



Integrated Screening Outcomes Surveillance Service

# **Congenital syphilis among women with a negative screen in pregnancy, England 2015-23**

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# Background

- **Syphilis is increasing in England** including a 29% rise in reports among women in the general population between 2022-2023<sup>1</sup>
- **Routine syphilis screening is offered to all pregnant women**, with 99.8% uptake.
- Although congenital syphilis incidence in England is below the World Health Organisation elimination threshold, transmissions still occur.
- Current guidance is to **repeat screening** for syphilis in pregnancy **only where risk of infection is identified**.
- The **Integrated Screening Outcomes Surveillance Service (ISOSS)**, part of the NHS IDPS programme, provides the only population-level surveillance on maternal and congenital syphilis in England

# ISOSS methods

- ISOSS conducts **national surveillance** of pregnant women with **syphilis, HIV and hepatitis B** in England
- All maternity screening teams submit data to ISOSS as part of the NHS IDPS programme
- Syphilis surveillance began in 2020 and covers **all pregnancies to women who screen positive for syphilis**, and **follow-up of any infants born to women requiring treatment in pregnancy**
- **All cases of suspected or confirmed congenital syphilis are reported to ISOSS** (regardless of timing of maternal diagnosis) and discussed by a Clinical Expert Review Panel (CERP)

Analyses on **all congenital syphilis** cases of **infants born between 2015-23** reported to ISOSS and discussed by the CERP by September 2023

# Clinical Expert Review Panel

- **All cases of congenital syphilis are investigated** by ISOSS who speak to all the clinicians involved in the care of the mother and baby
- Enhanced information collected includes screening and treatment history, management in pregnancy, access to other services (including sexual health) and social complicating issues
- **Anonymised case summaries** are presented to the IDPS CERP consisting of a **range of specialists** including maternity, paediatrics and sexual health as well as BASHH guidelines and UKHSA representatives
- The purpose of the panel is to:
  - establish the **circumstances** surrounding the transmission
  - identify any **contributing factors** and learning points
  - feed **recommendations** to the IDPS programme to inform national guidelines, policy and IDPS programme projects

# Syphilis in pregnancy

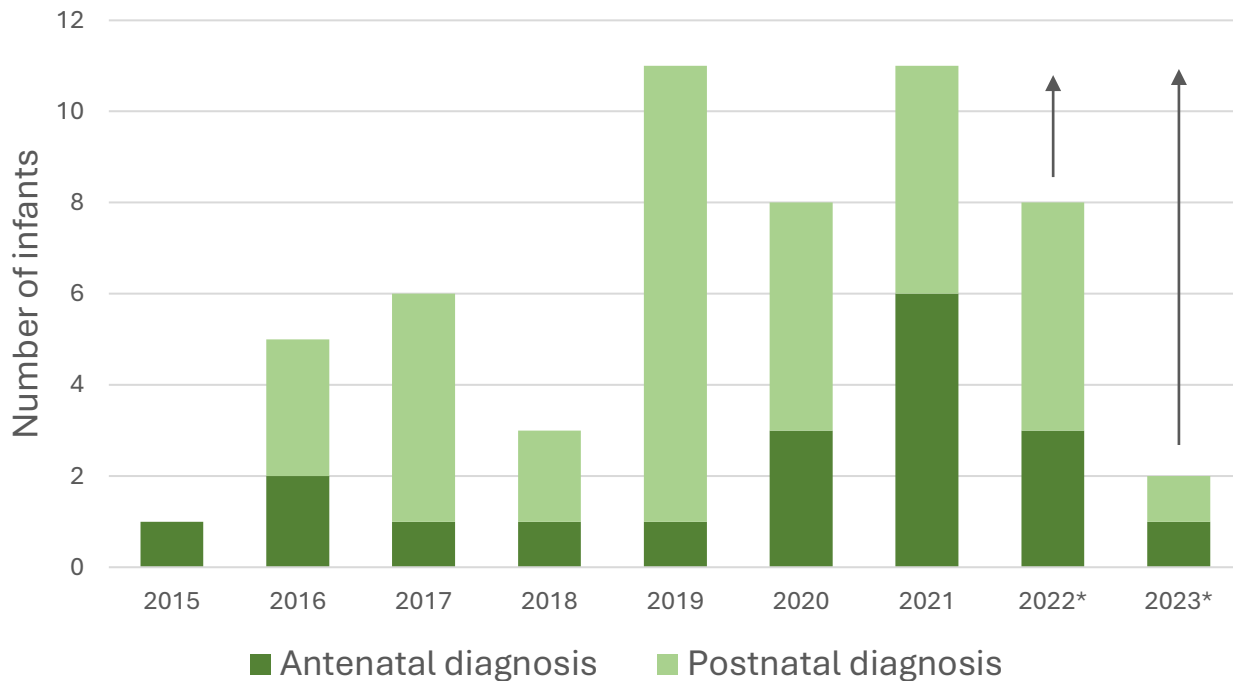
Annually ISOSS receive reports of **over 900 pregnancies** to women screening positive for syphilis:

