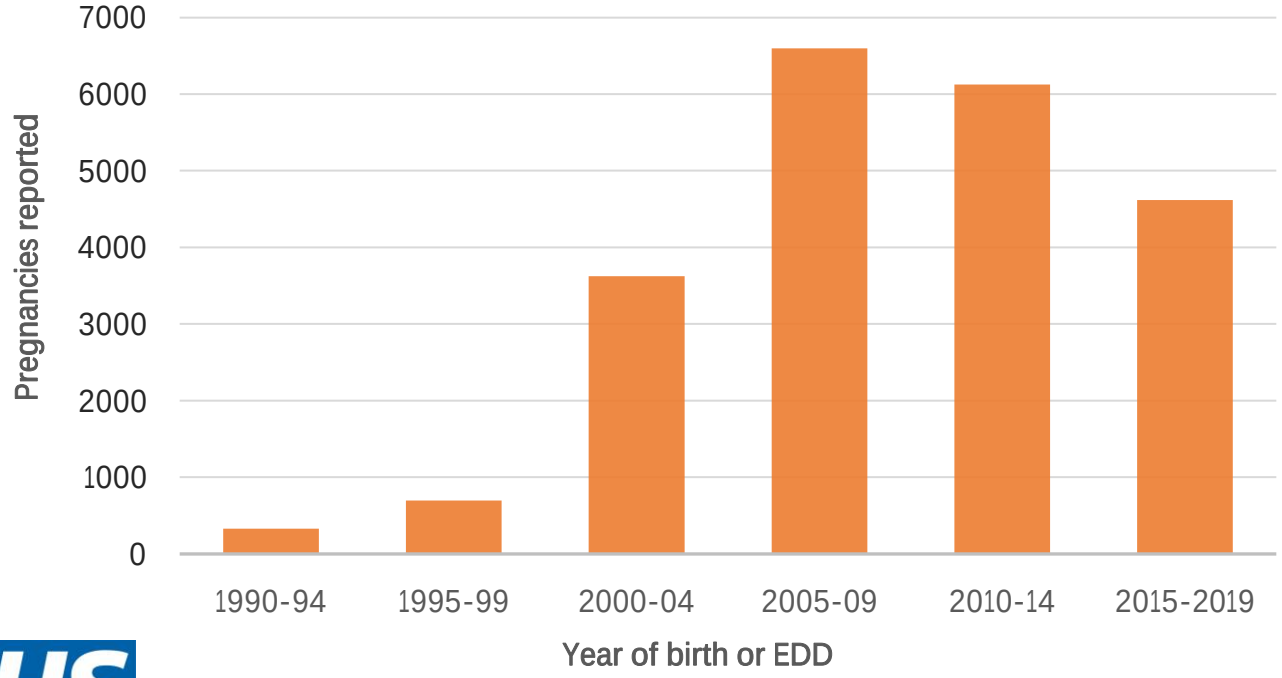
Integrated Screening Outcomes Surveillance Service – HIV surveillance

Maternity reports of all pregnancies in women with diagnosed HIV infection through maternity units; demographics, pregnancy management, outcome via the NHS IDPS programme

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.

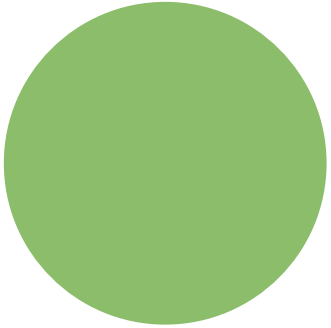
Pregnancies in women with a known HIV diagnosis, 1990 to 2019 (England)



