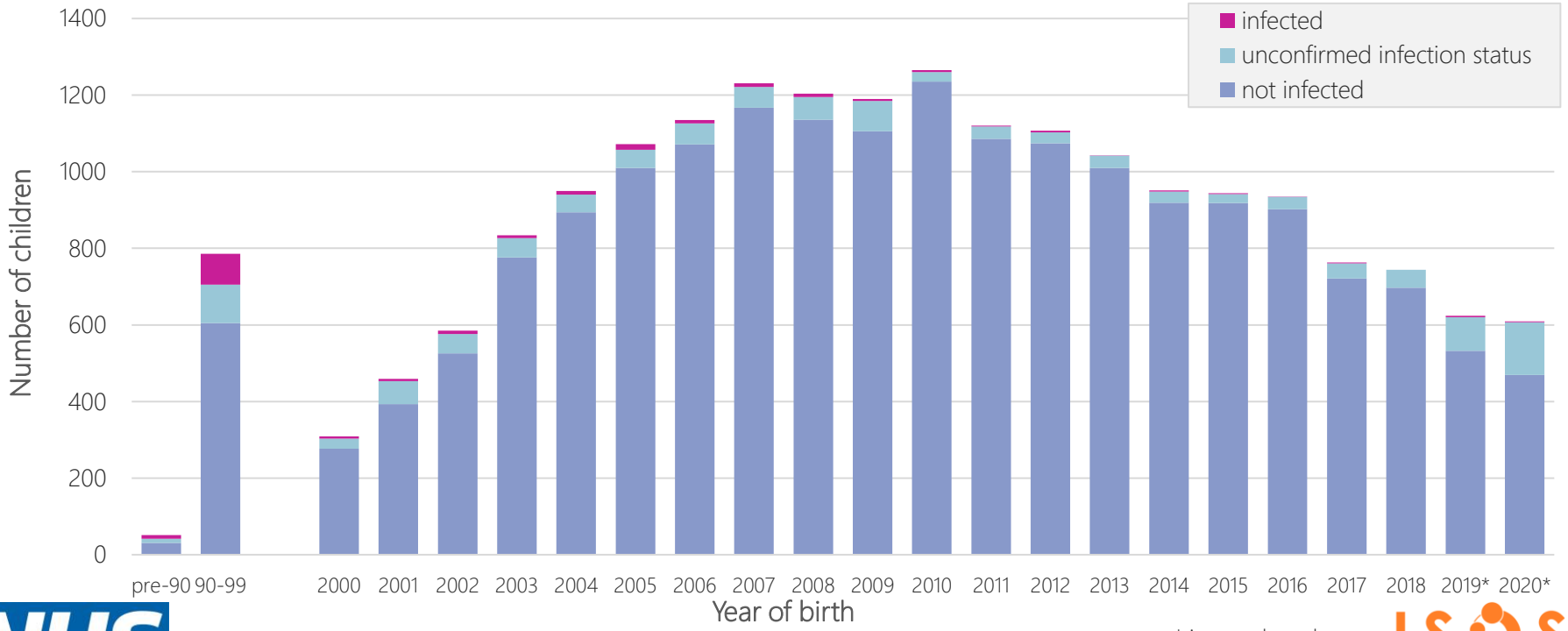
Infection status of children born to diagnosed women



