NHS Infectious Diseases in Pregnancy Screening Programme Handbook 2016 to 2017

Public Health England leads the NHS Screening Programmes
About Public Health England

Public Health England exists to protect and improve the nation’s health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

Public Health England, Wellington House, 133-155 Waterloo Road, London SE18UG  
Tel: 020 7654 8000  www.gov.uk/phe
Twitter: @PHE_uk  Facebook: www.facebook.com/PublicHealthEngland

About PHE Screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the NHS on the advice of the United Kingdom National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the four UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat.

PHE Screening, Floor 2, Zone B, Skipton House, 80 London Road, London SE16LH  
www.gov.uk/topic/population-screening-programmes
Twitter: @PHE_Screening  Blog: phescreening.blog.gov.uk

Prepared by: NHS Infectious Diseases in Pregnancy Screening Programme team
For queries relating to this document, please contact: phe.screeninghelpdesk@nhs.net

© Crown copyright 2016
You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit OGL or email psi@nationalarchives.gsi.gov.uk. Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

Published July 2016
PHE publications gateway number: 2016168
## Contents

Executive summary ...................................................................................................................... 4  
Introduction .................................................................................................................................. 5  
The NHS Infectious Diseases in Pregnancy Screening Programme ............................................ 6  
  General principles of screening ................................................................................................ 6  
  Screening policy ....................................................................................................................... 6  
  Programme governance ........................................................................................................... 8  
Infections screened for in pregnancy............................................................................................ 9  
  Human immunodeficiency virus (HIV) ....................................................................................... 9  
  Hepatitis B .............................................................................................................................. 12  
  Syphilis ................................................................................................................................... 17  
Infections that are not screened for ............................................................................................ 21  
IDPS screening pathway ............................................................................................................ 22  
Screening quality assurance services (SQAS) ........................................................................... 34  
  Screening safety incidents ...................................................................................................... 34  
Data collection and reporting ...................................................................................................... 35  
  Programme standards ............................................................................................................ 35  
  Key performance indicators ................................................................................................. 35  
  Standards data collection process ......................................................................................... 36  
  Screening outcomes ............................................................................................................... 36  
Appendix 1. Acknowledgments .................................................................................................. 38
Executive summary

The NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme has produced this handbook with support from the members of the programme advisory and task groups and in collaboration with screening coordinators and clinical nurse specialists from around England.

This practical guidance supports healthcare professionals and stakeholders in the operational delivery of the screening pathway. New screening coordinators will find the handbook a source of information to support their induction and practice.

The handbook provides an update of recent changes to the programme. It refers to supporting documents and clinical guidance that trusts should take into account to deliver a high quality screening programme.

Commissioners and screening and immunisation teams will find the handbook puts these documents into the context of the day to day work of the screening coordinators, midwives, screening laboratory teams and clinical specialists who make up the IDPS multi-disciplinary team (MDT).

The handbook provides:

- structure and governance of the IDPS programme
- a comprehensive outline of each of the 3 infections screened for
- clarity on the screening tests and terminology
- hyperlinks to information and supporting documents
- detail on the delivery of each step of the screening pathway
- the management of the care of pregnant women with any of the 3 infections within a robust multi-disciplinary framework
- key practice points to consider
- updates on current quality assurance, data collection and audit processes

The handbook will be updated annually to ensure it continues to be a valid reference document.
Introduction

This document aims to inform and support best clinical practice in the delivery of the NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme. It was developed in collaboration with screening coordinators and clinical nurse specialists from around England (Appendix 1).

The handbook is part of a suite of documents that are reviewed and updated annually.

1. Service specification 2016-17 (No.15). This document outlines the service and quality indicators expected by NHS England and the recommendations and standards of the UK National Screening Committee (UK NSC).

2. Programme standards. This document focuses on process standards to enable providers and commissioners to continuously improve the quality of the screening programme. It defines a set of variable standards with metrics relating to screening for HIV, hepatitis B and syphilis. The standards view the entire screening pathway and are based on the 10 themes that assess the whole pathway.

3. Laboratory handbook. This guidance is for laboratories that process specimens for the IDPS programme and highlights the requirements for screening. The handbook has been cross-referenced with International Organisation for Standardisation (ISO) 15189 Standards to reduce duplication of effort and resources for laboratory quality assurance.

There should be a seamless transition from the screening pathway into the following appropriate specialist services in line with national clinical guidance:

- British HIV Association (BHIVA) guidelines for the management of HIV infection in pregnant women 2012 (2014 interim review)
- Children’s HIV Association (CHIVA) guidelines on mother-to-child transmission
- British Association of Sexual Health and HIV (BASHH) UK National Guidelines on the Management of Syphilis 2015
- British Viral Hepatitis Group (BVHG) Consensus Statement – UK guidelines for the management of babies born to women who are HBsAg positive
- Immunisation against Infectious Disease. Hepatitis B: the Green Book, chapter 18
The NHS Infectious Diseases in Pregnancy Screening Programme

General principles of screening

Screening is a process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition. Further information regarding the general principles of screening can be found on GOV.UK

An antenatal and newborn screening timeline is available to illustrate the screening tests that are offered and the optimum times for testing.

Screening policy

The UK National Screening Committee (UK NSC) policy for the IDPS programme is to offer and recommend screening to all eligible women. This is to enable early detection and treatment for infections in pregnancy in order to significantly reduce the risk of mother-to-child transmission of infection.

The UK NSC recommends that systematic, population screening in pregnancy is offered and recommended to all eligible women for:

- HIV
- hepatitis B
- syphilis

The IDPS programme aims to:

- ensure equal access to uniform and quality assured screening across England
- provide women with high quality information so they can make an informed choice about their screening options and pregnancy choices. Some women may choose not to be screened or to accept screening for some of the infections and it is important that this choice is respected
- provide assurance that all women who screen positive for HIV, hepatitis B or syphilis, or are already known to be positive for HIV and hepatitis B, are seen by the IDPS MDT within specified timescales
Chronology of the IDPS programme

2001: UK NSC formed regional antenatal screening teams in Strategic Health Authorities across England to coordinate and modernise existing screening programmes, initially focusing on antenatal screening for Down’s syndrome.

2003: Department of Health’s document ‘Screening for infectious diseases in pregnancy’ consolidated antenatal screening for syphilis within an integrated screening programme for HIV, hepatitis B, syphilis and rubella susceptibility. (http://webarchive.nationalarchives.gov.uk/20031229024715/doh.gov.uk/antenatalscreening/)

2007: National strategic stakeholder workshop held to identify cross-cutting work to promote integration of discrete screening programmes into a more unified entity and to develop condition-specific work streams.

2008: Infectious Diseases in Pregnancy (IDPS) Programme Board established, with representation from main stakeholder organisations to provide organisational focus at national level.

2010: More formal programme structure developed with an overriding expert advisory group; publication and implementation of programme screening standards and laboratory handbook; programme manager appointed.

2013: NHS Screening Programmes became part of Public Health England’s Health and Wellbeing directorate. A new governance structure was developed for the IDPS programme. A new programme manager and team appointed as part of the NHS Screening Programmes structure.

