



Integrated Screening Outcomes Surveillance Service

Congenital syphilis in the UK- is it on the rise?

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Background

- **The Integrated Screening Outcomes Surveillance Service (ISOSS)** monitors screening outcomes for Public Health England's Infectious Diseases in Pregnancy Screening programme (IDPS)
- The goal of ISOSS is to collect, analyse and report obstetric and paediatric data on the **screened for infections in pregnancy: HIV, syphilis and hepatitis B** in order to:
 - assess key outcomes of the IDPS Programme
 - assess the IDPS Programme's impact on prevention of vertically-acquired HIV, syphilis and hepatitis B
 - protect the health of women with and infants exposed to these infections
- 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
- ISOSS collects **patient data under legal permissions granted to PHE under Regulation 3** of The Health Service (Control of Patient Information) Regulations 2002

Background

- ISOSS builds on existing projects and bespoke audits including:
 - the well-established **National Surveillance of HIV in Pregnancy and Childhood (NSHPC)**
 - the **Audit of perinatal HIV in children born in the UK 2006 to 2013 (now ongoing)**
 - the **Surveillance of Antenatal Syphilis Screening study (SASS) on pregnancies 2010-2011**
 - the **National Hepatitis B in pregnancy audit on pregnancies in 2014**
- Previous data on congenital syphilis in the UK comes from one off studies, including the SASS study (Townsend et al.) and the BPSU study (Simms et al.): **congenital syphilis is not a notifiable disease**
- **No population level data since 2015**
- In the past few years there have been **ad hoc reports** in the clinical community of cases of congenital syphilis, as well as clinician to clinician concerns. However **no national surveillance** has been available to provide true numbers
- **PHE's Syphilis Action Plan** was launched in 2019 and addresses the recent increase of infectious syphilis diagnoses identified in the general population
- The IDPS is leading the **maternity strand of the Syphilis Action Plan**

Methods

- In December 2019 ISOSS began the enhanced data collection of all cases of congenital syphilis born in the UK since 2015 to address the current data gap
- Drawing on the **pre-established comprehensive national paediatric and maternity network**, ISOSS methods are based on the enhanced data collection of HIV vertical transmissions in the UK
- The **ISOSS team interview all clinicians involved in the care of the mother and baby during and after pregnancy**
- An average of three interviews are conducted per case **across paediatrics, maternity and GUM**. Where multiple units are accessed for care the process is repeated for each unit and in some cases this includes **adoption services, medical advisors and safeguarding midwives**
- Patient data is collected without patient consent by ISOSS with **PHE Regulation 3** approval to do so, more information on ISOSS (including governance) can be found here:

www.ucl.ac.uk/isoss/governance

Methods

Detailed anonymised case reports are presented to the **IDPS Syphilis Clinical Expert Review Panel (CERP)**. The panel consists of relevant clinical specialists including maternity, laboratory, paediatrics and GUM

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 Syphilis Task Group** to inform **national guidelines and policy**

To date there have been 2 CERPS, with another planned before the end of the year

Following this review of cases born since 2015, the CERP will meet annually to discuss cases reported that year

Results

The enhanced data collection is **in progress** and not all CERPs are complete so results to date are **preliminary only** (*numbers are likely to change*) final findings and recommendations are expected to be published in 2021 by PHE

Year of birth	No of cases
2015	1
2016	5
2017	5
2018	3
2019	8*
2020	3
Total	25

25 cases are currently considered to be **confirmed congenital syphilis** cases born in England and are **under review by the CERP***

- **23/25 livebirths; 1 set of twins and 1 set of siblings**
- **2/25 stillbirths**

* One set of twins

*(a handful of were reported from **Wales and Scotland**, but discussions are ongoing about GDPR permissions so these are not included in any current analyses)

Region of child's birth	No of cases (%)
London	5 (20%)
North East	5 (20%)
North West	6 (24%)
South East	6 (24%)
South West/South Central	1 (4%)
Midlands and East of England	2 (8%)

Review of confirmed CS cases: snapshot

Maternal country of birth:

UK: 22/25

Romania: 3/25

Maternal ethnicity:

White: 24/25

Maternal median age: 22yr (IQR: 21,25)

Timing of maternal diagnosis:

Antenatal (screening or GUM): 7/25

Postnatal: 18/25

BASHH birthplan use:

1/7 diagnosed antenatally reported using BASHH birthplan

[www.bashhguidelines.org/media/1139/syphilis-birth-plan-2016.pdf]

Infant age at diagnosis ranged from 1st day of life to 22 months

Review of confirmed CS cases

Social issues identified included:

- Safeguarding
- Housing
- Intimate partner violence
- Foster care/adoption
- Mental health
- Drug/alcohol misuse
- Sex work

Clinical management issues:

- Penicillin allergy – treated with inappropriate alternative
- Missed clinical presentation/not referred to GUM when STI suspected

- Many women experiencing more than one of these social and clinical issues
- Unable to say if this group is representative of the syphilis maternity screen positive population

NB: CERPs not complete, please interpret with caution

Conclusions

This early review **does not indicate a substantial rise in numbers of congenital syphilis**: the ongoing population level surveillance carried out by ISOSS is required to monitor trends and inform **national guidelines and policy**

High rates of **adverse social circumstances** already identified in this group highlights the importance of work to address **inequalities** and barriers in access to care

There is not yet sufficient data to know whether the **transmitting group** presented here is representative of the syphilis screen positive population

ISOSS surveillance of **all syphilis screen positive pregnancies began in 2020** and will provide additional insights and contexts, including a national vertical transmission rate, for wider strategies including **Public Health England's Syphilis Action Plan**

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Members of the ISOSS Congenital Syphilis Clinical Expert Review Panel:

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