England births reported to ISOSS by December 2022

* incomplete due to reporting delay

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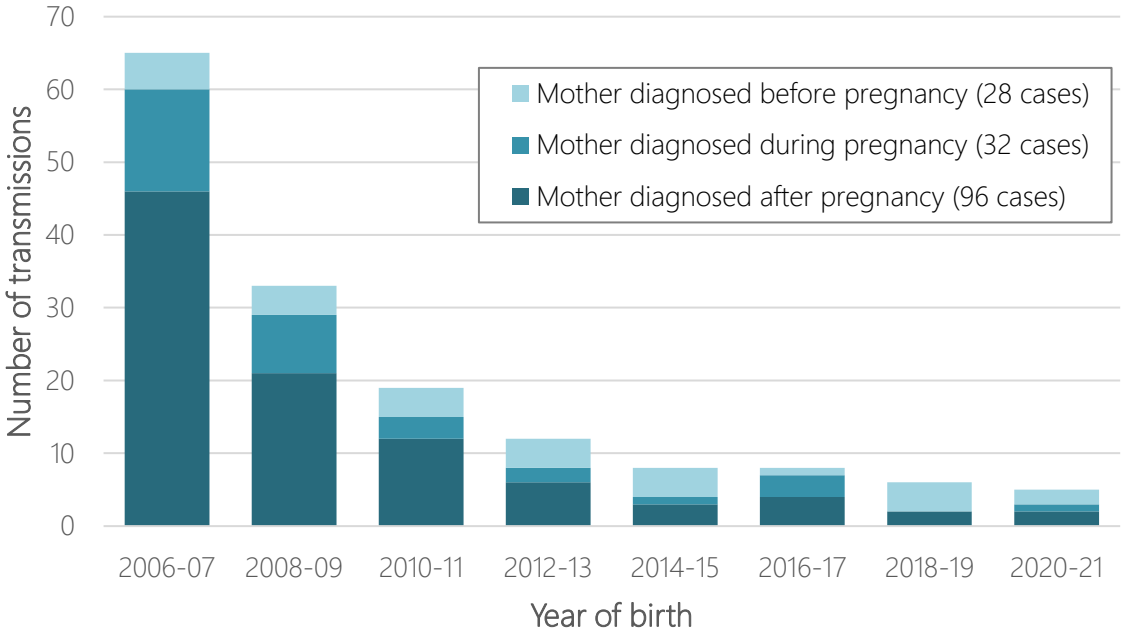
Vertical transmissions by timing of maternal diagnosis, 2006-2021*



62% of transmissions were in infants born to women *undiagnosed* by time of delivery

* Includes UK reports until 2020 when ISOSS became England only

For full details on UK HIV vertical transmissions, visit:
www.gov.uk/government/publications/integrated-screening-outcomes-surveillance-service-isoss-annual-report

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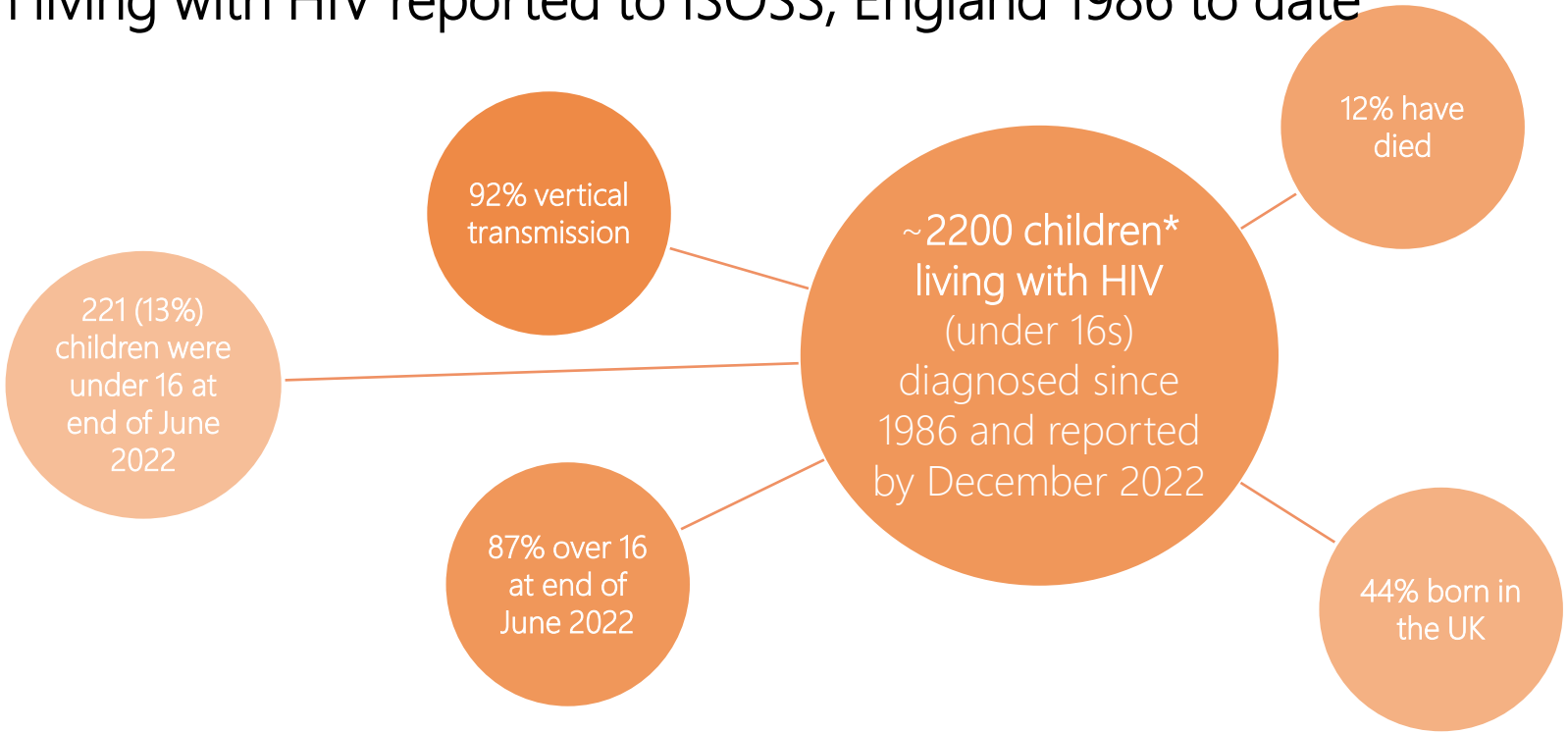
Children living with HIV reported to ISOSS, England 1986 to date