2016: Following two UK NSC evidence reviews, antenatal screening for rubella susceptibility ended on 1 April 2016. The best protection for pregnant women is to have 2 measles, mumps and rubella (MMR) vaccinations prior to pregnancy. IDPS programme produced revised screening standards, laboratory handbook and new screening handbook and supporting operational guidance and resources.
Programme governance

The IDPS programme has a governance structure that reports to Dr. Anne Mackie, Director PHE Screening.

The aim of the IDPS advisory group is to:

- advise on the implementation and development of the screening programme
- advise on its effectiveness and efficiency
- share information
- advise on programme standards, education and training, information, quality assurance and research and development

There are established task groups that support specific work streams and projects. The chairs of these groups report to the advisory group. The role of members is to challenge constructively as ‘critical friends’ and provide advice and opinion. Ultimate decision making lies with the programme officers and directors within Public Health England (PHE) and only the UK NSC makes recommendations on changes in policy matters.
Infections screened for in pregnancy

Human immunodeficiency virus (HIV)

History of screening

Universal antenatal screening for HIV was introduced in 1999 following a systematic review. The Health Service Circular 1999/183 ‘Reducing mother-to-baby transmission of HIV’ set the following national targets for test uptake and performance:

- Screening test to be offered and recommended to all pregnant women by the end of 2000
- Minimum antenatal testing uptake of 50% by end of 2000
- 90% uptake of testing everywhere by end of 2002

What is HIV?

Human immunodeficiency virus (HIV) is a retro-virus, which, if left untreated, leads to immunosuppression and eventually to acquired immune deficiency syndrome (AIDS). HIV is present in all body fluids such as blood, semen, vaginal secretions and breast milk. It can be passed on through unprotected sexual intercourse, direct contact with the blood of an infected person, sharing infected needles, from mother to child during pregnancy, at birth or when breast feeding.

CD4 cells, also known as T-helper cells, are white blood cells which play an essential part in the human immune system. One of their main roles is to detect pathogens and send signals to other types of immune cells, including CD8 killer cells, to destroy the infectious particles. CD4 cells are made in the spleen, lymph nodes and thymus gland. When HIV enters the body it targets and invades the CD4 cells in the blood. Once inside the CD4 cell the virus begins a complicated process of replication to produce new HIV virions. When completed, the new virons break through the cell wall and out into the bloodstream, destroying the CD4 cell. The new HIV virons then move to invade other CD4 cells and the process is repeated.

A normal CD4 count in someone who is uninfected and otherwise healthy is between 500 and 1,500 cells per ml of blood. Following HIV infection, the number of CD4 cells will gradually fall. The rate of fall varies from person to person. Eventually, if untreated, the CD4 count falls to a level where the immune system is no longer able to function adequately and the person becomes susceptible to opportunistic infections and HIV related cancers.

There is not a cure for HIV yet but, antiretroviral therapy can prevent further damage to the immune system. It does so by working to stop the virus at different stages from cell
invasion to replication, thereby enabling the CD4 count to be restored to a safe level. Early diagnosis of HIV infection reduces the risk of a person reaching a critically low CD4 count and experiencing serious health problems.

**HIV in pregnancy**

Mother-to-child vertical transmission is now rare in the UK following the widespread implementation of routine antenatal screening, antiretroviral treatment in pregnancy and avoidance of breastfeeding.

The risk of mother-to-child HIV transmission in an untreated woman in pregnancy is around 25%. However, with early diagnosis, effective treatment and subsequent viral suppression, the risk of transmission is now very low (under 0.5%).

In the UK and Ireland, information is sought on all pregnancies in diagnosed HIV positive women through the National Study of HIV in Pregnancy and Childhood (NSHPC). Among more than 12,000 pregnancies reported between 2000 and 2011 there was a four-fold drop in the rate of mother-to-child transmission from 2.1% to 0.46%. Mother-to-child transmission rates continue to decline.

**HIV tests**

**Screening**

The recommended screening tests must detect HIV-1 antibodies, HIV-1 p24 antigen and HIV-2 antibodies. Screening using a 4th generation assay is now established as the standard of practice in the UK.

The assays must have a high sensitivity (> 99.9%) and specificity (> 99.5%) and be able to detect all the major subtypes of HIV-1 and HIV-2.

**Confirmatory**

All results considered to be positive in the screening assay must be confirmed on the initial specimen by two further independent assays, using different methodologies, one of which should discriminate between HIV-1 and HIV-2. This is to confirm that the reactivity is specific for HIV and reduce the possibility of non-specific reactions giving false positive results.
Treatment and clinical guidelines

Maternal viral load is the key determinant in HIV mother-to-child transmission, with a higher viral load increasing the risk of transmission. Suppression of maternal virus through antiretroviral therapy is the main objective of HIV management in pregnancy.

HIV can be transmitted from mother to child by breastfeeding. The NSHPC report on perinatal HIV transmission in the UK noted adverse social factors as a frequent factor in HIV transmission. All mothers known to be HIV positive, regardless of antiretroviral therapy, and infant post-exposure prophylaxis (PEP), should be advised to exclusively formula feed from birth. This is in line with current BHIVA guidelines for the UK that recognise that formula milk is affordable, feasible, acceptable, sustainable and safe.

There may be social or financial pressures on women to breastfeed, and support of formula feeding is important. A House of Lords review recommends that local authorities provide free infant formula milk to HIV-positive mothers who have no recourse to public funds.

Where a woman chooses to breastfeed against advice she and the baby should be monitored regularly by the MDT for maternal adherence to ART; viral load monitoring of the mother and diagnostic testing of the baby should be performed regularly (monthly).

There should be a clear communications process in place to ensure all health care professionals caring for the mother and baby in the postnatal period are aware of the need to support the agreed feeding plan, for example, community midwifery teams, GP and health visiting service.

All pregnant women with HIV and their babies should be cared for by a defined MDT in line with guidelines from the following professional bodies:

- British HIV Association (BHIVA)
- Children’s HIV Association (CHIVA)

Further information is available from:

- Positively UK
- Salamander Trust
- NHS Choices HIV and AIDS
- National AIDS Map (NAM)
- Antenatal Results and Choices
Hepatitis B

History of screening

Guidance issued by the Joint Committee on Vaccination and Immunisation (JCVI) in 1988 recommended selective screening of those at increased risk of hepatitis B. The Health Service Circular 1998/127 “Screening of pregnant women for hepatitis B and immunisation of babies at risk” set new national targets:

• UK NSC recommended a universal offer of antenatal screening and a schedule of immunisation for babies at risk
• health authorities to ensure arrangements were in place by April 2000 for the delivery of the programme

What is hepatitis B?

Hepatitis B is an infectious inflammatory illness of the liver caused by the hepatitis B virus (HBV). The virus can follow a variable course with two possible phases; acute and chronic.

1. Acute hepatitis B refers to newly acquired infections. Affected individuals notice symptoms approximately 1 to 4 months after exposure to the virus. In people who acquire infection during adulthood, around 90% will clear the infection spontaneously after several weeks. They are cured of the infection, are no longer infectious to others and are immune to re-infection. Those who do not clear the virus spontaneously develop chronic hepatitis B and a smaller number develop a very severe, life-threatening form of acute hepatitis called ‘fulminant hepatitis’.

