

NHS Infectious Diseases in Pregnancy Screening Programme News

Gateway number 2014288

infectiousdiseases.screening.nhs.uk

August 2014

National hepatitis B in pregnancy audit update

A huge thank you to all those who have submitted data - we have now received over 1300 notifications! This important national audit will help to inform and shape the care of pregnant women with hepatitis B, and their babies. The aim is to bring this service on par with the excellent standard we have across the world for screening and caring for pregnant women with HIV.

Finding the time to collate and submit audit data is always a challenge for professionals in their busy clinical roles, particularly in trusts that have a high prevalence of a condition. The screening programme is conscious of this and is investigating new simpler methods of collation and reporting. The development of the web-based submission tool via a secure system will be evaluated for possible extension to encompass other infection reporting that are currently paper based, e.g. HIV, syphilis etc.

The next phase involves completion of brief referral information on the woman's attendance at specialist services and whether any women have defaulted the visit. Details will be sent out in the next few weeks.

For further information please visit the project website or contact the team by [email](mailto:) or call: 020 7905 2396.

Hepatitis B Specialists Meeting - book your place



Hepatitis B in pregnancy - 2014 and beyond, 9 September 2014

The UK National Screening Committee (UK NSC) Infectious Diseases in Pregnancy Screening (IDPS) Programme team are convening this multidisciplinary event in September.

The event will provide an opportunity for those involved with the screening and subsequent management of women screening positive with hepatitis B, and their babies, to gain an insight and understanding of the current priorities of the IDPS Programme in relation to

evidence, clinical practice and care.

Key speakers will provide the latest information, data and reports on policy and research relating to and commissioned by the IDPS Programme. The main focus will be on the current UK NSC National Audit of Hepatitis B in Pregnancy and the role of specialist clinical teams in the success of the audit.

For further information about the event and to book your place, visit the [events website](http://events). Early booking is recommended as numbers are restricted.

Perinatal HIV Audit

Thanks to effective antenatal HIV screening and interventions, less than 0.5% of infants born in the UK each year to diagnosed HIV-positive women are infected. 20-30 newly diagnosed children are reported in the UK each year, whose mothers were not previously known to be HIV-positive. These women were either not tested in pregnancy, or acquired HIV after their antenatal test, or after their baby was born through breastfeeding.

The UK NSC commissioned a review of this cohort of babies to inform a possible further reduction in the risk of perinatal HIV transmission. Thank you to everyone who has responded to the audit. Completed cases are being discussed by an Expert Review Panel, with clinicians from relevant specialities and lay representatives, who will prepare recommendations for the UK NSC.

Further information is available [here](#).

Rubella susceptibility

Following the UK NSC recommendation against antenatal screening in 2012, the IDPS Programme and PHE Immunisation Team are exploring alternative strategies directed towards population groups which continue to be at risk of rubella infection, and cessation of antenatal screening for rubella susceptibility. A comprehensive plan will be developed and in the interim antenatal screening in line with national standards and guidelines should continue.

Screening Coordinators - we need your help

Analysis of 2012 surveillance data highlighted a significant number of trusts are retesting ALL women for HIV and hepatitis B. Programme standards advocate 'where a prior diagnosis

of HIV or hepatitis B is documented and known to the healthcare professional this should be recorded and arrangements for prompt clinical evaluation made'

Research involves

participation in an on-line survey followed by a short telephone interview if necessary.

The findings will inform the current review of national screening standards and policy.

IDPS national event - Feb 2014

The national programme team held its first event to showcase infectious diseases in pregnancy screening since becoming part of Public Health England. The [synopsis report](#) includes presentations and feedback.

Care of women whose pregnancy ends AFTER screening

The screening programme conducted a survey several years ago on the care of women who miscarry or women who choose to have their pregnancy terminated AFTER they have already had screening tests performed for infectious diseases.

It demonstrated wide variation in the management of results and follow up of this cohort of women, particularly when the screened positive:

- some screening coordinators followed them up personally to ensure entry into the appropriate care e.g. GUM; Hepatology
- some notified the GP requesting that they ensure the women are referred for assessment and treatment as required
- some had no agreed pathway or policy in place

Recent Key Performance Indicator - KPI ID2 data has also highlighted that some units appear to have no robust process in place for follow up for women who miscarried.

The 2010 IDPS Programme Standards do not specifically advocate a separate care pathway for these women. However, Section 5.1 Positive Results does state:



'women should be contacted and advised about the results, at an appointment made for that purpose, within 10 working days of the result being made available to maternity services...'

The programme would like to reiterate that these women were booked for maternity care and screened as part of that care package. As such, the responsibility for giving the positive result is no different to a women continuing with their pregnancy and is just as important for the health of the woman and any future pregnancies.

Future revised Programme Standards and Service Specifications will clarify this issue further.

Pertussis vaccination in pregnancy matters

Immunisation against pertussis (whooping cough) in pregnancy has been recommended since 1 October 2012. There is a high risk of serious disease in young babies with pertussis and 75% of all cases in babies occur before they can be protected by the first dose of infant vaccine. Unfortunately, although it is rare, young babies can still die from pertussis. Babies that have died from pertussis in England over recent years all acquired pertussis in the first few weeks of life.

Women vaccinated in the latter stages of pregnancy generate high levels of antibody against pertussis which is transferred to their baby in the womb - thereby protecting the baby from birth. To allow time to provide the highest level of protection to their babies, women should ideally be offered immunisation between 28-32 weeks gestation, although they may be immunised up to 38 weeks of pregnancy.

