

# Pregnancy and Newborn Screening: Infectious Diseases in Pregnancy Standards

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We are committed to equality and diversity. These standards are intended to support improvements in healthcare for everyone, regardless of their age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation, socio-economic status or any other status. Suggested aspects to consider and recommended practice throughout the standards should be interpreted as being inclusive of everyone living in Scotland. We have assessed these standards for likely impact on the nine equality protected characteristics as stated in the Equality Act 2010. A copy of the impact assessment is available on request from the Healthcare Improvement Scotland Equality and Diversity Advisor.

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## Introduction

### Background to the pregnancy and newborn screening standards

Screening is offered to groups of the population to identify people who may be at an increased chance of a particular condition. Pregnancy screening is offered to help women make informed choices about their health and the health of their unborn baby during pregnancy. Newborn screening is offered to facilitate parents and carers to make informed choices about the health of their newborn baby. It is important that informed decisions are made in partnership with healthcare professionals at the respective stage of the screening programme.<sup>1</sup> Information on pregnancy and newborn screening, including national information produced by NHS Health Scotland, is provided to women throughout their pregnancy and following the birth of the baby.

### Infectious diseases screening in pregnancy

Each NHS board offers screening for infectious diseases to all eligible pregnant women in Scotland. Eligible women will be offered screening and those who accept will receive a screening result.<sup>2</sup>

The aim of this screening is to provide early identification of infectious diseases such as hepatitis B (HBV), human immunodeficiency virus (HIV) and syphilis. The early identification of these diseases will allow for management interventions to be offered to the mother to greatly reduce the chance of mother to child transmission.<sup>2, 3</sup> It also allows for appropriate assessment and management to be offered for both mother and unborn child.<sup>3, 4</sup>

### Policy context

National Services Division (NSD) has an ongoing role in the national multidisciplinary groups which monitor and evaluate the pregnancy and newborn screening programmes. Healthcare Improvement Scotland supports NHSScotland's screening programmes through developing new and, where appropriate, revising existing standards. A request to revise the *Clinical Standards for Pregnancy and Newborn Screening* (October 2005) was received from the Scottish Government and NSD in summer 2016.

NSD has developed and published a set of Key Performance Indicators (KPIs)<sup>5</sup> to document progress in areas that have been identified within the pregnancy and newborn screening programme as requiring additional support.

These standards should be read alongside other relevant legislation, standards and guidance such as the KPIs mentioned above.

### Scope of the standards

These standards apply to screening for infectious diseases in pregnancy and cover:

- eligibility and coverage, and
- screening and diagnosis.

**These infectious diseases in pregnancy screening standards should be read alongside the general standards for pregnancy and newborn screening:**

- **Standard 1: Leadership and governance**
- **Standard 2: Information and support**

Information relating to the development of the pregnancy and newborn screening standards can be found in Appendix 1 of the general standards.

The full suite of pregnancy and newborn screening standards is available on the Healthcare Improvement Scotland website ([www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)).

### **Format of the standards**

All our standards follow the same format. Each standard includes:

- a statement of the level of performance to be achieved
- a rationale providing reasons why the standard is considered important
- a list of criteria describing the required structures, processes and outcomes
- what to expect if you are a person receiving care
- what to expect if you are a member of staff, and
- what the standards mean for organisations, including examples of evidence of achievement.

Within the standards, all criteria are considered 'essential' or 'required' in order to demonstrate the standard has been met.

### **Terminology**

Wherever possible, we have incorporated generic terminology which can be applied across all health and social care settings.

The terms 'woman', 'women' and 'individual' are used within the standards to refer to all individuals with a female Community Health Index (CHI) number.

The term 'eligible women' refers to women who are invited for pregnancy screening.

The first antenatal contact can be defined as the first appointment with the midwife or hospital.

### **Quality of care approach**

The pregnancy and newborn screening standards are a key component in supporting the pregnancy and newborn screening programme in quality assurance of its services. Monitoring and improving performance against these standards, at a local and national level, aims to improve the quality of the pregnancy and newborn screening programme.

External quality assurance (EQA) of screening programmes is delivered using Healthcare Improvement Scotland's quality of care approach and the Quality

Framework.<sup>5</sup> This approach specifies how Healthcare Improvement Scotland will design and deliver EQA activity to support improvement in healthcare.

The quality of care approach emphasises the importance of regular open and honest self-evaluation using the Quality Framework as a basis, combined with other relevant data and intelligence including the performance against these standards. Any outcomes from the quality assurance activity will be risk based and set in the context of the programme capacity for improvement. Further information on this approach is available on the Healthcare Improvement Scotland website ([www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)).