- Of women booked 2021-22: 31.3% were newly diagnosed requiring treatment and 9.4% were previously diagnosed requiring treatment (**41% required treatment**)

Between 2015-23 there were **55 cases of congenital syphilis**, with a range of contributing factors identified including late antenatal booking and disengagement with clinical care

- For all 55 cases women were offered and accepted screening in pregnancy

# Congenital syphilis over time (CERP-reviewed by Sept 2023)



\*numbers for 2022-23 are increasing

# Women screening negative in pregnancy

- **24\*** of the 55 infants with congenital syphilis were to women who had a **negative screen in pregnancy**. There were 22 livebirths and 2 stillbirths
- **All 23 women** were identified as screen positive after delivery, meaning they acquired syphilis later in pregnancy.
- Negative screening results ranged from 4 - 20 weeks gestation



\*23 women as one set of twins

# Diagnosis (n=23)

- **16 women** were identified through **their infant's diagnosis**



- **4 women** were identified through **antenatal screening in a subsequent pregnancy**



- **2 women** presented at **sexual health with symptoms**



- **1 woman** was identified following her **partner's diagnosis**





# Maternal demographics

Women who screened negative in pregnancy ( $n=23$ )

Overall screen positive population 2021-22 ( $n=934$ )

22/23 (96%)  
women were UK-born

21/23 (91%)  
of women were of white ethnicity

Median age at delivery was 23 years



25% of women were born in Eastern Europe

70% of women were of white ethnicity

Median age at delivery was 30.9 years

# Regional breakdown

## Women who screened negative in pregnancy ( $n=23$ )

- South East (6)
- North West (5)
- London (5)
- North East & Yorks & Humber (4)
- East of England (2)
- Midlands (1)

## Overall screen positive population 2021-22 ( $n=934$ )



# Social circumstances

11/23 women had **adverse social circumstances reported\***. These included:

- **social services involvement** (9)
- **intimate partner violence** (6)
- **housing concerns** (5)
- **mental health issues** (5)
- **drug/alcohol misuse** (3)
- **not engaging with healthcare services** (2)



\*many women had  $\geq 1$  adverse social circumstance reported

# Potential indicators for rescreening

No women were offered rescreening in pregnancy

For **8/23 women**, **potential indications for rescreening** in pregnancy were identified following ISOSS review including:

- disclosure of multiple/new partners
- attendance with vulval lesions
- recurrent treatment for thrush and/or herpes

In other cases: there were UTIs, rashes, intimate partner violence and travel in and out of UK during pregnancy reported.

In one case the woman's ex-partner disclosed a syphilis diagnosis, woman ordered online sexual health testing kit with insufficient sample result not followed up by woman/raised with antenatal team

# Conclusions

- **Nearly half of infants** with congenital syphilis were **born to women who screened negative in pregnancy**
- This highlights the **importance of ‘negative now’ messaging** in pregnancy to ensure women are aware that a negative result does not mean they are protected from infection and to encourage discussions around sexual health promotion.
- **Nearly half** of women had **adverse social circumstances** and a third had indications for offering rescreening that were missed
- Consideration of **possible missed opportunities** to identify women who may be at risk and require retesting later in pregnancy is needed.
- **Ongoing surveillance by ISOSS** and the IDPS CERPs is vital to **monitor this increasing population** and support **wider public health initiatives** by BASHH, NHSE and UKHSA

# Acknowledgments

Thank you to all respondents who report to ISOSS, all members of the Clinical Expert Review Panel (full list of members on [www.ucl.ac.uk/isoss](http://www.ucl.ac.uk/isoss)) and our colleagues at UKHSA for their ongoing support

UCL are the commissioned data processors for NHS England's Infectious Diseases in Pregnancy Screening (IDPS) Programme who are the data controllers and owners

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More information on ISOSS: [www.ucl.ac.uk/isoss](http://www.ucl.ac.uk/isoss)

The ISOSS syphilis report for 2023 can be found on gov.uk