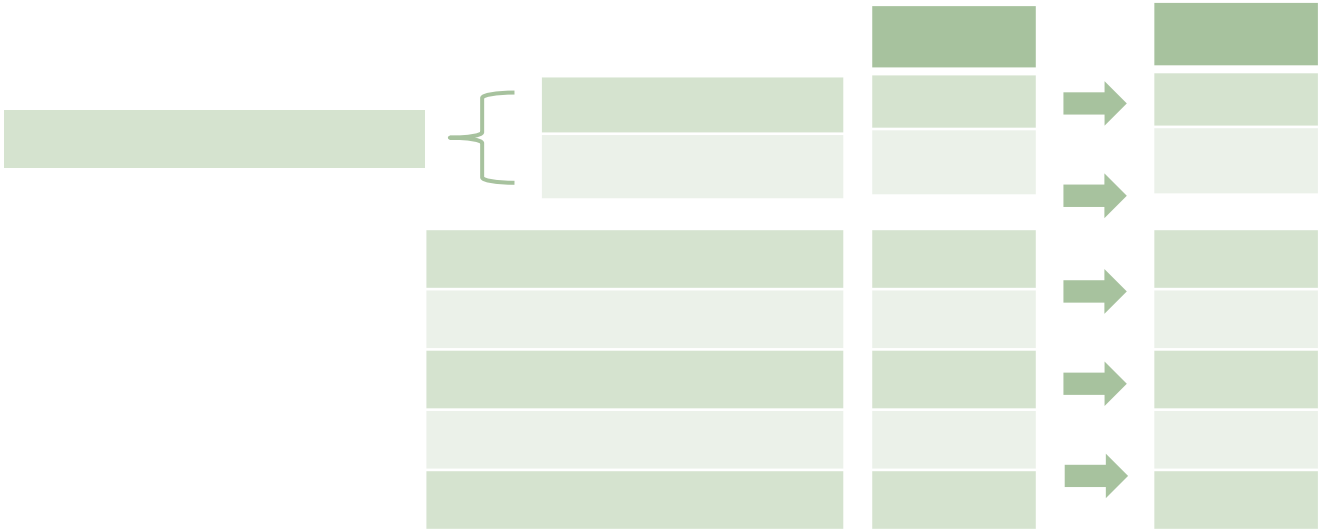
21,989 pregnancies in diagnosed women

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

Pregnancy outcomes, 1990 to 2019 (England)



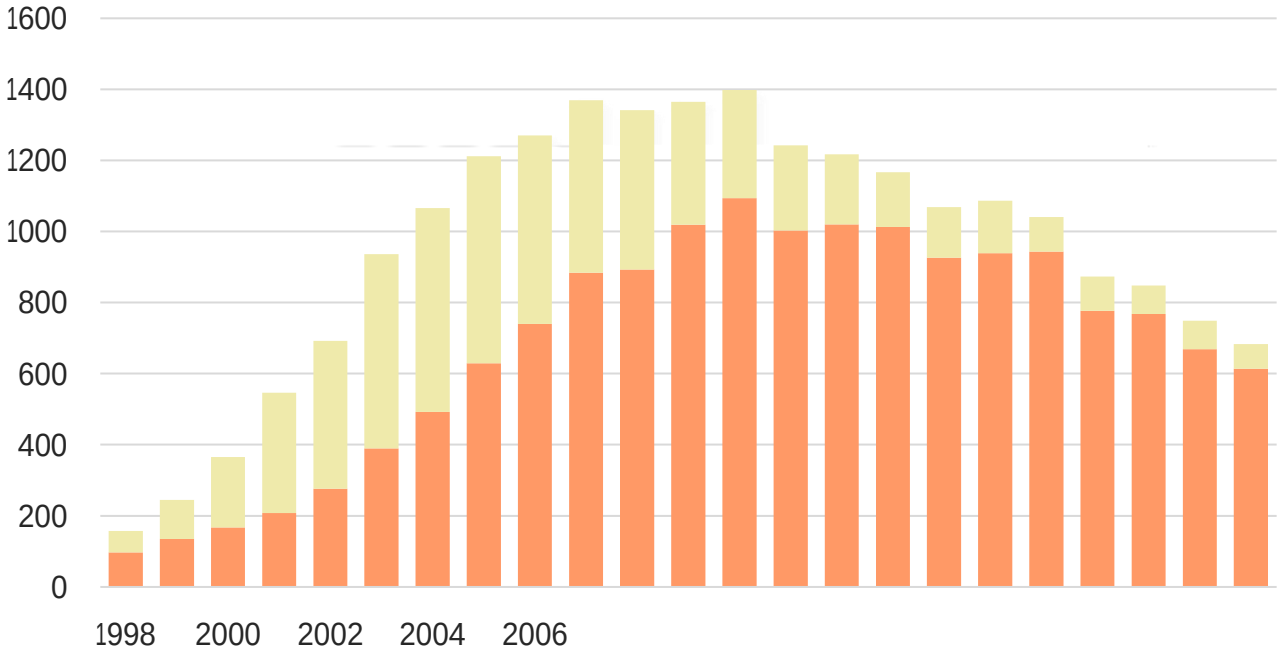
Maternal demographics, early 2000s and now (England)