## **Implementation**

Healthcare Improvement Scotland develops and publishes national standards to support organisations and health professionals in providing a high quality pregnancy and newborn screening programme. The implementation of these standards is for local determination.

## **Summary of standards**

**Standard 1:** All eligible pregnant women are offered infectious diseases screening.

**Standard 2:** Pregnancy screening for infectious diseases is safe, effective and person centred.

## **Pregnancy and newborn screening: infectious diseases in pregnancy standards**

### **Standard 1: Eligibility and coverage**

#### **Standard statement**

All eligible pregnant women are offered infectious diseases screening.

#### **Rationale**

Hepatitis B (HBV), human immunodeficiency virus (HIV) and syphilis can all be passed from mother to baby during pregnancy and birth. Infectious diseases screening is recommended for women to protect their health through early treatment and care. Early identification of these infectious diseases enables healthcare professionals to manage the disease and prevent mother-to-child transmission.<sup>1, 3, 4</sup> Screening should be offered for all three infectious diseases.<sup>4, 7</sup>

The provision of information is essential to support women and, where appropriate, their partners to make an informed and considered choice whether or not to undergo infectious diseases screening. Information should be in an accessible format and include details of both the benefits and limitations of infectious diseases screening.<sup>1, 3, 4, 8</sup>

Good communication between individuals and their healthcare provider is important, as the way that screening is offered can impact the decisions and choices made by individuals and their partners.<sup>1</sup> Information should be presented impartially.<sup>4</sup>

Women and, where appropriate, their partners should be fully involved and supported, with their decisions and choices respected by healthcare professionals.<sup>1, 3, 4, 8</sup>

#### **Criteria**

- 1.1** NHS boards have systems and protocols in place for timely and person-centred infectious diseases screening in pregnancy, which includes:
  - offering screening at the most appropriate stage in pregnancy
  - reoffering screening to women who decline or are at continuing risk throughout their pregnancy
  - timescales and methods for communication of results
  - the opportunity to discuss with women their results, further management and/or further testing, and
  - processes for follow-up diagnostic testing.
  
- 1.2** All women receive information about infectious diseases screening in pregnancy at least 48 hours before the first antenatal contact with the midwife or hospital service.



- 1.3** The decision to accept or decline screening for infectious diseases and/or referral for appropriate assessment is recorded and shared appropriately.

**What does the standard mean for the individual participating in pregnancy screening?**

- Women will receive information that:
  - is in a style and format appropriate to their needs and at least 48 hours before the first contact with the midwife
  - provides an overview of the screening process, and
  - outlines the benefits and limitations associated with screening for infectious diseases.
- Women will be:
  - offered an opportunity to discuss screening for infectious diseases with an appropriate healthcare professional to allow them to make an informed choice that will be respected, and
  - reoffered screening for infectious diseases later in their pregnancy, if appropriate.

**What does the standard mean for staff?**

- Staff can demonstrate knowledge of:
  - eligibility criteria for offering infectious diseases screening in pregnancy
  - the patient pathway, and
  - how individuals can opt in and opt out of the infectious diseases screening process.
- Staff will:
  - provide information and support to all eligible women that is sensitive to their needs and respect their choices, and
  - ensure decisions to accept or decline screening and/or referral for appropriate assessment are recorded and shared appropriately.

**What does the standard mean for the NHS board?**

- The NHS board will:
  - have an effective system in place to invite eligible women for infectious diseases screening at the appropriate time in their pregnancy, and
  - monitor the screening pathway of infectious diseases screening to ensure it is timely.

**Practical examples of evidence of achievement** *(NOTE: this list is not exhaustive)*

- Monitoring reports detailing completion of the infectious diseases screening pathway within an agreed and defined reporting period.
- Protocols for eligibility and invitation to the pregnancy and newborn screening service.
- Protocols for minimising barriers with reference to local population.
- Evidence that any woman who wishes to have screening undergoes the screening.

## **Standard 2: Screening and diagnosis**

### **Standard statement**

Pregnancy screening for infectious diseases is safe, effective and person centred.