2. Chronic hepatitis B refers to infections which fail to clear within 6 months. The risk of progression to chronic hepatitis B is inversely proportional to the age infection is acquired, with over 90% of infected infants becoming chronically infected. Once the infection becomes chronic it is unlikely to resolve and the person affected then becomes a lifelong carrier. Approximately 20% of chronic carriers will develop cirrhosis (permanent scarring of the liver) over a period of years, dramatically increasing their risk of developing primary liver cancer.

Hepatitis B is very infectious and is present in all body fluids such as blood, semen, vaginal secretions and saliva. It can be transmitted through unprotected sexual intercourse, direct contact with the blood of an infected person, sharing infected needles and from a mother to her baby during birth (perinatal transmission). Globally, perinatal transmission, from mother to baby, is the most common route of transmission. Hepatitis B infection is preventable by vaccination.
Hepatitis B in pregnancy

Babies born to mothers with hepatitis B are at high risk of acquiring HBV infection, particularly if the mother has a high level of HBV DNA (viral load) and displays hepatitis B ‘e’ antigen positivity (HBeAg) in her plasma. The risk of transmission depends on the status of the maternal infection. Without intervention, 70 to 90% of mothers who are ‘e’ antigen positive (HBeAg) will pass the infection to their baby compared to a 10% risk for mothers who are ‘e’ antigen negative.

Perinatal transmission can result in an acute or chronic infection, but babies have a much higher chance of being chronically infected. Without vaccination, 95% will have a sub-clinical infection (rather than acute hepatitis) and many become chronic carriers for life. This population has a 40% lifetime risk of death from cirrhosis or liver cancer.

The development of chronic infection after perinatal transmission can be prevented in over 90% of cases by timely vaccination (hepatitis B vaccine +/- hepatitis B immunoglobulin (HBIG)).

The mode of delivery and breastfeeding does not affect mother to child transmission if the baby receives appropriate management.

Hepatitis B tests

Screening

The recommended screening test for hepatitis B is an immunoassay to detect hepatitis B surface antigen (HBsAg). These tests are very sensitive and may detect women who are in the early incubation phase of an infection.

Confirmatory

All specimens that are positive for the HBsAg screening test must be confirmed using a neutralisation assay or an alternative HBsAg test of equivalent analytical sensitivity.

As part of the clinical pathway and follow-on care, further tests are required to assess infectivity and will identify hepatitis B antigens and antibodies and measure the maternal viral load (HBV DNA).

These antigens and antibodies are known as viral or ‘e markers’. Testing for ‘e’ markers and measuring a person’s viral load over the course of infection gives an indication of how the infection is progressing and/or if it is responding to treatment. In particular, finding the ‘surface’ and ‘e’ antigens (known as HBsAg and HBeAg) and their corresponding antibodies is very important in establishing the pattern of disease.
Antigens (and HBV DNA) are parts of the virus. They are a sign that someone has hepatitis B and may infect others.

Antibodies are created by the immune system to fight the virus. Antibodies are not infectious.

HBs Antigen (HBsAg): surface antigen

The term ‘surface’ refers to the outer surface of the virus itself. It appears 1 to 2 months after infection and disappears from the blood as the infection clears (World Health Organisation 2015). A positive result indicates that someone has acute or chronic hepatitis B. A negative result shows that a person has either never been exposed to the virus or that they have recovered from the infection and have rid themselves of the virus. If HBsAg disappears and protective antibodies appear (HBsAg negative, anti-HBs positive), this is considered a “cure”.

HBs antibody (anti-HBs)

The immune system creates this antibody to destroy the HBsAg of the virus. Anti-HBs appear if an infected person clears their virus (“cure”), or if a healthy person is successfully vaccinated. The HBs antibody also makes a person immune against hepatitis B, so they cannot be re-infected with hepatitis B.

HBV DNA (viral load)

This important test does not look for antigens or antibodies but monitors the amount of virus in the blood, known as the ‘viral load’. Viral load is an indicator of infectivity. The higher the viral load, the more infectious the infected person will be. A high viral load is considered as equal to or above $1 \times 10^6$ IUs/ml in an antenatal blood sample. A high viral load also increases the risk of cirrhosis and liver cancer. A very low amount or no trace of the virus is a marker of an individual’s good immune response to the virus or a good response to antiviral medication in a person who is receiving treatment. The specialist liver team will interpret this result.
HBc antibody (anti-HBc)

This antibody is created by the immune system against the core of the hepatitis B virus. It always becomes positive in an infection and stays for life, no matter whether the infection is cleared or becomes chronic. Anti-HBc does not appear in healthy vaccinated patients. Its presence shows that a real infection has occurred or is still present.

HBe antigen (HBeAg)

E antigen positivity is a sign that the virus is actively replicating. The viral load (HBV DNA) is usually very high in these patients. Together a high viral load and ‘e’ antigen positivity indicate that a person is highly infectious and can infect others easily. However, HBeAg is also a vulnerable part of the virus. The immune system might create anti-HBe antibodies (anti-HBe) which can negate the ‘e’ antigen. This is called HBeAg seroconversion. This is not a cure, but ‘e’ antigen negativity means the virus is being controlled by the immune system so it cannot replicate as rapidly.

HBe antibody (anti-HBe)

This is created by the immune system to destroy the HBe antigen. It is present in people recovering from an acute hepatitis B infection. E antibody positivity in chronic hepatitis B infection suggests lower levels of the virus are likely to be present in the blood.

ALT (alanine aminotransferase)

This is a liver enzyme that everyone has in their blood; it is not specific for hepatitis B. ALT levels are raised in conditions where the liver cells (hepatocytes) become damaged. If ALT is higher than normal it can be a sign of liver inflammation. It is important to observe ALT in chronic hepatitis B, along with the viral load (HBV DNA) and other ‘liver marker’ serology results. ALT levels interpreted in isolation are of no value.
Hepatitis B vaccination schedule

The MDT should have a local protocol in place to ensure babies born to hepatitis B positive women receive the appropriate vaccination and HBIG in a timely manner. Vaccination and HBIG (if indicated) should be given within 24 hours of birth, and further doses of vaccine should be given in line with the Green Book guidance.

<table>
<thead>
<tr>
<th>Hepatitis B status of mother</th>
<th>Baby should receive</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hepatitis B Vaccine</td>
</tr>
<tr>
<td>HBsAg pos and HBeAg pos</td>
<td>+</td>
</tr>
<tr>
<td>HBsAg pos and HBeAg neg/anti-HBeAb neg</td>
<td>+</td>
</tr>
<tr>
<td>HBsAg positive, e markers undetermined</td>
<td>+</td>
</tr>
<tr>
<td>Acute Hepatitis B during pregnancy</td>
<td>+</td>
</tr>
<tr>
<td>HbsAg pos, anti-HbeAb pos</td>
<td>+</td>
</tr>
<tr>
<td>HbsAg pos and known HBV DNA level equal to or above $1 \times 10^6$ IUs/ml in an antenatal sample (even if anti-HBe pos)* where viral load testing has been performed to inform the management of the mother.</td>
<td>+</td>
</tr>
<tr>
<td>HBsAg pos and infant born $\leq 1500$g, regardless of e antigen status</td>
<td>+</td>
</tr>
</tbody>
</table>

Treatment and clinical guidelines

All pregnant women with hepatitis B and their babies should be cared for by a defined MDT in line with the following guidelines from the professional bodies:

- British Viral Hepatitis Group (BVHG) Consensus Statement – UK guidelines for the management of babies born to women who are HBsAg positive
- Immunisation against Infectious Disease: the Green Book, chapter 18

Further information is available from:

- British Liver Trust
- Hepatitis B Foundation UK
- NHS Choices Hepatitis B
- European Liver Patients Association
- Antenatal Results and Choices
Syphilis

History of screening

Syphilis screening is a well-established part of routine antenatal care. In 1998 there was debate about the continuation of screening for syphilis prompted by low prevalence and the introduction of hepatitis B screening. A formal systematic review and national options appraisal by the Public Health Laboratory Service (PHLS) recommended that universal antenatal screening for syphilis should continue. The report was endorsed by the UK NSC which recommended continued screening.