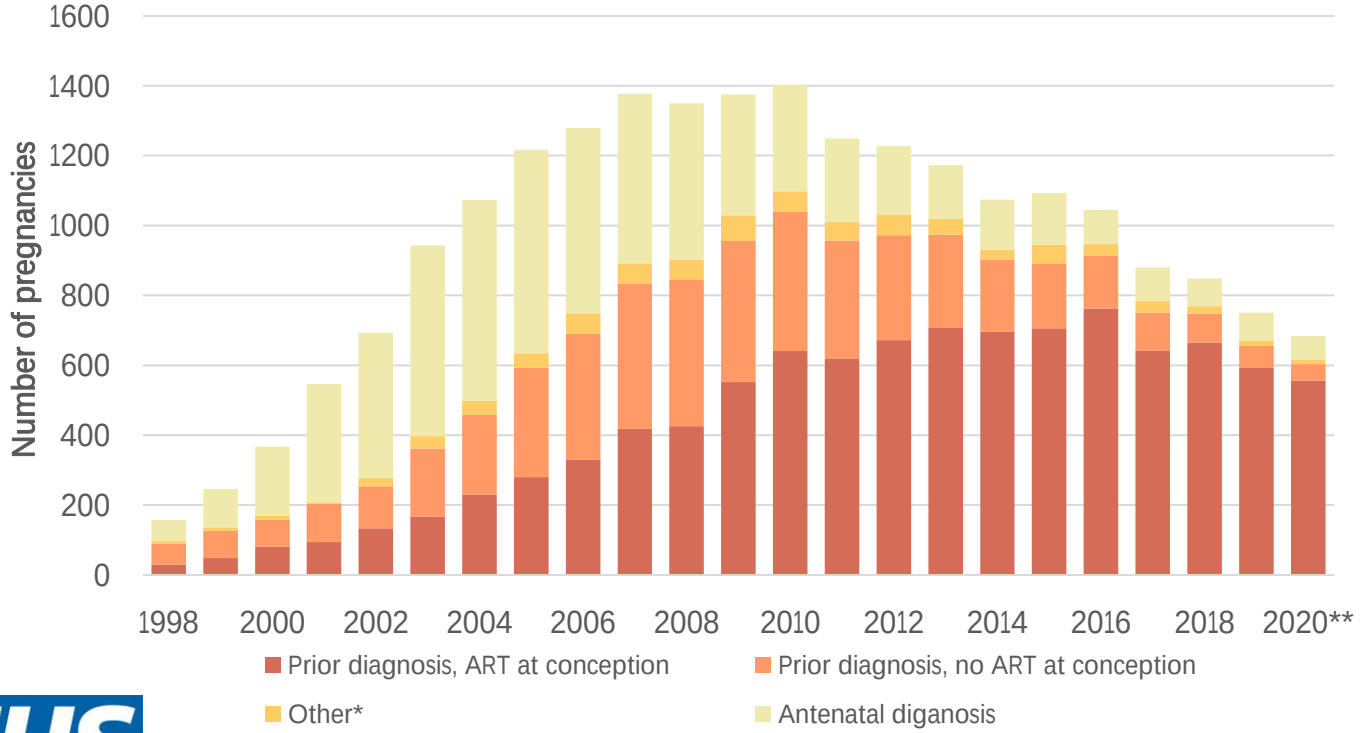
* includes the Baltic states (Estonia, Latvia, Lithuania)

Source: pregnancies reported through ISOSS maternity surveillance by December 2022

