



Integrated Screening Outcomes Surveillance Service

ISOSS is a part of the NHS Infectious Diseases in Pregnancy Screening Programme, NHS England: [GOV.UK](https://www.gov.uk)

ISOSS at Conferences

CHIVA: The ISOSS/CHARS team hosted a stand at the CHIVA conference (right) in London. We enjoyed meeting many of our paediatric and maternity respondents, and seeing ISOSS data showcased in presentations. Gabriela presented the first update on CHARs (see back page).



L-R: Saayma, Helen, Gabriela, Stella, Buthainah, Kate, Corinne, Laurette

HIV & Women workshop: Laurette presented on [maternal immunosuppression and adverse birth outcomes among women living with HIV](#) using data from ISOSS and UK CHIC at the International HIV & Women workshop in Seattle.



Maternity reporting updates

Green Card updates

- **Green card reports now ask for additional information** previously requested on notification forms. This includes booking date, timing of diagnosis, pregnancy status/outcome, infectivity status & syphilis screen-positive breakdown. This **change supports ISOSS to provide IDPS Standards data on your behalf** and information will be pre-populated on the notification form.

Forms updates

All infections:

- Gender
- Language for translational services
- Transfer of care details
- Screening team appointment type
- Whether diagnosis was a result of IDPS screening

HIV

- Registration with GP & awareness of status

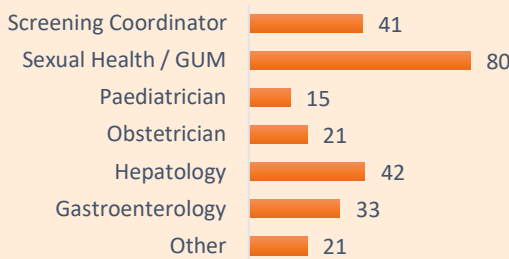
HBV

- Retesting details and changes in infectivity status

Respondent Survey Results 2023

Thank you to everyone who responded to our annual ISOSS maternity survey (107/269). We really value your feedback and will be taking this on board where possible.

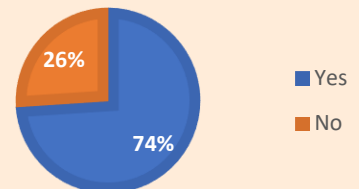
Fig 1. Reporting contributions



- The majority of respondents felt that format and functionality changes of forms in the past year have made reporting easier
- There was a great deal of interest in completing notification forms contemporaneously

- We received responses from all regions in the country
- Fig 1 shows a wide range of specialities contributing to reporting
- 74% of respondents felt that ISOSS submitting Standards on your behalf will reduce the reporting burden (Fig. 2)

Fig 2. ISOSS reducing burden of IDPS standards data



New output: Gestational diabetes in women living with HIV in the UK and Ireland: insights from population-based surveillance data

- Laurette Bukasa (Surveillance officer for maternity HIV), in collaboration with colleagues, has published a research article on gestational diabetes (GD) using ISOSS data from 2010-2020.
- GD prevalence increased over time but was not significantly different from the general population. Maternal age, ethnicity and CD4 count were found to be risk factors.



Maternity reporting tips: based on survey feedback

- **Outcome forms can be made available prior to the reported EDD** by request. Please contact the team if you would like access to the form earlier.
- **Save forms that you are working on every 15 minutes** (by clicking 'Save and Stay on Form' or 'Save and Continue Later') to avoid the portal timing out and losing entered information
- **NHS number is required for all women**, if no NHS number is available at booking, please indicate in the notes the reasons for this. You can then add it to the Outcome form.
- Please **ensure all information is correct and complete before submitting the Green Card**. Once submitted, you will have to contact the team to make edits.
- **HIV**: antiretroviral drug details can be entered into the notes section of the forms if you cannot find the correct drug or combinations in the drop down list on the forms.

Please remember to use team members' nhs.net email or our new team nhs.net email (england.isoss@nhs.net) when sending patient identifiable information

Team updates: new Surveillance Administrator for Syphilis



Buthainah is a Medical Physiology graduate from the University of Leicester with previous experience working as a research technician, processing microbiology samples and supporting data analysis. Buthainah is keen to learn more about infectious diseases in pregnancy. She is looking forward to contributing to the ISOSS team's work focussing on maternity and paediatric syphilis reporting.

New screening helpdesk email: The NHS screening helpdesk email has changed and is now england.screeninghelpdesk@nhs.net. This is similar to the ISOSS nhs.net email england.isoss@nhs.net. Please check you are contacting the right email address, especially when dealing with patient identifiable information

Paediatric reporting

CHIVA conference: Gabriela Toledo was delighted to present the first overview of paediatric HIV in England since the launch of CHARS in 2022. Key highlights:

- There are currently **469 children and young people in living with HIV in England**, of whom **16 were newly reported to CHARS since 2020**.
- **Median age** at most recent appointment was 16 years, with increasing numbers transferring to adult care
- **99%** were reported to be on ART at last follow-up
- **67%** are in follow-up, **32%** transferred to adolescent/adult care, **<2%** were lost-to-follow-up or gone abroad
- The majority had reassuring clinical markers (Fig 1)
- The full presentation is available on the [CHARS website](#)

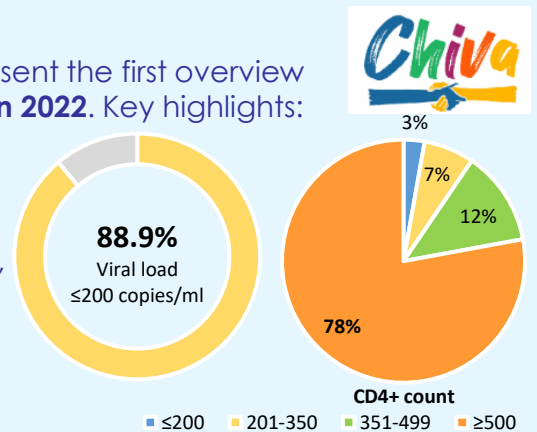


Figure 1. Clinical markers of children and young people at their most recent appointment.

CHARS updates: improvements to ART section

- The ART display now allows for easier updates/corrections to ART regimens. A reminder to check the **accuracy of ART data** when updating forms
- **Please notify us** of any ART inconsistencies in the form notes or via email (england.isoss@nhs.net)



ISOSS Updates (HIV Reporting)

- Thank you for all the responses we have received to the **paediatric HIV queries** that were sent out in **March**. We are grateful for everyone's time and support to ensure data accuracy.