What is syphilis?

Syphilis is an infectious disease caused by the bacteria-like spirochete Treponema Pallidum. It is transmitted primarily through sexual contact with an infectious lesion (chancre), but can be transmitted from mother to baby during pregnancy or at delivery. Syphilis infection is staged according to the duration of infection – the time from acquisition of primary infection.

Without treatment syphilis progresses through 4 stages:

- primary and secondary where a person is symptomatic and highly infectious
- latent (early/late) where the infection is found at lower levels
- tertiary where syphilis re-activates and serious health complications are common

Syphilis is not common in the UK but is prevalent in Eastern Europe, Africa and Asia. Since 2009 approximately 1 in every 700 pregnant women each year has screened positive for syphilis. However, not all those who screen positive will have active infection.

Syphilis in pregnancy

Syphilis may be transmitted transplacentally at any stage of pregnancy and may result in miscarriage, pre-term labour, stillbirth, and congenital syphilis (CS). This level of risk ranges from 70 to 100% in primary syphilis, 40% in early latent syphilis and 10% in late latent syphilis. Around two-thirds of babies with CS will be asymptomatic at birth but most will develop symptoms by 5 weeks of age. Untreated CS can result in physical and neurological impairments affecting the child’s bones, teeth, vision and hearing. There are fewer than 10 cases of CS diagnosed each year which could be prevented with early diagnosis and treatment of the mother.
The Surveillance of antenatal syphilis screening (SASS) study was funded by the IDPS programme to provide evidence to improve current screening practice. This was done by establishing what proportion of women identified at antenatal screening in 2010 to 2011 required treatments to:

- reduce the risk of transmitting syphilis to their babies
- review how they were managed
- review what happened to their babies

More than 1,900 pregnancies were reported, and more than 1,400 were confirmed positive. Only a quarter of these women had newly diagnosed infections, but about 40% of women required treatment in pregnancy (mainly penicillin). Six children born to women requiring treatment had confirmed congenital syphilis.

A 5-year study by PHE, UCL Institute of Child Health and the British Paediatric Surveillance Unit (BPSU) ran concurrently with this study (The incidence of congenital syphilis in the United Kingdom: February 2010 to January 2015 - Simms - 2016 - BJOG: An International Journal of Obstetrics & Gynaecology - Wiley Online Library).

Syphilis tests

Screening

The screening test for syphilis is an enzyme immunoassay (EIA) that detects antibodies to *Treponema pallidum*, or an alternative immunoassay of equivalent analytical sensitivity. A total EIA, that can detect both treponemal IgG and IgM antibodies, is recommended because of the test’s high diagnostic sensitivity.

These first line serological screening tests rely on a woman having mounted an antibody response to their infection and may therefore be insensitive in very early treponemal infection.

Confirmatory

All EIA positive results should be confirmed using the same assay to confirm reproducibility.

A *Treponema pallidum* particle agglutination (TPPA) or *Treponema pallidum* haemagglutination (TPHA) assay must be performed as a confirmatory test on the same screening specimen. These assays are sensitive and specific and a combination of a positive result with both EIA and TPPA/TPHA gives a strong likelihood for past or current treponemal infection.
Management in pregnancy

There are three possible reasons for a screen positive result in pregnancy:

- current syphilis infection
- syphilis infection in the past which was successfully treated
- false positive or detection of another Treponomonal infection (Bejel, Pinta, Yaws)

Treponemal antibody tests cannot differentiate syphilis. All women who screen positive will need a comprehensive sexual health assessment and examination by the genitourinary medicine (GUM) team. This is to determine the stage of infection and identify any health complications. Only those women with acute infection or inadequately treated previous infection will need treatment. It is vital that the GUM team makes a clear maternal diagnosis and management plan for the mother and the baby and communicates this to the MDT. A single dose of benzathine penicillin is effective in most cases.

Maternal treatment is not indicated where:

- there is a biological false-positive test
- syphilis was adequately treated pre-pregnancy

Maternal treatment is indicated where:

- there is active syphilis of any stage
- there is an unclear history of syphilis treatment prior to the current pregnancy

Any woman who requires treatment for syphilis in their current pregnancy should be referred to fetal medicine by 26 weeks’ gestation, particularly when there is evidence of early infection as indicated in BASHH guidelines. Ultrasound findings of fetal hydrops or hepatosplenomegaly can be suggestive of a fetal syphilis infection.

Neonatal management

There should be an MDT plan of care and/or neonatal alert process in place for babies requiring assessment and treatment at birth. The diagnosis of CS can be very difficult. Most infected neonates are asymptomatic at birth and passive transfer of maternal IgG across the placenta may cause reactive neonatal syphilis serology, even in the absence of CS. Neonatologists should liaise with GUM teams for guidance. All babies born to mothers with positive treponemal serology requiring treatment need clinical evaluation and syphilis serology tests.
Clinical guidelines

All pregnant women with syphilis and their babies should be cared for by a defined MDT in line with guidelines:

- British Association for Sexual Health and HIV (BASHH)

Further information is available from:

- NHS Choices Syphilis
- Antenatal Results and Choices
Infections that are not screened for

The UK NSC reviews screening recommendations for the UK on a regular basis. The reviews are carried out by experts using defined criteria and are available for consultation before the UK NSC reached a decision.

Systematic population screening in pregnancy is not recommended for the following infections which may be present in pregnant women:

- rubella susceptibility
- chlamydia
- cytomegalovirus
- group B streptococcus
- hepatitis C
- toxoplasmosis
- chickenpox (varicella susceptibility)
- parvovirus B19

The hyperlinks connect to the latest review documents for each infection.

Rash illness in pregnancy

Information and advice to pregnant women regarding rash illness should reflect the “Guidance on Viral Rash in Pregnancy”. This was produced by the Health Protection Agency’s Rash Guidance Working Group and sets out the investigation, diagnosis and management of pregnant women who have, or have been exposed to, a rash illness. All pregnant women with rash illness, or contact with rash illness, should be referred for medical management and laboratory investigation in line with the HPA guidance document. Page 19 of the document has an algorithm for the follow-up of women exposed to rash in pregnancy.