Timing of maternal HIV diagnosis, England 1998-2020



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



Conception on ART

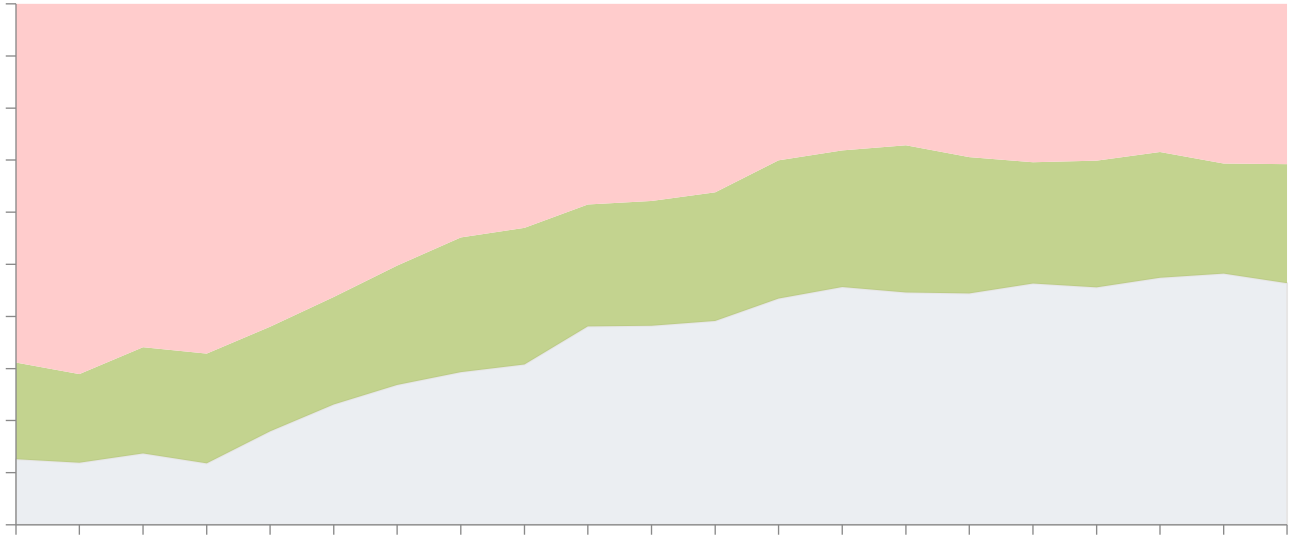
20.1% in 2000-2004

75.5% in 2015-2019

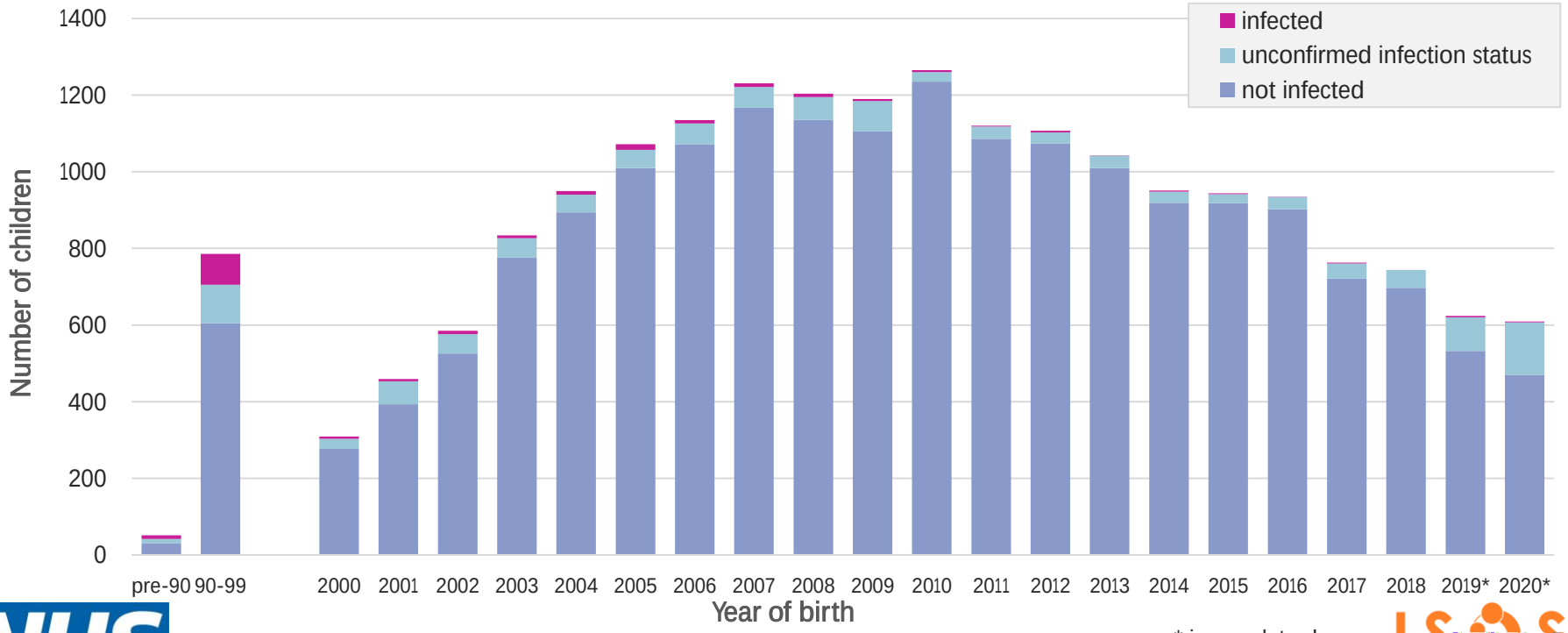
* contains pregnancies lacking information on precise timing of diagnosis and/or ART use