Pertussis vaccination in pregnancy can significantly prevent serious disease and death in young babies. Approximately 60% of all pregnant women in England are currently being vaccinated in pregnancy. This is a testament to the midwives, nurses and GPs who are delivering this programme.

ALL pregnant women should be given the opportunity to be vaccinated and informed about



the importance of vaccination and sign-posted to vaccination services in their local area.

For further information:

- [Health Protection Agency - background](#)
- [Department of Health and Public Health England - continuation of temporary programme 2013](#)
- [Public Health England vaccine update - January 2014](#)
- [Public Health England vaccine update - archives](#)

Monitoring congenital rubella cases

Although there have been few confirmed reports of congenital rubella in recent years, awareness of rubella infection and congenital rubella among health professionals caring for pregnant women must be maintained.

The last significant rubella outbreak in 1996 had 14 associated congenital rubella cases. Since then there have been about 20 cases in total, two-thirds of these maternal infections were acquired in the UK.

Maternal infections resulting in live births of congenitally infected infants are generally only retrospectively diagnosed.

Comprehensive paediatric active surveillance through the British Paediatric Surveillance Unit (BPSU) is crucial in this and reporting is therefore essential.

With the planned change in national screening policy, and the WHO Europe goal to eliminate rubella and congenital rubella from the European Region by 2015, it has been agreed that monitoring of congenital rubella through the BPSU will continue, with support from the UK NSC.

For further information visit the [Royal College of Paediatrics and Child Health website](#).

View the latest [British Paediatric Surveillance Unit bulletin here](#).

Plans to improve the follow up of babies born to hepatitis B positive women

Testing infants born to hepatitis B positive mothers for hepatitis B surface antigen at the age of 12 months identifies any infants who have become chronically infected despite vaccination, allowing early referral for specialist management.

Missed testing can have devastating consequences for the infant as hepatitis B infection is generally asymptomatic in infants, permitting silent, undetected progression to chronic liver disease and even cirrhosis in young adulthood.

Testing at 12 months has historically been poor. Since September 2013 Public Health England

Colindale has been offering a free of charge dried blood spot (DBS) testing service for these infants to improve immunisation completion and 12 months testing - over 600 dried blood spots have now been tested.

The Public Health England Immunisation and IDPS Programme teams are working collaboratively to explore new ways to enhance the follow up of high risk infants.

For further information see the [Health Protection Agency website](#).

Policy news

Following the UK National Screening Committee [meeting on 18 June](#), the UK NSC has recommended earlier screening for [Edward's Syndrome \(T18\) and Patau's Syndrome \(T13\)](#) in pregnancy. The Committee recommended against screening for atrial fibrillation, type 2 diabetes and parvovirus.

Current policy consultations

- [Dementia](#) (closes on 9 October 2014)

- [Preterm birth and bacterial vaginosis](#) (closes on 17 October 2014)
- [Gauchers disease](#) (closes on 6 November 2014)

New consultations due to start soon

- [Amino acid metabolism disorders](#)
- [Sudden cardiac death](#)
- [Depression](#)



UK National
Screening Committee

Big changes to screening websites

As part of the government's plan to drastically reduce the number of websites, the screening sites will be undergoing major changes over the course of 2014.

All the screening websites (the UK Screening Portal, Continuing Professional Development site and the websites of the eight non-cancer screening programmes) will be closed down, probably by the end of 2014. Information for the public will be moving to NHS Choices (where it can be better linked to general information about the conditions being screened for), with content for professionals going to the gov.uk website. Our e-learning modules will also be moving to a new home in due course.

Rest assured that we are working hard to minimise any disruption and any risks from the transition. We hope that the final outcome will be a better experience for all the visitors to our websites. In particular,

we can provide a more integrated approach to providing information across all the NHS Screening Programmes - both cancer and non-cancer.

These changes should make it easier for people to find the information they need, increase the number of visitors to our screening pages and allow us to better integrate our information with that of other parts of government and the NHS.

In preparation for the transition, work is currently being carried out to review and update content on the current websites. During this process, some parts of the websites might not work quite as expected so if you find anything wrong, please accept our apologies and let us know at phe.screeninghelpdesk@nhs.net.

Look out for more information over the coming months.



The current UK Screening Portal

Screening Matters newsletter

The latest issue of the UK NSC's Screening Matters newsletter was published in June. It covers the usual mix of policy and programme news.

www.screening.nhs.uk/screeningmatters

Other news in brief

UK NSC review

The [independent review](#) of the role, terms of reference and membership of the UK National Screening Committee has now closed. Many thanks to everyone who took part.

2013-14 quarter 3 KPI data

Key Performance Indicators (KPIs) for NHS Screening Programmes for the [third quarter of 2013/14](#) have now been published.

Antenatal and newborn e-learning module

The UK NSC's popular [antenatal and newborn screening e-learning module](#) has just been updated, including new questions in the quiz.

Education Resource for PICU/ NICU Practitioners

The UK NSC has just launched a [new educational resource for PICU/NICU](#)

practitioners.

The resource covers the three newborn screening programmes:

- Newborn Hearing (NHSP)
- Newborn and Infant Physical Examination (NIPE)
- Newborn Blood Spot (NBS)

The aim is that units can use this self-directed tool for staff who can work through the scenarios and examples of evidence in their continuing professional development.