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Supported breastfeeding among women with diagnosed HIV*

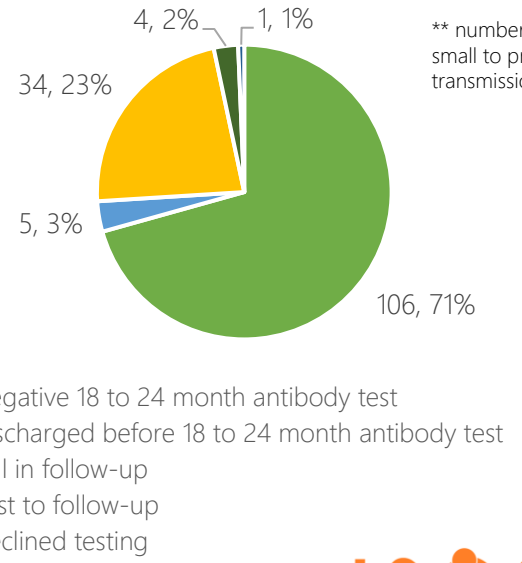
* includes UK-wide reports until 2020, when ISOSS became England only

- Among 8,526 livebirth deliveries to women diagnosed with HIV since 2012, there have been 267 (3.1%) reports of breastfeeding or intention to breastfeed
- Supported breastfeeding has been confirmed in 203 infants. Women had stopped breastfeeding in 150/203 by Dec 2021.

Key characteristics of cases of supported breastfeeding	
190/201 (95%)	Mother diagnosed before pregnancy
170/201 (84%)	Mother born abroad
35 years (31-40)	Median age at delivery (IQR)
	Duration of breastfeeding (where stopped)
1 day – 2 years	Range
56 days (23-140)	Median (IQR)

IQR: interquartile range

Current status of infants where breastfeeding has stopped** (*n*=150) (data source: ISOSS HIV Report 2022)



See BHIVA pregnancy guidelines for breastfeeding guidance: https://www.bhiva.org/pregnancy-guidelines

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Paediatric follow-up of HIV-exposed infants born in 2018-2019

1277 infants were born to women diagnosed with HIV by the point of delivery in 2018-2019.

1271 (99.5%) were given neonatal post-exposure prophylaxis after birth.

Duration of neonatal prophylaxis:

- 2 weeks: 24.7% (184/744)
- 4 weeks: 73.9% (550/744)
- 6 weeks: 1.3% (10/744)

1229 (96.2%) were reported as uninfected via follow-up testing.

Infant testing:

- 808/1229 based on negative 18-24-month antibody test
- 421/1229 based on negative PCR and/or antibody under 18 months (including 83 infants lost to follow-up)

44 (3.4%) only had birth PCR:

- 34 still in follow-up
- 12 lost to follow-up
- 2 died

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ISOSS is a part of NHS England's Infectious Diseases in Pregnancy Screening Programme.

Data are collected under legal permissions granted under Regulation 3 of The Health Service (Control of Patient Information) Regulations 2002.

For more information, visit the ISOSS website at www.ucl.ac.uk/isoss.

Acknowledgements

All **ISOSS** respondents

Members of the **Clinical Expert Review Panel**

ISOSS Annual Report (HIV)

The ISOSS HIV report for 2022 can be found at www.gov.uk/government/publications/integrated-screening-outcomes-surveillance-service-isoss-annual-report.

UCL team (2022-2023)

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Surveillance Manager: Helen Peters

Surveillance Coordinator: Kate Francis

Surveillance Officers: Laurette Bukasa, Rebecca Sconza, Gabriela Toledo, Emily Dema

Surveillance Administrators: Corinne Hill, Elena Ahmed, Saayma Akhi, Buthainah Ahmed, Stella Georgiou

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