At booking, midwives should use the new national leaflet to:

- discuss the vaccinations to protect women and their babies
- raise awareness of rash illness or contact with rash illness in the current pregnancy
- advise women to inform their midwife, GP or obstetrician urgently if they develop a rash or are in contact with someone who has a rash, at any time in pregnancy
- advise women who develop a rash or are in contact with someone who has a rash to avoid any antenatal clinic or maternity setting until clinically assessed, to avoid exposing other pregnant women
IDPS screening pathway

1. **IDPS Programme**
2. Identify eligible population
3. Inform: Provide information on HIV, hepatitis B & syphilis
4. Offer: Offer AND recommend screening for HIV, hepatitis B & syphilis
5. **Screening accepted**
6. URGENT screening—women presenting in labour unbooked / no record of screening results
7. Test: Sample taken & sent to laboratory
8. Screen negative
   - Offer results to women who miscarry or terminate following screening and follow-up as required
   - Discuss results before or at next antenatal appointment and offer sexual health advice
9. Confirmed Screen Positive
   - Refer to Multidisciplinary Team (MDT)
10. **Screening declined for one or more infection**
11. Known positive women (HIV, Hep B)
12. Offer screening for other infections
13. **Post delivery: mother and baby follow up:**
   - HIV: BHIVA/CHIVA guidelines
   - Hep B: Green Book
   - Syphilis: BASPHI
14. Intervention/Treatment Contact women and manage as per local clinical guidelines
Each condition has a screening pathway that describes a woman’s ‘step by step’ journey from booking to delivery. The pathway goes from identification of the eligible population and the offer of screening through to timely referral and entry into care and specialist services. The pathway correlates with the themes of the programme standards. Healthcare professionals must be familiar with these pathways and the timeframes in which to refer women in line with the programme service specification.

This section provides additional guidance to further support healthcare professionals in their day-to-day delivery of the IDPS programme.

All trusts should have a process in place in all departments, such as maternity assessment units, gynaecology wards and delivery suites to manage women who book late or present with no reliable documentation of their screening status.

Trusts should use the free NHS screening programmes booklet ‘Screening Tests for You and Your baby’. The booklet is available in English for trusts to order. Downloadable versions are available in 12 other languages.

Practice points

1. Provision of interpreter services is necessary to ensure that mothers for whom English is not their first language have direct access to the information they need.
2. Provision of local support is necessary for those with learning disabilities, physical disabilities or communication difficulties.
3. The booklet is reviewed and updated regularly so it is important not to stockpile supplies and to only use the most recent version.
4. The booklet is not a stand-alone document and should be used to support the discussion about each screening condition at the booking visit.

All women booking for antenatal care should be offered and recommended screening for each of the 3 infections: HIV, hepatitis B and syphilis. The screening tests must not be offered as a suite of tests.

Practice point

1. IDPS screening results are an indicator of current infection status. Screening for syphilis should be offered in each pregnancy regardless of any previous testing or treatment.
2. Screening for HIV should be offered to all women irrespective of any recent flu vaccination. Some concomitant conditions (like rheumatoid), some infections and
therefore vaccines can produce cross reactive antibody that could show up on a range of other tests. There are further assays done on all 'positives' that will reliably confirm or exclude real infection.

3. Information should be provided on the availability of sexual health testing at any point during pregnancy should a woman consider herself to be at risk or if she changes her sexual partner.

A blood sample should be taken in line with local protocols and sent to the laboratory with a completed request form, paper or electronic, for analysis in line with the IDPS laboratory handbook.

There should be a local process in place to identify and follow up women who have declined screening. A blood sample should be taken for the tests accepted and sent to the laboratory with completed request form, paper or electronic. The laboratory request form must clearly identify the specific infection(s) declined.

Practice points

1. If a woman declines any of the three infections a process should be in place to notify the screening coordinator directly.

2. The midwife who offered the initial screen should inform the woman that she will be contacted by a member of the local MDT to discuss their choices.

3. The screening coordinator must be notified in order to facilitate the formal reoffer by 20 weeks’ gestation at a face-to-face meeting. Examples of how women are followed up include:
   - contacting the women by phone to arrange an appointment to coincide with her 18th to 20th week scan
   - arranging an appointment or home visit to suit the woman

4. If the woman declines the formal reoffer of screening, the local MDT will be responsible for further management in line with local clinical protocols. The onus of the reoffer is to facilitate an informed choice and not to coerce women to accept screening.

If a woman discloses that she is positive for HIV or hepatitis B a screening test is not necessary. This information must be recorded in the maternity notes and on the laboratory request form irrespective of local policy concerning retesting of known positive women.
This should be recorded as ‘known positive’ on the laboratory request form and reported accordingly to the screening coordinator to ensure timely referral to the local MDT. The woman should be offered screening for the other infections and be referred directly to the local MDT for assessment and management of her condition within 10 working days as per IDPS screening standard No 5.

**Practice point**

1. Some trusts retest all known positive women in each pregnancy, often as a failsafe process. This should be recorded as ‘known positive’ on the laboratory request form and reported accordingly to the screening team to ensure timely referral to the local MDT.

**Urgent screening**

Women presenting in labour/unbooked/no record of screening results

There should be a system in place to ensure tests are offered and performed for all women presenting in labour either unbooked or with no reliable laboratory evidence of screening results.

**Practice points**

1. Where this has not happened on delivery suite, screening should be offered prior to discharge from maternity services.
2. The maternity service should liaise directly with the laboratory to ensure the laboratory has the necessary clinical information to inform prompt analyses.
3. Point of care tests should not be used for routine screening purposes.
4. There should be robust processes in place to ensure all results are obtained, reported and managed appropriately.
5. The screening coordinator / specialist midwives should be informed of any woman screened on delivery suite or postnatal wards to ensure appropriate tracking and follow-up.

**Test**

Sample taken and sent to laboratory

The appropriate blood samples should be taken and sent to the laboratory for analysis accompanied by a completed request form as outlined in the IDPS laboratory handbook.

**Practice point**

1. There should be a local process in place to highlight any samples sent for analysis with incorrect or incomplete request forms so that the necessary changes can be made by the originator and improvements to practice made.
Results

IDPS results are an indicator of current infection status. No invasive tests, amniocentesis or chorionic villus sampling (CVS) should be carried out until the results of screening for all the infections are received. Some trusts have processes in place to review all results within 10 days of tests being taken to ensure women are not missed.

The results should be discussed before or at the next antenatal appointment and recorded in the health records. Retesting can take place at any time in pregnancy as the IDPS results are an indicator of current infection status.

Practice points

1. All women should receive their results.
2. Midwives should inform the woman of the availability of sexual health advice and testing at any point during pregnancy should she consider herself to be at risk or if she changes her sexual partner.
3. Sexual health advice includes:
   - recognition of the signs and symptoms of sexually transmitted infections
   - information on 'safe sex' practices – the use of condoms to protect against sexually transmitted infections
   - awareness of sexual history of sexual partner/partners and when further testing is needed

Inconclusive results

There should be an agreed process in place between the laboratory and the screening coordinator/specialist midwife to alert them to an inconclusive result and the need for a repeat sample within 2 weeks after the initial sample was taken to exclude recent infection.

Practice points

1. Women need to be informed of the need for the repeat sample to facilitate confirmation of either a negative or positive screen result.
2. If the repeat sample is also inconclusive, advice and or referral should be sought from the infectious disease clinicians for further management.