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

Mode of delivery among diagnosed women, England 2000-2020



Infection status of children born to diagnosed women

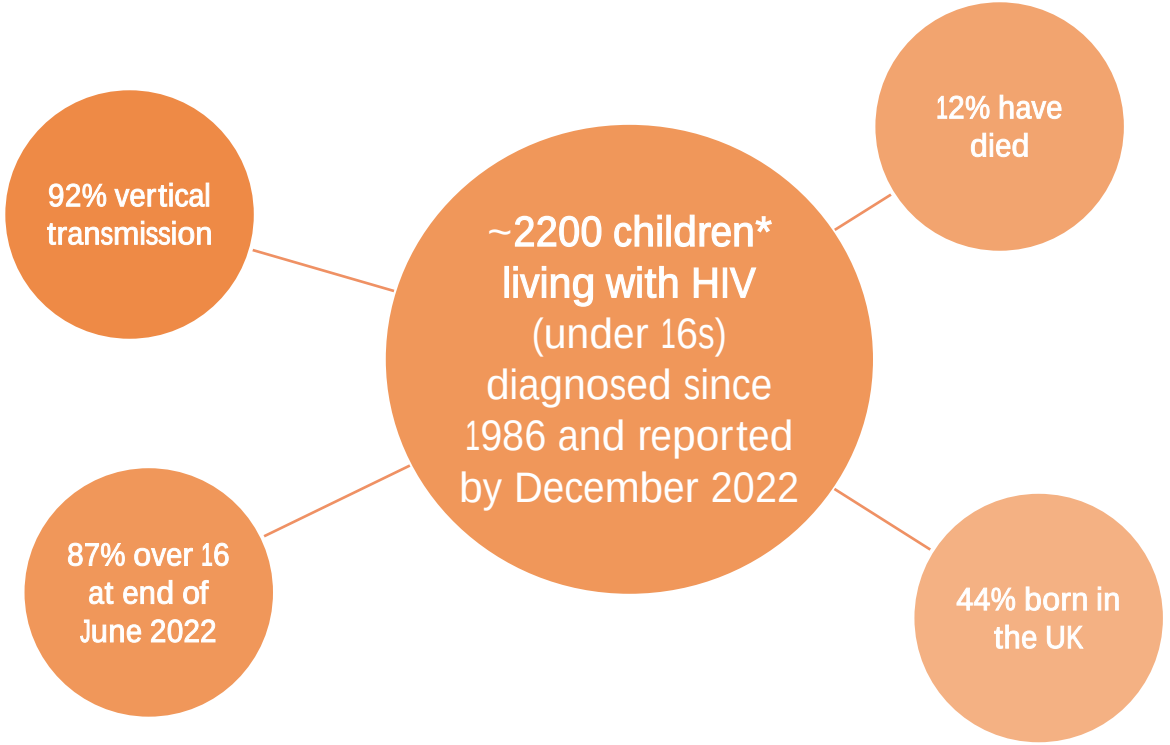


England births reported to ISOSS by December 2022

* incomplete due to reporting delay

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

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


92% vertical transmission
12% have died
~2200 children* living with HIV (under 16s) diagnosed since 1986 and reported by December 2022
87% over 16 at end of June 2022
44% born in the UK

Supported breastfeeding among women with diagnosed HIV*

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

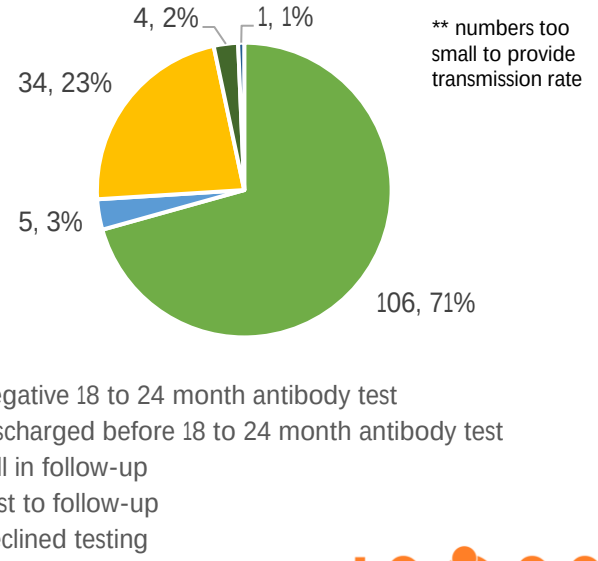
Among 8,526 livebirth deliveries to women diagnosed with HIV since 2012, there have been 267 (3.1%) reports of breastfeeding or intention to breastfeed

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

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

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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