### **Rationale**

Screening for infectious diseases can take place at any point during pregnancy and birth. Women who have opted out of screening for infectious diseases or who present later in pregnancy, or at birth, can be screened for infectious diseases and receive treatment to minimise the risk of mother-to-child transmission.<sup>3</sup>

Women at continued risk of infection and where an infectious disease has not been detected (screen negative) or have opted out should be reoffered screening later in pregnancy.<sup>3, 4, 9</sup>

Women who undergo screening should be asked how they would like results to be communicated. This should be respected in the event HBV, HIV or syphilis has been detected (screen positive).<sup>3</sup> Where a screen positive result has been detected, women should be initially contacted using their preferred method. To reduce anxiety, women should be invited to attend an appointment as soon as possible to discuss their results further.<sup>3</sup> Due to the emotional impact a positive result can have on an individual, results should be delivered by healthcare professionals who are appropriately trained.<sup>3, 4</sup>

Care for women who have received an HBV positive result should be multidisciplinary and include neonatal immunisation. The baby should be immunised within 24 hours of delivery and receive a regular immunisation programme within the first 12 months as this has shown to be effective in reducing and/or preventing transmission of infection from mother to baby.<sup>3, 4, 7, 10</sup>

Women who have been identified as HIV positive during screening should be managed by a multidisciplinary team, as this allows for the easy flow of information and care planning of both the mother and baby.<sup>3</sup> Treatment during pregnancy should focus on suppressing the virus in the woman through anti-retroviral therapy.<sup>7</sup> Information and care planning should extend from pregnancy through to the birth of the baby including the risks involved with breastfeeding.<sup>7</sup>

Women who have received a positive result for syphilis during screening should undergo further assessment to confirm whether the positive result is a syphilis diagnosis and requires further treatment.<sup>3, 7</sup>

When making decisions and informed choices, individuals and, where appropriate, their partners should be fully involved and supported, with their decisions and choices respected by healthcare professionals.<sup>1, 8</sup>

## **Criteria**

- 2.1** Women who decline or do not attend for infectious diseases screening are reoffered screening later in pregnancy in line with national guidance.
- 2.2** Women who are screen negative will be offered a screening test for infectious diseases in later pregnancy where appropriate.
- 2.3** All screen negative results (samples that do not require supplementary/confirmatory testing) are reported to the maternity service within 5 working days of the screening laboratory receiving the sample.
- 2.4** Women who are screen negative will have their results communicated to them at their next routine antenatal appointment.
- 2.5** The screening laboratory will undertake confirmatory tests for all screen positive samples and have the results issued to the named clinician within 8 working days.
- 2.6** Women who are screen positive or are known positive are seen by the multidisciplinary team within 5 working days of the status being reported to the named clinician.
- 2.7** Babies born to a mother with hepatitis B receive the first dose of neonatal hepatitis B vaccination, with or without immunoglobulin as required, within 24 hours of birth.
- 2.8** Women who participate in screening receive an infectious diseases result and this is recorded and shared appropriately.

### **What does the standard mean for the individual participating in pregnancy screening?**

- Women will:
  - be offered screening for infectious diseases throughout their pregnancy, if appropriate
  - receive a result (either positive or negative) within the agreed timescales, and
  - be offered an opportunity to discuss screening for infectious diseases with an appropriate healthcare professional to allow them to make an informed choice that will be respected.

### **What does the standard mean for staff?**

- Staff can demonstrate knowledge of:
  - the eligibility criteria for infectious diseases screening
  - the patient pathway, and
  - what diseases are being screened for during infectious diseases screening.
- Staff will:
  - provide information and support to all eligible women that is sensitive and respects their choices, and
  - ensure decisions to accept or decline screening and/or referral for appropriate assessment are recorded and shared appropriately.

### **What does the standard mean for the NHS board?**

- The NHS board will:
  - have an effective system in place to invite eligible women for infectious diseases screening throughout their pregnancy
  - monitor the infectious diseases screening pathway to ensure it is complete
  - identify pregnant women who have been missed from infectious diseases screening, and
  - have an effective system in place to offer women with a positive diagnosis multidisciplinary care within the agreed timescales.

### **Practical examples of evidence of achievement** *(NOTE: this list is not exhaustive)*

- Documentation demonstrating discussions, decision-making and information is shared appropriately between teams.
- Records of vaccination of all babies at risk of hepatitis B (HBV).
- Monitoring reports detailing completion of infectious diseases screening pathway within agreed defined reporting period.
- Protocols for eligibility and invitation to the pregnancy screening service.
- Evidence that any woman who wishes to have infectious diseases screening undergoes the screening.
- Audit of quality assurance of infectious diseases tests.

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or email [contactpublicinvolvement.his@nhs.net](mailto:contactpublicinvolvement.his@nhs.net)

## Healthcare Improvement Scotland

Edinburgh Office  
Gyle Square  
1 South Gyle Crescent  
Edinburgh  
EH12 9EB

0131 623 4300

[www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)

Glasgow Office  
Delta House  
50 West Nile Street  
Glasgow  
G1 2NP

0141 225 6999