Confirmed screen positive

Results should not be communicated, either written or electronic, to the maternity service until confirmatory tests are completed on the screening sample.
Women who have a confirmed screen positive result or those already known to be positive should be invited for specialist assessment within 10 working days of the positive report being received from the laboratory, or known positive status reported to the screening coordinator (IDPS standard 4). The time between the initial contact with the woman and the appointment should be as short as possible to minimise the duration of any anxiety she is likely to experience.

The purpose of the face-to-face appointment with a member of the MDT (screening coordinator/specialist midwife/clinical nurse specialist) is to facilitate reporting of a new positive screening status or comprehensive assessment of a known positive woman’s condition and care. It should not be presumed that women who are known positive fully understand their condition, the implications for their current pregnancy and the current treatment and care regimes available in the UK.

Resources are available to support the specialist team in their discussions with the woman and her family, including:

- IDPS leaflets on each of the three infections
- IDPS counselling resource – a pictorial, ‘easy read’ desktop tool

A triage system should be adopted to complete any further tests and assessments within local clinical protocols. The principles of the assessment visit are to:

- form a proactive working relationship with the woman
- carry out a holistic, person-centered assessment
- provide a central, continuous point of contact for the woman
- act as the key advocate for the woman when required
- assist the woman in the successful navigation of complex health and social care systems

Practice points

Generic

1. Robust processes are needed to keep track of women who test positive for any of the infections, but then move out of the area.
2. A neonatal alert system could be used to identify babies of screen positive mothers who will need neonatal assessment and treatment.

HIV

1. Midwives should reassure women who test positive for HIV that they can significantly reduce the risk of mother-to-child transmission of the infection by adherence to treatment and avoidance of breastfeeding.
Hepatitis B

1. Counselling on the risk of hepatitis B transmission and the importance of the complete vaccination schedule is the most important practice point when caring for hepatitis B positive pregnant women.
2. Hepatitis B is a notifiable disease – processes must be in place to inform the ‘proper officer’ at the local health protection team.
3. Women who test positive for hepatitis B should be supported to inform close family members of their result and to arrange testing with the family GP or local sexual health service. Family members who test negative should then be encouraged to seek hepatitis B vaccination.

Syphilis

1. It is important that if a woman tests positive for syphilis, her sexual partner is also screened and treated as necessary. A woman who tests positive for syphilis should be reminded to abstain from sex until both she and her partner are treated appropriately.
2. Treatment for syphilis does not offer any future protection against re-infection.

Women who miscarry or terminate their pregnancy

A local protocol should be in place to ensure women who miscarry or terminate their pregnancy after screening receive their results and are followed up as required:

- screen positive – the laboratory should notify the screening coordinator/team to facilitate appropriate onward referral into specialist services and close the maternity care episode
- screen negative – arrangements should be in place to notify the woman of her result by maternity services

Practice points

Examples of how women are followed up include:

- direct telephone communication by the screening coordinator
- home visit by the community midwife as part of post miscarriage support
- letter communicating negative results with details of miscarriage support

This contact also provides an opportunity to check measles mumps and rubella (MMR) vaccination history and advice on immunisation with MMR if needed, before any future pregnancy.
A multidisciplinary approach is vital to
• improve health and well-being outcomes for the woman and her baby
• ensure women are seen by the most appropriate clinician in a timely manner
• ensure the delivery of person-centered coordinated care
• empower women in managing their condition
• facilitate and enable informed choice
• reduce health inequalities by equity of access to coordinated MDT services
• make best use of finite resources avoiding duplication

Accurate and timely communication and handover between all professionals involved in the screening and clinical pathways in acute and primary care settings is essential to reduce the potential for errors and ensure a seamless pathway for service users. It is important that named clinical responsibility remains clear at all times and that the clinical responsibility is clarified at handover of care.

Current clinical guidelines (BHIVA page 43 and BASHH page 734) on the care of pregnant women with HIV and syphilis endorse the MDT approach to the screening and clinical pathways. This approach provides the opportunity for management of women with more than 1 infection and also to manage more effectively any social issues that many of these women have.

An MDT approach involves appropriately utilising knowledge, skills and best practice from multiple disciplines and across service provider boundaries. An effective MDT depends on robust working relationships. The membership of the IDPS MDT will vary locally and may include some or all of the professionals in Figure 1. The screening coordinator/team should oversee the screening programme and act as a link between other members of the IDPS MDT.

The screening MDT should:
• demonstrate local knowledge of the range of local health and care services including the voluntary and community sector
• take responsibility for coordinating the care planning process and ensuring that identified activities and interventions take place as agreed
• liaise with other providers to ensure delivery of the care plan
• monitor and review care plans and agreed outcomes in partnership with the woman and to evaluate outcomes
• provide direct care and support where appropriate throughout the pregnancy

“…a well-functioning team is much more fun to work in!”
Peter Kohn, Director – Office of CCGs
Assessments carried out by each discipline and resulting patient plans must be worked up as a collaborative effort and include the woman. Records should be shared with all members of the team. A management process should be in place in line with national standards and clinical guidelines.

Practice points

The majority of antenatal and new-born screening will be paid for as part of the Maternity Pathway Payment (MPP). This includes the laboratory screening tests, midwifery resource and administration of the first hepatitis B vaccination +/- HBIG.

Confirmatory laboratory costs and outpatient appointments, such as Hepatology and GUM, are paid for via other routes as clarified in NHS England’s guidance for providers and commissioners. A locally agreed clinical protocol should be in place to support the MDT to conduct any further tests to inform ongoing timely entry into clinical care.
HIV

Women newly diagnosed positive or already known to have HIV should be referred to the specialist team coordinating their care in accordance with BHIVA guidelines.

Hepatitis B

Women positive with hepatitis B, newly diagnosed and known, should be managed in accordance with clinical guidelines from the British Viral Hepatitis Group (BVHG). All newly diagnosed and known positive women require a current assessment of infectivity including viral load measurement. There should be a local MDT protocol to support this, including clarification of funding arrangements to support timely and appropriate referral to hepatology services.

Viral load assessments should be carried out at the initial assessment appointment to support appropriate triage of women into specialist services. All newly diagnosed women and known positive women with a high viral load (equal to or above 1x10^6 IUs/ml in an antenatal sample) should be seen by a specialist hepatologist/gastroenterologist within 6 weeks of the positive result being reported to maternity services.

Hepatitis B is a notifiable disease and local arrangements should be in place to inform the Proper Officer (health protection team) of all screen positive results in line with ‘Green Book’ requirements. The woman must be informed of this statutory notification.

The MDT should ensure arrangements are in place to prescribe, order and store the vaccine (+/- HBIG as required) in advance of the estimated delivery date. It is vital that staff on the delivery suite are aware of this process and how to access the vaccine at all times.

Eligibility for HBIG remains unchanged where serial viral load testing has been performed to inform the management of the mother. HBIG should be administered at birth to any woman who is HBsAg seropositive and known to be positive for HBeAg, negative for anti-HBe or to have an HBV DNA level equal to or above 1 x 10^6 IUs/ml in any antenatal sample.

The main mechanism by which transmission occurs is perinatal exposure and it is this risk that is amenable to HBIG prophylaxis given post-natally; viral status in late pregnancy is therefore probably the best overall indicator of need for HBIG. Where viral markers and viral loads have fluctuated during pregnancy, however, the precise risk at the point of delivery is unlikely to be known and risk of in utero exposure earlier in pregnancy cannot be excluded. Although HBIG is unlikely to be of benefit in preventing in-utero exposure it will be difficult to attribute any subsequent infection to this route of transmission.
HBIG should therefore be offered to infants of any women where HBV status is designated as high risk on any antenatal sample, even if viral loads below $1 \times 10^6$ IUs/ml have been recorded at other points in the antenatal period.

**Syphilis**

Guidelines for the assessment and management of syphilis in pregnancy and infancy have been developed by the British Association of Sexual Health and HIV (BASHH).

There should be a local MDT protocol to ensure effective communication between the GUM team and screening coordinator on the plan of care for the woman and the outcome of the maternal assessment in GUM and plans for neonatal care.

**HIV**

Both BHIVA and (CHIVA) guidelines outline that local protocols must be in place to ensure multidisciplinary links and close working relationships between maternity services and specialist services are established and function well.

**Practice points**

1. Good communication skills and sensitivity to cultural issues are very important, especially around the need for HIV positive women to avoid breast feeding.
2. Women should be reassured that antiretroviral HIV treatment is not harmful to their baby.
3. Specifically ensure that all post-natal care givers are aware of the need to advocate formula feeding – for example, community midwives should be part of the MDT to support formula feeding.

**Hepatitis B**

1. Ensure processes are in place so the mother is aware of the importance of the immunisation schedule.
2. Offer and administer the vaccine +/- HBIG (HBIG) as required to the baby within 24 hours of delivery and record in the specific hepatitis B page of the Personal Child Health Record (PCHR) – see IDPS standard 7.
3. There should be a process to ensure that the HBIG administration documents are completed and returned to the supplying laboratory at PHE Colindale – ideally coordinated by the screening coordinator.

4. There should be a process to inform Child Health Information Systems (CHIS) and GP/health visitor of the administration of the initial vaccine/immunoglobulin and the need to schedule further vaccinations/serology in line with Green Book guidance.

Practice points

1. If an infant is identified as having missed HBIG at birth despite being eligible, HBIG can be given up to 7 days after birth. Assuming vaccine was given at birth, there is limited advantage in giving HBIG later when an active response to vaccine will have already started.

2. There is evidence to suggest that babies who are less than 1,500 grams in weight born to hepatitis B positive mothers may have a lower response to hepatitis B vaccine and therefore need to be given HBIG as well as vaccination regardless of the viral load of their mother.

3. Very premature infants (born ≤ 28 weeks of gestation) should have respiratory monitoring for 48-72 hours when given their first immunisation, particularly those with a previous history of respiratory immaturity. If the child has apnoea, bradycardia or desaturations after the first immunisation, the second immunisation should also be given in hospital, with respiratory monitoring for 48-72 hours. (Green Book p174).

Syphilis

There should be a neonatal alert and plan in place for any baby requiring neonatal examination +/- serology at birth in line with current BASHH guidelines. This specifically applies to babies whose mothers had treatment for syphilis in their current pregnancy.
Screening quality assurance services (SQAS)

Each English screening programme has a defined set of standards that providers have to meet to ensure local programmes are safe and effective. Quality assurance (QA) is the process of checking that these standards are met and there is continuous improvement across screening and referral pathways, so pregnant women and their babies have access to a high quality service wherever they live.

QA is essential in order to minimise harm and maximise benefits. Formal QA visits to a local screening programme provide the forum for a review of the whole multidisciplinary screening pathway, and an assessment of the effectiveness of team working within the screening centre and associated referral sites.

Screening safety incidents

An incident for screening programmes is defined as an actual or possible failure at any stage in the pathway of the screening process which exposes the programme to unknown levels of risk, for example where screening or assessment has been inadequate, with potentially serious consequences for the clinical management of individuals.

The guidance documents explains the incident management procedures for NHS screening programme providers and commissioners and provides a form for notifying incidents to SQAS. This guidance should be read alongside NHS England's Serious Incident Framework.

The Screening Incident Management Resource is available for health professionals working in NHS population screening. The e-learning resources examine why screening incidents occur, the steps that can be taken to avoid them, how to manage them, learn from them, and optimise the quality of the patient experience.
Data collection and reporting

Programme standards

The programme has 7 standards for 2016 to 2017. These will be reported via local data collection processes. The laboratory and maternity service should have an agreed process in place to coordinate and ensure timely collation and submission of data.

<table>
<thead>
<tr>
<th>IDPS Standard</th>
<th>Data collected by</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. HIV coverage (KPI ID1)</td>
<td>Maternity service</td>
</tr>
<tr>
<td>2. Hepatitis B coverage</td>
<td>Maternity service</td>
</tr>
<tr>
<td>3. Syphilis coverage</td>
<td>Maternity service</td>
</tr>
<tr>
<td>4. Test result turnaround time</td>
<td>Screening laboratory</td>
</tr>
<tr>
<td>5. Timely assessment for screen positive and known positive women</td>
<td>Maternity service</td>
</tr>
<tr>
<td>6. Timely assessment of women with hepatitis B (KPI ID2)</td>
<td>Maternity service</td>
</tr>
<tr>
<td>7. Hepatitis B – timely neonatal vaccination</td>
<td>Maternity service</td>
</tr>
</tbody>
</table>

Key performance indicators

Key performance indicators (KPIs) for the NHS screening programmes were introduced to measure how well the screening programmes are doing in important areas. They contribute to the quality assurance of screening programmes but are not, in themselves, sufficient to quality assure or performance manage screening services. They help local screening services identify potential problems so they can be put right and have led to changes in practice and implementation of measures to prevent errors occurring in the screening pathway.

The IDPS programme currently collects matched cohort KPI data on HIV coverage and data on hepatitis B referrals. There are plans to pilot 2 new coverage metrics for the other conditions (hepatitis B and syphilis).
Standards data collection process

Surveillance data for the IDPS Programme was previously collected by the National Antenatal Infections Surveillance Monitoring (NAISM) team at Colindale via the PHE regional Field Epidemiology Service (FES) teams (formerly the Health Protection Agency).

Data has been collected since 2004, supported by regional health protection teams and epidemiologists, and the pre-PHE regional antenatal and newborn screening teams. Since 2006, this data has been used to produce the annual Health Protection reports.

The programme has identified a need to:

- reduce duplication between data requested by NAISM and the screening team within PHE
- collate matched cohort data across the screening pathway
- ensure consistency of reporting, whether regional or national, against the programme standards to support quality assurance processes
- simplify the process and reduce the effort of data duplication for screening coordinators in trusts

From 2016, the IDPS programme will coordinate data collection in line with the other antenatal and newborn screening programmes. A data dictionary and data submission tool is available to facilitate data collection from screening coordinators and laboratories. Data will be submitted annually with a submission deadline of 30 June for the previous screening year (1 April to 31 March).

Data will be submitted to the programme annually and will be received, stored and analysed by the programme centre and an agreed data extract sent to PHE Centre for Infectious Disease Surveillance and Control to include in its health protection reports (PHE CIDSC HIV & STI department). A data report will also be produced by the IDPS Programme for NHS Screening Programmes.

Screening outcomes

Collation and analyses of screening outcome data is essential to

- monitor the performance of the screening programme
- identify areas for further audit and research
- review all positive cases to inform screening programme pathways and standards
The IDPS programme commissions the Infections Group in the Population Policy and Practice Programme at University College London (UCL) Institute of Child Health to collect data on screening programme outcomes. The IDPS programme is undertaking a review of data collection processes and systems in order to establish a single submission and governance structure.

Current projects include

- enhanced HIV in pregnancy audit through the National Study of HIV in Pregnancy and Childhood (NSHPC)
- surveillance of antenatal syphilis screening (SASS) study
- hepatitis B in pregnancy audit

The IDPS team also supports the continued monitoring of congenital rubella cases through the British Paediatric Surveillance Unit rare conditions active reporting scheme.

All trusts should continue to report HIV confirmed pregnancies to the NHSPC. A process should be in place to review the outcomes for their local population to inform local screening processes. Local data on outcomes can be requested directly from the NHSPC team at UCLH.
Appendix 1. Acknowledgments

The IDPS Programme would like to acknowledge the chairs of the IDPS advisory and task groups who contributed to the consultation process in the publication of this handbook – Dr. Jane Scarlett, Dr. Pat Tookey, Dr. Steve Higgins and Dr. Ashley Brown.

The team would also like to thank the members of the IDPS Midwifery and Specialist Nurses Forum for their significant contribution to the development of the document.

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharon Webb</td>
<td>Programme Manager IDPS</td>
<td>Public Health England (PHE)</td>
</tr>
<tr>
<td>Aileen Masson</td>
<td>Project Lead IDPS</td>
<td>Public Health England</td>
</tr>
<tr>
<td>Mary Kean</td>
<td>Senior Quality Improvement Manager</td>
<td>Public Health England</td>
</tr>
<tr>
<td>Sarah Dermont</td>
<td>Clinical Project Lead / HIV Specialist Midwife</td>
<td>PHE / Chelsea &amp; Westminster NHS Trust</td>
</tr>
<tr>
<td>Hazel Allen</td>
<td>Consultant Nurse, Hepatology</td>
<td>Royal Bournemouth and Christchurch</td>
</tr>
<tr>
<td>Sue Alston</td>
<td>Midwife for Infectious Diseases and Clinical Audit</td>
<td>Sheffield Teaching Hospitals</td>
</tr>
<tr>
<td>Bridget Auker</td>
<td>Specialist Midwife, ANNB Screening</td>
<td>Basildon and Thurrock University Hospitals</td>
</tr>
<tr>
<td>Lynn Baines</td>
<td>ANNB Screening Coordinator</td>
<td>University Hospitals of Morecombe Bay NHS Trust</td>
</tr>
<tr>
<td>Lynn Bowman</td>
<td>Community/Screening Midwife</td>
<td>South Tees NHS Foundation Trust</td>
</tr>
<tr>
<td>Tara Boyle</td>
<td>ANNB Screening Coordinator</td>
<td>Whittington Health</td>
</tr>
<tr>
<td>Joanne Caines</td>
<td>Clinical Nurse Specialist Maternal Hepatitis</td>
<td>University Hospitals Birmingham</td>
</tr>
<tr>
<td>Jane Chukwuma</td>
<td>Virology Midwife</td>
<td>Bart's Health</td>
</tr>
<tr>
<td>Margaret Costello</td>
<td>Specialist Midwife- Infectious Diseases in Pregnancy</td>
<td>Northwick Park</td>
</tr>
<tr>
<td>Janet Duckworth</td>
<td>Substance misuse/BBV/Community Midwife</td>
<td>Morecambe Bay</td>
</tr>
<tr>
<td>Jill Fearnside</td>
<td>ANNB Screening Coordinator</td>
<td>Watford</td>
</tr>
<tr>
<td>Sarah Fiadjo</td>
<td>ANNB Screening Coordinator</td>
<td>Princess Alexandra Harlow</td>
</tr>
<tr>
<td>Kay Francis</td>
<td>HIV Lead Midwife</td>
<td>North Middlesex</td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
<td>Location</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-----------------------------------------------</td>
<td>----------------------------------------------------</td>
</tr>
<tr>
<td>Ana Gonzalez</td>
<td>Specialist Midwife</td>
<td>Royal Free London</td>
</tr>
<tr>
<td>Hilary Goodman</td>
<td>Integrated Lead for Antenatal Services/Lead Midwife, Screening</td>
<td>Hampshire Hospitals</td>
</tr>
<tr>
<td>Kirsty Jones</td>
<td>Fetal Medicine and Screening Midwife</td>
<td>Mid Cheshire Hospitals Trust</td>
</tr>
<tr>
<td>Mandy Jones</td>
<td>Antenatal and Newborn Screening Midwife</td>
<td>Macclesfield Hospital</td>
</tr>
<tr>
<td>Heather Johnson</td>
<td>ANNB Screening Coordinator</td>
<td>Wexham Park, Frimley Health</td>
</tr>
<tr>
<td>Heather Longworth</td>
<td>ANNB Screening Coordinator</td>
<td>Liverpool Women's Hospital</td>
</tr>
<tr>
<td>Fiona McCormack</td>
<td>ANNB Screening Coordinator</td>
<td>Peterborough and Stamford Hospitals Trust</td>
</tr>
<tr>
<td>Cleo McKenzie</td>
<td>ANNB Screening Coordinator</td>
<td>Dudley Group</td>
</tr>
<tr>
<td>Karen Mercer</td>
<td>Clinical Nurse Specialist, Viral Hepatitis</td>
<td>Lewisham and Greenwich NHS Trust</td>
</tr>
<tr>
<td>Natalie Perks</td>
<td>Deputy Screening Midwife</td>
<td>Walsall Healthcare</td>
</tr>
<tr>
<td>Alison Perry</td>
<td>Fetal Screening Coordinator</td>
<td>Leeds</td>
</tr>
<tr>
<td>Rhonda Reddington</td>
<td>HIV Specialist Midwife</td>
<td>Bart's Health</td>
</tr>
<tr>
<td>Sheila Reed</td>
<td>ANNB Screening Coordinator</td>
<td>County Durham and Darlington</td>
</tr>
<tr>
<td>Ruth Rice</td>
<td>ANNB Screening Coordinator</td>
<td>Plymouth</td>
</tr>
<tr>
<td>Pat Schan</td>
<td>ANNB Screening Specialist Midwife</td>
<td>Western Sussex</td>
</tr>
<tr>
<td>Anne Tunbridge</td>
<td>HIV Specialist Midwife</td>
<td>Whittington Health</td>
</tr>
<tr>
<td>Sabine Turpin</td>
<td>Specialist Midwife for Antenatal and Newborn Screening</td>
<td>East Sussex Healthcare</td>
</tr>
<tr>
<td>Gretta Wong</td>
<td>Hepatology Clinical Nurse Specialist</td>
<td>Mid Cheshire, Crewe</td>
</tr>
</tbody>
</table>